

## INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

**The quality of this reproduction is dependent upon the quality of the copy submitted.** Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

# UMI

A Bell & Howell Information Company  
300 North Zeeb Road, Ann Arbor MI 48106-1346 USA  
313/761-4700 800/521-0600



# **Unruly Death: The Social Organization of AIDS Suicide**

by

**Barbara M. Herringer**  
B.A., University of Alberta, 1972  
B.S.W., University of British Columbia, 1987  
M.S.W., University of British Columbia, 1989

A Dissertation Submitted in Partial Fulfilment of the  
Requirements for the Degree of

**DOCTOR OF PHILOSOPHY**

in the Faculty of Human and Social Development

We accept this dissertation as conforming  
to the required standard

---

Dr. Marie L. Campbell, Supervisor (Faculty of Human and Social Development)

---

Dr. Brian Wharf, Departmental Member (Faculty of Human and Social Development/Social Work)

---

Dr. Christine St. Peter, Outside Member (Women's Studies)

---

Dr. Holly Devor, Outside Member (Sociology)

---

Dr. Kathryn McCannell, Outside Member (University of British Columbia, Social Work)

---

Dr. Dorothy E. Smith, External Examiner (Ontario Institute for Studies in Education, University of Toronto)

©Barbara M. Herringer, 1998  
University of Victoria

All rights reserved. This dissertation may not be reproduced in whole or in part by photocopying or other means, without the permission of the author.

Supervisor: Dr. Marie L. Campbell

### ABSTRACT

The decision to contribute my words to the discussion regarding HIV and AIDS emerged from my experience of the illness and subsequent death of my brother Jay, a gay man who killed himself eighteen months after a diagnosis of AIDS. The inquiry begins from my own experience of confusion, fear and eventual loss. Employing Jay's journal of his eighteen month "journey" with AIDS, I illustrate what can be learned about the social organization of AIDS "suicide" through the method of inquiry known as institutional ethnography. I assumed, when I began the analysis that I had found Jay's standpoint, his voice, that his words would show me the real Jay and how he finally made, by himself, his decision to die. Yet I found the narratives of medical, professional and immune and self-help discourses interjecting, defining, categorizing and being reflected in his words and actions.

The analysis (that begins from Jay's journal as entry points) makes visible how a variety of ruling practices, ways of knowing, and authoritative knowledges organized Jay's account of his experience of living with AIDS, as they must have done his life itself and his decision to die. Thus, my central methodological interest has been to illustrate a way of knowing that is not simply a subjective rendering, nor an ideological account available only as discourse, but rather one which offers insight into how various social relations (might have actually) organized the everyday life of a man living/dying with AIDS.

This project is not about who owns truth but rather about how HIV disease works

today; that is, how concepts, institutional practices, and professional discourses intersect with and become part of the daily lives of actual individuals. The analysis displays the "work" involved in choosing to live or choosing to die by those with HIV disease and the discursive practices that "rule" those choices. The inquiry makes visible from an account of one person who lived with HIV/AIDS and those caring for him, how the standpoint of the everyday differs from the standpoint of professional action. While it is individual people with AIDS who will decide whether to take their own lives, depending on the circumstances in which they find themselves, I have attempted through this inquiry, to articulate how these decisions are fully social. As my research progressed, I discovered how my brother's death by his own act was turned from a heart-breaking attempt to take charge of his life -- an unruly act--into conformity with official rules. I have shown what it means to say that his death, as well as his life with AIDS, was discursively organized and ruled.

**Examiners:**

---

**Dr. Marie L. Campbell, Supervisor (Faculty of Human and Social Development)**

---

**Dr. Brian Wharf, Departmental Member (Faculty of Human and Social Development/Social Work)**

---

**Dr. Christine St. Peter, Outside Member (Women's Studies)**

---

**Dr. Holly Devor, Outside Member (Sociology)**

---

**Dr. Kathryn McCannell, Outside Member (University of British Columbia/Social Work)**

---

**Dr. Dorothy E. Smith, External Examiner (Ontario Institute for Studies in Education)**

## TABLE OF CONTENTS

### Acknowledgements

### Dedication

### Fore(words) Friends, Family & AIDS

The Twenty-fourth Monday in Ordinary Time.....	1
Reclaiming a Life: Ways of Telling AIDS.....	13

### Chapter One AIDS Narratives/AIDS Histories: The Problematic of a Discursively Organized Life and Death

Introduction.....	21
An “Historical” Account.....	27
A Personal Account of Living & Thinking about Dying with HIV/AIDS.....	43
Jay’s Journal: Excerpts from a Personal Account.....	44
Conclusion.....	54

### Chapter Two Marked Bodies: Fear, Loathing, Homosexuality & AIDS

Introduction.....	58
Constructing Homosexuality/Constructing AIDS.....	66
Early Knowledge.....	68
Emerging Identities.....	74
Categorizing and Classifying Sexuality and Gender.....	76
Theorizing Sex and Gender.....	90
Homosexuality, Identity and AIDS.....	98
Conclusion.....	102

### Chapter Three Conceptualizing Suicide in the Context of AIDS

Introduction.....	104
Suicide as Mental Illness.....	106
AIDS & Suicide.....	110
Conclusion.....	118

## **Chapter Four            Theory & Methodology: Toward a Social Organization of Knowledge of AIDS Suicide**

Introduction.....	121
Theoretical Considerations: The Knowledge Debates.....	127
Critical Turns in the Knowledge Debates: Discursively Organized Knowing....	130
Discourse, Ideology and Ruling: Smith’s Contribution.....	139
The Analytic of Social Relations.....	152
Methodological Strategies.....	157
Institutional Ethnography.....	158
Problematic: A Route to Visibility.....	160
Experiential Data & Textual Materials.....	166
The Study.....	169
Conclusion.....	171

## **Chapter Five            The Work of Choosing to Live**

Introduction.....	174
“Will my sexuality be only lived in my dreams...?” .....	176
Becoming “Jay with AIDS...a PWA”.....	186
Family, friends and professional care.....	208
Conclusion.....	217

## **Chapter Six            Unruly Death: “Is suicide a legitimate option...?”**

Introduction.....	219
“But my dilemma...” .....	221
“Going Naturally”: a good death?.....	225
“Love myself, heal myself...”: An approach to AIDS.....	245
Conclusion.....	258

## **Chapter Seven        Defining Death: AIDS, Suicide and the Coroner**

Introduction.....	260
The “Crown’s” Work & Responses to Suicide.....	264
Suicide and the Work of the Coroner.....	275
Doing Judgements: Making Death into an Official Account.....	278
“ In a depressed state of mind...” .....	283
“I find his death to be suicidal...”.....	290
Conclusion: What the Coroner’s Work Accomplishes.....	299

## **Chapter Eight            Conclusions.....304**

<b>Bibliography</b> .....	314
<b>Appendix One</b>	
Jay's Journal .....	337
<b>Appendix Two</b>	
Judgement of Inquiry .....	364

## ACKNOWLEDGEMENTS

My deepest appreciation to the men and women with HIV/AIDS who have shared their experiences with me over the years, and to those caring for and about them politically and practically. I want to remember my wonderful friend Stephen Denslow, who died three months after Jay. Time spent with him over the twenty years we knew one another, was one of the greatest joys of my life, and I miss him daily.

My mother Helen, who lost her husband and her son within four years, has taught me about resilience. She has nursed several people since then, has challenged her church, and has kindly wondered what was going on with this project! Steve, Michael, and Chris who also lost a brother, have shared their loss and tears with me. Our conversations about life and death and what counts have helped me think through many parts of this project.

My profoundest acknowledgement to my supervisor and friend Dr. Marie Campbell for her love of research and her ability to help me see my way clear throughout the long process of this inquiry. She exhibits a rare dedication to scholarship, to thinking, to politics, and to the joy of ideas and how best to show how they work!

To my committee members Holly Devor, Kathryn McCannell, Christine St. Peter, and Brian Wharf, my thanks for persevering during several dry spells! This was a truly multidisciplinary group whose ideas and encouragement as colleagues and researchers helped me believe that my approach had much to offer. And my thanks to George Smith, who sat on my committee as an expert advisor, and who himself lived and died with HIV/AIDS before I finished the project. His work has been so influential to both community activists and scholars, and continues to be an inspiration and impetus to me in my own work.

To my friends and colleagues in Vancouver, Victoria, Prince George and elsewhere who have taken an interest in my work and encouraged me to keep going--many thanks! Lynn, Sharon, Margot, Christine, Melinda, Sandy, Theresa, Linda (as always).

And to Barbara, the love of my life, who was there through Jay's life and death with AIDS and who knows my profound feelings of loss for him--this day would not have come without her love and support in more ways than I can name. She made sure I was able to get away to work and never ceased to ask hard and perceptive questions about the direction I was going. She is one of the most creative thinkers I know and being with her has sparked me to take many risks over the years.

While they may not be able to read, three furry beings kept me grounded during the last seasons of writing. Maudie knew when it was time to nudge me for a walk, and Guido and Lily nestled around the computer chair or rolled in the last drafts to help me lighten up!

**DEDICATION**

**In memoriam  
Jay Herring 1953-1989**

## FORE(WORDS)

### Friends, Family & AIDS

#### *The Twenty-fourth Monday in Ordinary Time<sup>1</sup>* *(for Jay, 1953-1989)*

I.

*step on a crack  
break your mother's back*

*shatter a mirror  
seven years bad luck*

*if you eat meat on Friday*

*if you miss church on Sunday*

*if you don't say your prayers*

*if you think bad thoughts*

*if you if you if you*

*love the wrong sex*

*fuck the wrong men*

*mom says he's in intensive care with some kind of pneumonia  
she knows what it is and prepares for flight  
the first one there*

*I hold the phone so calmly tell her to relax my head my heart  
this is not happening this is not happening as I phone the brothers  
tell my lover.*

*PCP CMV KS TB like a chant*

*a death chant*

*PCP CMV KS TB like a death chant*

---

<sup>1</sup>Herringer, B. (1996). *The Twenty-fourth Monday in Ordinary Time*. In R. Elwin (Ed.), Countering the myths: Lesbians write about the men in their lives. Toronto: Women's Press.

ii.

*I soar cross country  
a glittering winged serpent  
secret spells clasped in my talons  
poised to strike the enemy  
you lie fragile  
shell-less and fluttering  
in a starched nest of tubes  
alarm bells  
flashing lights  
beeps and  
code words uttered by strangers with gloved  
hands suctioning poking tying you  
to your pallet*

*I beat my wings around your head to rouse you  
drop sacred beads at your feet and head  
chant ancient songs above the clamour  
you relate dreams and stories you  
become lazarus flailing from the entrance of the tomb  
fleeing the stench of your own death*

iii.

*There is a gesture in your eyes this afternoon  
your black hooded gaze freezes me  
we flounder hesitant & clumsy  
thick & stammering in this new language its  
syllables breathless with death  
like prisoners or nuns we whisper fragments  
behind mesh before you return  
to the torture chamber and I  
can only throw myself against the door or  
chant with the loved ones  
of the disappeared*

*Some days are ordinary I rub your feet we discuss  
projects lovers tell family stories cry*

*There is no etiquette for the dying*

iv.

*Sometimes your name rises in my  
throat like hysteria today  
in the sun the iridescence like your  
blood shimmering on the  
hospital sheet sweet  
droplets in the cup of your ear  
leaking*

v.

*when she told us later she said  
he went out that morning without  
saying a word then I  
heard a collision in the parking lot*

*when I heard the key in the lock I thought  
he'd come back for his wallet but  
it was the police  
don't go to the window they said and I*

*had yelled at him this morning told him  
I am freaking out too  
held my baby boy crying the two of us  
I had my plane ticket I*

*needed to be home for awhile I said I  
love you but I need to be home for awhile  
I said.*

vi.

*your spirit flew like your body  
hurtling across west end skyline  
before I saw you  
flat slabbed under glare  
the nurse hushed in the corner coroner's  
orders the protocol of suicide*

*I cannot grieve you alone they are  
afraid I will capture your soul breathe  
life clip a lock of hair chant or rage  
until your hands warm to my touch*

*instead I lift the stain dappled sheet lightly  
from your limbs a voyeur imprinting the  
glint of bone the glaze of blood the  
soft seep weeping over your body will you  
collapse if I touch you*

vii.

*your body draped white  
sheet to your chest you  
could have been expecting a  
massage a lover  
to puzzle your bones mend  
the mosaic of skin and  
teeth to staunch  
memory and brain to capture*

*the poems of your life spilling  
on the trauma room floor*

viii.

*for weeks I carry your broken bones under  
my skin your wild heart at night in my chest  
my feet on earth deliberate so I will not take  
flight with you  
the weight of you flung against the sky in longing*

*I expect transformation*

*you with a message you peace(d) together  
come in for tea sit in the garden the roses  
brilliant blood like the last time I saw  
your body tell me tell me are you  
flesh and blood not an outline teasing  
blood flesh word I need  
one word and it is not you  
dead*

*let's talk for a day a night what could I  
do but rub your feet make tea the words like  
fog between sleep across worlds you in the  
out of reach  
me in ordinary time*

*I construct our story from the scraps  
of bones an archeologist poking  
in ruins for clues and sustenance longing for  
messages in dreams or you out of the corner  
of my eye around the corner your earring glints  
or a tie flutters I am  
doubting Thomas faithless without signs  
if I toss your ashes under the full moon would you  
speak for an instant  
read a poem sing tell me  
tell me*

The day that my brother Jay killed himself and the few weeks immediately afterwards was probably the most terrible time in my life. Even these many years later I miss him terribly—his travel adventures, phone calls from across the country, the times we lived in the same cities, the newsletters he would create and send all over the world to his friends,

seeing him at the Vancouver Folk Music Festival or marching together in some demonstration. He was a gay man who had his first sexual experience as a young teen, “came out” in his early twenties and died on April 24, 1989 when he was 35, eighteen months after a diagnosis of full-blown AIDS. For several months after his death I felt a terrible physical ache and a sense of anxiety and I’m sure, like my three surviving brothers and our mother, as well as Jay’s friends, I kept reliving that day, blaming myself for some words I did not say, or may have inadvertently said to him during his illness. The most vivid memory I have of the day my brother Jay killed himself is walking into what was called the trauma room and seeing his body covered with a white sheet just to his chest. The room glaringly bright, no soft corners only knife-sharp light that hid nothing.

These “fore (words)” are intended as a personal introduction to this inquiry. My initiation into the world of HIV/AIDS began a few months before Jay’s diagnosis in late February 1988, when a dear friend, with whom I’d had a relationship in our younger days, told me that he had full-blown AIDS. Stephen called from the hospital. It was a great shock, and a physical response, to imagine a man I’d known most of my life, dying. After we hung up I raced to the hospital. We clung to one another crying. I was furious that he hadn’t called earlier. It was our old pattern. I wrote:

*December 11, 1987*

*Stephen has AIDS. I have been trying to contact him at home and at the studio, and before he finally got my message and called, I knew. He called from St. Paul’s on Tuesday afternoon—and I went down to see him. I couldn’t believe that he hadn’t contacted me or had someone contact me. The women from the studio have been involved. He has pneumocystis pneumonia [sic] PCP and has lost a lot*

*of weight. He had been wearing an oxygen mask but has graduated to oxygen thru little nose plugs. George is travelling in Asia and Steve doesn't want to call him. I cannot quite believe he has AIDS, that he could die within a year or two. I have told him I would like to be part of his support network and have called M. To arrange a meeting of Steve's friends...Saw him yesterday but he was pretty groggy from an internal x-ray. When he first told me I was sitting at the computer writing a policy paper. After I finished talking with him it was as if my own life passed before me. And now, two days later, I'm feeling quite down--somewhat angry; at a loss as to how best support him. We've known one another for 20 years. Part of the anger--which I spoke to him about--was the fact that I wasn't told, and his "straight" friends were. He says he couldn't deal with telling those he feels really close to. When we talked again I said I just wanted him not to be so protective, to trust that I care for him and want to be there. Both of us crying... I think of Jay.*

Shortly after this I wrote Jay who was living in Quebec and working in Ottawa. I received a return letter in January letting me know that he was well. It was a melancholy letter about his Christmas and New Year with a group of fairy friends enjoying themselves in the deep winter of Quebec, wondering what 1988 would bring for them. It talked about AIDS, about what the disease was doing to friends he knew. He was shocked and saddened to hear about Stephen, but he didn't mention anything specific about himself. I didn't want to read between the lines of Jay's letter, but my partner thought he was also sick.

One Saturday morning several weeks after receiving Jay's letter as I was getting ready to meet with my research group to work on our graduate project, my mother called long-distance in great distress. "Jay's in hospital with some kind of pneumonia!" She didn't say he had AIDS but it was clear from her description that that was the diagnosis. Jay had collapsed in his doctor's office and had been rushed immediately to hospital. I remember the roar in my ears and chest, the terror and helplessness, anger, and disbelief as I listened to her, and then hung up the phone. It was a physical, visceral sensation. I

also was unable to believe that now both Jay and Stephen were dying. A few minutes later I told my partner and called two of my other brothers who lived nearby. None of us could believe what was happening.

My mother arrived in Ottawa first; two of my brothers and I flew in as soon as we could. Jay was on life supports in intensive care and we were told by the AIDS specialist that he had a thirty percent chance of survival. All day we moved between the waiting room, his room and the hospital cafeteria and in the middle of the night back to an aunt's apartment. We watched for signs of change as we stroked him and spoke to him. We stood by as medical staff ran to his room to check numerous machines as emergency bells sounded, or as they syphoned fluid from his lungs, adjusted heart monitors or oxygen flow, and were alert for signs of failure. Social workers and members of the hospital chaplaincy were available, and we talked by phone to family members and friends who couldn't travel but wanted updates. One night while sitting with Jay I made a quick entry in my journal, followed by others during the week:

*February 23, 1988 (11 p.m.)*

*I am sitting in Ottawa General—Jay critical with AIDS—PCP, weak heart and lungs. Drs. unsure of outcome. Said 30% chance he'll live. I've left the room for a few minutes while the nurse bathes him. He was on 80% oxygen until a few minutes ago—now on 60%—is hooked up to ventilator and has extra ventolin every four hours. Mom here since Sunday. Jay arrived here Saturday. He is very sad + frightened. Angry too. Stroked my face, crying. Tried to hug me but couldn't for all the tubes. I went for a quick tea + when I came back his wrists were tied down. He has unconsciously (or maybe not) tried to pull out the oxygen tube and according to the nurse, nearly died this morning. He cannot talk and has to try to write. Is very weak. Wrote, "I feel like a fucking prisoner" + then began to cry. Mom is struggling. Says this is harder and more terrifying than when Dad was dying. I cannot believe it, + yet it is expected...I am going day by day*

*Feb. 25/88*

*Jay is improving! Began yesterday. On 30% oxygen; still trying to regulate BP. Chris arrived last night; Steve this a.m. [brothers]. So many emotions—from profound sadness, anger, hope, love, blankness, dread. All of us experiencing so much, privately. Sharing bits with one another—what I did not experience/feel with Dad [I had been out the country when my father died]...Jay may be off respirator in a.m. He is breathing a lot on his own. Still many tests, heart ultrasound, Bps, air, etc. Talked with Dr. G, infectious diseases, who was very pessimistic 2 days ago + who now says Jay is doing well. I asked about AZT—he has many patients on it, says 80% are working at jobs—those who cannot tolerate it are taken off. He says Jay has a 50% chance of living another year...Jay may move out of ICU in a few days, then stay on pentamidine for a few weeks. I'd like to stay until he's out of here. He is very exhausted little energy—he is breathing on his own. Have massaged his feet, hands, head. Done a bit of hands on...Not much time alone as much to-ing and fro-ing by staff. In all, staff very kind + attentive, caring. Sometimes get the feeling they would prefer we weren't here—but overall, okay. (Lazex, dopamine, digoxin, septru, pentamidine, something for thrush, etc. Heart monitor, ventilator, bp monitor, IVs for dopamine, food, pentamidine). All rooms surround 2 main nursing stations. Must phone from ICU waiting room. Bright yellow door, pale yellow walls. Jay wrote to say he is hallucinating purple. Chris says moving from yellow to white constantly can do that.*

*March 1/88*

*On plane home—very tired—flight 90 minutes late. Jay moved from ICU abt 5:30 on Friday + is doing so much better since last week when they did not expect him to live. He must wear nose plugs, is very weak, but has good appetite. On pentamidine, digoxin, ventolin. I feel so sad. Have not really cried. Have had bouts of anxiety—some of it about telling a university friend that Jay has AIDS—have I jeopardized his privacy—chance of jobs? Then I think, why not tell, educate? It is as though I'd stepped into an alien realm—death so close to people I love—Steve, Jay. Mom so worried abt him—not wanting to think beyond the day—where will he stay once he's out of hospital? He wants to come to Van sometime in May. Worries abt how this is affecting Mom—*

*Here we all are at hospital—in + out of the room along with nurses, cleaners, doctors, nurses, a friend or two—We were all in there at times, or 2 at a time, or alone or none of us. Trying to allow him his privacy—the balance but support + his need to be alone as he his getting better, stronger. He had a shower, beard trim + hair wash today, so looked more alert. I have gone through times of feeling such helplessness—was my presence positive; am I too pushy, know-it-all, too*

*overwhelming. Tried just to be, massaged his feet, held his hand, told him what I could of Steve's experiences. Tried to normalize w/o minimizing the terror of death. He talked today about feeling somewhat able to pursue the process of dying with a kind of curiosity abt "the other side". Would there be a light? A person? Dr. G. in about AZT. I expect Jay will enroll in the treatment. G. says it's helpful in destroying virus--Jay talked today abt how bad he has felt abt himself in his life; how little self-esteem--how ugly he felt--so went with anyone who would have him! Said he ended up with alcoholics until Vancouver and G (clowns, fun, etc.) Always saw being gay as sexual and/or political, not a celebration of our lives.*

*It was hard to leave, in some ways felt my support was more for Mom than Jay; she told me she didn't think she could live if he died...Jay said he could not see the future. He was extremely sick all winter. Could not cook. Began to see psychologist + told him he could not see anything. Could not call friends, felt like Howard Hughes--a hermit. He has begun a journal--says he may as well use his writing skills so that it will help others sometime. He also wants to write some of his travel stories.*

After a tense week Jay was moved first to a private room, then to a ward, and three weeks later, discharged. Our mother remained in Ottawa for the month, and as he gained strength he decided to make arrangements to move back to Vancouver. His friends helped pack up his flat, he sold an old car, and sadly and with embarrassment, resigned from his sessional position at Carleton University. He stayed for a few weeks in Calgary to be there for our younger brother's wedding, and arrived in Vancouver in May 1988. He lived with friends for awhile until he found an apartment. He quickly became active in the Vancouver Person with AIDS (PWA) Society and organized two out-of-town retreats for PWAs over the summer and fall; with his legal training he also became an advocate. That June, he and Stephen, both weak but feeling optimistic, and a few other friends participated in one of the first Vancouver AIDS walks through Stanley Park--it took us nearly all day! There was great hope. I remember feeling that they would somehow survive.

Throughout the summer Jay revised his Masters of Law thesis and made plans to produce what he was calling his international video law project. He had made contacts in Beijing through various provincial and federal trade connections, and produced a video with another brother who would travel with him to Asia. They travelled to China and Thailand in November 1988. Jay presented his ideas at Beijing University and several other places and made enough of an impression that the project was funded. Jay called me in mid-December, just before his 35th birthday, saying he was home, and not feeling very well. My partner and I had just relocated to Victoria and had invited Jay and others in our families for Christmas. Despite feeling sick, Jay decided to come. He was incredibly uncomfortable physically and on Christmas day I called the hospital trying to find a druggist who could fill a prescription--he had thrush in his throat, a terrible cough and could barely move. Shortly after returning to Vancouver he was back in the hospital for a few days.

Throughout January and February 1989 his former exuberance for the video project and other schemes faded. His blood count was low so he had transfusions; his doctor suspected TB so he had a bone marrow test and was trying to maintain some level of health in order to take part in a clinical trial for a drug that would help curtail pneumocystis carinii pneumonia (PCP). He was on drugs for PCP, had an ulcer between his stomach and esophagus, a kaposi sarcoma lesion, and continuous problems with candida. At the end of February he was admitted to hospital again with PCP but felt he would recuperate from this "stumble". He was discharged in early March and our mother flew out to help him get back on his feet. Throughout March he seemed to deteriorate

emotionally and had two admissions for what appeared to be an overdose of sleeping pills. My journal reads:

*March 27, 1989*

*Jay was in hospital late Feb + I went over for a few days. Met with his doctor a couple of times; saw the social worker, etc... Called Mom and she came out to be with Jay after discharge. He has been up and down emotionally for quite awhile + told her one day last week that he felt on the edge of despair. He went back into hospital on Thursday for severe depression... has this fearful, terrified stare. He fell getting out of bed and wouldn't get up. Stayed in fetal pose; wouldn't let Mom touch him or cover him. She called Chris and they took him to St. Paul's. They did CT scan + spinal tap but found no medical reason for the depression.*

In late April, three days before Jay died two of my brothers and I, and my mother who had been in the city taking care of Jay, met with him in his apartment to talk about how we could work together to make sure he had everything he needed when our mother went back home for awhile. His apartment living room was small so while Jay and mom sat on the couch, the three of us sat on the floor. I will never forget Jay's demeanor—he who was usually in control of various projects or schemes sat wringing his hands. We tried to sort through how meals would be taken care of, and other necessities accomplished. He was passive. I said, “Jay, we don't want to organize your life, you've got to let us know what would work.” He responded, “It's too late.” We talked together about Mom coming back, that this was just for awhile. It was awkward and sad. We ordered pizza later and one of my brothers and I drove out to pick them up. “What did Jay mean by that?” he asked. We seemed unable to talk about it. When we got back Jay's mood had shifted and we talked of other things.

The next morning was the annual Peace march, an event that Jay took part in

whenever he was in Vancouver. I knew he wouldn't have the energy for the march itself, but asked if he'd like to walk with me down to the park, a couple of blocks from his apartment to listen to music afterwards. He agreed but as we got to the door of the building there was a soft rain and he decided not to go and took the elevator back to his apartment.

On Sunday I took my mother for brunch with some friends. Both of us were distracted and worried about Jay and came back to his apartment early. I realized I had a strong feeling that he was going to kill himself. But when we got there he has showered and changed--there was sense of gaiety about him that didn't ring true, but I was happy to see him smiling and talking. Mom was leaving for home on Tuesday and I'd be heading back to Victoria after my meeting the next day. I stayed for awhile and said my good-byes to both of them and told Jay I'd call the next day and would see him again soon.

I was called out of my meeting the next morning for a phone call. It was Stephen's lover George telling me that Jay had jumped from his apartment building and had just been taken to the hospital. Nothing made sense. I could hear George's words but could not unravel them to obtain their meaning. I called my partner in Victoria and told her that I was leaving for the hospital. I returned to the meeting to say I'd had a family emergency, got into my car and tried to remember how to drive. It was an absolutely glorious Vancouver Spring day.

I had been into this hospital countless times during the last two years, often visiting Jay on one floor and Stephen on another. I raced to the emergency room to find out if he was still alive. His name was written on a huge white board behind the nurses

station. I demanded to see him and was told they didn't know if he was dead—he hadn't been pronounced dead officially. I wanted to see his body. I cannot remember who of my family or friends was there when I arrived. My mother wasn't yet at the hospital. Eventually we were told he was dead and were able to see the body, but only in the presence of a nurse, because he had committed suicide. Jay was lying on a metal table in what was called the trauma room. It was glaringly bright and exposed. A sheet covered his body from his feet to just below his shoulders. I walked to the table—he was cool to my touch. "Oh, Jay." His eyes were partially opened and there was a small rivulet of blood in the cup of his right ear. His familiar face was broken. I lifted the sheet to see what else was damaged. I had expected his body to be unrecognizable from the fall. I cannot remember if my youngest brother Chris came in with me then or if I was already with Jay. I couldn't cry.

## **Reclaiming a Life: Ways of Telling AIDS**

I have made use of words in different forms in order to understand Jay's life and death. The first "method" I chose to explore my feelings about Jay's death was to embark on the suite of poems presented at the beginning of this foreword. The poetry "method" is about me. The subsequent method I've chosen as a social scientist is one that enabled me to explore the way in which the social relationships about AIDS are organized—it was a world that both Jay and I shared, but in a taken for granted way. As a poet I attempted to make sense of Jay's illness and death through a different use of words than I am using

now to begin to describe the social organization of these terrible events through a method of research. The tasks are both similar and different. With poetry I used a form that would help me tell the fragmentation I felt in losing my brother and the “worldly” tasks that ensued. In the days and weeks that followed his death I experienced what I suspect many in these situations encounter—a tremendous sense of unreality, or dissociation. I saw the rest of the world existing in “ordinary time”—people living their lives, going to work, missing buses, having lunch— while I felt as though I was existing in a realm outside my usual life. Perhaps Jay’s “time” was changed as well when the dailyness of his life as a writer/researcher, a sessional instructor of communications law at an eastern university, a lover, a friend, brother, son, and so on, was transformed into that of a gay man with AIDS, his life transcribed into document time, discourse, and organization. In this documentary realm, the latter tends to take on status as the official knowledge of the experience, translating a life into abstract categories, such as “suicide” by which it can be made accountable. At least this is what I have come to understand from Dorothy Smith’s (1990a and 1990b) approach to the social organization of knowledge which I will discuss in Chapter Four.

This project is not about who owns truth—that if the truth about AIDS does not exist in medical or professional discourse, it must then lie in the personal experience of a person with HIV disease. It is rather about how HIV disease works today; that is, how concepts, institutional practices, and professional discourses intersect with the daily lives of actual individuals. What I intend with this work is to focus on how the experiences of gay men with AIDS are organized through the practices of the medical and professional

management of their illness and death, and to begin to reveal the whole range of social practices and pressures that engender those experiences and subsequent choices (Kinsman, 1987, 1989; G. Smith, 1990). Particularly I am interested in showing the “work” involved in choosing to live or choosing to die by those with HIV disease, and the ruling or bureaucratic practices involved in defining a particular death. This inquiry is an attempt to illustrate what might be learned about the social organization of AIDS “suicide” by investigating an account of a gay man living with HIV/AIDS who took his own life, as well as the accounts of those who have intimate relationships with him.

Smith’s method of inquiry using institutional ethnography appealed to me because I saw it as a way to grapple with the same questions of form and method that as a poet I worked with in attempting to come at transliterating my experience into form(s) on the page through a mapping of letters, phrases, syntax, grammars, sentences, pauses, space, and so on. Institutional ethnography offered me a way to do science that can trace the complexities of a life and a death related to the transformative experience of a stigmatizing disease. As I wrote the suite of poems I did not concern myself with whether I needed evidence for what I said or felt. However, as I write institutional ethnography I cannot say what I do not have evidence for. The research starts in the everyday/everynight world of people, and my evidence comes from using their experience as a way in, or an entry to the broader social relations of HIV/AIDS.

The later decision to undertake this institutional ethnography and contribute my words to the discussion regarding HIV and AIDS emerged, as did the poetry, from my experience of Jay’s illness and death. Since he died I have begun to think and write about

intersecting accounts or stories written and told against the backdrop of AIDS. There are Jay's words through his journal (presented in Chapter One), notes to himself and others about his struggle to live and to come to terms with his pain, and his feelings. My words intersect his at times, expressing my own confusion and loss as his sister, as a lesbian and as a social worker. Finally the seemingly dominant narrative of medical and professional discourse interjects, defines, categorizes and reflects on what words or actions are to be acknowledged on the shifting terrain of HIV and AIDS. I wanted to show this relationship, and what I began to see as the discursive organization of Jay's journal.

As a woman who has inhabited the related realms of practice, policy, research and education within the profession/discipline of social work; as well as a feminist who has been involved in grassroots cultural and social organizations for many years, I have been continually intrigued by apparent ruptures between what happens in the daily lives of workers and clients for example, and the policies, legislation and education that often purport to describe the experience, while governing and organizing their lives and our work. I was aware of several gaps or disjunctures that became glaringly apparent during the eighteen months between my brother's official diagnosis of AIDS and the day he took his own life; and which I will talk about in various chapters. In an effort to try to understand them, I embarked on this project.

One vivid moment that made visible to me the break between Jay's experience of living with AIDS, and the authority of the discourse and practices inserting and organizing themselves into the lives of those with the disease was first hearing he had collapsed, was rushed to intensive care, hooked up to various life supports and not

expected to live. Through the maze of tubing and machines it became clear that we were now on opposite sides of a chasm. He had entered a world in which his homosexuality was seen to have caused the pneumonia that is one of the many infections of acquired immune deficiency syndrome. We were told to expect his death in a matter of hours or days. He had acquired a new identity and was becoming a North American and world-wide statistic. His life was no longer his in the sense of being able to determine who would know about him. He was “known” in an official capacity now as his everyday life was catapulted into a mesh of social relationships outside of him – hospitals, physicians, nurses, social workers, homemakers, worried family and friends, and AIDS service organizations. As a gay man with AIDS he was also entered into media and cultural commentaries on the disease; political debates about quarantine and safer sex; the right to die and assisted suicide, the privileging of persons with AIDS by labelling some innocent, some guilty victims; and academic theorizing about identity and homosexuality. His private life became public. His journal shows traces of this organization as he wrote for example that he was “reborn”.... “I am Jay with AIDS...a PWA”.

After he killed himself another such moment illustrating the separation between everyday experience and its discursive organization took place in the trauma room of the hospital to which he was taken. One of my brothers and I wanted to see our brother’s body and were not allowed to be in the room alone with him. A nurse was required to be there with us. This was the hospital’s policy as determined by the coroner. As a result, our grief was publicly displayed in front of this woman who, although no doubt sympathetic, could not waive this organizational requirement and appeared extremely

uncomfortable in one corner of the highly lit room. Did the hospital expect that we would take his body? Were we thought to be possible of rendering this death not a suicide? My urge was to examine his body, to see for myself the damage that had been inflicted on himself by this once exuberant, living, gay man. We were allowed to gather ourselves in the "family" room to await other family members racing to the hospital to see if his death was the truth. We knew he was dead and yet were required to have the doctor pronounce it officially and determine when we could be with his body. Later, coroner's requirements also meant that the memorial service had to be delayed while we waited for the release of his body that travelled from hospital to morgue to funeral home in the black body bag that was included in our final billing.

In a different way, these stories help locate the particular accounts around which I am creating or constructing my study of the social organization of knowledge regarding AIDS-related suicide. These include personal meanings and experience, professional meanings, and the intersection and overlap of professional and personal accounts. My intention through this inquiry has been to reveal the social organization of AIDS which "captured" Jay when he was diagnosed with AIDS, and when he subsequently took his own life. How does the everyday world of Jay and of other gay men get turned into a system in which the ways they want to live and die are ignored? As Diamond (1993) suggests, "what the work [of living and dying] actually involves, as compared with how it is written and spoken about in administrative discourse is a theme of this research...." (p. 247).

There have been many stories about AIDS throughout the 1980s and 1990s. This

project is intended to offer one version of AIDS suicide, a chronicle, or travelogue into the past for the purpose of investigating how AIDS suicide works in contemporary society for some people, and how someone with AIDS might make the choice to live or to die. It is an analysis of a certain corner of the world, a small piece that may illustrate how some knowledge is created at this time in a specific place. Arranged with other puzzle pieces, be they creative art or creative science, it may begin to shed light on a certain page of AIDS history in Canada. This “story” of AIDS suicide needed to be told in a more detailed personal account before moving into an analysis of the social relations that keep it in place societally. And while this is about Jay, and about me his sister responding to his life and most particularly here, his death, it is about more than this. It is about how we, his family and friends were entered into AIDS life and suicide, and what our experiences may say about it. It is also how I re-place Jay’s experiences into the context of “life with AIDS in Canada” in order to learn more about them.

The passion and grief that fuelled my earliest writing about Jay’s death in the creative forms of both the journal and the suite of poems has also motivated this “scholarly” writing. It too has a rigorous form through which I am disciplining myself to reclaim Jay’s life and death from those who took him, and his life’s efforts. The same pain, loss, grief and impotence drives me to make sense of what happened. This reclamation gives voice to Jay’s life and the way he chose to end it, rather than allowing it to end on someone else’s terms. I began this project wanting to understand perhaps my own pain and loss, and the devastation wreaked by a disease and a response to it. What shifted was my initial focus on my individual reactions. As I worked through the analysis,

the project became one of attempting both an investigation into, and a disclosure of those external social “forces” that overtook Jay and me, and which ultimately organize the lives and deaths of others with HIV disease. I discovered that his journal shows me how he was taken up by AIDS in his life as well.

## Chapter One

# AIDS Narratives/AIDS Histories: The Problematic of Discursively Organized Life & Death

*What is to become of me? I go to Vanc. + live on welfare. Maybe get some freelance work. Going to the west coast to die? Going home to die? What is death? Will it be 1 year, 2,3,4,5, or 10? How do you fight this thing... (Jay's Journal March 19, 1988)*

*Support, care and quality of life are concerns of the division...Activities included palliative care, homemaker services and mental health issues while others involved collaboration with the United Way and Family Services Canada to name but a few. Consultations with provincial governments have been maintained... (Health and Welfare Canada, Federal Centre for AIDS Report for 1988).*

*In identifying ideological methods, the contrast drawn is not between biased and unbiased (objective), procedures for generating or reading accounts. We do not suppose there is one objective account of 'what actually happened' against which other accounts may be measured. The lived actuality remains a resource in memory in a relation of reflection through which 'what actually happened' arises. Here ideological practices in encoding and constituting 'what actually happened' will be contrasted with procedures which are directly expressive of the lived actuality in experience. The latter we will call 'primary narrative' modes of expression. The difference is not one of accuracy, completeness or truth. It is one of methods of telling and interpreting (Smith. 1990a, p. 157).*

## Introduction

Jay amazed me with his resilience. I was unaware that he had written “how do you fight this thing?” –this AIDS thing for which there were no assurances regarding how long he might live. Nonetheless, I was continually struck by the efforts he made to keep himself well, the work he did to advocate for others with HIV disease, and the manner in which

his personal experience was dealt with by various professionals such as doctors, nurses, social workers and complementary health professionals—massage therapists, acupuncturists. When I decided to inquire into the social organization of AIDS suicide a few years after his death, using his journal seemed the best place to begin. The journal (see Appendix One) records feelings, plans and fears to reveal his everyday/everynight account of his life with AIDS under the spectre of death. It also refers to various issues emerging in Canada as a result of HIV disease in the late 1980s. For example, while Jay was trying to figure out how long he would live now that he had been diagnosed with AIDS, it appears that the federal government was unsure of much about AIDS in 1988 as well. Its efforts are reflected in the excerpt above in which one of the “supports” for persons with AIDS is helping them to die comfortably through palliative care programs. As I learned more about what had been evolving within governments, community, and professional organizations while Jay was sick, it was not possible for me to understand what was unfolding in his account of his life without noticing how he was positioned within a particular historical, political or organizational location.

Throughout this inquiry I discovered, not surprisingly, things of which I had been unaware when I first began. As I discussed in *Fore(words)*, I sought to reclaim and make sense of Jay’s life and death first through poetry, and then through a social science inquiry. I remember for example, an early conceptualization in which I juxtaposed various narratives (Jay’s, mine, and the professional) to illustrate their connectedness or reliance on one another (Herringer, 1992). I realized however, that that particular exegesis did not provide an entirely effective way to show how living/dying with AIDS worked.

What took me a long time to figure out as I worked through my analysis was that Jay's journal is more than a daily account of what he was experiencing as a gay man with AIDS. From initially attempting to "reclaim" him and present his experience as a kind of testament, I gradually discovered that his journal instead shows me how he was taken up by AIDS in his life. It illustrates how he was in a sense "captured" by AIDS as a result of his diagnosis. This chapter is about how Jay's narrative, or his personal writings which I want to honour, and which I seized upon initially with the hope that I could reveal a straight-forward picture of his struggle, turns out to be a stranger's account. By that I mean that the journal is replete with AIDS discourse and with evidence of the social relationships of the ruling institutions of HIV disease, for example, the influence of the medical establishment on his life, the power of what has been called "immune" discourse to supposedly provide a way to overcome the syndrome, his ambivalence toward being "helped", and his dilemma about whether or not suicide is a legitimate option.

As his sister reading his journal after he killed himself, and previously as a listener to his "talk" about his life with AIDS, I discovered that there is a difference between Jay's journal as his narrative "experience" and how, as a discursive account it gives me access to the institutional ordering of his daily life, thoughts, and actions. In the late 1980s for example, there were particular facts about HIV disease confronting those newly diagnosed. One overarching fact was that a diagnosis of AIDS was almost certainly a diagnosis of imminent death. Jay's written account of his everyday experience of living with the diagnosis of AIDS, of watching his body deteriorate, of struggling with the reassessment of a once joyful homosexuality, of attempting to comply with various

drug testing, is intertwined with the powerful voices of biomedical and professional discourses that supported that approach. Historically stigmatizing definitions of homosexuality and AIDS, notions about the proper way to approach death, and the practical application of these definitions, seemed to seep into the consciousness and day-to-day lives of gay men who lived and are living with the disease. Jay's personal narrative is permeable, its boundaries yielding to and embedded in an emerging history of HIV/AIDS in the late 1980s. I saw that Jay's lived experience seemed transformed as he wrote about it in his journal. He appeared to be waging a struggle between what he was experiencing socially, emotionally and medically; that is, ignoring his own knowledge about his life with HIV as the disease ravaged his body, and what was being presented as fact, about HIV disease elsewhere. There is evidence in the journal that he believed he might be able to overcome the then-terminal diagnosis through positive thinking, or by complying with various drugs, by eating properly, by not being sexual. Seeing the journal as discursively organized is what I count on to re-constitute an analytic account in which I can begin to replace the missing pieces—or the social relations.

From first juxtaposing and giving equal “weight” to three discrete narratives as I mentioned earlier, I came to realize that what I was attempting to illustrate through analysis, was how people “know” about AIDS. Jay's journal, as an exhibit or chronicle of a certain moment in the history of AIDS, offered me a glimpse into a life being lived in the shadow of a life-threatening illness—not any illness, but what some were calling at the time, a “gay” plague. For me, the journal as Jay's “voice” has been a place to begin an inquiry into the circumstances of his decision to die by his own choice and at a time of

his choosing. Trying to reveal how someone lives a life organized by the history and contemporary enactment of knowledge about AIDS, homosexuality and death/suicide gave rise to the problematic (a technical term used by Smith which I will discuss in Chapter Four) or puzzles of the inquiry. The puzzle I began to piece together was how to remain or be at the centre of one's life when it is subordinated, defined, submerged and almost at the total mercy of external "forces" ( that I describe more fully in Chapters Two and Three in a discussion of how ideas about homosexuality or suicide are played out in official terms). I want to show here how the "history" of HIV disease as it continues to be presented, is based on official/scholarly/professional knowing and penetrates into the narrative of Jay's life, as journalled. This is my topic for inquiry.

The starting point into the social organization of AIDS "suicide" by a gay man is from within what Kinsman (1989) refers to as the "local historical experience" of HIV/AIDS, and Jay's resistance to it--a resistance in which I was involved as his sister, a social worker, and a neophyte AIDS activist. In the problematic as I understood it when I first began, are the actual social relations that I began to trace. I fill in for example, what Jay does not say, and although I cannot analyse what actually happened since I was not there every moment of his life with AIDS; nonetheless, using what I do know from the time I spent with him and with others who have had HIV/AIDS, of the time I have spent in AIDS organizations, and at conferences specific to HIV/AIDS, and the reading I've done, I began to figure out what could be learned about the social organization of AIDS "suicide" in the late 1980s.

This chapter presents two pieces of text about which I have been talking--excerpts

from Jay's journal, and what I consider to be some of the influential "historical" issues of the late 1980s. While I am not attempting to provide a detailed history either epidemiologically or socially, this brief look may suggest a sense of how at the time of his illness, Jay was embedded in a social construction of a particular knowledge of AIDS built up from the medical and professional practices and policy, somewhat reluctant federal and provincial responses, the actions of emerging AIDS community groups and relevant literature regarding HIV/AIDS. Knowledge of how Canada is dealing with HIV disease still comes through government documents as translated through media and culture, from community-based AIDS organizations, or first hand experience of the illness from those with the syndrome and their family or friends. As will be evident in Chapters Two and Three, for example, ideas about homosexuality and about suicide form the environment, or lived/social "knowing" of a person's life with AIDS. The analytic point of presenting a "factual" historic review here is to provide a means of focussing on the early response to HIV/AIDS by the Canadian government and by community groups and to begin to show how these responses were actualized in what is revealed in Jay's account--in other words how a personal AIDS narrative and an historic account intersected in the late 1980s and what that may reveal for the present.

## **An “Historical” Account**

Grover’s (1992) work supported my contention that many of those critiquing AIDS in terms of how it was represented culturally, tended to ignore “the relationship between these representations and the lived experience of those people coping with AIDS” (p. 232). Her criticism is aimed at what she sees as an essential quandary in a great deal of writing and broadcasting on AIDS-- “it ignores the communities with the greatest stake in AIDS as subjects, as viewers or readers, and uses them only as objects of its discourses” (p. 231). Others (Mykhalovskiy & Smith, 1994; G. Smith; 1995; Kinsman, 1992a) have found that this misrepresentation exists as well in the professional discourse about AIDS and HIV. The practice of repression can be seen to be organized through depersonalizing those with the syndrome. People living with HIV/AIDS are objectified through texts and representations that are created and taken up by others without their presence. I remember for example, an AIDS conference committee meeting several years in which the local hemophilia group did not want to work with us in organizing the event because the society organizing it was perceived as “too gay”. We are left with only the concept of AIDS expressed through hate or fear.

Fear of contagion sparks varying reactions. Early in the epidemic for example, Lopez and Getzel (1987) note that as the number of persons with AIDS grows into the tens of thousands, the shattering of illusions and myths is often accompanied by mounting fear, panic and diffuse rage. Weeks (1988) argues that “it has become more than a ghastly and relentless disease. It has come to symbolize an age where fear,

prejudice and irrationality battle against reason, responsibility and collective endeavour”

(p.10). Fear of contagion also often isolates both the person with HIV/AIDS and those who would support them. Altman (1987) notes:

For most people it has been the fear of contagion rather than the experience of loss that has made the disease a reality. The ability of the media to create panic, not only in the United States, but virtually throughout the world, means that widespread awareness and fear of AIDS coexists with considerable ignorance of its real impact ( p.1).

Accompanying the literature on cultural representations of AIDS exists a vast technical and medical literature on HIV and AIDS that until recently has remained distinct from any insider knowledge of the syndrome. Each year for example, the International Conference on AIDS, organized primarily by medical and research professionals, produces thousands of scientific abstracts on various aspects of the disease; and yet until recently, no persons living with HIV or AIDS were invited to speak. Persons with AIDS infiltrated the conferences in Montreal (1989) and Amsterdam (1990) and disrupted sessions demanding that their voices be heard. They were protesting other people’s words about their lives. The appropriation of voice that gay activists struggled against extends the debate that continues to rage in Canada’s cultural communities regarding the appropriation of voice.

Throughout my work in this area I have been interested as well in the way AIDS confronts our attitudes, values, social relationships, helping networks and institutions. It confronts our notions of individual and community practice and, because it extends across so many issues, traditionally-drawn boundaries will need adjusting if our work is to be effective. I came across Treichler’s (1988) work early in my readings and was

interested in her argument that “AIDS exists at a point where many entrenched narratives intersect, each with its own problematic and context in which AIDS acquires meaning” (p. 63). Because I was trying at that time to locate a method of using narrative and accounting for the way language is used in AIDS discourse, her observation that there is a continuum, not a dichotomy between popular and biomedical discourses that plays itself out in language, was appealing. Throughout the history of AIDS, she argues, the scientific text of AIDS has been not only re-read, but continues to have its facts adjusted. Stereotyping, homophobia, and confusion exist in biomedical discourse. Repeatedly however, outside interventions from AIDS activists and their allies, attempt to influence that discourse, as in the disruption of scientific conferences mentioned above. The political actions of the gay communities in contesting explanations, meanings, resources have resisted the hegemony of biomedical authority. Treichler suggests that:

to challenge biomedical authority--whose meanings are part of powerful and deeply entrenched social and historical codes--has required considerable tenacity from people dependent in the AIDS crisis upon science and medicine for protection, care and possibly a cure. These contestations provide a model for a broader social analysis, which moves away from AIDS as a lifestyle issue and examines its significance...with the cultural and material resources available to us (p. 40).

Because of the extreme political agendas linked to AIDS, Treichler suggests that we do not know whose meanings will become the official story. She calls for an “epidemiology of signification--a comprehensive mapping and analysis of these multiple meanings--to form the basis of an official definition that will in turn constitute the policies, regulations, rules and practices that will govern our behaviour for some time to come” (p. 68).

The way in which the history of AIDS is being re-written, adjusted, and ultimately

socially constructed presented itself to me recently. As members of a provincial AIDS strategy advisory committee we were to comment on various aspects of a document in progress. In the preamble to the strategy document the authors had presented the history of AIDS from the point of view of what the British Columbia government had accomplished in the last fifteen years. There was great discussion and general consensus that this was not the place to laud what had been in the 1980s a lack of response to HIV/AIDS and to those dying as a result of it. Instead, the document now reads from the point of view of community contributions and responses, and the later government support. Yet, even the community response privileges and silences various versions of how individuals and groups have been affected by HIV disease in the province. Like Jay's lived experience, once these other stories of AIDS whether community or government are inscribed in text (print, film or other media) they reflect those experiences from the standpoint of the text (Smith, 1990b). The fact that a provincial AIDS strategy will appear in 1998 for the first time, speaks to the committee's consternation with the government's revisionist approach, as committee members still grapple with how to remain "true" to what they recall as their community's contribution to an activist agenda for those with HIV. What has been evident for many years is the gap between "the needs of the community-based AIDS organizing and state and often professional regulatory practices at the federal and provincial levels" (Kinsman, 1997, p. 215).

Jay was writing about his experience with AIDS in the late 1980s, approximately five years after the syndrome began to be viewed as a concern by gay men, then by

medical health officials, professionals and those ordinary Canadians attuned to current health or cultural affairs. As seems evident in Jay's account, when someone is diagnosed with AIDS, he or she is catapulted into an already-existing mesh of bureaucratic health and social networks and demands. He was embedded in a social construction of a particular knowledge of AIDS, built up from various sources: medical, affected communities, media, relevant literature and so on. In Canada some of these social relationships included the struggle to define responses to the disease among persons with HIV/AIDS, governments, health and social professionals. When Jay was diagnosed with AIDS in February 1988, I had already been collecting as much information as possible about it from various sources--health, culture, spiritual, political, activist, and government documents. I was also involved in the care of my friend Stephen who had been diagnosed with AIDS two months before Jay, and I spoke with people working in the area such as physicians and social workers, members of the local persons with AIDS society, and other men who were sick. As a graduate student in social work at University of British Columbia at the time, I also began to search whatever was written in that body of literature--a friend finishing his thesis on an aspect of AIDS found approximately 34 articles written by social workers (Baisley, 1988).

What I saw when Jay returned to Vancouver in late May, 1988 two months after being discharged from the hospital, was he and others demanding alternate treatment options, vitamins, food supplements, experimental drugs, and the money to purchase AZT, the only drug available at the time. What they faced was a Social Credit government lead by a pro-life roman catholic premier who, with his minister of health

believed that those with AIDS had invited it upon themselves, and were ready to enact quarantine legislation, not make AZT available, refuse to fund education regarding HIV/AIDS and basically ignore the ever-increasing numbers of those infected and dying in the province (Herringer and Solomon, 1989). This response to HIV/AIDS in the late 1980s was evident not only in British Columbia, but across Canada as well. In this highly stigmatizing context persons with HIV/AIDS faced the definition of their disease as terminal, an approach taken up by health professionals within public health who then saw their response as providing palliative care rather than advocating for treatment, open access to clinical trials or experimental drugs, research, and realistic education programs (G. Smith, 1989; Kinsman, 1992a, 1997; Rayside and Lindquist, 1994). The framing of HIV/AIDS within the palliative care and public health discourses had a profound effect on gay men like Jay who, as will be seen in Chapter Five, worked exceedingly hard to choose to live during an era in which resources and policies, such as they were, were directed toward caring for them as they died, held them responsible for their illness, and expected them to die a natural and proper death.

A sense of the enormity of the disease may be useful to place this study in context. However, presenting “numbers” of people infected or dead is only one lens. As will be illustrated in detail in Chapter Seven, statistics themselves are constructed factual accounts. Nonetheless, as of December 1, 1997 there are 30 million people living with HIV disease world wide (Office of the High Commissioner for Human Rights and UNAIDS). This contrasts quite markedly with statistics presented even five years ago by the British Columbia Centre for Excellence in HIV/AIDS in its publication Forecast

(1993) which placed the number of people living with HIV infection world wide at approximately 20 million. Estimates in Canada seem difficult to pinpoint but the Centre suggests as of August 1997 approximately 15,000 people have AIDS, while between 42,500 and 45,000 are infected with HIV. The centre also reports that BC continues to have the highest AIDS incidence rate in Canada. More than 1300 cases of AIDS have been reported in BC and it is estimated that close to 9000 people are infected with the virus.

One would assume from these statistics that the actual lives and deaths of those infected with HIV/AIDS would have had a tremendous impact on our knowledge about current health practices, attitudes, education of professionals, lovers, friends and families. In Canada however, relatively little experiential knowledge about the dailyness of living/dying with AIDS from the standpoint of affected gay men has found its way into the intellectual discourse. In one of the few accessible examples, the television public was introduced to AIDS through Dr. Peter, a young man who regularly talked to CBC Vancouver about the progression of his illness until his death in November 1992. Two Canadians, George Smith (1990a, 1990b) and Gary Kinsman (1989, 1991, 1992a, 1996, 1997) both gay activist sociologists have done pioneering research from the standpoint of persons with AIDS. Eric Mykhalovskiy and G. Smith (1994) examined the social organization of the delivery of social services from the standpoint of clients with HIV disease. Their report, prepared for Health Canada, is an excellent example of research that involved those affected by HIV disease, and offered ways to work with bureaucrats and advocates. More recently Canadian sociologists, Adam and Sears (1996) have presented

their research on the work, family and personal relationships of men and women with HIV disease. Kinsman's ongoing work on homosexuality (1987, 1988, 1991, 1993, 1995a, 1995b, 1997), and the management of AIDS in Canada (1992, 1997) has helped me understand the importance of an historical analysis to a study of social organization.

In Canada, as in most developed countries, the administration of a highly bureaucratized society and its health care system is complex. The "health" work is generally undertaken within a closed administrative system from which the language of health, the language to define what HIV disease is, or how individuals live and die with it, for example, emerges. The history of the organization of AIDS in Canada is an illustrative site of the ruled or regulated versus the "unruly". Those who have documented it (Kinsman, 1992a, 1997; Rayside and Lindquist, 1992) suggest that there has been a fundamental struggle in Canada between public officials and AIDS activists regarding diverging visions of health care. I want to problematize some of the issues as a way of showing what was happening during the time that Jay was ill, and what might have been organizing his experience and that of other gay men with HIV/AIDS at the time.

There are several threads within the history of HIV/AIDS that I became aware of in Jay's account. First of all, health officials believed the disease could be managed in a traditional mode; that is, by protecting those who were not yet infected, while the newly formed community AIDS activist coalitions, some public health officials and medical practitioners with large HIV/AIDS caseloads, focussed more on patients' rights. The approaches had significant implications. For example, proponents of the traditional public health model tended to treat those with AIDS as irresponsible and needing to be policed.

Secondly, rather than a proactive stance on research into treatment, the government left the solutions to drug companies while keeping outmoded drug-approval mechanisms in place. This approach relied on the expertise of medical doctors, researchers and epidemiologists (Rayside and Lindquist, 1992, p. 50; ) and did not include community partners. Opposing this rather closed policy focus, activists who had experienced first-hand the work involved in caring for those with HIV in their own communities, demanded funding be provided to groups who could assist infected people locally. They wanted to establish needle exchanges, condom distribution programs, education for both those with HIV/AIDS and those not yet infected, and wanted an acknowledgment of the discrimination facing those with HIV/AIDS. Those with HIV sought more involvement in the governmental policy process (Kinsman, 1996).

The struggle began when AIDS was first reported in Canada in 1982<sup>2</sup>, approximately eight months after the syndrome was described in the United States.<sup>3</sup> Due

---

<sup>2</sup>Although 1981 is viewed as the date when the first cases of AIDS were reported to the Center for Disease Control (CDC) in Atlanta, Georgia, retrospective study currently assumes that the virus and its associated diseases have been active for a much longer time. It was not until larger numbers of cases could be received through a sophisticated tracking facility, that diagnosis and transmission could be more conclusively documented. These retrospective studies indicated that unusual cases of Kaposi's Sarcoma (KS) had been diagnosed in France and Belgium in the late 1970s. As well, scientists believe KS has been present in young central African men for decades (Altman, 1987).

<sup>3</sup> AIDS is an acronym for Acquired Immune Deficiency Syndrome: Acquired because it is not genetically inherited, but contracted. Persons with AIDS are known to have had a normal immune system prior to the onset of the syndrome. The viruses involved are found in everyday environments and do not usually attack people with healthy immune systems. Immune refers to the body's natural way of protecting itself from disease and infection. Deficiency indicates the immune system's diminished ability to protect the body against foreign substances. Syndrome refers to a pattern or grouping of symptoms which tend to develop because of the diminished capacity of the immune system to fight infection (Greig, 1987; DePaul and Liberman, 1986; Baumgartner, 1985). AIDS is thought to be caused by a virus that attacks the body's immune system. The result is that the immune system is weakened and unable to resist certain types of infections or cancers which are unusual in anyone whose immune system is functioning normally. The HIV, or Human Immunodeficiency Virus, attacks the body's T-cells which are normally responsible for recognizing infections, and altering the immune system to begin producing

to the particular incubation period of HIV, it is thought to have been initially introduced in Canada in 1978 (DePaul and Liberman, 1986). According to the Federal Centre for Disease Control (Health and Welfare Canada, 1989) as of March, 1988 there were 1622 diagnosed cases of AIDS in Canada (1589 adults and 33 children), while of this number, 885 persons had died. Close to 82 percent of the cases were homosexual and bisexual men (42 percent of these men also reported injection drug use). In the early 1980s numbers of reported cases were apparently doubling every ten months to one year.

AIDS activist organizations emerged from the already established gay and lesbian social movements and drew on the knowledge and expertise of the feminist health movements in Canada and the United States (Trussler & Marchand, 1993, 1994; Kinsman, 1992a, 1997). In British Columbia the response to HIV/AIDS took hold in 1983 when AIDS Vancouver was established by several local physicians and persons with HIV/AIDS. When they felt their issues were not being addressed, those with HIV/AIDS broke away and formed the Vancouver Persons with AIDS Coalition in 1986 and became the first association of its kind in the country. The group, in which Jay became active two years later in 1988, had a political agenda, specifically regarding treatment options, and continually challenged the government to make drugs available. The province was dealing with two conflicting agendas regarding HIV/AIDS during the 1980s. A conservative Social Credit government ignored the issue for several years

---

antibodies. The diseases which take advantage of the ravaged immune system are known as "opportunistic infections". Two of the most common are Pneumocystis carinii pneumonia (PCP), a parasitic lung infection; and Kaposi's Sarcoma (KS), a rare type of skin cancer. It is the opportunistic infections that cause death. When these diseases occur as a result of the AIDS virus, the person is said to have AIDS.

despite continued lobbying by AIDS community groups and supportive health workers and officials. In Vancouver itself, the local government was somewhat more progressive and supported educational initiatives on its own. In the same year as AIDS Vancouver was formed, for example, British Columbia made AIDS a reportable disease, but then seemed to turn away from the epidemic (Herringer and Solomon, 1989). The evidence suggests that physicians as well as government officials were less than coordinated in their responses. While on the one hand the province initiated free HIV testing and systems exist to ensure that test results were confidential, in October 1987 a recommendation was proposed by provincial doctors to take blood tests of patients they suspected of carrying the virus without the patients' consent. It was overwhelmingly endorsed at a BC Medical Association meeting, despite warnings that it might drive carriers of the disease underground. The recommendation which would allow health professionals to order tests without fear of a law suit was sent to the BCMA executive and board. Although it did not pass in 1987, concern with mandatory and compulsory HIV testing still exists.<sup>4</sup>

A further fear was emerging in BC in the late 1980s from the debate regarding the use of quarantine as a health measure in the case of AIDS. Proposed amendments to the

---

<sup>4</sup>Dr. Michael Rekart, Provincial Director of the sexually transmitted disease control clinic, distinguishes between mandatory and compulsory testing. Mandatory testing is used as a prerequisite to receiving service and the person tested has a choice. Compulsory testing, on the other hand, is required by law or policy and the person has no choice. Not only are both forms of testing seen as an invasion of privacy, but it would inevitably lead persons concerned that they may have AIDS, to avoid testing altogether. Opposition to this type of testing is also based on concerns as to the use of the information in discriminatory practices in employment and insurance policies. In the late 1980s Rekart indicated that the provincial government had no plans for mass compulsory testing. In order to control the epidemic, everyone would have to be tested, and those who tested negative would be retested over time. Anyone entering the province as a visitor would have to be tested as would persons returning to British Columbia.

Health Statutes Act introduced in July, 1987 would have allowed sweeping powers by medical health officers to quarantine against his/her will, anyone exposed to the AIDS virus. After public outrage from both AIDS community groups, supporters, and the opposition, the Act was amended to specify that anyone who "willfully, carelessly or because of mental incompetence" spreads AIDS, can be quarantined. Bill 34 became law on January 9, 1988 and requires that a medical officer seek a court order to require testing for AIDS or other communicable diseases. In addition, the health officer can order the person to take treatment, adequate precaution, or to isolate him/herself. Quarantine for up to one year may follow by court order if the person "willfully, carelessly or because of mental incompetence" exposes someone to the disease. Opponents to quarantine legislation argued that quarantine is not feasible for an incurable illness. People would have to be quarantined for life for a fatal illness. The human rights implications of testing and quarantine demanded rational and sensitive consideration; and while proponents believed society has a right to protect itself from threats to public health, opponents continued to argue that when dealing with stigmatized groups, the need for protection must be balanced with the type of society in which we choose to live.

Not surprisingly perhaps, in 1986 under the Social Credit government, despite the numbers of persons with HIV disease, British Columbia was the only Canadian province that refused to pay for AZT (at that time the only drug available to persons with AIDS). Despite public protests, only those on income assistance were eligible, and it was not until 1991 that this policy was rescinded. Rayside and Lindquist (1992) capture the climate of those years:

Through the 1980s, Premier Vander Zalm resisted making AIDS a priority issue and was reluctant to approve educational materials that contained explicit messages that verged on 'condoning' behaviour he regarded as immoral. As late as 1989, one provincial official likened AIDS to a self-inflicted wound, and Health Minister Dueck suggested that some people's lifestyles had 'invited' the disease (p. 71).

In the late 1980s however more knowledge regarding HIV disease, and support for those infected and affected was being made available despite government unresponsiveness.

With the Vancouver PWA Coalition and AIDS Vancouver, advocacy and support groups' actions kept HIV in view. St Paul's Hospital in Vancouver's west end created a multidisciplinary team of social workers, nurses, doctors, and other specialists. I accompanied Jay and another friend on many occasions to the Infectious Diseases Unit and found it to be an informative and supportive place, not only for those with HIV, but lovers and families as well. Further significant developments for activists included the formation of the Canadian AIDS Society in 1986, which emerged as an umbrella organization of AIDS service organizations in response to the federal government's lack of initiative on AIDS funding and treatment issues (Kinsman, 1997; Rayside and Lindquist, 1992). Throughout the 1980s the debates surrounding issues of access to drugs, funds for education and support, research, direction regarding testing, human rights concerns, and the challenge to traditional public health responses were transformative in many ways. Rayside and Lindquist (1992) suggest that the "clash between the traditional containment-and-control approach to disease and the cooperation-and-inclusion model has resulted in the traditional medical model's giving ground" (p. 94).

It was the activist AIDS groups that ultimately forced the federal government to adopt the National AIDS Strategy in 1990. Kinsman (1992a, 1997) has traced the federal government response to AIDS and suggests that it can be viewed in five periods.<sup>5</sup> During the early 1980s AIDS was virtually ignored. The Laboratory Centres for Disease Control in Ottawa collected statistics, and small community projects emerged to offer support services. Through the mid-1980s, designated by Kinsman as the second phase, the federal government funded some community-based projects under its Health Promotion branch. He argues that under then-Minister Jake Epp, government AIDS policies were defined by public health and palliative care. As mentioned earlier this response assumed that those with HIV/AIDS would die, and thus created programs aimed to protect the general public from infection. Kinsman (1997) suggests that during this time:

A relation developed between AIDS organizations and State regulation, which was sometimes 'consensual' but sometimes conflictual, as at the National AIDS conference in May 1988 in Toronto when AIDS activists burned an effigy of Epp at the end of a demonstration against federal AIDS policy (p. 217).

During the third period, AIDS activism particularly around treatment issues, became more prevalent. At the V International Conference on AIDS in Montreal in 1989, then conservative Health Minister Perrin Beatty announced the forthcoming strategy that would be based on the emerging government strategy of "consultation" and partnership. Perrin's strategy came more than eight years into the AIDS crisis in Canada, and while it was still rooted in the public health/palliative care discourses, community-based groups

---

<sup>5</sup>On December 1, 1997 Minister of Health Allan Rock announced a further period of the National AIDS Strategy by committing \$42 million dollars for a further five years. He intends to create an advisory board to assist with its direction. Activists point out that this is not new money.

felt that some of their treatment concerns would be addressed. It was during this period however, that George Smith's (1990b) research into the lack of a treatment strategy was being undertaken. According to Kinsman, Smith believed that this national AIDS strategy

...was designed basically to solve the political problems the Minister and the Department of Health and Welfare faced with regards to AIDS, rather than the specific problems faced by people with HIV infection. The strategy, in other words, was designed from the standpoint of the federal government (p. 218)

In the early 1990s there was little significant change in federal AIDS policy, although there was some move away from the centrality of public health and palliative care to support for HIV/AIDS as a chronic and progressive condition. Kinsman suggests that during the fifth period in the mid-1990s under the Liberal government federal funding allotted to HIV/AIDS under the national strategy was actually underspent. Deficit reduction, restraint, and cutbacks in health transfer payments to provinces actually contributed to the remobilisation of AIDS activists. While the National Strategy had been announced with great fanfare at the V International AIDS Conference, ironically on the eve of the XI International Conference in Vancouver in June 1996, the strategy was being phased out. It reemerged in December 1997 after protests and lobbying by AIDS groups and their allies. According to Kinsman (1997) the National AIDS Strategy is an administrative document formulated through a consultative process but one that emerged as the federal government's "framework for incorporating community-based groups into a state regulatory strategy" (p. 219) while ultimately ignoring the standpoint of those living with HIV/AIDS, or of AIDS activists. He argues that the process of collaboration or partnership grew out of the discourses of management, and strategic planning, which,

rather than centring the community, drew “partners” into an administrative web in which they are ruled or regulated.

The conservatives’ partnership strategy has had a profound effect on Canada’s ongoing response to HIV disease and the individuals and groups affected by it, and the related management discourses continue to regulate various responses and policy/practice directions of HIV/AIDS even in 1997-98. It is only now for example, as I finish work on this project, that the province of British Columbia has created an advisory committee to its AIDS strategy, and is seeking a full-time director to implement it. This has come about after nearly a decade of community organizing initially by gay men, and now through the emergence of activist women with HIV/AIDS, aboriginal peoples, transgendered people, and people with disabilities, lobbying by rural groups and those in Vancouver’s urban core who have been devastated by the disease (Pare, 1997). While the voices of these individuals and groups and their experiences with HIV/AIDS are at various policy tables, they are still often there as George Smith said years ago, working on an agenda that is emerging from the standpoint of government. What has changed however, is a greater understanding by those affected by HIV/AIDS, of the contradictory nature of their relationship with government (Personal Communication, 1998).

## **A Personal Account of Living & Thinking about Dying with HIV/AIDS**

In the following discussion I want to provide an illustration about what I mean by saying that Jay's account of his life and dying with AIDS is organized discursively. I am arguing here that his life is an actualization of AIDS histories and discourses. As I worked through the analysis in each chapter I kept wanting to present more than just journal excerpts or moments. I went back and forth using long passages and then putting them aside, or deciding on the minimalist approach of working with a few lines. Finally however, I decided that I would include here, each of the entries from which the excerpts I analyse in the subsequent chapters are taken, because I believe it is important for readers to hear Jay. I discovered that my reading of his journal is an active process, because like poetry, it has within it a set of instructions on how it is to be read and what it intends. One of the things I see him attempting to grapple with in his journal, and in the talks he had with me and others about AIDS, was his own ethical and philosophical confrontation with the terror of the end of his life, and what death might be like. A second feature of his life as written about in his journal is the struggle to come to some decision about how he was to live and to die. Some may think that presenting his journal entails a lack of privacy--that he would not want his personal thoughts and vulnerability displayed in this way. In deciding to use it I took several things into account. Jay had kept journals most of his adult life and began this journal very soon after he was discharged from intensive care. He told me then, that "maybe it will help others sometime." He had also begun to

send some of his AIDS writing out to publishers; for example, shortly after he left the hospital in March 1988 he responded to a call for personal articles about living with HIV/AIDS by submitting the first series of journal entries.

His physical journal consists of two small red notebooks that contain an intermittent collage of entries that are sometimes dated. It holds random notes, lists for vitamins and groceries, questions for doctors and others about the state of his health, various calculations in an attempt to figure out his budget, and other jottings regarding his daily life.

## **Jay's Journal: Excerpts from a Personal Account<sup>6</sup>**

**December 1987**

Reasons for living

The beauty of the earth, summer,  
winter, spring and fall/north +  
south

Reasons for not living

Politicians are corrupt

I can't see a picture of my life 6  
months from now--fearful of this  
future block.

Depressed. Can't relate well to  
people; don't want to interact.  
Tired, sleep all the time, no  
energy for anything.

---

<sup>6</sup>I have formatted these pages as they were written in the journals.

No excitement for things.

Don't feel it's worthwhile to make plans, as I fear death by AIDS.

Maybe death is a welcome relief.  
On to the next chapter.

### **March Monday week 2.2 [1988 in Hospital]**

I can't tell dates anymore.  
Altho' this was the possible day of my release. Unfortunately I have been running a high fever, along with nausea – I used to eat ravenously, but now must force myself. Threw up the other day. Drinking lots of liquids. My weight is still down. Must start eating more fresh fruit w/ sugar. Pears, grapes – refreshing.

I am disappointed about the days of fever, as they have laid me low. But I have been getting encouragement from many channels. Cathy called + it was hard but she has faith. Paula<sup>7</sup> walked in the room in tears for 20 minutes hugging me and saying how unfair. When she calmed down we were able to look at the thing more realistically.

Mom is still here, maybe till the end of March. She is my rock that is sustaining me.

---

<sup>7</sup>Friends

I try not to worry about the worldly/material stuff I have to deal with. As things are working out so well.

I will stay w/ Terry + Ed<sup>8</sup> till I go west -- no questions asked. Bless them.

### March 14

I have been pre-occupied with worrying today. What is going to happen. I am scared.  
Called Ken + Michael<sup>9</sup> + got cheered up -- this after crying for awhile -- pent up tears.

I get released on Wed! I'm excited + scared. I've been here for ? 3 ½ weeks? Can't remember. Now it is like a womb I must leave. When I walk out these doors, I will be re-born. A different Jay than who staggered in that cold clear Friday in Feb.

I am Jay w/ AIDS  
I am a PWA  
entitled to all that is available to this select but growing company of people.

I had always wanted to work on an AIDS committee + do home-care etc. But I

---

<sup>8</sup>Cousin and husband

<sup>9</sup>Friends

was scared to death of  
facing AIDS so directly.  
I wasn't ready.

Now that I am with + among  
them, I will lose my fear +  
feel in community w/ my  
brothers in our new metamorphosis.

In a world of complacency,  
+ tastelessness for real  
life, the shock of mortality  
+ AIDS brings you back from  
such complacency. There is  
no more time for such  
things.

P.B. called this a.m. I  
told him that he was my best  
friend + why couldn't we be  
closer dammit. We ended up  
crying and finally saying  
choked-up good-byes.

I look like a refugee victim  
from a concentration camp.  
I am down from 200 lbs.  
to 162! I haven't been  
162 since on the way up!  
or at weight watchers in  
high school. Drawn, hollowed out  
face -- emaciated legs (they used to  
be so big + muscled)  
my ribs showing. I still have a  
stomach tho'! I'll probably  
look great in my clothes that  
haven't fit for years!  
Weird way to lose weight.  
Now I have to concentrate on  
putting it back on! What a  
switch for me.

Had the IV taken out today. Feels

good not being attached to a  
couple of plastic bags, tubing  
+ a wheeled pole!

Also showered myself today,  
will victories never cease?

Have had a few erotic dreams  
lately. Will my sexuality be  
lived only in my dreams, now?  
I'm certainly afraid of sex now --  
I was in the past, too,  
but homi-ness [sic] won out.

### **Wednesday**

I have been released!  
I checked out of Ottawa General  
about 1:30 p.m. w/ the help  
of Paula and Mom. They loaded  
me onto a wheelchair, + covered  
me w/ flowers + wheeled me  
right out of that tomb/womb  
hospital. I felt like a  
bridesmaid, w/ daisies +  
orchids + lovely spring floral  
arrangements in my arms.

I am getting flashes of the  
horrible time in I.C.  
Mom showed me the notes  
I wrote while in I.C. +  
under "the tubes" writing  
is like a 2 year old + the  
messages range from the  
mundane (will you scratch  
inside my ear?) to the  
mystical ("the Shaman  
woman..kissed my tender  
sides...") Even some hallucinatory  
Spanish. I was a bit freaked  
out when I saw these notes  
today + realize how out of

it I was. Mom said it was  
70/30 death/life  
for a couple of days.

I almost died.

But the love of my family  
+ friends saved me.

Now I want to hug everybody  
even Sister J at the  
hospital.

Thanks to the doctors +  
nurses at O.G.H. They helped  
save me, too, + I hug them.

**Sat. March 19**

What is to become of me? I go to  
Vanc. + live on welfare. Maybe  
get some freelance work. Going  
to the west coast to die? Going  
home to die? What is death?  
Will it be 1 year, 2, 3, 4, 5,  
or 10? How do you fight this  
thing. Hardest thing is  
calling up friends + telling  
them.

**No date (sometime in January 1989)**

I love + accept myself exactly as  
I am

I let go of fear  
I let go of anger  
I let go of delusion

Right now I focus on the  
moment. I am in the moment.  
I am focussing on me.

I will try to be gentle with  
myself + do things that I enjoy.

I will enjoy my life, each day  
of my life. I will continue to  
attempt to focus on the  
very moment I am in. How do  
I feel. At the moment calm,  
content + cocooned in my apartment  
feeling OK at this moment.

But, under this calm exterior is  
still a lot of fear. My medications  
are failing me (except for the  
thrush in the throat, thank god!)  
Had a bone marrow test last week  
+ if it indicates an O.I. [opportunistic infection],  
including TB, then I can't do the a.penta-  
madine clinic, which I have been  
working towards for 6 months on  
the double blind study. SHIT.  
I cried in IDC<sup>10</sup> today in front  
of the gentle Dr. F.  
So what do I do?  
I'm looking for another doctor  
to review my case--perhaps  
Dr. J.  
W. the social worker has  
agreed to see me for some counselling.

Joe has asked his faith healer friends  
to include my name in their prayers  
+ he may visit as he has some  
healing powers too.

The Reiki treatment helped  
a lot, relaxed the throat--but  
what pain in just laying on of  
hands, Also opened my bowels!

---

<sup>10</sup>Infectious Diseases Clinic

Doing a lot of affirmations:

I love + accept myself  
exactly as I am

I must do more work in this area.  
Will visit K. Thurs. for a  
healing hands on treatment.

What else can I do that I am  
not doing? I'm sure I'm  
on the right track -- feel positive  
about your power to change this  
crisis into a manageable regime  
again.

Again, I am overwhelmed by  
my friend's and family's response.  
I see from this that we have all  
pulled closer, + even when they  
cause me pain in some way,  
I know they do it out of love.  
And I love them. Like the day  
of the bone marrow test. I was  
a wreck. They all kept calling + I  
was in tears for 2 days, which,  
with my bad throat was agony.  
But Bob, Steve + Chris<sup>11</sup> came  
over + I cried in their embraces  
which felt good.

But my dilemma:

a) Love myself, heal myself -- this  
is one approach. I'm not sure  
what love is -- how do you  
love yourself. This I must work  
on. Louise Hay et al.<sup>12</sup>

---

<sup>11</sup>Friend and brothers

<sup>12</sup> Hay has written on self healing as well as on ways to combat AIDS. See discussion in Chapter 6 regarding her influence.

b) Stephen Levine, + Emmanuel's Book<sup>13</sup>  
 seems to encourage you to accept  
 death -- "the removal of the tight  
 shoe". If I am truly dying  
 (which contradicts the fact that  
 if I choose to change I need  
 not die), -- should I move towards it  
 + embrace it?

--when will it happen?

--will I be scared; I have

lots of fear about this now, esp.

with such low hemoglobin.

--will it happen quickly?

--should I will it quickly?

--is suicide a legitimate

option if things get too out of hand

(I don't want to suicide -- I want

to go naturally)

**Thurs. Feb. 2/89**

G. from AIDS Van

was over yesterday + he held

me while I cried about my

fear of death + loathing of my sexuality,

+ where to find my heart. He said my ability to cry

and feel emotion was on the right

track towards self healing. What a

beautiful man!

Re transfusion: In middle of  
 meditation receiving this gift of

blood I had sudden flashes

of colour, red, + warmth that

spread throughout my body.

Mandalas of red health.

I love myself + accept myself

exactly as I am.

---

<sup>13</sup>Levine has written several books on death and dying. Emmanuel's Book was one Jay read that I am not familiar with.

I am healing  
The process has begun.

**Monday Feb 6/89**

I love + appreciate all of myself,  
and accept myself exactly as I am.

I certainly have more energy,  
after having slept 2 days  
following transfusion....

We are all being taken  
care of. Let go of the fear  
of this illness, no-one will  
let you go -- you have lots  
of support.

They love me  
I love them  
I love me + accept me  
exactly as I am!

**Tues. Feb. 21/89**

I love myself  
I forgive myself  
I forgive all the others + release them.

I am well  
I am becoming strong  
I have a better appetite.

Last week felt I was having an  
attack of PCP. On drugs for that.  
Developed ulcer between stomach +  
esophagus; makes eating difficult,  
painful.  
Went to see Dr. W., he will  
do gastroscopy brushings next week  
"to see what we may see".  
Nice guy.

Then over to Dr. C.'s, head of  
infectious diseases on St. Paul's  
AIDS team. He has something up  
his sleeve for this candidas.  
Tells me I need more weight!  
Down to 156! Definitely need to  
get some flesh on my bones.

I am well  
I am strong  
I LOVE AND APPRECIATE MYSELF

-My medications + procedures + diet  
+ vitamins ARE WORKING!

#### **Last entry (sometime in March/89)**

I have chosen renewal + life!  
I can heal myself  
I love myself + accept myself  
I forgive myself + all + I release  
the past, + live in this very  
moment.  
I have breath, life, a loving mother  
+family helping me.

I choose to change my mind, +  
live + accept my life.

## **Conclusion**

By 1989 the political and bureaucratic organization of AIDS in Canada was becoming extensive. In addition to professional and medical authorities entering their theories and perspectives into professional discourses and practice, organizations established by persons with AIDS and their supporters had emerged in British Columbia and Ontario. When Jay collapsed in February, 1988 these networks were already being put into place.

To catch him? To entangle him? To teach him how to be an AIDS “victim” or “patient”; that is, how to live and how to die? Writing this dissertation begins to illuminate how much Jay and his friends and family became part of something more than ourselves; first, when he was given an official diagnosis of AIDS, and subsequently when he took his own life. In this realm the official knowledge of the experience takes precedence, translating a life into abstract modes of knowledge and ultimately organizing that experience (Campbell, 1992, 1994; Smith, 1987, 1990a, 1990b, 1991). In my discussions with those with HIV disease and others involved in AIDS organizations, with family, friends, and professionals following my brother’s death, I learned for example that professionals and AIDS advocates were frequently asked questions about how to “take one’s own life”. These workers also said that suicide among this population was not uncommon (Personal communications, 1992, 1993, 1994). While there is no record of the numbers of those who have taken their own lives without assistance, or with assistance by physicians, lovers or others, I keep hearing how commonplace it is. Yet there is little research on AIDS and suicide from the standpoint of those most affected. At the 1996 International AIDS conference in Vancouver, for example, seven research projects among the thousands of papers that were presented, were directly related to HIV and suicide (XI International Conference on AIDS Abstracts, 1996; Ogden and Young, 1997).

The focus of my research is not to highlight the numbers of gay men who may have killed themselves as a result of having AIDS, or to seek causal relationships regarding why some gay men with AIDS may take their own lives while others do not. Rather it is an attempt, through the method of inquiry known as institutional ethnography

(See Chapter Four) to unravel some of the social processes of HIV disease and AIDS—how the words and images, the representations of the disease, might organize, reflect, and contribute to the understanding of AIDS by, in this case, gay men themselves, and their decisions about life and death. Throughout this work, I will illustrate how Jay's experience is embedded in relations that already have a history—psychological and psychiatric classifications; societal morals regarding suicide and ideas about “a good death”; ideas about how one chooses to live or die; ideas about illness and personal responsibility; the role of social and health agencies; and so on. My responsibility as a researcher is to make the relationships Jay entered into more visible. As others have urged, I have been working with community, professional and academic AIDS activists in the production of knowledge that makes visible how these social processes that extend beyond the everyday world of persons living with HIV/AIDS are organized. As some AIDS researchers have suggested, the knowledge outside lived experience takes precedence (Kinsman 1987, 1989, 1991, 1992a; G. Smith, 1990a, 1990b). For example, society hears about the numbers of people who have died; rarely how their dying worked or was organized or was taken from them. They also learn how many people with HIV and AIDS are on social assistance, not as Mykhalovskiy and Smith (1994) observed, about the struggle they have to get services in the first place.

In this chapter I have presented excerpts from journal account of a gay man's daily experiences of living with AIDS in the late 1980s; and, I have begun to show how his life may have been bound up in the organizational responses to HIV/AIDS during that time. Chapters Two and Three present concepts I have found helpful in guiding my

analysis. Chapter Four presents the theory and methodological approach I employed, while Chapters Five through Seven will analyse the relations of power and authority connecting Jay's experience and that of the administration and organization of the disease by various professionals.

## CHAPTER TWO

### MARKED BODIES: Fear, Loathing, Homosexuality & AIDS

*I remember the early years of the AIDS crisis, desire and death and fear, all mingled together. To be afraid of our desire—we thought we'd escaped that, and now we're being called back. We who had been afraid of going to hell, and had come out of that night, now we're afraid to die. For sex, all for sex (Wagenhouser, 1991, p. 65).*

*...it is no surprise to any gay person that death holds down the center around which the sliding signifiers of AIDS discourse swirl; for centuries in the West, death has been held out as the penalty for homosexuality. All of the discourses of AIDS has encoded the homosexual Other (Patton, 1990, p. 127).*

*Population and personal narratives come together in a particularly disturbing way when the agent of the epidemic's spread is identified with the body of the 'infectious' patient him- or herself. In such depictions, the person with AIDS, seen as irremediably given over to death, becomes the source of others' deaths; he or she is, simultaneously and paradoxically, the active bearer of disease and the passive sufferer (Kruger, 1997, p. 77).*

*Have had a few erotic dreams lately. Will my sexuality be lived only in dreams now? (Jay's Journal, March 1988).*

*G. From AIDS Van was over yesterday + he held me while I cried about my fear of death + loathing of my sexuality...(Jay's Journal, February 2, 1988)*

#### Introduction

As I read Jay's journal and encountered excerpts such as the two quoted above, my curiosity was aroused. I could not ignore Jay's juxtaposition of his fear of death with the "loathing" of his sexuality that suggests he has internalized popular condemnation of gay

men by the general public, religious groups, and the haze of homophobia and heterosexism pervading psychological and sociological discourse. In Chapter One I discussed how I began to see Jay's account of his life with AIDS as discursively organized, and that the problematic or puzzle with which I began the inquiry prompted an explication of how he is to remain at the centre, or in control of his life when it is subordinated and defined by external "forces". Society's fear and hatred as reflected in responses to AIDS, or in a gay man's response to an AIDS diagnosis prompted me to examine a portion of the research literature that perhaps formed the environment, or lived social "knowing" that Jay was experiencing in his living/dying with AIDS.

Discourse on homosexuality and on suicide as it relates to HIV disease seems to shape how these issues are to be understood and put into practice. For several years I have been interested in what others have written about AIDS and suicide, the continuing conflation of homosexuality and HIV disease, about professional responses to the disease, and about the work required in living with a body under siege. While reflecting on this information in light of my knowledge of Jay's experience, I was searching for ways in which the exiguous literature I had begun to read about these connections either supported or contradicted what I had learned. My reading was concurrent with data gathering through interviews, workshops, seminars, conferences, volunteer work on boards of community AIDS agencies, and time with friends with HIV disease talking about how daily living actually works for them. As questions arose in interviews or field work, or during the analysis, I returned to the literature. It has been an ongoing exercise, and the literature included here and in the following chapter provides a conceptual frame

for the inquiry. I have focussed on two strands that I believe are important in providing a conceptual understanding. First, how homosexuality has come to be linked with illness, contagion and sin; and how an identity as “homosexual” is said to be achieved by focussing on the debate between essentialism and social construction. Chapter Three takes up the second strand through an examination of the literature on the relationship between AIDS and suicide. Both areas are foundational to my broader inquiry into the social organization of AIDS related suicide.

As I mentioned in Chapter One, I had wanted at first to present or reclaim Jay’s life through his journal as another “face of AIDS” until I began to see how his life was socially organized by the history and contemporary enactment of knowledge about AIDS, homosexuality and suicide—it was not just an individual struggle. When Jay was diagnosed with AIDS in 1988 the “obvious” link between his homosexuality and the syndrome was evident in already-existing government arguments for the implementation of quarantine legislation, lack of treatment options, and lack of funding (See Chapter One). Prior to his diagnosis however, his experience of the pleasure, passion, or fear of sex with other men would have clashed with the picture of homosexuality as regulated by government, and the religious or legal sanctions placed on it (Kinsman, 1988, 1992a). The stigma of homosexuality has framed AIDS discourse and the medical and social responses to it from the moment the syndrome was called “gay plague”. For community activists and academics familiar with HIV/AIDS discourses in various forms, the conflation of HIV and homosexuality has been a given. I am not suggesting that the interferences of race, class or gender do not also have a significant bearing on one’s

relationship to HIV disease—access to early diagnosis, health care coverage, violence, isolation and so forth; however, my interest here is only in the relation of homosexuality and HIV and how it works.

While my thinking during the last few years has held the link between sexual orientation and AIDS as central to my larger argument, I began to feel that perhaps there was nothing more to be said about it. However, I do think that anyone, regardless of their political stance still tends to assume a “they must be gay” response, when hearing that someone is HIV positive. At this stage in the history of AIDS however, it is perhaps merely a taken-for-granted juxtaposition. It is my contention that the stigma of homosexuality continues to attach to persons diagnosed with HIV regardless of who they are. When Jay was diagnosed with AIDS, I came across a personal account by Dreuilhe (1988) who wrote during his experience with AIDS that, “The media and the public are naturally fascinated by the bond AIDS establishes between sex and death, that copulation between the two most effect-laden[sic] primitive forces, now forever linked in people’s minds with homosexuals” (p. 72). Ten years later, Kruger’s (1997) analysis of AIDS narratives proposes that far from being disentangled, homosexuality and AIDS continue to be twinned:

On the one hand, AIDS is constructed as an invariably fatal weakening of an individual’s bodily defenses, a depiction often used to reconfirm an identification between disease and a gayness imagined as itself always already weak and vulnerable. On the other hand, AIDS is understood in terms of the narrative of the epidemic ‘spread’ largely attributable to gay ‘immorality’ and ‘unnaturalness’ (p. 77).

It appears that despite scientific and medical advances ongoing reactions to AIDS belie

any sophistication as those with the disease continue to be stigmatized and scapegoated ( Gilmore and Somerville, 1994). Thus, while no segment of society remains unaffected by the complex of diseases that constitutes the syndrome, I am nonetheless confining myself here to the experience of gay men, since AIDS was first “marked” as a gay disease, and this mark continues to permeate most AIDS discourse. As Patton (1993) asserts, the “social disease known as AIDS is actually homosexuality” (p. 158). AIDS is not the only issue facing gays; nonetheless, the implications of Patton’s statement are far-reaching. Through Jay’s illness I became aware also, of the simplistic relationships between gay sex and AIDS that were being presented as truth by both gays and heterosexuals; and therefore agree with Crimp (1988) who suggests that:

AIDS intersects with and requires a critical rethinking of all of culture: of language and representation, of science and medicine, of health and illness, of sex and death, of public and private realms (p. 15).

My intent here is a personal attempt at “critical rethinking” with regard to homosexuality and ultimately, the implications that conceptual struggles regarding sexual and gender identity may have on HIV disease.

From the beginning the AIDS “patient” (I use this word in deliberate contrast to those persons living with HIV disease who have organized against the victim label assigned to them by the professions) has been constructed as a gay man. The very nature of the disease process and its social stigma intensifies the stresses of the person with AIDS. Gilman (1988) suggests that the “initial categorization of AIDS as a sexually transmitted disease (albeit in a very specific context) strongly marked the initial construction of the disease” (p. 248). It is my contention that this construction has had an

impact on the organization of AIDS-related death. Ideas about, and representations of self-as-disease have the potential to remove persons with AIDS further and further from society. Not only are they susceptible to greater physiological infections, but they may also be unable to resist the stigma that continues to seep through most discourse about the disease.

Much of the research regarding AIDS has focused on the race to find a cure, and certainly through the alleviation of various opportunistic diseases the possibility of living longer with HIV disease has increased to an average of ten to twelve years. Living longer presents a new context—people living with possible serious illness in the new shifting Canadian health scene—health promotion, wellness, the fraying social safety net. What I continue to see in the literature is the contrast between the medical/technical approaches to AIDS and the cultural post-modern approach of representation and metaphor, both of which seemingly ignore the social reality of those affected by the disease. They both seem conceptually fragmentary and yet are interconnected—different pitches of the same voice, different words in the same poem or song. Despite Sarah Schulman's observation that the field of AIDS and HIV continues to be transformed so rapidly that those who write about it do so with the understanding that by the time their words appear in print, they will be largely obsolete (Schulman in Yingling, 1991, p. 291), each “word” provides the opportunity to move deeper and ask further questions. Considering the fact that AIDS nears the end of its second decade, and seemed only to reach Canadian consciousness in the mid-1980s, the amount of scientific and popular literature is significant.

The practices of socially constructing an image of AIDS provide a theoretical

focus in much of the medical, social sciences and cultural literature I read. While the AIDS-patient-as-homosexual construction has been challenged recently from a number of directions, including by women living with HIV/AIDS, the concept of homosexuality has had a profound influence on others with HIV/AIDS who tend to be portrayed as social outcasts regardless of their sexuality or gender. As I read and thought about this relationship in the context of Jay's life, I also wanted to see what had been written that may have conflated HIV disease not only with homosexuality, but also with suicide.

Gilman (1988) suggests that the label GRID or gay-related immunodeficiency, "structured the idea of the patient suffering from AIDS in such a marked manner that the patient was not only stigmatized as a carrier of an infectious disease but also placed within a very specific historical category" (p. 247). In his intriguing analysis of disease and its representations in art, Gilman argues that we "construct boundaries between ourselves and those categories of individuals whom we believe (or hope) to be more at risk than ourselves" (p. 4). If we are provided with an image (through various media) of someone described as insane, or someone gay or a person with AIDS, we can remain the "healthy observer", the "good". The reaction of society to people with HIV and AIDS continues what he aptly describes as a "liturgy of Otherness"; that is, we diffuse our own universal anxiety about being attacked/struck down by illness by selecting a "certain number of categories onto which [we] project [our] anxieties...We are afraid of Jews, Blacks, Women, Homosexuals, Madmen, Gypsies, and others we designate as 'different'" (p. 11). In a world of "other", if we know who is dangerous, we know who to attack.

These theoretical and actual boundaries have been constructed and deconstructed

through the relatively short history of AIDS, and are evident even now in the construction of innocent vs. guilty victims; pure vs. contaminated blood; risk groups vs. those who seem safe. What we continue to see in this view is the social construction of persons living with HIV/AIDS as social outcasts. Art critic and AIDS activist Douglas Crimp (1992) decries false portraits and images of persons with HIV and AIDS that tend to emerge in both the popular media and in art. He argues that a liberal approach to combatting the bureaucratic abstraction of AIDS has been to "give AIDS a face" (p. 119) in which the "face" has become a genre that perpetuates stereotypic images of the so-called risk groups—gay men, poor blacks, prostitutes and addicts. He argues that the "comfortable fantasy that AIDS would spell the end of gay promiscuity, or perhaps gay sex altogether, has pervaded American and Western European culture for a decade now. But we fail to understand its pervasiveness and its representational effects..." (p. 130). Those with HIV/AIDS are not only created as social outcasts; the disease has been hailed as a means of suppressing the gay community and gay lifestyle. Watney (1989) notes that in AIDS "the categories of health and sickness...meet with those of sex, and the image of homosexuality is reinscribed with connotations of contagion and disease, a subject for medical attention and medical authority" (p. 126). This conceptualizes what I was seeing in the organization of AIDS and the lives of those I knew with the disease.

## **Constructing Homosexuality/Constructing AIDS**

Throughout my reading it was not surprising to find that sexuality continues to be a ground of contested meanings and is, I suggest, a key factor in the organization and administration of AIDS. For example, ongoing debates about the etiology of sexual orientation have had an effect on how services and funding for HIV disease have developed. Perhaps sexuality is also a factor in the work of choosing to live or die by a gay man with HIV disease. It is as though AIDS is a catalyst both literally and figuratively, for controversy and revelations about the gay body in the late twentieth century. AIDS has rammed through the gay male body and been refracted into scorching health care, religious, metaphysical and definitional crises. It has become the ultimate postmodern metaphor for the eruption of gay male North American culture into millions of identities—sexual, cultural, racial, class. It has exploded in issues of choosing death, the right time to die, has alternately thrust sex into public places and buried it in education advocating abstinence and chastity.

The marking or reading of the gay male body as the original and prime site for AIDS has had serious consequences for all people with AIDS: women, children, heterosexuals, racial minorities. Those of us on the other side of this illness can only speak in metaphor in an attempt to unravel the meaning of dying from a disease that many believe you should die from because of your perverted bodily desires and behaviours. For gay men, the weakening of their physical selves through disease is like the ultimate "scarlet letter" tattooed on their bodies for sexual crimes. Indeed, suggests

Gilder (1989), not only is AIDS a medical epidemic; it could be considered a political one as well.

Regardless of the extent of their sexual activity, or even sexual practices, Western society has been unable to accept gay sexuality as merely another form of desire among a constellation of desires. Indeed, it appears that any deviation from the heterosexual norm is intolerable. As Weitz (1990) notes in her discussion of stigma, AIDS has reinforced the belief that homosexuality is immoral, sinful, and deserving of punishment. The very nature of the disease process and its social stigma intensifies the stresses of the person with AIDS. Ideas about, and representations of self-as-disease have the potential to remove persons with AIDS further and further from society. Not only are they susceptible to greater physiological infections, but they may also be unable to resist the stigma that continues to seep through most discourse about the disease. Nowhere in either spoken, written or visual discourse, is AIDS simply a syndrome, or simply a metaphor. It is clearly political and is being used politically in every institution across the political spectrum whether gay controlled or government controlled. The tremendous literal and figurative force of AIDS on gay communities continues the historic condemnation of same-sex relations, since sexual activity between men was criminalized long before it received its official medical label of "homosexuality" in 1869 (Kinsman, 1987). The naming that has been applied to gay men and by gay men has changed since then; and, certainly naming becomes a powerful force in the face of death: homosexual, homophile, gay, queer. This series of labels ascribed to, or taken on, from the turn of the century through the 1990s attests to specific political strides and setbacks.

Since approximately 1981 the history of gay male sexuality and identity, and the history of AIDS, have become intertwined and inseparable. This history is itself bound up in the contradictory and fluctuating discourses of human sexuality generally. Ten years after the so-called sexual revolution, with gay identity emerging in urban centres, acquired immune deficiency syndrome threw sexual identity issues into further confusion. It appeared that sex could kill, and was killing gay men in record numbers. Sexuality and AIDS are situated within an historical and cultural context and can be seen as to produce a political epidemic, not only a medical one. "Serious talk about sexuality," argues Laqueur (1990), "is thus inevitably about the social order it both represents and legitimates" (p. 11). The following section examines the historical development of the homosexual category from the nineteenth century onward, and provides a brief survey of modern research which has attempted to theorize the category.

### **Early Knowledge**

The road from "invert" to "queer" has taken activists and researchers over unsettling and yet, exciting terrain during the last 150 years. The historical map through this topography to the mid-1990s indicates myriad highways and secondary routes that have been travelled to gain an understanding of sexual identity, homosexual identity, and sexual orientation. Despite the artificial separation of academic expertise, knowledge creation in one area is not separate from knowledge about the other. What we know about sexuality and identity, and who we are as sexual beings is situated within a complex tangle of political, economic, social, legal, religious, and scientific relations. Like other disciplines,

the science of sex appears to have been situated historically within a nature versus nurture, or essentialist versus social constructionist debate.

As Lorber (1994) observes, sexologists and sex therapists have tended to rely on a biologically universal notion of sexuality, of which homosexuality is often seen as the unhealthy expression. Psychoanalytic theories, on the other hand, place the foundation of sexuality in early attachments within the family. Rather than a universal, biological drive, “the psychological components of sexuality are fantasy, desire, and passion” (p. 56). Individuals choosing members of the opposite gender have, according to these theories, successfully negotiated the Oedipus complex. Gender identity and sexual orientation are observed to have been formed early. Thus, individuals whose gender identity is incongruent with their genitalia (transsexuals); or those whose sexual orientation is not heterosexual (homosexuals), are seen to have had no choice.

A further perspective to be discussed later is that of social construction in which sexuality is perceived to be learned in a social and historical context. Lorber notes that

Social constructionists argue that cultures and societies organize sexual practices into approved, permitted, and tabooed patterns that are internalized by individuals and that meanings of sexual behavior change over time.... Approved practices are actively encouraged; permitted practices are tolerated; and tabooed patterns are stigmatized and often punished....All sexual desires, practices, and identities are not only gendered but reflect a culture's view of nature, the purpose of life and procreation, good and evil, pleasure and pain; the discourses about them are permeated with power (p. 56).

Because of the ongoing resiliency of the debate among the biological, psychological and the social, it is within its context that the following discussion on the development of homosexuality and identity is situated, for as Kinsman (1991) argues, “sexual difference

is a key aspect of social struggle and regulation” (p. 95).

The issue of sexual identity continues to be contentious not only within the lesbian and gay activist and academic movements, but also in the work of sex researchers; and, is interwoven with the historical and cultural discourse of homosexuality, bisexuality, and biology (De Cecco and Shively, 1984). This is despite the fact that, as Maynard (1991) notes, the adoption of a sexual identity by the early gay and lesbian movement was intended as a longer term strategy of challenging identities that were set in place by systems intent on regulating lives through identity. Western scientists, particularly within the discourses of sexology and psychiatry, have studied homosexual identity to locate and document its etiology. A prime motivation for this work has been to discover how individuals might change their homosexual identity, or to provide ways that they might adjust to it. More recently, there is interest in what homosexuals think of themselves and how homosexual identity develops.

Those who study sexuality encompass a broad intellectual territory: history, medicine, biology, sociology, psychiatry, psychology, law, lesbian and gay studies, cultural studies, women's studies, minority studies, religious studies, and various professional areas of study, to name a few. Virtually no field within the academy is without scholars in this area; and, each adds to the sophistication and complexity of the knowledge. Emerging from these disciplines are models and theories reflecting the ongoing struggle over definitions and categories of sexuality.

Dynes (1992) dates medical interest in homosexuality to the seventeenth century, and argues that this was the beginning of the medico/psychiatric interest in homosexual

behaviour to serve the legal system. Although scholars may dispute 1869 as the year that Benkert provided the label that was to presage a radical break from previous ideas of sexuality, the category of homosexual as an indicator of a person's sexual orientation is generally assumed to have been assigned to individuals beginning in the late nineteenth century (Kinsman, 1991; Irvine, 1990; D'Emilio, 1992). Regardless of the date, homosexuality has been historically categorized as sinful, immoral, perverted, a mental illness, and a disease. Homosexuals were perceived as deviants rather than living and sexual individuals, and definitions of homosexuality were based on moral, generally Christian, ideas of relationships and sex. During the Victorian era, homosexuality was constructed by experts within the medical and legal professions who believed in the essentialist and dichotomous notion that heterosexuality was natural; and, consequently, homosexuality was deviant (Weeks, 1989; Kinsman, 1987, 1996). Legal definitions and medical terminology were officially created to organize this deviance, and it is suggested that the knowledge that was produced about homosexuality and lesbianism allowed social institutions and agencies to "understand, classify, police and regulate...sexual lives" (Kinsman, 1987, p. 28).

The history of what might be termed the official study of sexuality, or sexology, is situated within the episteme of the modern era coincidental with the blossoming of science and the search for truth, the rise of capitalism, and the beginning of changing sex and gender roles in Western society. One of the casualties of this upheaval was the erosion of the church's authority in sexual matters. Homosexuality became less a moral concern dominated by church authority, as the medicalization of the category gained

prominence. Whether or not historians can claim to assign specific dates, there was a shift from same-gender acts of sodomy (any non-procreative sex act) condemned by the churches and by law, to the unfolding of a homosexual identity in which medical discourse recognized a distinct person (Irvine, 1990). Such a category of person generated what Richardson (1984) describes as a "long history of definitional crises" (p. 79) about the meaning of such an identity. Indeed, not all scholars accept the creation of the modern homosexual through medical discourse that seems to allude to the passivity of those involved as homosexuals (Kinsman, 1991). In her discussion of the significance of medical labelling at that time, Irvine (1990) wonders if the category created a subculture that organized itself around the concept of homosexuality; or, if the medicalization was a response to label/define or control an existing subculture.

As well as the erosion of religious authority, the industrial revolution dramatically transformed family relations, and consequently same-sex relations (Kinsman, 1987; Weeks, 1989; Irvine, 1990; D'Emilio, 1992). With the migration of families and individuals to urban centres for example, men worked outside the home, middle class women tended to be relegated to the home, while middle class spinsters began to live and work independently of family. Although not entirely cut free from previous mores, the migration left room for individuals to consider the less rigid ties to reproduction (Herringer, 1989). Nonetheless, this nascent sexual freedom was situated within a male-dominated society in which male and heterosexual sexual experience was the norm, and began to solidify what Devor (1993b) refers to as the ideological gender schema of modern society.

Political and social ideas regarding public and private spaces emerged during the early nineteenth century. Although they appear inseparable as though one did not affect the other, "public" was the domain of commerce, work, law, welfare. "Private" on the other hand, was the space into which the state could not intrude except in its capacity as the parent of the nation. According to Kinsman (1987, 1991) it was within these limited public spaces that same-sex networks emerged; and, with private space often limited, male homosexual activity took place in public spaces such as parks or washrooms. While the state had tended to dictate what legitimate sexual activity was permissible or normal within public and private spaces, resistance to these restrictions existed at the same time. Sexual science was interested in sexuality generally; and, with the boundaries of public and private shifting so significantly it seemed important to create boundaries within which one would know at least, who was masculine and who was feminine.

The history of legal and psychiatric intervention into the public and private lives of gay men, particularly the notion of homosexual acts as sex offenses, "established a history of homosexual sex *per se* as itself a social threat (Kinsman, 1992b, p. 14). What he refers to as "regulatory strategy" against homosexuality was evidenced for example, in Canada's acceptance of Britain's Wolfenden report of 1957. The report, effected by various post-war social changes in the late 1950s, supposedly attempted to decriminalize some sexual activities between men by focusing on a public/private distinction. It made recommendations only. In Canada, criminal law did not change until 1969 when it established "acceptable" gay sex as that which happened in private; and, illegal gay sex as that which took place in public, or with minors. Homosexual acts moved from being

regulated under the law, to being regulated as mental illness. Homosexuals were sick, not criminals. Kinsman (1991) contends that:

In official discourse, lesbian and gay concerns and our sexualities now became questions of sex in public or sex in private along with whether it was with adults or youths. Heterosexual hegemony was not so much challenged as shifted in form. The 'sickness' model was firmly established as the hegemonic explanation of homosexuality (p. 21).

### **Emerging Identities**

Early research into sexuality seemed more interested in various sexual behaviours and gradually shifted to understanding how a person acquired a certain sexual preference (Cass, 1990); thus, while sex between individuals of the same gender has existed throughout history, an identity constructed around that sexual activity is relatively recent, and is culturally diverse. The naming, or identity labelling, was done by professionals, and terms such as "homosexual" were used by them. Interestingly, many of those doing the categorizing engaged in these behaviours themselves and wrote about homosexuality extensively. Men such as Ellis, Krafft-Ebing, and Hirschfeld conducted sex research into the causes of homosexuality, and attempted to determine who were homosexuals. Their work, and that of others including Ulrichs and Freud, was extremely important in the medical/psychiatric categorization of homosexuality (Richardson, 1984; Kinsman, 1987, 1991; Coleman, 1990, Irvine, 1990,). Coleman notes that Ulrichs and Hirschfeld for example, developed a construct of homosexual identity which represented a shift from sin to essentialist science. In their view, individuals were homosexual because of biological urges. The way a person moved or spoke; how they behaved in childhood—all could be

signs of inversion. Homosexuality was the third sex or "Urning" within a theoretical frame that tended to conflate sex and gender, as well as sexual variation, gender role, and social status (Coleman, 1990)..

Irvine (1990) notes that Ellis constructed "inversion" as a biological anomaly much like colour blindness, and "homosexuality" as a characteristic that one acquired. Krafft-Ebing apparently found that a person became an invert through masturbation. Freud's research gave the social environment of a child's parental influences a primary location in the determination of sexual orientation and, a belief that individuals were born as bisexual males and females (Coleman, 1990). Irvine (1990) also argues that the possibility of gender chaos was at the root of much early research in which homosexuality was evidenced by feminine behaviour in men, and masculine behaviour in women. Homosexuality was indicative of social disorder, and "gender rebellion thus became a primary signifier of the homosexual condition" (p. 243).

What Kinsman (1987) refers to as "regulatory strategy" against homosexuality can also be illustrated in these early concepts. For example, locating homosexuality in causal theories such as biological determinism, while appearing to provide an avenue to social tolerance, may instead provide an alternate route to disease or abnormality. Certainly for those theorists, categorizing homosexuality as congenital would perhaps lessen the social threat that it was contagious, or that a seemingly normal individual could be seduced or converted to homosexuality. In a compelling article about Hirschfeld's work, for instance, Schmidt (1985) suggests that the results of such biological investigation which concluded that homosexuality was congenital, did not save German

homosexuals from oppression in the early 1930s. Rather than being able to convince the legal profession that homosexuals could not help who they were, Hirschfeld and his followers met forceful opposition until finally his institute in Germany was ransacked and his extensive library on sexology publicly burned shortly after Hitler's rise to power.

## **Categorizing and Classifying Sexuality and Gender**

The need to categorize and classify sexuality and gender is evident in the remarkable number of studies and theories that have emerged during the last fifty years. The work appears to reflect in various eras, both essentialist and social constructionist perspectives. This section will review these perspectives.

In post-war America, in the late 1940s, a landmark study by Kinsey and group (Cass, 1990; McWhirter et al, 1990; Coleman, 1990), developed a seven-point heterosexuality-homosexuality continuum that classified human sexuality. One end of the spectrum was heterosexual sex acts, the other homosexual, with bisexuality appearing as a merger of the two. As a "0", a person was classified as completely heterosexual, while a "6" categorized an individual as totally homosexual. Perhaps a more astonishing fact for the time, was the number of Kinsey's subjects who placed themselves in the middle of the continuum as having had sex with both men and women. Kinsey's classification system was based primarily on sexual behaviour—and who the object of that sexual behaviour happened to be. While it did not take into account social or personal meaning, this rather simple model paved the way for more complex examinations of sexuality and identity.

According to Irvine (1990) Masters and Johnson's sex research in the 1960s and 1970s reflected "their belief in the biomedical model and the primacy of physiology in understanding human sexuality" (p. 249). While reporting that sexual response in heterosexuals and homosexuals was the same, a further aspect of their work was therapeutic intervention to convert homosexuals into heterosexuals. Irvine argues that their research biases are reflective of an ideology and belief that:

....physiological data will reveal essential "truths" about human sexuality; an ethos that stresses the superiority of marriage and commitment; and a liberal tendency that emphasizes individualism and free choice while minimizing the importance of the socio-political contexts (p. 250).

In other sex research, Shively and De Cecco (1977) argued that unlike Kinsey's findings, there was more to sexual identity than where sexual acts placed an individual on a continuum. In an attempt to capture the complexity of sexuality, rather than to proffer cures, their work examined what they considered to be the four components of sexual identity: biological sex, gender identity, social sex-role, and sexual orientation. Because their discussion of each component begins to clarify meanings in the sexual identity literature, I believe it is useful to provide them here.

Gender identity is defined for example, as a person's "basic conviction of being male or female" (p. 41) but it does not always relate to that person's biological sex. Social sex-role refers to cultural attributions generally associated with being a woman or man, and is generally related to how a person looks or behaves. We expect that someone who looks and acts like a man, is a man. Interestingly, in earlier work, Shively and De Cecco's respondents equated the presence of masculinity in heterosexual and homosexual men

and women with the absence of femininity. Making use of two sets of continua, one which places feminine and masculine at opposite ends of the scale; and the second set composed of two scales, one which moves from "not at all masculine" through to "very masculine", and alternately from "not at all feminine" to "very feminine", the authors term mid- range males or females as androgynous, and individuals who are not masculine or feminine as undifferentiated.

In a review of research previous to theirs, Shively and De Cecco note that feminine behaviour in men may be dealt with through transvestism. Where there is a conflict between gender identity and social sex-role for example, a man who looks masculine and is perceived as masculine by others may see himself as female. They suggest that these individuals may decide to become transsexuals.

After gender identity and social sex-role have been developed, individuals develop sexual orientation. Noting that previous research (such as Kinsey's) based sexual orientation on a bipolar scale which tended to illustrate that an individual was either homosexual or heterosexual, Shively and De Cecco argue that sexual orientation includes both a physical and an affectional preference. In the first, a preference for "male and/or female sexual partners"; and, in the second, a preference for "male and/or female emotional partners" (p.45). Both physical and affectional preferences could also be seen as scales of independent continua between homosexuality and heterosexuality.

Conceptualizing sexual orientation as a physical/affectional theory that acknowledges behaviour and fantasy rather than merely physical behaviour, suggests the need for a broader exploration of the complexities of differing sexual expression.

Weinberg (1978) examined the possible relationship between what a man did sexually, and whether or not he defined himself as homosexual because of this behaviour. He found that many of the men he studied who had sexual contact with other men without identifying as gay, changed the "meaning of their feelings, fantasies, and behaviours" (p. 155) after having ongoing contact with other gay men. Being with other gays supplanted the previous negative definitions of homosexuality that they previously held.

In 1979 Vivienne Cass published her six-stage model of homosexual identity formation. She argued that earlier studies outlined various types of homosexual identity, and focused on how homosexuals "managed" their identity. In contrast, Cass was curious about "how" homosexuals acquire identity, and based her developmental model on the clinical work she had done with both gays and lesbians. By moving through the stages of identity confusion, identity comparison, identity tolerance, identity acceptance, identity pride, and identity synthesis, Cass suggests that a homosexual's personal meaning about him or herself shifts. He or she begins to imagine the possibility of an alternative to heterosexuality and a synthesis into "one image of self receiving considerable support" (p. 235) rather than condemnation from others. Cass suggested that "instead of being seen as the identity, it [homosexual identity] is now given status of being merely one aspect of self" (p. 235). She believed that gays and lesbians play an active part in their identity acquisition.

During the 1980s a great deal of debate ensued within the pages of the Journal of Homosexuality regarding the need for a deeper contextual and definitional analysis of

sexual orientation and identity. As with Shively and De Cecco's (1977) earlier work that argued for the need of shared and finely-honed meaning regarding sexual identity, Cass (1983/84) argued that use of the term "homosexual identity" was fragmented and confusing, and sought to place it in a theoretical context. Her wide-ranging discussion critiqued common assumptions made about homosexual identity, and attempted to provide indicators for future research. She argued that researchers had tended to assume that the terms "homosexual identity", "gay identity", "lesbian identity", "homosexual self-identity", "gay self", "lesbian self", "sexual identity", each had generally the same meaning. Short of developing a similar set of words to be used in their research, Cass suggested defining within their work, what the words meant in the context of particular research. Within that context as well, she strongly argued that theoretical and research links must be made between the study of homosexual identity and the existing psychological literature on identity in general in order to guard against unfounded personal assumptions about homosexual identity entering the research.

One of the first assumptions she believed needed unpacking was the relationship between identity and self-concept, terms which tended to be conflated within the homosexual literature. In her own definitional work, Cass suggested that "identity" should be called "self-identity" to distinguish it from both presented identity or "that picture of self presented to others with regard to a specific socially defined category" (p. 111) and from perceived identity, or "that image held by another about self with regard to a specific social category" (p. 112).

A further assumption with critical implications, according to Cass, was the

conflation of sexual identity with homosexual identity--a major implication being of course, that homosexual identity was the result of sexual activity. Believing that each was a separate concept requiring an explicit definition, she delineated sexual identity as "the individual's overall conception of self as a sexual being" (p. 116) separate from the object of affection. Homosexual identity, may include both sexual and non-sexual images of the self.

Within the non-sexual aspects of homosexual identity, Cass discussed a model which distinguished between homosexual identity and gay identity; the first being linked to one's sexuality, the latter implying a link to the gay community. Cass argued that this split tended to reflect a political stance that saw gay identity as a more developmentally mature response to a stigmatized social status. She believed that:

A theory purporting to outline identity formation should (1) offer a clear definition of what "identity" means and of its relationship to self concept, (2) outline the structural components of identity, (3) trace the changes that occur as identity develops, and (4) describe both internal and external factors influencing such changes. Conceptually, it is necessary to keep distinct the cognitive, behavioral and emotional changes, and to trace each area through all stages of development (p. 118).

Following her brief mention of a homosexual group identity which she pointed to as a significant developmental stage, Cass discussed implications of those researchers who argued that a homosexual identity did not exist. Although this will be discussed more fully later in my paper as the essentialist versus social constructionist debate, it is interesting that Cass noted that homosexual identity may be "fact, construct, or....fanciful illusion" (p. 121).

Like Cass, De Cecco and Shively (1983/84) urged those working in the area of

sexual identity to move to a more critical and rigorous examination of meanings. The authors located four contexts in which they suggest, the discourse on sexual identity exists—the historical, bisexual, homosexual, and biological. Each context could be examined through biological, psychological and socio-cultural lenses. Considering the breadth of sexual experience possible, biology tended to provide the basic assumption in most research that the sex of one's partner determined sexual orientation. Ultimately they argued that the focus on sexual identity had to shift from viewing those relationships strictly in biological terms, to their complex structure of social relationships—economic, political or sexual. In this way, the role of anatomy as the only analytic in producing discourse on sexual relationships, was questioned.

In a companion study presented at the same time, Shively, Jones and De Cecco (1983/84) surveyed the literature on sexual orientation to determine how it has been used both conceptually and operationally. They concluded that the broad discrepancies in definitions were "symptomatic of an underlying conceptual confusion" (p. 127) that seemed to stem from confusion on the nature of a sexual relationship. Again, refocussing on sexual identity and sexual orientation within the broad context of sexual relationships would, they suggested, ground research in this area.

Using the ego development model of social theorist Habermas, Minton and McDonald (1983/84) conceptualized homosexual identity as a life-long process toward acceptance of a positive gay self image. In their rather abstract view, a homosexual moves first of all through the symbiotic and egocentric stages in which, as would a child, s/he has no sense of a self differentiated from the physical or social world, and

subsequently as s/he grows older, is able to make that differentiation. In the sociocentric stage, the individual views the world from the position of self that is separate from the social and physical surroundings. Finally at the universalistic stage the self is in a position to evaluate the societal norms s/he faces. Minton and McDonald reinterpret these stages to encompass a homosexuality identity process.

Weinberg (1985) examines the problems of biologically-derived models and the consequences of relying on them in the study of sexual identities. Through his critique of Minton and McDonald's development model, his first concern is that while the construction of stage models based on biology may lend credibility to psychoanalytic stage theories regarding homosexual identities, they are not able to explain sociocultural change and may instead reflect the professional training of the researchers rather than the lives of homosexuals. Secondly he suggests that a biological developmental model adopted by social scientists is "the transfer to social identities of moral and ideological attitudes derived from biological notions of normality" (p. 79). Finally, Weinberg argues that application of a biological framework on sexual and social identity development promotes a linearity of thinking and masks the actual complexity of such development. Not only that, it curtails alternate routes to the same identity, or assumes that everyone acquires identity in the same manner. Rather than aiding in the understanding of identity formation, these types of models tend then to be critical of people who waiver developmentally from them, by assuming a fixed end point to be achieved--the integrated self. Ultimately says Weinberg, such models rule out the possibility of change during one's life.

Another development in the increasing acknowledgment of the complexity and dynamism of sexual identity is evident in the work of Klein, Sepekoff and Wolf (1985). Their Klein Sexual Orientation Grid (KSOG) fleshed out the earlier Kinsey Heterosexual-Homosexual Scale to provide evidence that sexual orientation is not reducible to merely homosexual/heterosexual or even homosexual/bisexual/heterosexual acts, but includes emotional and social preferences, self-identification, and a homosexual or heterosexual lifestyle. The KSOG asked respondents to describe their past, present and ideal sexuality in relation to seven variables of sexual orientation including: sexual attraction, sexual behaviour, sexual fantasies, emotional preference, social preference, self-identification, and heterosexual/homosexual lifestyle (p. 40). As in Cass's work, the KSOG brought a much broader range and complexity to sexual orientation than had the Kinsey scale. It pointed to the importance of recognizing sexual orientation as a changeable process, experienced in very different ways whether one is gay, straight or bisexual; and, the variety of expression within each orientation. They note that their study "attempted to point out the pitfalls of conventional labeling" (p. 47).

In 1987 Coleman proposed, as a clinically diagnostic instrument, a model for assessment of sexual orientation that included nine dimensions: First, current relationship status defined within a range of single or coupled; second, current self-identification sexual identity on a scale ranging from exclusively homosexual through to unsure; third, ideal future sexual orientation identity making use of the previous range; fourth, indication of comfort with current sexual orientation ranging from very comfortable through very uncomfortable; fifth, physical identity, defining one's biological sex as male

or female; sixth, gender identity, thinking of oneself as a physical male or female, and in fantasies imagining self as a physical male or female; seventh; sex-role identity defining one's interests, attitudes, appearance and behaviours as traditionally male or female; eighth, sexual orientation identity as measured by behaviour, fantasies, emotional attachments; and finally, past and present perception of sexual identity compared to idealized future (p. 22-23).

Although Coleman employs Likert-like ratings within the first four areas, in the last five he has clients indicate within a circle how they perceive more precisely, the percentage of their sexual orientation. He suggests that once the client has filled out the circles, various meanings and implications, goals for therapy are able to be discussed. Once again, as with the KSOG, an attempt was made to grasp the complexity of sexual orientation.

One of the acknowledged preeminent sexologists, John Money, captured the core of his work in a 1988 volume. Money's research falls primarily into the essentialist frame although he believes that "nature and nurture combine" (p. 78). He remarks that he began using the term "gender" in the early 1950s to differentiate the gender identity and gender role of an individual from his or her sex organs; and, subsequently used the term "gender-identity/role" in an attempt to conceptualize their unity. His classification scheme for gender cross coding accounts for both biological and social coding, and attempts to capture both ongoing and episodic cases of gender variance from homosexuality through to transsexualism. While Money has identified and categorized scores of sexual variances, he appears to believe that sexual orientation is fixed. For example, he proposed

a further refinement of nature/nurture with the addition of "critical period" in which intervention at a critical period in a child's life, could lead to homosexuality.

Into the 1990s several studies have pushed the need to expand our conceptions of gender. Cass (1990) defined gay or lesbian identity as "the sense that a person has of being a homosexual/gay man/lesbian....experienced as a recognition of 'who I am'"(p. 246). Objective and subjective aspects of homosexual identity may differ. Objectively we may look at ourselves and who we are through the labels offered by society--labels such as homosexual for example. Cass argued that such labels tend to assume that all people who use them are the same--there is no variation in who might be homosexual. Subjective identity is a feeling about ourselves as being or knowing we are homosexual. These subjective and objective facets are developed through what Cass described earlier as homosexual identity formation, which does not include only sexual knowledge of self but an integration and changes in "the areas of cognition (thoughts, fantasies, hopes), emotions and actions" (p. 247).

Despite the fact that she has relied on a stage model to describe identity, Cass appeared to understand the complexity and range of homosexuality and does not adhere to the notion that it is forever fixed. While Kinsey included overt homosexual behaviour as the indicator of the expression of sexual preference and its development, Cass (1990) argued that the "study of gay/lesbian identity suggests...that many other dimensions of behaviour are involved in the experience of being a homosexual" (p. 257). As well, not everyone experiences his or her homosexuality in the same way; sexual expression for example, may be assigned different meanings. Cass's argument that researchers must

include accounts of meaning that gays and lesbians give to their sexual preference rather than the researchers' interpretation of that meaning is an important one. She belied the notion that identity and sexual preferences are simple behaviours open to observation only, and acknowledged the complexity of sexual identity formation and sexual preference. Her assumption that the individual plays a dynamic role through making various choices in the process of acquiring identity is a refreshing departure from the notion that sexual preference is unconscious. While for the purposes of this paper I am interested in gay male homosexuality, I appreciate that Cass acknowledged that identity acquisition is different for men and women because of our differing social expectations. She (1990) notes that a

fully developed identity is one in which self-identity, presented identity and perceived identity are congruent in describing a positive homosexual image (p. 263).

Jacobs and Cromwell (1992) using cross-culture analysis, challenge the Cartesian dualism of the roles and labels Western society has adopted. They argue that classification systems such as Klein's sexual orientation grid, Shively and De Cecco's components of sexual identity and Money's schema of gender transposition are inadequate to describe the complexity of gender. The meanings assigned to sexuality and the words assigned to categories of difference are not neutral nor applicable to cultures other than our own. Each culture constructs gender through adherence to various sex and gender roles--for example, if a boy of any culture has been sex-typed as a male and socialized within that culture as a gendered man, he will most likely identify with his classification as male. As he develops, he may be assigned other gendered labels such as

"father" or "grandfather". For some, the labels male or female may not support or match their gender identity. The authors give the example of a 62-year-old formerly married father who feels he is a woman, and undergoes counselling and surgery in order to have her sex conform to her gender identity. "...her sex was male, is now female; her gender identity is, and always has been, 'woman' (p. 48). In other cases, sexual identity rather than gender identity may change. They suggest:

Gender identity includes many different areas of a person's life: sexuality, sexual identity, and sociocultural roles. Sexual identity on the other hand, refers to a self-definition based on the way individuals conceptualize their sexual preference and practices, i.e., the way people define their sexual desires and experiences (p. 49).

Through a discussion of gender variance among differing cultures, Jacobs and Cromwell conclude that given anthropological evidence two fundamental principles emerge--the "range of human genetic and phenotypic variation is not fixed..."; and that "culture is the matrix into which all aspects of life are fitted and through which life is interpreted, codified and acted out" (p.62). Given this, cultures are able to define as many sexes and genders as they want, and categorizations of sexual orientation must take this into account.

Nearly ten years after exhaustive analysis of homosexual identity formation, the urge to differentiate and clarify such concepts as gender identity concepts, and attempts to move from a primarily biological etiology to a contextualized understanding of sexual relationships, Paul (1993) analysed what he saw as the resurgence of biological models of sexuality. Within his discussion of childhood cross-gender behaviour, he contends that researchers still tend to assume that homosexuality is the mark of a defective male or

female and hence can come to no consensus regarding sexual identity. Paul suggests that categories (heterosexual, bisexual, homosexual) are useful as social descriptors but not as "intrinsic traits predictive of the sum of an individual's erotic and affectional desires" (p. 45). Again, he concludes that what emerges is an essentialist research agenda substituting absolutes for fluid sexual boundaries.

In her research into gendered sexuality, Devor (1993a) also points to the fluid and changeable nature of human relationships and moves beyond the range of the heterosexual/homosexual binary. She suggests a classification system that may move us away from the Western societal dominant gender schema that "is a cognitive filter which teaches members of society to recognize and understand only certain forms of behaviour as gendered" (p. 34). Devor argues that the ideological base of this gender schema severely restricts peoples' range of sex, gender, and sexuality possibilities through a series of binaries under which individuals are socialized and categorized; for example: biological sex=male or female; social gender=man or woman; and sexuality=heterosexual or homosexual. As a result, individuals are generally unable to imagine identity that is not linked to gender. They see themselves as gendered and recognize the gender attributes of others who in turn recognize them; thus reinforcing and legitimizing particular modes of being.

Devor argues that because sex, gender and sexuality have been conflated "all sexuality is gendered...and all gender has sexualized elements. Gender is thus, in part, a product of the social meanings given to biological sex status, sexual desire, sexual practice, sexual identity and sexual attributions" (p. 36). Consequently, she suggests a

conceptual shift to gendered sexuality which would recognize the interplay among sex, gender and sexuality. Rather than the limited binaries presented above, she has moved to the following descriptors for her taxonomy:

female and male heterosexual, or female and male homosexual, to refer to the sexes of individuals; straight woman and straight man, or lesbian woman and gay man, to refer to the genders of people in sexual relationships (p. 36).

Here, male/female refers to biological sex; homosexual/heterosexual refers to the sexes of persons interacting together and includes behaviour, fantasy and desire; straight, lesbian or gay refers to the genders of persons interacting together and includes behaviour fantasy and desire; finally, man/woman refers to social genders.

Devor's reconceptualization of formerly simplistic yet ideological referents regarding gender, moves the debate from its essentialist retrenchment to an acknowledgement of the importance of the "social". Her taxonomy reveals the complex of relationships and combinations of gendered sexualities that exposes the paucity of earlier schemas, while at the same time responding to lived reality.

The brief review of sex research presented above, while by no means complete, does illustrate, I believe, the inherent power of categories and classification regarding sex and gender. It illustrates as well, the struggle between biology and culture regarding issues of sex, gender, sexual orientation. Lorber (1994) argues that "gendered sexual statuses are such powerful political, legal and ideological constraints on individuals' sexuality and emotional relationships that alternative statuses are almost unthinkable" (p. 79).

## **Theorizing Sex and Gender**

Theorizing and research regarding gendered sexuality seems to have coalesced around two arguments. While sociologist and AIDS activist, Epstein (1994) may consider it dead, the essentialist versus social constructionist debate continues to rage; and, there appears little room for consensus among scholars and activists about the nature and complexity of homosexual identity. Simply stated, essentialists argue that homosexuality is a category that has existed in all societies and cultures throughout history (Boswell, 1980). According to many lesbian and gay scholars, and others who espouse a social constructionist point of view, contemporary heterosexuality and homosexuality are not transhistorical, innate categories fixed in time across cultures (Weeks, 1985, 1989; Padgug, 1989; Epstein, 1988a, 1988b; Kinsman, 1988, 1991; Newton, 1988; Vance, 1988; Halperin, 1990; D'Emilio, 1992). This perspective assumes that the foundation of sexuality and sexual orientation is not biological but is socially made; and, that homosexuality is a "conceptual product of the late nineteenth century, when the spread of a capitalist economy and the growth of huge cities were allowing diffuse homosexual desires to congeal into a personal identity" (D'Emilio and Freedman, 1988, p. 226).

In an earlier analysis, Epstein (1988b) tackled the essentialism versus constructionism debate and summarized the arguments as follows:

[E]ssentialists treat sexuality as a biological force and believe that sexual-identity labels represent genuine, underlying, more-or-less fixed differences among groups of people. Constructionists, on the other hand, stress that sexual identities are social constructions--that sexuality can be more fluid and malleable than we think, and that identities develop historically in a wide variety of ways in different cultures (p. 48).

Social constructionists may totally or partially reject the biological view, and yet as Gross (1993) points out,

....however these theoretical perspectives may vary in assigning ontological causes for the appearance of homosexuals in our midst, they both seem to agree that such people do exist here and now (p. 113).

Much research suggests the existence of an ontological homosexual, or a "belief in homosexuality as a state of being" (Richardson, 1984, p. 79) and for whose existence a cause may be discovered. In this conceptualization, sexuality is indeed recognized as a drive deserving of expression, but only in conjunction with what or who is deemed normal. As with most epistemological constructs, researchers within the broad area of sexual science tend also to view the dominant gender as male and heterosexual. Within this frame, there is little space for the complexity of sex, or for the acknowledgement of the range of gendered sexual expression which actually exists in society. Consequently, few would be considered "normal".

Despite the fact that essentialist analysis tends to view reality in rather simplistic terms, it has exerted a powerful force throughout legal, religious, and medical institutions. Devor's research (1993a, 1993b) and others' (Irvine, 1990; Lorber, 1994) also point to the prevalence of an ideologically-based dominant gender schema, in which essentialist analysis is the "grand narrative" of Western culture, in this case, one in which biology determines gendered behaviour. As Irvine notes, "sex and gender are thought to be stable categories of meaning seamlessly unfolding over time" (p. 18). Interestingly, observes Kimmel (1993) in describing the work of Whisman (1992), more gay men tend to believe in the biological base of their homosexuality than do lesbians because

gender privilege gives them the possibility of access to higher status positions; if their homosexuality is biological it can be overlooked and they can claim their 'rightful' (read: masculine) status (p. 580).

Historically the essentialist belief that homosexuals as individuals have always existed, and the essentialist analysis of an individual's biological sex drive was thought to be useful to counter the legal criminal definition of sexual practices. If it is natural, and has always existed, it cannot be condemned. But of course, what is supposedly natural can be conceptually reversed and become an abnormality where the biological causes of homosexuality can be determined, located, and eliminated. Through an examination of essentialist medical and psychiatric discourse on sex, Richardson (1984) argued that essentialist hegemony had been confronted historically with what she termed "definitional crises":

The crises have arisen in deciding what is essential to the homosexual category: Is it a particular pattern of sexual behaviour? Is it a particular sexual identity? Is it an underlying orientation? (p. 89)

The social constructionist theory appears to create space for alternate answers to the above questions; and, to answer them, not all who might call themselves social constructionists employ the same methods or analyses in their work. Vance (1988) suggests that there are multiple degrees of social construction from radical to middle-ground. Aside from the agreed upon ground that sexual acts vary across time and cultures, a further theoretical position argues that the object of an individual's sexual desire is socially constructed. Conversely, another position suggests that sexual desire is fixed, but that behaviour based on desire is socially constructed within a particular culture. In her view the radical perspective argues against any natural sexual impulse

arising physiologically—it too, is constructed. Contrarily, the middle-ground position accepts a physiological sexual impulse from which "acts, identity, community, and object choice" are socially constructed (p. 19). Given the divergence of perspectives, Vance argues that those using the term must define it within the context of their work, as well as provide clarity regarding what it is they believe is constructed.

Kinsman (1987, 1991) also argues against a hegemonic definitional focus of social construction and in several articles and books has put forward what he calls an historical materialistic account of how sexualities have emerged. He approaches sexuality through an exploration of how an individual's experiences, including the lived, daily experiences of his or her sexuality, are socially organized and changeable over time, while suggesting that most social constructionists argue their position from "ungrounded or autonomous discourse theory" (1991, p. 95). An analysis of sexuality is not located in speculative accounts; rather the "lesbian and homosexual in official discourse, were part of broader shifts in class and social organization" (1987, p. 23).

Homosexuals, however named throughout history, were not passive recipients of legal/medical categories, labels or constructs. From Kinsman's historical materialist perspective, any investigation or analysis of lesbian or gay sexuality (or heterosexual, bisexual, transgender) must begin in their daily lives, not in the definitional category assigned to them in medical, legal or other official discourse. According to Kinsman (1991) "Sexuality is not some 'natural' essence outside history and social organization but is socially made and regulated. A history of sexuality is a history of social relations" (p. 96). This approach resonated with the way I was attempting to approach the topic of

AIDS suicide as I worked to explicate the social relations of sexuality and HIV disease that I saw in my brother's journal. Particularly useful was the way in which he explained that the social relations he was exploring were specifically those of "heterosexual hegemonic relations". Kinsman uses this term to indicate what he sees as the contradiction emerging from the "lived experiences of lesbians and gays, and the ruling relations that organize heterosexuality as 'normal', 'natural', and 'healthy' while at the same time constructing same-gender eroticism as 'unnatural', 'deviant', 'sick', or 'dangerous' (p. 94). This construction can be seen in the way that AIDS continues to be presented as a the logical outcome of an abnormal sexual lifestyle. I will elaborate on the analytic of social relations in Chapter Four.

Kinsman is critical of a social constructionism in which theory seems to arise from categories located within discourse, rather than from lives grounded in social relations from which the discourse emerges. While he appreciates the contribution to sexual discourses provided by Foucault for example, he argues that:

...contrary to Foucault's suggestion, the 'homosexual' did not spring forth fully formed from the pages of medical, psychiatric, or psychological discourse in the late nineteenth century. The 'homosexual' did not simply emerge off the pages of official or professional discourse....There is an important mediation between the worlds of official discourse and the courses of action they mandate for the police and other agencies that impact on everyday social life (1991, p. 97).

In his view, remaining in the realm of ungrounded discourse theory does not provide lesbians and gays with a foundation from which they can resist claims against them, or from which they can begin to transform society. Kinsman (1987, 1991), Patton (1989), Weeks (1985, 1989) Watney (1988), and others, analyse the way in which science,

medicine and the professions have produced the concept of homosexuality as though it were an objective form of knowledge. In his work on the official discourse of sexual regulation Kinsman (1987) argues:

People's diverse and varying experiences of sexual pleasures and dangers are inscribed into the categories and conceptual frameworks relevant to the work of sexual policing. Actual everyday erotic experiences are removed from the lived character of people's everyday worlds and are inscribed into the categories of sexual policing, for instance, into categories of 'public/private' so that they can be more effectively managed and contained (p. 40).

In addition to the theoretical terrain, both the essentialist and social constructionist perspectives posit differing responses, since the way gay identities are conceptualized, not surprisingly, influences the manner in which they can be politically strategized and practically implemented (Kinsman, 1988; Vance, 1988; Epstein, 1988b; Kimmel, 1993). The notion of an essential, natural, or fixed sexual identity may create a "gay people", a kind of ethnic culture. If homosexuality is biologically determined, then it would seem that there is little individuals can do by way of political response regarding the differences between heterosexuals and homosexuals. Many homosexuals, have since the early 1970s, embraced a "gay" identity and many applaud current biological research because of its implications for gay rights (Horowitz, 1988; Epstein, 1988b; Kimmel, 1993). If individuals are born gay, and thus did not choose their orientation, they deserve rights available to any minority, as limited as these may be. Practically, this is illustrated in community building, the provision of separate services and institutions, the move toward protective legislation, or perhaps in separatist politics, and so on. Horowitz (1988) suggests that many lesbians and gays experience this need to separate from straight

society to feel comfortable, and essentialist analysis

....reifies this oppressive necessity into a sense of fixed limits to emancipatory possibilities. It celebrates the gay ghetto as a liberated zone, but is blind to the limits of ghetto life (p. 13).

Reaction to oppression can certainly coalesce minority groups; it also creates backlash from the majority—for example the bombing of abortion clinics; race hatred; the murder of women students in Montreal; the ongoing stigmatization of persons with AIDS who are presumed to be gay; gay bashing, and so on. Social constructionists on the other hand, believe that their position broadens the political repertoire in which gays may engage because it places gay identity within the constructed frame of human sexuality in general, and thus can contest the institutionalization of a gendered order that has the power to regulate certain sexualities and genders (Horowitz, 1988; Maynard, 1991; Kimmel, 1993). Ultimately something which has been constructed, can also be deconstructed; in other words, there is room to interrogate what has been taken for granted and to pose different questions, answers, and solutions.

A resurgence of essentialism exists within what is called queer identity politics in which young queers are not necessarily challenging the broader gendered order, but defending as Maynard (1991) suggests, the besieged borders of their own turf. In many ways, while queer nation envisions itself in radical opposition to the status quo (both gay and straight), like early versions of essentialist identity politics, it reasserts the existing order, through the submergence of various other identities within its borders—those of race and class. Nonetheless, because of lack of attention paid to person with AIDS, for example, ACT-UP (AIDS Coalition to Unleash Power) has used identity to politically

organize against government bureaucracies seen to be withholding assistance, and groups of people with HIV disease have created Persons Living with HIV/AIDS societies across North America.

Kinsman (1992b) argues that "we need to elaborate an analysis of the relation between our diverse experiences of oppression as queers and how this gets 'worked up' into concepts of identity" (p. 6). He suggests a politics not based on fixed notions of identity but one that allows, as feminists have argued, for the diverse expression of social circumstances, and calls for a "move from identity politics to social and political analysis and action...We need collective social and political action to transform the social relations organizing the various forms of oppression we face" (p. 7). In recent comments Epstein (1994) too, argues that the point is perhaps not to try to solve the debate surrounding essentialism and social constructionism, but rather, to determine ways in which conceptualizations of sexual identity are "developed, appropriated, deployed and fought over" in what he calls a political sociology of knowledge (np).

## **Homosexuality, Identity and AIDS**

In New York in June, 1994 hundreds of thousands of lesbian, gay, bisexual and transgendered peoples celebrated the twenty-fifth anniversary of the Stonewall riot in New York which gay historians mark as the beginning of the gay liberation movement. In the emergence of North American lesbian and homosexual identities, it is one of the agreed upon historical moments or currents (Snitow, Stansell & Thompson, 1983; Weeks,

1985, 1988; Kinsman, 1987; Escoffier, 1990) which has had an impact on the "historical present" as it relates to AIDS. Throughout the 1970s and 1980s lesbian and gay activists worked with some success to overturn moralistic views and medicalized definitions of themselves as sick. The closet door opened with an outpouring of popular presses, a burgeoning cultural renaissance, and political action. This is not to suggest that every closeted lesbian or gay threw off mantles of invisibility into the startled face of a heterosexually-dominated society. However, the word "pride" emerged in connection with lesbians' and gays' descriptions of themselves as they created self definitions as normal, sexual beings.

Crimp (1992) argues that it is crucial to remember that there was a history of gay and lesbian culture before AIDS, and that AIDS cannot be understood apart from that history without ignoring the contributions of lesbians and gays in the fight against the disease. Yet ironically AIDS has reinforced the image of gays as not only sick, but now contagious. Patton (1993) suggests that there is a queer paradigm; that is, "you can begin as a queer, and therefore as uniquely susceptible to AIDS, but whatever your cultural status....regardless of how you contracted the virus you become nominally queer" (p. 154). Gays continue to be viewed as mentally ill, unpredictable and unreliable, as child molesters. Despite the fact that homosexuality was removed from the psychiatric community's list of mental illnesses and personality disorders more than twenty years ago, the myth persists that gay men are psychologically disturbed. This medicalization and stereotyping by a powerful profession extends to other allied professions and informs professional attitudes and research in the mental health, legal and social welfare fields

(Cain, 1993, 1994; O'Brien, 1995). Gilman (1989) observes that, "The internalization of the stigma of the polluting touch with all of its biblical associations reaches even into the self-representations of the person with AIDS" (p. 321). Thus, the gay man today, regardless of the state of his health, continues to be organized by official discourses as a result of the AIDS epidemic--medicine, law, culture, media--all shape and organize his daily experiences.

Epstein (1988) argues that not only is the growing legitimacy of lesbians and gays as a distinct interest group paralleled by an increasing homophobia; but the essentialist political response "helps to solidify the conception of AIDS as a 'gay disease,' as a marker of gay identity" (p. 50). Alluding to the emerging gay identity and consequent visibility of gay communities during the 1970s, he suggests that it was only inevitable that gay white males would be the first to be associated with what became known as AIDS, since the drug users and the poor, being largely from the black and latino communities (and in Canada, from aboriginal communities) died unnoticed by white middle-class men. The gay communities have thus found themselves in the position of "claiming a special need for government funding and medical resources while simultaneously having to combat the notion that AIDS is a gay disease" (p. 50).

Conversely, constructivist politics tend to link AIDS with various risk practices rather than to gay group identity. The dilemma of this politic is that AIDS organizations are attempting to respond to all groups, consequently leaving little energy for the gay communities they were originally serving. This issue has been raised at several conferences and workshops I have attended over the last few years, and in the groups

with whom I have been involved, it continues to emerge. Epstein suggests that what is at stake are contested definitions of the gay community. Ultimately, he suggests that these political battles are forcing gay men to rethink questions of identity. He argues for the strategic importance of an essentialist vision of community in the face of AIDS, while acknowledging differences within the gay community. "We should accept that constructionism and essentialism both speak to certain aspects of truth in our experiences and use the contradiction to our own best advantage" (p. 53). I found Epstein's position in this debate of little use in helping me with my own stance regarding the social relations that construct AIDS-related suicide because his definition of both seems limited. I agree however, with Kinsman (1991) that we do not need to abandon our identities as lesbians and gays, but instead, recognize that the categories of identity that we ascribe to ourselves today are not as he says, "the completion of our destinies" (p. 102). Holding fast to an identity that was worked up in the 1970s or 1980s does little to capture the complexity of lived sexualities in the late 1990s. What has been helpful for my analysis has been the notion that sexuality is continually being created and thus can be transformed, perhaps even in the context of the HIV crisis.

## **Conclusion**

Throughout this chapter I have begun to provide a conceptual frame for the argument presented in my dissertation. I was interested in what appears to be the inextricable link between homosexuality and AIDS and sought literature that would provide signposts to issues in the history of homosexuality, as well as in twentieth century research. While I found that the “social” has entered more fully into research over the last twenty years, I was somewhat surprised to discover the depth of the struggle between biology and culture. For political gay men, the debates as discussed above, have existed for years, although it appears that AIDS seems to have provoked the discussion of sexual identity at a more critical level. One explanation may be that AIDS has the capacity to destroy the preferred identity and replace it with a more highly stigmatized one at a time in history when cultural and sexual minorities are fighting for voice, recognition, human rights, and are making some gains. AIDS appears to have politicized many white gay men who, since the early 1970s gay liberation, have been able to express their sexuality in a somewhat more freeing social climate than previously.

The strategies available through the biological/essentialist or social constructionist frames to better understand the complexities of practices and desires of gendered sexuality appear to offer conflicting messages, as I noted above. The debates and their resultant strategies do not appear to assuage society's fear and hatred of homosexuality as reflected in its response to AIDS, or in a gay man's response to an AIDS diagnosis. However, perhaps launching themselves from the place of their

everyday experiences, and using those experiences to strategize a future against the continued regulation of their bodies, may propel gays and their allies to counteract and challenge the dominant and hostile voices. It is from this place of knowing that they may gain the knowledge to create a new discourse emerging in actions necessary to confront the fusion of the person, stigmatized sexuality and life-threatening disease.

The next chapter further outlines the conceptual frame that informed my analysis, through an examination of the material specific to AIDS and its relationship to suicide.

## CHAPTER THREE

### Conceptualizing Suicide in the Context of AIDS

*Satan seeks the ruin of our Bodies, as well as of our souls, and tempts Men often to Self-Murther (Richard Gilpin, 1677, quoted in MacDonald & Murphy, 1990).*

*Is suicide a legitimate option if things get out of hand (I don't want to suicide—I want to go naturally) (Jay's Journal, January, 1989).*

#### Introduction

The literature on suicide in general is enormous; but in attempting to reflect on it conceptually, I limited myself to its specific relationship to HIV/AIDS of which there is a small but growing literature. I was not surprised to discover that despite the fact that the 1990s offers some medical hope to those with HIV disease, and has seen a heightened debate regarding the right to die and assisted suicide (Ogden, 1994) many persons with AIDS elect not to allow the syndrome to run its inevitable course. Despite this, at the XI International Conference on AIDS in July 1996, only seven papers out of the thousands presented, were specific to issues of suicide, assisted suicide and euthanasia (Starace and Ogden, 1997). My contribution, "Unruly Death: Toward an understanding of the social organization of AIDS suicide" (Herringer, 1996b) was among them.

The work of figuring out "is suicide a legitimate option" —a question Jay posed in his journal and that will be examined more fully in Chapter Six—led me to issues of how suicide has been discussed in relation to HIV/AIDS over the last several years, and

whether it made sense in relation to what I saw him dealing with. In order to investigate the social relations of AIDS suicide I needed to know what had been said about it since the early days of the syndrome in the 1980s. Consequently, after Jay killed himself I sought out anything I could find on the relationship between AIDS and suicide. As I read through the professional and theoretical literature on AIDS, suicide, and AIDS-related suicide I realized that in order to begin to understand how self-killing has become so entrenched within the medical and psychiatric domains, I needed to understand its history. Professionals such as coroners or social workers find instructions in the discourse about how to read an experience so that it might be categorized as suicide. The professional discourse itself is historically cumulative and recursive, influenced perhaps by earlier social and political actions and debates about self-killing. Definitions of self-killing may have changed, but the act to which it refers has existed and been recorded for centuries. The term as we know it is thought to have been used in the English language in the late seventeenth century; and while it is constructed from Latin roots is not a Latin word (Giddens, 1970). By the 1600s, self-killing had become an act prohibited by the laws of God and “man”, and it appeared that experts were seeking a term by which they could envelope its complexity in order to more easily contain the act. Both the definitional debates as well as the debates regarding the meaning of the act itself have been longstanding. I have focussed on one debate below.

## **Suicide as Mental Illness**

Early medical psychiatrists assumed that self-killing was a mental illness and began compiling case studies as another body of work on suicide. With two approaches vying to explain self-killing--medical case studies and statistical analysis--differences emerged along theoretical and empirical lines. There was a clash between questions regarding the reality of the social factors emerging from statistics that explained the regularity of suicide rates, versus the views of psychiatrists who examined the psychological precursors of suicidal acts and were thus committed to an individualistic notion of etiology (Giddens, 1970). Social versus individual "causes" of suicide were argued in both sociological and psychological terms, and as will be discussed later, were reflected in decisions by coroners' inquests. Ultimately the tension focused on how to define the relationship between suicide and mental disorder. It was widely believed that mental illness was determined through heredity; consequently there was no place for the etiological role of social factors.

Because of the tremendous focus on the medicalization and link to mental illness in so much of the contemporary suicide research, I turned my attention to a search for how this has occurred. Kushner (1989) argues that the conceptual change in suicide from its earlier designation as a crime to one of disease, coincided with the growth of institutional psychiatry in post-civil war America. A profession of self-styled insane asylum directors trained in the general medical knowledge of the day but with no psychiatric training, formed the Association of Medical Superintendents of American

Institutions of the Insane. This association became, in the early twentieth century, the American Psychiatric Association which produces the DSM-IV—Diagnostic and Statistical Manual for Mental Disorders, an assessment tool used widely by various social and health professionals, including social workers. During this time (the mid-1800s) medical explanations for what caused suicide were influenced not only by emerging cultural values and clinical experiences but by what Kushner describes as :

the rivalries that surrounded the establishment of the psychiatric profession as it grew from a collection of asylum superintendents in the 1840s into the competing specialities of neurology and psychological psychiatry at the beginning of the twentieth century (p. 39)

Medical treatment of the day was based on the notion of imbalance in the physical system, which if unchecked could lead from melancholy to insanity and eventually, to suicide. In addition, with the emerging use of disease classification, suicide could be used to understand other types of mental illness. Statistical analysis of suicide was expected to “confirm a widely shared assumption that insanity in general and suicide in particular resulted from a combination of organic and emotional predispositions, exacerbated by the pressures of ‘modern’ civilization” (Kushner, p. 42).

In its publication, the American Journal of Insanity, the organization of asylum superintendents used its collection of statistics to come to some understanding of the origins of suicide. Because the statistics reflected an increasingly high suicide rate in cities, urban life and its complexities was selected as a cause. A fascinating aspect of Kushner’s examination of the American developments regarding suicide is that with the insistence that the causes of suicide could be eliminated through a controlled moral life of recovery

in a “lunatic asylum” preferably located in a rural environment, those managing the institutions began to emphasize the preventability of suicide as a means of increasing public support for the maintenance of the asylums.

Some medical practitioner/psychiatrists also believed that the statistics had provided an irrefutable link between urban conditions and the moral and physical symptoms of suicide, and thus hoped to create a reform agenda for modern society. In the concurrent reading I was doing in both AIDS suicide and general discussions of the issue, this aspect of Kushner’s history was invaluable. Psychiatric approaches and solutions to suicide remain influential to this day and are prevalent in the professional literature. As I analysed the coroner’s judgement of inquiry into my brother’s death for example (Chapter Seven) I was made even more aware of the pervasiveness of psychiatric discourse.

A nineteenth century iteration of the debate more prevalent in the seventeenth and eighteenth centuries was the issue of moral responsibility regarding suicide—determinism versus free will. By the 1800s common belief held that insanity was due to an organic cause; the issue became whether suicide was the result of the insanity, or was an immoral act. Ultimately Kushner illustrates that in the face of emerging psychiatric practice that was beginning to take into account neurological considerations, insanity and morality as causes of suicide lost credence. What emerged was both a psychological and organic explanation for suicide. The struggle among sociological, psychiatric and psychoanalytic theoretical conceptualizations of suicide resulted in:

....two contradictory explanations for the causes of suicide...Social and popular theorists attributed suicide to the conditions brought about by modern civilization, while psychiatrists insisted that suicide's etiology was rooted in individual disorder--whether organic or psychological. This contradiction led to contrary prescriptions for the prevention of suicide: Sociologists urged social reform, while psychiatrists insisted that individual behavior, not social structure, must be altered (p. 61).

In Kushner's view, methodological and theoretical differences regarding the etiology of suicide among sociologists, psychoanalysts and neuropsychiatrists since the beginning of the nineteenth century have prevented consensus.

Most discussion of suicide generally begins with Durkheim, although his sociological examination of suicide as a social phenomena and index of a society's state of health presented in 1897 followed the earlier fascination with suicide statistics in the mid-1800s. Giddens (1971) contends that suicide was a much-discussed social problem in the nineteenth century; and, while many of the studies prior to Durkheim's linked suicide rates to social factors, his work differed because of his attempt to provide a "coherent sociological theory" (p. 38). His contention was that suicide rates themselves created an entirely new fact, separate from individual reasons for committing suicide. While sociologists (Douglas, 1967; Atkinson, 1978; Smith, 1990a) have taken up suicide through differing approaches, Durkheim's approach to the sociological study of suicide his examination of self-killing is still often used as the base for contemporary research, particularly in its reliance on suicide rates. Douglas argues for example, that suicide is a cultural phenomenon, while Atkinson suggests that causal factors are not helpful in understanding suicide. Instead, he moves the discussion toward an examination of the social meanings of suicide, and how those meanings might be organized. Smith's (1990a)

inquiries move the discussion to an explication of the ideological nature of “suicide” and the use of term for the “...apparatus of governing, administering, and managing” (p. 144). True to the positivist science of the day however, Durkheim described social phenomena in general as “things”, and analysed data on suicide gathered through official sources not taking into account the reliability or origin of the numbers. He was searching for causes of a particular kind of death in the levels of social integration and regulation of nineteenth century society.

This route across a small corner of the landscape of self-killing and its conceptualizations helped my thinking about the organization of AIDS-related suicide. The primacy of suicide prevention having emerged from the need for asylums to maintain their footing makes sense in light of the similar focus of recommendations emanating from most current studies which I will examine below.

## **AIDS & Suicide**

Much of the literature presents suicide as an irrational act. When this assumption is attached to the person with AIDS who kills himself, the conclusion is that the act is irrational because of the effects of the disease on the brain, or the depressive nature of those with the disease. In other work, the focus is on the numbers of people with AIDS who may have killed themselves. Because Jay took his own life, by himself, I did not focus attention on the growing literature regarding euthanasia and assisted suicide although certainly these are important issues in relation to those with HIV disease

(Ogden, 1994). Nonetheless, de Wachter (1991) estimates that between ten and twenty percent of deaths among persons with AIDS are the result of euthanasia or assisted suicide. Among Dutch people with HIV/AIDS, Laane (1995) estimates assisted suicide at 26 percent, while Ogden (1994) estimates that in British Columbia, assisted deaths were ten to twenty percent of people dying from AIDS.

I wondered what professionals were saying and doing about suicide as a response to AIDS. Battin (1994) for example, presents what she calls the “rational structure of end-of-life choices in AIDS”. In her discussion on the timing of suicide, she suggests that various questions such as “Shall I go early, or late? Or shall I not plan an exit time at all...” are not questions “likely to be asked by the person whose suicide is the product of despair, depression, or self-blame for having contracted AIDS; they are questions characteristic of rational choice...” (p. 578). She argues that in areas where assisted suicide is available to those with HIV disease, those in the person’s life have a moral obligation to protect the rationality of the person’s choice. While presenting risk factors believed to be related to suicide among persons with AIDS, Starace (1995) also suggests that there is no sense of the magnitude of the phenomenon since there appears to be no consensus on methodological strategies such as how suicidality is defined, or what even constitutes a suicide case. Hall and Stevens (1988) state for example that “suicide is a common phenomenon in people with AIDS and cannot be discussed without examining the role of stigma” (p. 115). They note that in the San Francisco area, “it is well known that people with AIDS/ARC kill themselves singly and in groups” (p. 119). However, they argue that because the majority of those persons with AIDS are likely to be

depressed, confused, ambivalent or overwhelmed, the notion of rational suicide is questionable.

An 1989 AIDS Alert bulletin notes that almost every patient who is HIV-infected will consider suicide at some point. Maj (1990) reports a recent Cornell University study (Marzuk et al.) in which men aged 20-59 with a diagnosis of AIDS are approximately 36 times more likely to commit suicide than men in that age group without AIDS, and more than 66 times more likely to kill themselves than men in the general population. The study also suggests that "the presence of concomitant psychiatric syndromes especially depression and delirium may increase the rate of suicide in AIDS patients" (p. 559). Maj also points out that a 1988 Texas study revealed the following factors predictive of a suicide attempt:

multiple psychosocial stresses, perceived social isolation, perceiving oneself as a victim, reliance on denial as the central or only defence, substance abuse and perceived unavailable social support (p. 558).

According to Boldt (1988) suicidologists are looking for an exact definition of suicide to standardize and improve research. Suicidologists generally refer to suicide as: willing and wilful self-termination, which originated as a "bureaucratic assertion to achieve simplicity, uniformity, and comparability in certifying and classifying suicidal deaths across the many intra- and international jurisdictions" (p. 93). He suggests that those who attempt to research and analyse suicide often use the term "suicide" as though its meaning was self-evident and there was no need to understand further. A glance through the literature on suicide shows quite a different view, with debates continuing on how to name it as an experience. Glass (1988) for example, argues against assisted suicide and

euthanasia for persons with AIDS and considers that suicide itself is a disease that physicians need to diagnose, treat, and prevent since

from the clinical view, careful evaluations of suicides, even in terminally ill patients, almost invariably reveal evidence that the suicide occurred as a manifestation of a psychiatric disorder rather than a rational choice (p. 1370).

Lester (1992) reviewed the literature on homosexuality and suicide based on research reported through the 1980s in which none of the evidence for a higher rate of suicide for homosexuals was conclusive. The presentation of the material in his text perhaps says more about Lester than the studies, since it is included under the heading "Psychiatric Disorder and Suicide" which also lists suicide prevalence for those with mental retardation, multiple personality and fire starters!

More recent research (Cote et al. 1992) recommends that standard practice include on-going psychiatric assessments of suicide for persons with AIDS. Suicide is strongly associated with psychiatric syndromes including depression, psychosis and dementia. As I read these research presentations it appeared that the medical profession seemed to organize its assault against suicide in the area of better assessments of persons with HIV disease. A study examining anxiety, depression, and suicide prevalence and health care workers' response needs concluded that anxiety, depression and suicide are central themes in HIV/AIDS and health care workers must be knowledgeable and respond appropriately (Sherr, Davey, McCreaner, Green and Hedge, 1991). While these researchers provided short training courses in counselling for doctors, nurses and health advisors who had recorded suicidal tendencies in HIV/AIDS clients, they found that the training was not enough to unseat commonly held myths such as that discussing suicide

with someone may lead to them killing themselves. An interesting result was that the health care workers thought that anxiety and depression were different for people with HIV disease. This result reflects how “difference”, as discussed here, is also socially constructed.

Like Maj’s (1990) work, much of the research into the relationship of suicide and HIV disease reports a link between neuropsychiatric disorders, psychosocial problems and HIV. Others suggest that factors such as discrimination against those with HIV disease because of stigmatization against perceived as members of risk groups, isolation, and societal fears about the disease “may make suicide a preferable option for patients who are already suffering from the intractable and excruciating advance of HIV disease” (Slome, Moulton, Huffine, Gorter, and Abrams, 1994).

In a study of depression, aggression and suicide in patients with HIV disease, researchers concluded that their data show that HIV positive patients have emotional disturbances and that the disease is seen with pre-existing depression which they believe is the result of a permanent conflict between morals and desire (Rosa, Espinosa, Vidal, Cruz, and Angulo, 1992). On the other hand, long term survivors of AIDS, described as those who have lived with AIDS for three years or more, were found in one recent study to have low rates of depressive mood disorders (Remien, Rabkin, Katoff, and Williams, 1991). One conclusion of the researchers was that a diagnosis of AIDS alone does not appear to lead to an increased risk for suicide.

Training in coping strategies, interviews that focus on risk factors, the use of screening instruments, and nursing interventions designed to deal with maladaptive

responses to receiving a diagnosis of AIDS are all suggested measures regarding the prevention of suicide. These research reports appear to be offering conflicting advice about interventions available to health care professionals and those with HIV/AIDS that arise from their conflicting assumptions about the syndrome. This is confirmed in Marzuk and Perry's (1993) editorial introducing a special issue of the journal *AIDS Care* focussing on suicide and HIV. They compare two studies exploring whether or not HIV illness is a direct cause of suicide, or whether it increases chances for suicide in a vulnerable population. They conclude that the papers highlight

...the relationship between suicide and hopelessness, previous attempts, and social support. Most of all they remind us that no single variable or even set of variables is a compelling predictor of suicide...clinical awareness and judgement remain the best guides (p. 389).

In the same issue Pugh et al. (1993) review the literature on suicide and HIV disease, and like Starace (1995) discuss the methodological problems they faced. The core of the article however, is their focus on six case reports of gay men who committed suicide; and while the authors admit that their findings are inconclusive, nonetheless they are interesting. First of all for example, like Jay, four of the six jumped to kill themselves.

Pugh et al. observe that:

...the choice of jumping as a method of suicide may reflect a real difference between suicide in this sample compared to men in the general population and may be related to psychiatric and medical morbidity. In general, suicide by jumping, compared to overdosing for example, is associated with greater psychiatric morbidity (p. 397).

Secondly, four of the six men had an AIDS diagnosis which supports earlier findings that suicide increases as terminal patients become more ill, and among those who have lived

one or two years with AIDS. Thirdly, their work suggests that those men with a past psychiatric history are more likely to kill themselves; and finally, life events and various stressors such as receiving a diagnosis, and deteriorating suddenly, seeing the deaths of others around them with a similar disease may act as catalysts for suicide.

In their discussion of HIV-related mental health nursing issues Hall, Koehler and Lewis (1989) observe that "those recently tested as HIV positive, those who are first experiencing pain and/or loss of function, and those at the final stage of illness are also at greater risk of suicide" (p. 281). Interestingly they include the "worried well" and the bereaved significant others as at risk of suicide. Hall *et al.* in writing about the nurse's role in suicide assessment or intervention, seem to draw attention to a conflict inherent in social work, and perhaps in coroner duties as well—that is, understanding that a person may want to take his or her own life, but as a professional, feeling bound to prevent it:

The dilemma experienced...may result from identification with the patient, a perceived conflict with the usual advocacy role of nursing, or a belief in the rights of individuals to terminate their own lives (p. 282).

The social work profession is not immune to the widely held ideas and values about HIV disease or death and dying issues. Clarke (1989) suggests that the social work "profession's historical neglect of certain social issues such as human sexuality and dying, death and bereavement, for example, has rendered [it] unprepared to respond to the AIDS crisis" (p.2). However, social workers appear to have contributed primarily to the analysis of AIDS-related voluntary euthanasia and assisted suicide (Ogden 1994a, 1994b; Ogden and Young, 1996; Neron, 1996) while my work focuses on self-killing (Herringer, 1996, 1997). In their survey of registered social workers in British Columbia for example,

Ogden and Young's (1996) data suggest that with regard to voluntary euthanasia and assisted suicide, social workers were able to set aside their personal values or choices and respect the choices of others. Indeed, a small number--six out of the 527 survey respondents--admitted involvement in voluntary euthanasia. Chapters Five and Six discuss the social work response to HIV/AIDS more fully.

I found my foray into the suicide and HIV literature to be somewhat disappointing. While it did provide a sense of supposed reasons for self-killing, the recommendations for prevention, more finely-tuned assessments and other professional interventions seemed to provide a limited analysis. What this particular literature did not provide was an examination of how suicide works, or a discussion of how people with HIV disease may choose to take their own lives. In his discussion of suicide, James Hillman (1964) observes:

The medical model itself supports the standard rule: any indication of suicide, any threat of death, calls for the immediate action of locks and drugs and constant surveillance--treatment usually reserved for criminals. Suicide means death, the arch-enemy. Suicide is pre-judged by the medical model of thought. It can be understood medically only as a symptom, an aberration, an alienation, to be approached with the point of view of prevention (np).

His notions regarding suicide are reflected in my continuing survey of the professional literature regarding AIDS. There appears to be some agreement that rates of attempted and completed suicide seem to be high in patients with AIDS because of the high mortality of the illness and the social isolation that ensues from it. However, Paske (1989) questions whether persons with AIDS have any "moral obligation passively to wait for death when they know that much of their dying process will be painful..." (p.

226). He appears to be providing space for those with AIDS to consider suicide as a “legitimate option”.

## **Conclusion**

Clearly its transformation through the centuries from sin, crime, and mental illness, and the inability of medical and social sciences to agree on its etiology, has a profound impact on how we conceptualize suicide today. Despite the fact that the 1990s offers increasingly optimistic medical hope, many persons with AIDS elect not to allow the syndrome to run its inevitable course (Ogden, 1994). Nonetheless, self-killing has generally been hidden, because to talk about it is to appear irrational, or to be promoting suicide—still a prohibited act. It seems that persons with AIDS cannot make a choice to “go naturally” or to have a “good death” that includes taking their own lives. While suicide is a common act ( Sherr et al. 1991) facts produced by the state through its professional and administrative mechanisms show that because the majority of persons with AIDS are likely to be depressed, confused, ambivalent or overwhelmed, the notion of rational suicide is undermined, officially. The taking of his own life by a person with AIDS becomes constructed, then classified, as an individual and psychological problem, one of deviance or pathology, rather than a rational decision. The most important aspect of this literature for my study is that suicide by people with AIDS is not accepted. It is rationalized as mental instability, or may actually be part of the dementia associated with the disease. It is also generally the target of efforts to prevent and/or to silence, the fact

that persons with AIDS do kill themselves or are assisted in doing so. Suicide is not a legitimate option--yet Jay asked in his journal "is suicide a legitimate option if things get too out of hand?"

The various approaches to homosexuality and suicide were useful in my examination of the work of choosing to live or die with AIDS. My work shows that incidence rates of AIDS-related suicide are still difficult to ascertain; nonetheless it is spoken of as clinically commonplace by professionals and AIDS activists familiar with the syndrome. Jay is not the only person with AIDS to have killed himself, yet there continues to be much silence regarding this unquiet, or unruly, option.

This silence extends as well, to the many silences in social science research on AIDS (Kinsman, 1989). As I spent time with Jay and others with HIV disease, as I read medical, academic, government, popular, new age and cultural information about AIDS it was clear that the lived experience of persons living with HIV/AIDS was (and is) often widely and wildly different from its theoretical representations. And it is these representations that tend to become the "facts" of the experience. Yet, while the discourse on various aspects of AIDS whether regarding homosexuality or suicide, offers useful contextualization, it essentially limits what can be learned about the syndrome. Smith (1987) argues that discourse, which "is like a conversation within texts", occurs within the abstract context of particular ruling and administrative regimes--for example the medical profession or legal or religious administrations. In her critique of sociological discourse for example, she suggests that it is "maintained by practices that determine who can participate in it as fully competent members" (p. 61). With regard to suicide Smith

(1990a) claims that

Suicide is not and cannot be simply a characterization of a death. Rather, it is an account of a death made warrantable and recorded in the work of a state agency. It expresses a relation between state interests, the established frame of reference in which those interests are realized as an array of legally warranted categories, and an event that is constituted as such by practical activities of agents of the state (p. 144-45).

Similarly in AIDS discourse specific to suicide, those attending conferences or reading the journals, become competent in the approaches and categories through which the discussion takes place. As professionals, one of our tasks is to understand the complexities of our work; and the task of understanding how death, and particularly a “suicide” is a public and social process, can perhaps assist us in rethinking it. As Prior (1989) observes, “the discourse on death is composed not merely of what people say and write about death...but of the range of practices, activities and settings which embrace death” (p. 3). Chapter Four presents the methodological approach I chose to examine practices, discourse and the everyday life of a gay man with AIDS who took his own life.

## **CHAPTER FOUR**

### **THEORY & METHODOLOGY: Toward a Social Organization of Knowledge of AIDS Suicide**

#### **Introduction**

The focus of this chapter is to examine the theoretical underpinnings or ground for my methodological approach, and to present more practically, the process of how I undertook the study. The problem I am addressing arose as a problem about knowing. I experienced someone's life ending by his choice and have been made aware in conversation with others involved in AIDS work that they have also experienced this. When I first read Jay's journal after his death, I expected to be able to know about his personal struggle with AIDS—that is, to see in his writing a reality that I was not privy to during his life. But between his life with AIDS and his accounting for that life in the journal, there was a disjuncture or gap. This point of disjuncture is the place from which my questions about AIDS life and death arose. The problematic, or puzzle, that emerges from the rupture produced in the moment between the lived experience and the account of it, is a methodological device that puts me, the researcher in the analysis, and gives me a place from which to speak, as a knower, reflexively. How do people “know” about AIDS? How does one live a life that is organized by the history and contemporary enactment of knowledge about AIDS, homosexuality and death/suicide? As I worked with Jay's account of his life with AIDS, and remembered the circumstances of his death and how it

had been defined by the coroner, I grappled with the question of what can be learned about the social organization of AIDS “suicide” by investigating the account of a man who talked and wrote about his transformation into a “person with AIDS”; a man who later took his own life.

I saw what was going on during Jay’s illness and after his death as a clash of knowledges—that is, that his life was organized by a social world that dominated his own sense of self. And, I saw my task as researcher to use data to explicate the social relations of power and authority that Jay became caught up in following his diagnosis. Smith (1990a) describes it this way: “Between the lived actuality and the factual account are the socially organized practices producing the account” (p. 72). The account becomes, she suggests, a kind of “virtual reality”. The point here however, is not that there are different modes of knowing; rather that one’s knowing—what one is to think and do from knowing differently—is at issue. Only one version—the professional or bureaucratic—is authorized. Jay’s account of his experience for example, has a different character from the official/ruling AIDS and related discourses. It provides, as Campbell and Manicom (1995) argue, “a real-life context against which...to reflect on administrative practices and their powerful effects on people’s lives...Administrative practices can be explored as courses of organizational action that construct everyday life into something different from how it is experienced” (p. 7-8).

Jay’s life with AIDS as I remember it, his life as he recorded it in his journal, and his death were the impetus for my research. I am not analysing what actually happened since I was not there every moment of Jay’s life with AIDS. I am rather, explicating how

the journalled account of his life was bound up with AIDS discourse and its official ruling practices. It is the possibilities that I am able to demonstrate from the data I have collected to fill out my understanding of Jay's words. My inquiry begins in the journal entries Jay kept throughout his daily life with AIDS—a journal that ended several weeks before he killed himself, and it shows how his diagnosis transformed and altered his stance in the world. I am generating a landscape or view of a life with AIDS into which the journal is one opening; and as I do so, I am re-constructing an account that has the “no longer obvious” social relations put back together. The journal is expanded, or at least what I can make of it is.

I was interested in making visible what I saw in Jay's account of his experience of living with AIDS, which is how other ways of knowing, other knowledge and authority organized his life. Thus, the central methodological interest throughout this inquiry is to illustrate a way of knowing that is not ideological or available only through discourse, but rather one which offers insight into how various ruling practices penetrate into the everyday life of a man living/dying with AIDS. I wanted a critical study which would situate the inquiry in the actual and organized and social world of real individuals. However, as I will discuss later, using Jay's account and other personal interview data is not intended to juxtapose the official accounts I will be examining. As Kinsman (1989) has shown in his analysis of sexual regulation, first-hand accounts “serve as a beginning point for analysis to disclose features of the social organization...from outside the confines of ruling relations” (p. 33). They offer a way to see past the boundaries of official discourse. Kinsman (1989) also observed that using what he called first-hand

accounts are crucial to start an analysis that has the ability to move beyond official discourse into the textually-mediated character of, in my inquiry, living/dying with AIDS. Jay's everyday world is the problematic (a feature of Smith's approach which I will discuss below) and what I know from him is where my analysis begins. Given the data with which I am working, I also sought a method that would enable me to interpret and contextualize how AIDS "works" in a gay man's everyday life. One of the major epistemological debates in social science research is the location of the researcher vis-a-vis the "subject" of the inquiry, and Smith's (1987, 1990a, 1990b) approach which I used in this project, acknowledges that what I know plays a major role in my investigation.

The literature regarding sexuality and suicide (Chapters Two and Three) was helpful in contextualizing my analysis. I did not want to rely on statistical analyses of suicides, nor on trying to speculate what meanings might be ascribed to the sexuality of someone with HIV disease. Aspects of the work of researchers in these areas has become part of the social relations of HIV/AIDS, and as I will illustrate throughout my analysis (Chapters Five through Seven) various ideological categories and professional knowledges from disciplines such as suicidology for example, often enter into official processes such as finding death to be a suicide. During the time that I was beginning to think about the direction to take my interest in AIDS-related suicide, I sought other studies that might provide direction. Gary Kinsman's work (1996a, 1997) about sexual regulation, and about the AIDS crisis in Canada from the perspective of gay men helped me focus my analysis. One of the first articles I read by George Smith (1990b) recounted his use of D. Smith's method in two studies; the first regarding the policing of gay men,

and the second concerned with investigating the management of the AIDS epidemic in Ontario. As an activist ethnographer he said he was extending his member's knowledge of both the gay and AIDS communities to "grasp how a ruling regime works with a view to transforming it" (p. 629). Later I talked with Eric Mykhalovskiy in Toronto, who with George Smith, had initiated an institutional ethnography into what it was like for those with HIV/AIDS living in Toronto trying to obtain social services. Their final report, Hooking Up to Social Services (1994) found that the "work" involved for persons living with HIV/AIDS to access services is a social process, not a simple matter of going to the right office, filling out forms and being eligible. They were able to show the submerged level of oppression existing for persons with HIV/AIDS that makes their "work" a terrible burden. Similarly, I wanted to be able to show the effort and activity that I saw as Jay negotiated his life, and ultimately his death, with HIV/AIDS.

The knowledge often given precedence about what it is like to live with HIV/AIDS is constructed through language and text produced and organized by social, cultural, legal, and religious professionals who tend to re-present the everyday experience in various "official" or authoritative versions. A basic assumption in my research however, is that "our knowledge of contemporary society is to a large extent mediated to us by texts of various kinds...The primary mode of action and decision in the superstructures of business, government, the professional, literary and artistic discourses is utterance--verbal and, more important, textual" (Smith, 1990a, p.61-62). The conflation of HIV/AIDS and homosexuality for example, was particularly evident in the early days of the epidemic, and scientific knowledge created around the disease has been criticized

by a broad-based AIDS movement that has attempted to mitigate what it believed to be entrenched anti-gay assumptions<sup>14</sup>. Because these, and other conflicting beliefs about living/dying with HIV/AIDS continue to permeate ongoing approaches and strategies developed to deal with the syndrome I want to begin first, by taking note of what Swift (1995) refers to in her work on the critical approach to child welfare, as the knowledge debates in social science, particularly as they pertain to the theoretical foundations of the method I have chosen to anchor my analysis of AIDS-related suicide. I wanted to understand more clearly how it is that particular ways of knowing are privileged in accounts of AIDS experiences.

Thus, the following section generates a brief account of the various developments in social science including postmodernism/poststructuralism's contribution to the critique of modernist critical social science. The second section develops Smith contribution as one of the critics of modern sociology, showing how she addresses the lack, in social science, of attention to discursivity, ideology and ruling. The chapter concludes with a discussion of how institutional ethnography addresses the methodological practicalities of my inquiry.

---

<sup>14</sup>See George Smith (1990, 1995). His research uncovered that it was not so much the homophobia inherent in individual government bureaucrats that delayed treatment for persons with HIV/AIDS in Toronto, but rather the lack of a drug approval mechanism .

## **Theoretical Considerations: The Knowledge Debates**

Using a framework developed by Neuman (1991) Swift (1995) summarizes three prominent paradigms--positivism, the interpretive school, and critical social science--which "have stirred interest and opened the way for further thinking about the nature and uses of knowledge within the social sciences" (p. 15). She observes that:

As Neuman's discussion makes clear, each of these paradigms arises from different social purposes, concerns itself with different problems, and seeks knowledge for different purposes. They also use different evidence and 'truth tests' as proof of veracity (p. 16).

She also suggests that because the premises of positivist social science are so well known, it is seen to be synonymous with science. It defines the object of study as something to be examined through various agreed upon rigorous methods, and tests possible relations between theory "a" and other theories, while searching for causal or logical relations. The rules are explicit, and a test of the goodness of the new knowledge includes a demonstration of the research design's adherence to these rules. Knowledge obtained in this way has generally been accepted as more credible than knowledge obtained through feelings or personal experience. Jackson (1991) argues that scientific inquiry generally requires a movement from actual life (in the case of human and social sciences) to a system of categorization, classification, testing hypotheses against reality, interpretation of results and creating theories. In this view each theory or fact builds knowledge that contributes to the world's developing progress. She notes that in quantitative research the "social world exists and can be measured as an object independent of social actors and of the research" (p. 1). The individual in the positivist paradigm is thus shaped by pre-

existing social conditions.

According to Swift (1995) interpretive social science as traced back to Weber, contrasts with positivism in a fundamental way. It views reality as fluid and “seeks knowledge for the purpose of better understanding human beings and the nature of their social interaction” (p. 15). The fluidity assumes no fixed boundaries between “everyday” or “common sense” knowledge, and the knowledge produced by science. Unlike the acted-upon individual in the positivist approach, the subject of interpretive science is able to use knowledge to make sense of his or her social world. This complex social context is the site of research, and the building of knowledge is an interactive process between researcher and subject with the focus of research being of a descriptive nature.

Critical social science, as developed by Marx, moves assumptions about subjects and knowledge building further from the positivist project than does interpretive science. While Swift observes that it shares ideas regarding social meanings and interaction with the interpretive paradigm, it is “fundamentally concerned with changing oppressive social realities” (p. 16). Here, reality is not self-evident; it is assumed to be complex and contradictory, “...composed of both apparent phenomena and hidden realities or ‘essences,’ which operate to shape surface appearances” (p. 16). As well, individuals are not seen to be acted upon by outside forces, instead they create and sustain them. Swift argues that while

human beings are viewed as creative, adaptive and able to act in the interests of changing reality...The contradictory nature of social reality means that people can be misled and oppressed by myth, illusion, and ‘false consciousness’—devices which allow those with greater power to maintain positions of control (p 16).

In doing critical social science, researchers develop knowledge to get at the hidden realities, as well as activist-oriented resources to provide citizens with what they need to change their oppressive conditions. This approach eschews neutrality and cites as evidence changes in peoples' social reality. Swift argues that:

For Marx and Engels, the nature of consciousness is at the root of debates about knowledge because the development of ideas is seen as proceeding from human consciousness, which in turn is derived from the conditions of 'real life'. Consciousness...is thought of as a social product..(p. 17).

Marx and Engels dismissed the view of their contemporaries which held that science begins in abstract theories rather than in real life, and that somehow consciousness was split from the real conditions of people's lives. This ahistorical conception of reality gave precedence to abstract categories which could then present and describe a kind of universal world view. Swift suggests they conceptualized reality as a

unity of both surface appearances, which we often think of as objective reality, and of hidden realities or essences, which represent the social relations acting to create and sustain surface appearances ( p. 18).

Swift draws on critical social science to present an in-depth examination of the hidden realities of child neglect, however I was more interested in the critiques of it by postmodernism/poststructuralism and ultimately, in Dorothy Smith's move from critical social science toward her approach to inquiry that, while in agreement with the postmodern critique on several points, posits experience as central.

Ironically, it was Jay's experience as described in notes he called his "AIDS World Tour" (See Chapter Five) made to panellists discussing the body and AIDS at a semiotics conference at University of British Columbia that alerted me to the approaches

to HIV/AIDS by cultural critics/scholars (Triechler, 1988, 1990; Watney, 1990; Weeks; 1990; Crimp, 1989) and thus influenced my early thoughts about this project. In the personal and research accounts I have read since about persons living with HIV disease and the extrapolation from the everyday world into the wider social context, most assume and conceptualize an outside structure/force that impinges on everyday life. The cultural or humanities literature about AIDS often centres on the representation of the disease in the lives of gay men—how the media structures this representation and so on (Gilman, 1988; Triechler, 1988; Crimp, 1992). For example, Gilman (1989) argues that “the depression of the sufferer is to no little degree the result of the internalization of the stigma associated with society’s act of ‘representing’ the person with AIDS” (p. 321). While I agree with Gilman on the level of discourse, his work does not adequately show how relations of stigma constitute such experiences with AIDS. Nonetheless, the “postmodern turn” is influential in contemporary knowledge creation about HIV disease, and because it contributes to a critique of critical social science I wanted to discover the way in which “experience” and “discourse” are approached in this tradition.

### **Critical Turns in the Knowledge Debates: Discursively Organized Knowing**

In the following section I intend to demonstrate aspects of the contribution of the postmodern/poststructuralist debates to critical social science, and then to show how this is addressed in Dorothy Smith’s social organization of knowledge. Both approaches contribute to the critique of critical social science and its lack of attention to discursivity;

however, Smith is committed to the conceptual and methodological importance of experience (Campbell and Manicom, 1995), while the former most often insists that reality exists primarily in texts (Rosenau, 1993; Smith, 1996).

In her discussion of postmodernism and the social sciences Rosenau (1993) reminds readers that historically, science attacked the authority of both the crown and the church, an authority basing its legitimacy on theology. Discounting theology, positive science based its authority and legitimacy on objectivity, “rigorous procedures of inquiry, the material rather than the metaphysical” and laid claim to its own truth (p. 9). This must have been a heady time for philosophers and thinkers—imagining that it was possible to attain what formerly only a supreme being was thought to be capable of. The Enlightenment project, seen as synonymous with modernity, envisioned that rational autonomous human beings could progress toward an ideal society. Modernity, suggests John (1994) is “characterized by the pursuit of truth that has the character of absolute certainty, [and] marks the inauguration of modern philosophy” (p.50). With the development of philosophical and scientific theories, natural laws were considered ultimately attainable by (male) individuals through the exercise of reason, and formed the basis of man’s natural rights. Over the last twenty years what has come to be known as postmodernism or poststructuralism has emerged in reaction to modernity.

The terms are elusive. Lather (1991) interchanges the terms postmodernism and poststructuralism, although she also notes that she uses “*postmodernism* to mean the larger cultural shifts of a post-industrial, post-colonial era and *poststructural* to mean the working out of those shifts within the arenas of academic theory” (original emphasis, p.

4). John (1994) also considers poststructuralism to be the conceptual foundation of postmodernism, while Weedon (1997) suggests that postmodernism was initially used to “describe developments in the fields of architecture, and subsequently taken up in a wide range of areas, including philosophy, social theory, cultural criticism and the arts” (p. 171). In her view, poststructuralism is “either conflated with ‘postmodernism’ or seen as a postmodern set of theories” (p. 171). Smith (1996) in recognizing the imprecision of the terms, uses them to:

...identify a rather general current of thinking that has developed in North America and is based upon thinking originating in France and associated with the work of Michel Foucault, Jacques Lacan, Julia Kristeva, Jacques Derrida, Jean-Francois Lyotard, Jean Baudrillard, and others. These theorists may have little in common other than their problematizing of traditional epistemologies, particularly those foundational to the Marxisms of post-Second-World-War France, but in North America they have come to be foundational to an influential intellectual community in the humanities and social sciences (p. 196).

Lather (1991) suggests that “at one level, the problematic of postmodernism is to ‘make of our disorders new knowledge’ (Hassan, 1987, p. 81, quoted in Lather, p. 40). Her discussion of Foucault suggests that his shift from “a search for formal structures and universal values to how we are constituted as subjects of our own knowledge” is “against that which presents itself as finished and authoritarian” (p. 38). In an effort to situate her research as praxis, she outlines what she considers a shift in the current understanding of scientific inquiry: “postpositivism is characterized by the methodological and epistemological refutation of positivism...much talk of paradigm shifts...and by an increased visibility for research designs that are interactive, contextualized, and humanly compelling because they invite joint participation in exploration of research issues...” (p.

52). Postpositivism is marked by inquiries which recognize that knowledge is ‘socially constituted, historically embedded and valuationally based’ (Hendrick, quoted in Lather, 1983, p. 506).

Nicholson (1990) argues that the postmodern critique of modernity “focuses on such diverse elements as the modern sense of the self and subjectivity, the idea of history as linear and evolutionary, and the modernist separation of art and mass culture” (p. 3). Thus, it has tended to dismiss Marx, whose materialist and historical explanation for understanding consciousness and oppression is deemed modernist and outmoded. In his reading of Marx, Rubenstein (1981) argues that Marx’s work emphasizes the “interpenetration of sub- and superstructure” (p. 122) and points to his understanding of ideas which are the products of social actors, not products of the mind. Rubenstein suggests as well, that Wittgenstein places “...a similar emphasis on understanding ideas in the context of practical life, and on a corresponding critique of traditional philosophy for failing to do this”(p. 125). Both Marx and Wittgenstein argue that one’s activities/actions cannot be separated from social structures.

The social as it exists in people’s activities however, has no place in the postmodern critique which is taken up through a focus on language as the underlying theoretical commonality (Swift, 1995; Weedon, 1987, 1997; Mills, 1997; Nicholson 1990; John, 1994). Weedon (1987, 1997) provides background for me to begin to understand the genealogy of poststructuralism and its intellectual scope across the social sciences. She locates language as the “place where actual and possible forms of social organization and their likely social and political consequences are defined and contested”

(p. 21). She argues as well, that language is “also the place where our sense of ourselves, our subjectivity, is *constructed*” (original emphasis, p. 21).

The implications of the poststructural approach to subjectivity, language and ideology were of particular interest for me theoretically and methodologically because I wanted to present the complexity and contradictions of Jay’s life/death. For example, while in positivist science and its attendant philosophy, humanism, the subject is rational and unified, the subject position in poststructuralism is constructed. And it is here that language is crucial; for Weedon notes that subjectivity is a place of “disunity and conflict” created through “discursive practices—economic, social and political—the meanings of which are a constant site of struggle over power” (p. 21). In early AIDS conferences for example, those with HIV disease were invisible except as subjects of clinical or basic research. In the late 1980s, persons with AIDS stormed an international conference demanding that their voices be heard, and in subsequent conferences have been present physically, as participants, researchers, and as subjects of research. Various meanings could be ascribed to individuals or groups regarding who can speak about/for AIDS. Scientists for example could be seen as saviours seeking out treatments, or as manipulative and greedy pawns of the multinational drug companies. Persons with AIDS could be portrayed as whining faggots flaunting the logical outcome of their sexuality (AIDS) in public, or as activists grabbing hold of the health agenda to demand treatment and to create space for the naming of their experiences. As Weedon suggests, in these battles over meaning, positions often become solidified.

The centrality of language in poststructuralism emerges from the structural

linguistics of de Saussure who assumed that language “constitutes social reality”, rather than reflecting it (Weedon, 1987, 1997; Mills, 1997; Smith, 1996). In de Saussure’s view, language is a system of signs, each consisting of a signifier (sound or written image) and a signified (meaning). While the signifier and signified are related to one another, there is not a natural connection between the sound or written image and the concept it is meant to identify. For example, the term or signifier “homosexual” has no meaning other than that which emerges from its difference from other signifiers such as “heterosexual” or “normal individual”. The implication here is that meaning already exists in language thus divorcing it from the person or subject who speaks. Like the positivist subject, language and meaning are fixed or structured, and ahistorical (Weedon, 1987, 1997; Smith, 1996).

Poststructuralists beginning with Derrida, critiqued the structuralist insight by suggesting that the signified, or the meaning is not fixed—it is rather deferred. Derrida shifted the focus from speech to that of writing and textuality. Weedon observes that in his vision

signifiers are always located in a discursive context and the temporary fixing of meaning in a specific reading of a signifier depends on this discursive context....Consequently it is always open to challenge and redefinition with shifts in its discursive context. What it means at any particular moment depends on the discursive relations within which it is located, and it is open to constant rereading and reinterpretation (p. 25).

However, in her view this “discursive context” which Derrida theorizes as “relationship of difference between written texts” (p. 25) ignores the social context in which the text exists. Contrary to Derrida, Weedon insists that a feminist poststructuralism must take this social context into account. In her example of how the social order is constructed

within text, she suggests that an examination of women's magazines for example, uncovers a variety of subject positions available to women--wife, mother, sex object, etc.

These different positions which magazines construct in their various features, advertising and fiction are part of the battle to determine the day to day practices of family life, education, work and leisure. How women understand the sexual division of labour, for example, is crucial to its maintenance or transformation (p. 26).

Her analysis appears to hold for the discursive context of AIDS as well. In the 1980s the subject positions available to gay men with HIV disease were few--the preeminent seemed to be that of terminal patient. Popular culture through television and magazines certainly reinforced this through the visual presentation of "faces of AIDS" or pictures of men dying in doorways because of hospital closures.

John (1994) notes that while Derrida insisted that no meaning exists outside of texts, Foucault introduced the "notion of discourse that implies the political aspects of the discursive text" (p. 54). The term "discourse" is used in so many disciplines that Mills (1997) argues its usage presupposes that scholars share a common knowledge of it. As I have come to understand it through my excavation of AIDS texts, versions of the term as it has been developed by Foucault, seem to be most commonly used. Instead of conceptualizing the signifier and the signified, and chains of signs, he envisioned them as practices, and found meaning always takes the forms defined for it by historically specific discourses (John, 1994; Mills, 1997). These practices "that systematically form the objects of which they speak" (Foucault, 1972 cited in Mills, 1997, p. 17) were also institutions such as law, religion, and education located in and structured by what Foucault termed a "discursive field" (Weedon, 1987, p. 35). As Mills understands

Foucault, “a discourse is something which produces something else (an utterance, a concept, an effect), rather than something which exists in and of itself and which can be analysed in isolation” (p. 17). Discourses within each discursive field may hold unequal power. For example within the discursive field of AIDS, medical discourse is granted greater status with regard to the syndrome than the activist or social work discourse. These competing views are carried forward through language and through institutional organization that controls the meaning of health, treatment, death, and so forth; and, each considers its discursive field to be “the truth”. Mills (1997) suggests that Foucault is not so much interested in which discourse represents the truth, but in how one discourse becomes dominant and supported. In my example of the domination of medical discourse over social work as they relate to HIV/AIDS, the medical enterprise, as the dominant or true discourse, has been supported physically through government funds for research, the status of its opinions, etc. Power thus plays a crucial role in Foucault’s conception of discourse. It is a model of power in which various forms of subjectivity and behaviour are produced. Farangis (1993) argues that Foucault’s achievement is to claim the inextricable link between knowledge and power. Foucault through his studies of the discourses of sexuality, psychology, penal systems, and so on takes the human sciences to task for becoming agents of power through their shaping of individuals.

Farangis notes that:

....Foucault reconceptualizes power and embeds it in the socialization processes of everyday life...The real transactions of power are not in the relationships of citizens to the state but in the relationships of people to teachers, doctors, therapists, social workers, and psychiatrists. These are not the benign and

amelioratory aides of the welfare state but rather moral agents whose disciplinary power is based on their membership in the credentialed knowledge elite (p. 364).

The production of knowledge by those involved in the human sciences (social workers, doctors, therapists, psychiatrists, as named above) rather than offering a means of emancipation, has instead often subjugated people through various norms and rules developed through scientific discourse, or has made them objects of inquiry. It has taken concepts such as deviance and normality and shaped how people view themselves.

The primary principles of poststructuralism as articulated by Weedon (1987, 1997) position it as a theory which contributes to knowledge production by offering an historically specific analysis that is able to illustrate the workings of power and show how it can be resisted. Like other aspects of critical social science it displaces the rational humanist subject, and sees “subjectivity and consciousness, as socially produced in language, as site of struggle and potential change” (1987, p. 41). Within the realm of critical social theory, postmodernism sees itself as engaging in a critique of knowledge, scientific and otherwise. When I began to read postmodern essays reflecting and speculating on AIDS I more often than not, tended to sense that little of the theory appeared to emerge from lived experience, or to refer back to it. It was speaking among texts. This seems to be an intriguing oversight in the postmodern critique. In its ongoing disillusionment with the modern and the hegemony of what Lyotard (1984) calls “incredulity toward metanarratives”, it seems to have entrenched a new metanarrative in which the subject disappears into an abstract discourse and does not exist outside it. Skeggs (1991) argues that postmodernists see the world as opaque, or lived on the

surface:

There is nothing that hides behind its surface appearances. It is not a case of people saying what they mean—rather they don't mean anything—for there is no meaning to be had...There is a complete absence of lived experience—other than that of the author—in postmodern accounts. The methodology of play and gamesmanship suggested by Lyotard is an aimless epistemology (p. 259).

I am not dismissing its theoretical importance out of hand; however, I could not envision its methodological possibilities for my particular project. It was my desire to be able to begin my inquiry in my brother's in-text account of his lived experience that initially lead me to consider Smith's approach to the social organization of knowledge. My interest was to discover what was in back of the text, accounting for it. It was my more careful re-reading as I did my analysis, of various aspects of these intellectual debates in the social sciences that illuminated in a different way for me, Smith's insights and what they could offer my project. I began to see my brother's experience as one thread in the fabric of the social organization of AIDS that could be followed and elaborated to understand more about both his life and how it was transformed by AIDS.

### **Discourse, Ideology and Ruling: Smith's Contribution to the Critique of Critical Social Science**

Dorothy Smith's contribution to the epistemological debates is apparent in her approach to the social organization of knowledge which began in opposition to what she calls professional sociology. This section examines the key conceptual/methodological issues of her project—first, the feature of “experience,” and then her use of “discourse” as organized experiences. The remainder of the section discusses the relation of ideology to

discourse, and the relation of ruling to both discourse and ideology. The section concludes with a discussion of how these issues relate to what I am doing with Jay's journal and my inquiry.

Smith's approach differs from the postmodern/poststructuralist project in a fundamental way. She argues that she is in agreement with the postmodern/poststructural rejection of sociologies that require "an archimedean point, objectifying as authoritative a unitary consciousness grounded in and reproducing existing relations of power" (1996, p. 173). Her sociological project, as does the postmodern, also rejects the modernist meta-narrative that ignores all but its own interpretations. However, while both agree that the positivist subject position is unitary, fixed and linear, Smith argues that the poststructural subject position is also individuated--now however, it is multiple and discursive. The postmodern/poststructuralist critique "has rejected the subject of modernity, only to multiply it as subjects constituted in multiple and fragmented discourses" (p. 173).

Her own method of inquiry has developed from several directions (Smith, 1987, 1990a, 1990b; Campbell and Manicom, 1995; Townsend, 1998). The first, based in her life as a mother and an academic was her exploration into what "it means to explore the social from the site of women's experience" (Smith, 1990b, p. 1). She has described women's practice of consciousness raising about their lives to find a language with which to speak about themselves individually and collectively, because of their exclusion from society's institutions. Consciousness-raising was and is a practice in which women take voice, or as theologian Nelle Morton (1987) suggests, hear one another into speech. Smith is not assuming however, that only women will be "researching" women, or

creating knowledge solely about women. As George Smith (1990b) argues, the ontology and epistemology of her method, while starting from and taking up the standpoint of women, “intends a science of society rather than a form of ideological practice” (p. 631). This idea of women’s standpoint has led her critics to assume that Smith directs her project primarily as a critique of gender. However, Campbell and Manicom (1995) note, it is not only feminists who are attracted to Smith’s approach, but “men and women wishing to analyse a variety of relations of power, such as the workings of racism and heterosexism and the organization of the state” (p. 6). Smith has also drawn on aspects of various scholars and thinkers such as Marx, Schutz and Garfinkel (G. Smith, 1990b; Campbell and Manicom, 1995). She looks to Marx for his insights into ideology and relations of power, to Schutz for his phenomenology of everyday experiences as primary reality, and to Garfinkel’s ethnomethodological observations on how individuals draw on “common-sense” knowledge in making sense of the world (Heap, 1995). In a recent article (1996) she draws theoretically from Volosinov and Bakhtin to develop “an account of ‘referring’ or ‘representing’, indeed knowledge, as *essentially* social...” (p. 174), a notion to which I will return later.

Smith’s alternative to both critical social science and to postmodernism/poststructuralism is to insist that knowledge is a “form of social act in which an object world is constituted by participants as a world in common”; knowledge that “preserves people’s active presence” (1996, p. 181). Thus, she proposes to develop social science beginning in experience which “orients to the social as it organizes people’s everyday/evernight living” (1996, p. 172). She argues that she is not talking

about research located in the subjective realm of inner experience with “self as sole focus”. Rather, in creating knowledge grounded in a person’s experience of his or her own life, her project “does not treat experience as knowledge, but as a place to begin inquiry” (p. 172). Campbell and Manicom (1995) describe both the methodological and conceptual importance of experience in Smith’s work. Methodologically, it “provides a standpoint, a place to begin an inquiry, and a place to return to, to demonstrate its usefulness” (p. 7). Conceptually, it provides a “real-life context against which, for instance, to reflect on administrative practices and their powerful effects on people’s lives” (p. 7). According to Smith (1990a):

**Our knowledge of the world is given to us in the modes by which we enter into relations with the object of knowledge. But in this case the object of our knowledge is or originates in the co-ordering of activities among ‘subjects.’ The constitution of an objective sociology as an authoritative version of how things are done is from a position in and as part of the practices of ruling in our kind of society. Our training as sociologists teaches us to ignore the uneasiness at the junctures where multiple and diverse experiences are transformed into objectified forms. That juncture shows in the ordinary problems respondents have of fitting their experience of the world to the questions in the interview schedule...The persistence of the privileged sociological version (or versions) relies upon a substructure that has already discredited and deprived of authority to speak the voices of those who know the society differently. The objectivity of a sociological version depends upon a special relationship with others that makes it easy for sociologists to remain outside the others’ experience and does not require them to recognize that experience as a valid contention (p. 24).**

Various academic and professional disciplines provide procedures for engaging with the world that actually limit knowledge. Smith alerts us to the fact that academics or practitioners exist in a conceptual world and reinvent “new” knowledge within it. Researchers often rely on knowledge, procedures, rules, concepts that have little to do with what actually exists in people’s daily lives and yet which permeate their daily lives.

Academic/theoretical knowing and experiencing are separate—intellectuals usually move from the local or the place of our experiencing bodies/lives, to the conceptual order in which the ways of thinking about things already exist. In her critique of modern sociology Smith (1990b) posits several working assumptions central to her inquiry which I have paraphrased below:

- . in working with an insider's standpoint the researcher no longer needs a "totalizing theory or master-frame" that places the knower outside the society in which she is active;
- . the research objective is to explore the actualities of our society rather than those of a generalizing science. "Without a totalizing theory or externalizing master-frame, the mode of inquiry begins where people are and explores the actual practices engaging us in the relations organizing our lives";
- . the researcher "seeks access to the extended or macro-relations organizing society through an analysis of the micro-social" (p. 9-10).

By positing experience as a starting place for research, and hence for creating knowledge as "a project of inquiry that explores concepts, interpretations, ideology, knowledge, ideas as socially organized and organizing principles" (Smith, 1990b, p. 11) she foregrounds an approach to knowledge development which has resounding implications for social research. Smith argues that "experience as spoken, is always social and always bears its social organization" (1996, p. 172), and thus places the experiencing individual at the centre of his or her life as subject and knower, rather than as an object of the research or one with no reference beyond the discursive. She asserts (1987, 1990a, 1990b, 1996) that, unlike in the postmodern project, a separation between the material and ideal does not exist. It is a place from which she suggests, one might be able to tell the truth

about how the social world works:

The project is to explore concerting and co-ordering and hence the organization and relations that generate the varieties of lived experience. As a project of inquiry rather than of theory, it must rely on the possibility that truth can be told about in the following very ordinary sense: that when people disagree about statements made about the world, accuracy or truth is not decided on the basis of 'authority' but on the basis of referring back, in principle at least, to an original state of affairs, extraneous to the account of it. In a sense, it wants an account of knowledge which takes for granted that people's experiences are various and that a social theory of knowledge will grasp it as a definite mode of coordinating activities among people (1996, p. 172).

The poststructural notion of the subject position as located only within and affected by discursive fields is different than what Smith is proposing. For her, the subject in his or her everyday experience exists prior to the text and after it. Smith insists that discourse "and other dimensions of the objectified organization of corporations, governments, professions, etc. are themselves also understood as being 'in the living' and hence investigatable as people's actual practices" (p. 172). In providing discourse with a materialist reality, she is in opposition to the approach in which all voices within discourse are deemed valid, and which thus preclude any ability to sort through various knowledge claims.

Within the broad discursive field of AIDS (Weedon, 1987) exists numerous discursive approaches about HIV/AIDS from pop cultural representations through legal, medical and psychiatric, religious and social work texts. Each of these areas may also have a range of ideas and concepts about HIV disease within it. Much of what we learn and know about society comes to us through a variety of discursive "texts"—newspapers, television, art, film, books, journals, and so forth. While Jay's journal offers a surface

context, a phenomenological location, it is also an entrance to the discourse about AIDS evident in texts such as those listed above. When I thought of Jay for example, I saw him talking with friends about AIDS, or reading about it, prior to his diagnosis. After his diagnosis he became, as a “PWA”, part of what people were reading and talking about with regard to AIDS, as well as part of the category “AIDS” and the discourse re-creating and re-producing AIDS. Both Smith and the postmodernists acknowledge that discourse is social. In Smith’s view however, the theoretical discursive focus in postmodernism precludes any social reality outside the text. Smith (1987) describes her use of discourse:

The notion of discourse used here derives from Foucault. But because we are talking sociology, not philosophy, we want to address discourse as a conversation mediated by texts that is not a matter of statements alone but actual ongoing practices and sites of practices, material forms of texts (journals, reviews, books, conferences, laboratories, etc.) the methods of producing texts, the organization of powers intersecting with other relations of ruling in state agencies, universities, professional organizations and the like....texts are understood as embedded in and organizing relations among subjects active in the discourse (1987, p. 214).

Rather than being relegated to an existence in discursive space, Smith is suggesting that what she calls the knowing subject, lives in a world in which both theory and practice coexist. This formulation reminded me of one I read years ago in a book on feminism--and while the title of the book and it’s author elude me--the statement regarding feminist praxis was “Our theory is that our practice is our theory”. Like lived experience, theory exists in an historic context. A fundamental point in Smith’s (1996) approach is that in this lived world, the rupture or gap between theory and practice can be investigated--or made problematic and puzzled about. The sociology she envisions is embodied and

committed to figuring out “how things are put together, and hence to producing knowledge that represents the social as it is” (1996, p. 173). In order to do this, she argues that sociology must discover an alternative to the postmodern/poststructural inability to refer to anything beyond discourse. Her alternative proposes theory which formulates “....referring, representing, inquiry, and discovery as the locally organized social practices of actual people” (p. 173). Being able to refer back and forth among discursive texts is a way to coordinate various perspectives. Smith provides a wonderful example of this through a story in which she and a friend are attempting, with the use of a map, to find a house they have never been to. Smith, driving the car in which they travel, looks for streets “that behave” as her navigator says they will as she reads the map, and they find the house successfully. She suggests that the process of referring back and forth from the map text to the street signs, and how the streets curve is a dialogue that

relies on cartography’s systematic and technical development of symbols that in actual local situations of reading instruct the reader to find in the actuality objects and relations that can be recognized and affirmed as intended by those symbols...The map tells her what features of the world to find and recognize as expressions of the relations it draws, but she has to look outside the map to find them (p. 192).

The map, however, does not provide the means by which it is to be read—as with any text, Smith argues, the person reading brings to it what she knows about her local setting; in this case, those indexed by the map. Thus, in Smith’s project in which discourse is prominent, it is both active and dialogic; and the process of moving among texts and the ability to relate back to actual lived experience—referring—coordinates their activity. In discourse, however, the terrain is not streets or land masses, but “maps of relations in

motion, the dynamic of which generates changes in how we are related, what we experience, and what we do and can do” (p. 194).

Smith is interested in the activity, or dialogue of discourse, including its ideological representations. In a project that relies on the conceptual importance of experience (Campbell and Manicom, 1995) she does not use ideology as it is most often used in sociology to mean biased knowledge that has emerged as a result of intellectual pursuits--the religious right, or new left, for example. Instead, she employs it as a social form that exists in the concepts and categories that constitute documents/texts. Ideology is a practice, able to be explored, and is

...a feature of organization itself rather than simply of the intellectual practices of individual participants in a discourse (Smith, 1990a, p. 63).

She credits Marx with bringing into perspective a “new materialism” that situates knowledge in what people actually do rather than in assumptions about those activities. Like metaphor, however, discursive ideological practices or concepts reflect ourselves and our social world, and also have a way of cloaking how we actually live. Ideology--concepts as practices--can be excavated through analysis. She takes Marx further by applying his analysis to concepts as they exist in social science:

His method identifies as ideological definite procedures or methods of thinking and reasoning about social relations and processes. Ideology names a kind of practice in thinking about society (p. 35).

If ideology is a practice, where can the “practice” of it be located? How can it be seen to work? Beginning with the experience of a person with AIDS for example, is a way to show the ideological makeup of AIDS discourses. Starting in Jay’s account of his

experience offers me one entrance to the social organization of AIDS in Canada and what has driven it in particular directions; and from there, from his standpoint, the inquiry begins. Rather than beginning inquiry in experience however, social scientists often apply an objective or abstract category to something they observe, which in turn becomes entered into everyday use. In her (1988) study on class relations of an elementary school classroom for example, Manicom discovered that categories and concepts are active processes that “provide a method for selecting from and organizing, daily experience at the local level” (p. 65). She offers an excellent illustration of this from her interviews with teachers:

...some of the teachers...talked about certain children having ‘less knowledge’ than others. The children were described as lacking in knowledge: teachers said the children did not know animal names, or the special names of animal babies, or which animals lived at the zoo or at the farm. Yet, as the teachers talked, they also discussed how these same children ‘knew so much’: these six year-olds know about welfare cheques, about not being able to buy things until the cheques arrived; they know about family members going to jail; they knew about petty crime in their neighbourhood. They were ‘streetwise’. Thus, the concept of ‘having knowledge’ encompassed, or referenced, only certain kinds of knowledges: knowledges articulated to the mandatory curriculum (p. 66).

I recognize how this view of concepts relates to my research as well. Those involved in various aspects of AIDS work such as activism, health or research, talk and exchange ideas about what they do through various concepts and categories which distinguish it as “AIDS work”. For example, throughout Jay’s illness I was aware of the language of my professional social work training which is a patchwork of other professional languages such as psychology, sociology, or education. He, having been trained professionally as a political scientist and later as a lawyer, used other language; and both of us having been

involved in lesbian and gay worlds, then the world of AIDS, used yet another. The knowledge about AIDS that appeared to take precedence however, was that of the professions. And while our talk illustrates the origins and ideological makeup of various concepts and categories such as homosexuality or PWA, the categories and concepts are also embedded in how we do what we do. Those participating in a particular discourse for example, have verbal short-hand, jargon, phrases or categories that take up particular meanings. The “talk” that Jay used in his journal account, and the talk used by people I interviewed for this project including social workers, coroners, and those involved with suicide counselling was replete with categories and concepts created in the discourses of psychology, social work, medicine, and religion, many of which have been produced either in academic or administrative locations. How various terms come to be constructed vanishes and the concept remains as something to name what then stands for those in the conversation, as a real thing (Manicom, 1988). My strategy became one of revealing this socially organized split between the everyday and discourse created about it (theory/practice). Smith (1990a) suggests that social scientists reexamine discourse and re-embed it at its source—at the site of the experiencing and embodied subject. Beginning to understand that concepts are “active” in coordinating how people make meaning and how they relate to each other was helpful in analysing my data because I could begin to see how they are illustrative of social relations and ruling. As I thought of activists and social workers who may not agree with the discourse or language surrounding various aspects of HIV/AIDS I also became aware, as Manicom argues, that people nonetheless

participate in, orient their daily activities towards the discourse and documentary practices which, from many other settings, both local and extra local, enter into and organize/regulate/structure....their work processes (p. 67).

She also notes that

categories and concepts are constructed such that they intend particular interpretations; yet both the social construction and the perspective from which the concept has been constructed disappear from view--the concept floats free and neutral, as a 'tool' simply to be used in one's work and one's talk (p. 64).

We become locked into what Smith (1990a) calls an ideological circle. That could be for example, where a gay man participates in the construction and use of definitions of his life (as they apply to him) that are constructed for administrative and organizational ruling practices, not a description of who he is as it emerges from his actual life with AIDS. Smith's (1990a) reconfiguration of Marx's "three tricks" is illustrative:

Trick 1: Separate what people say they think from the actual circumstances in which it is said, from the actual empirical conditions of their lives, and from the actual individuals who said it.

Trick 2: Having detached the ideas, arrange them to demonstrate an order among them that accounts for what is observed...

Trick 3: Then change the ideas into a 'person'; that is, set them up as distinct entities (for example, a value pattern, norm, belief system, and so forth) to which agency (or possible efficacy) may be attributed. And redistribute them to 'reality' by attributing them to actors who can now be treated as representing the ideas (p. 43-44).

George Smith (1990a) suggests that this type of ideological circle is a two-phase process where:

....events are analysed as documenting an underlying pattern originating in textual discourse....and a second phase where the underlying pattern operates as part of the procedures for selecting, assembling and ordering these 'facts' (p. 269).

Ideology then, is defined as a “circular organization of routine...practice that makes it possible to describe events and individuals located in the everyday world...in the abstract...” (G. Smith, 1990, p. 270). This process in which local experiential knowledge is subordinated to discursive knowledge, and how that discursive knowledge is coordinated and managed through concepts and categories within various documents and texts is what Smith calls ruling (Campbell, 1998; Campbell and Manicom, 1995). Throughout their fieldwork in a nursing setting for example, Campbell and her researchers noted “how the written word organizes what gets known and how it authorizes that version of it” (1998, p.59). Smith (1987) uses the term “ruling” or “relations of ruling” to identify:

...a complex of organized practices, including government, law, business and financial management, professional organization, and educational institutions as well as the discourses in texts that interpenetrate the multiple sites of power. A mode of ruling has become dominant that involves a continual transcription of the local and particular actualities of our lives into abstracted and generalized forms...Its characteristic modes of consciousness are objectified and impersonal; its relations are governed by organizational logics and exigencies. We are not ruled by powers that are essentially implicated in particularized ties of kinship, family, and household and anchored in relationships to particular patches of ground. We are ruled by forms of organization vested in and mediated by texts and documents, and constituted externally to particular individuals and their personal and familial relationships. The practice of ruling involves the ongoing representation of the local actualities of our worlds in the standardized and general forms of knowledge that enter them into the relations of ruling. It involves the construction of the world as texts, whether on paper or in computer, and the creation of a world in texts as a site of action. Forms of consciousness are created that are properties of organization or discourse rather than of individual subjects (p. 3).

I thus see “ruling” in my inquiry as a feature of social life, and I was aware of how it related to the professions with whom Jay had contact following his AIDS diagnosis.

Again, beginning in the written account of his experience (outside of ruling) offered me a way to trace how his everyday life was structured through bureaucratic and administrative ways of knowing (ruling) and to figure out how these social relations worked in his particular setting--living/dying with AIDS in Canada in the late 1980s. Campbell and Manicom (1995) observe that ruling relies on specialized knowledge, and that “ a central task of ruling is *to organize and generate knowledge in a form that is useful for ruling practice*” (p. 9, original emphasis).

### **The Analytic of Social Relations**

Jay's life with AIDS is not separated from the larger ruling structures about which Smith writes, and was not a static phenomenon, but an active, continual process of “working” at living within the embeddedness of the organization of the HIV/AIDS. They are not separate--Jay's account of his living with AIDS on one side, and the AIDS institutions (medical, professional, and so on) on the other. Rather they exist as part of one another (theory/practice) in relationship. In order to show, or explicate how the social organization of Jay's trans/formation from a gay man to a PWA who took his own life works, I want to discuss Smith's device of social relations. This is a method of investigating the ways in which ideological and discursive practices are bound to, and coordinate people's everyday local activities. Social relations provide a way to analyse what might be described as the two solitudes of AIDS--the ordering or ruling of AIDS through professional discourse on the one hand, and the experience from the standpoint of

a gay man on the other—are actually all of a piece. In research we try, as Manicom (1988) argues, to build bridges between the material and conceptual that we have separated in our writing without realizing that “the separation is a social construction, an historical product, daily reproduced as we have gone about, and continue to go about our sociological work” (p. 41). I have found this difficult to work through in my analysis because like Manicom, I kept attempting to make links between what Jay wrote in his journal (the everyday lives of persons with AIDS) and the broader social structures that have emerged as a result of the syndrome. She points out:

instead of formulating the relation as a dualism and then seeking the connections, we need to formulate it as a unity and prise it apart...Now I try to speak and write about everyday life **embodying** the social relations....I have shifted from a language of tracing and connecting to a language of embodiment, of double moments. And I would insist on claiming that this is more than a change in the words I am using. It is not merely a transformation in language; it is a transformation in how to conceptualize the problem (p. 44).

The language of embodiment is crucial when attempting to work within the social world and Manicom offered an important way for me to reconceptualize my work. She, as many feminist poets and artists have done in their own media, offers a way to rethink the way we do science and, which Smith and others mentioned above, (Manicom, 1988; Campbell and Manicom, 1995 for example) are working toward. It is a method that helps document an analysis of what is contained in the wholeness of our social world. Earlier I mentioned that Smith (1996) does not recreate what she calls “the old theory/practice split” (p. 172). In “prising” apart the wholeness and documenting what we see, the social relations come into relief. Perhaps it is because I am working and reflecting on my brother’s death and other deaths from AIDS, as well as on the political, social and

economic struggles connected with the syndrome, that I imagine the wholeness to be somewhat like the AIDS quilt that covers an area the size of several football fields. Its wholeness consists of thousands of six-foot squares dedicated to people who have died. I focus on Jay's quilt piece created by his friends and family, separated out from the others. However, it is pulled back into the larger quilt as I see another square dedicated to a small child, and another, and another. I see that his piece is not separate. It shapes and is shaped by the entire quilt. I can examine it only as it exists within the whole, using one momentary imagined separation to reveal an embodied understanding of the whole. Kinsman (1989) argues for example, that AIDS discourse is embedded in power relations:

In the AIDS crisis there is a complex interweaving of medicine and morality with social surveillance and regulation. AIDS is socially organized in the context of an already existing social power relation--relations of class, gender, race and sexuality and also in an already existing series of power relations in the health care and medical professions (p. 42).

Jay entered into the power and authority relations of AIDS and death, sexuality, support, and so on that were created before he found himself near death. It is as though he inherited (along with the disease) the circumstances of the AIDS world and its social arrangements--arrangements of the late twentieth century industrialized society and its particular ordering of social life. These relations are not fixed objects, but the activities of people. The device of social relations provides a way of being able to look at how individuals are organized vis-a-vis one another. Social relations are:

....concerted sequences or courses of action implicating more than one individual whose participants are not necessarily present or known to one another (Smith, 1987, p. 156).

Central to my inquiry is the explication of the relationship between the prior and ongoing social organization of the AIDS world, and Jay's everyday activity in doing the work of living with AIDS as revealed through his journal and notes. Throughout my analysis I kept in mind five features of social relations that Manicom (1988) outlines:

First, there is not one reified, ahistorical set of social relations available for analysis. Rather, social relations "must be displayed as they actually work and have been produced historically, not as abstract categories" (p. 47). Second, "[p]eople's daily practices are articulated to particular sets of social relations, and in this articulation individuals also become one of those who bring social relations into being" (p. 48). Third, social relations are historical processes. Fourth, social relations, because they are processes, bring together the work or activities of people in various locations. Fifth, because of the ongoing nature of social relations as active processes, it is not possible to 'capture' them in their totality (p. 47-49).

Possibly the most significant phrase here is that social relations are processes. Manicom's lucid examination of the class relations involved in elementary school education helped me understand that social relations were not just threads, or a trail of bread crumbs I could follow from Jay's journal through the forests and underbrush to some understanding of AIDS and its social organization. The social relations in Jay's everyday experiences with AIDS are organized as he bumps up against the systems put into place to "deal" with AIDS. Following Manicom, the social relations I am explicating in this project are those of power and authority, that worked to transform Jay's life. They are embodied in the activities of his life with AIDS; and hence, are practices lived by a man with AIDS and others like him. These power and authority relations brought him into contact with specific events and procedures surrounding HIV disease in the late 1980s. According to Manicom:

Social relations are practices; they are done by people. Social relations are processes; they are ongoing....they have a spatial and temporal character....they are practical activities and courses of action carried out by real individuals. Social relations bring the work of various individuals into an organized relation one with another (p. 47).

For example, prior to friends being diagnosed with AIDS my knowledge of the syndrome came from such "texts" as television, film, books, newspapers, lesbian and gay journals, talk and so on. However, throughout Jay's illness and the aftermath of his death I came to understand more immediately, the struggles he and others experienced as their lives and deaths were caught up in and shaped by events and activities outside them. Jackson (1984) notes that "individual experience is embedded in complex social relations within which it is produced. These social relations consist not only of the ongoing activities of the individuals being studied, but also those circumstances in which these acting individuals find themselves..." (p. 8). My knowledge and experience of HIV disease helps me both immerse myself in, and recognize, these power/authority social relations that were part of Jay's life, that another researcher would have to learn elsewhere. I brought this knowledge to my analysis. While Chapters Five through Seven will describe these relations more fully, the following sections outline the methodological strategies for doing so, through the research design Institutional Ethnography.

## **Methodological Strategies**

Through the foregoing discussion I have presented the theoretical and methodological issues pertinent to a social organization of knowledge inquiry. Following Jay's account I attempt, through the method of institutional ethnography, to unravel or reveal how the words and images, the representations of the disease, might organize, reflect, and contribute to the internalized understanding of AIDS by, in this case, gay men themselves, and their decisions about life and death. The following section describes institutional ethnography, an approach used to explicate how knowledge is socially organized. My project, developed using Smith's theoretical and methodological approach, was designed to explore the life and death of a gay man with AIDS and to reveal how knowledge about HIV disease is constructed about the everyday life of someone with the illness.

As I began to grasp more clearly the connections between theoretical considerations and the methodological procedures emerging from them, I realized that Smith's approach would allow me to get beneath the statistical and descriptive picture of HIV disease that I kept seeing throughout Jay's life. Scientific work on HIV/AIDS, both basic and social, has limitations. For example, much of the early research on HIV/AIDS emerged from epidemiological data to monitor the scope and pace of the syndrome—in many ways, this indicated merely the surface nature of the epidemic, and AIDS research continues to be overwhelmingly in the basic or clinical sciences. This is not surprising given the urgency to find an effective treatment. However, science examining the effects

of HIV/AIDS on those with the syndrome, their families, friends, and communities falls short, not necessarily in terms of quality, but in the amount of work being produced in the social sciences, particularly that which begins in the experience of those with HIV/AIDS.

### **Institutional Ethnography**

George Smith (1991) suggests that institutional ethnography is a “method of research which investigates a ‘section’ of the social world from the standpoint of the organization of the work of those who produce it” (p. 7). In my project, “institution” is made up of the practices and knowledge of the medical and social work professions, the ruling organizations of the AIDS world; as well as the discourses of popular culture in which AIDS often becomes “representation”, again often divorced from life lived/experienced with AIDS. Ethnography is also used differently here. Moving beyond what she sees as ethnography’s focus on methods of observation and interviewing, Smith is interested in an exploration of how things “work”. Some ethnographers rely on a positivist approach through which an objective reality can be captured through the research process. Swift (1991) argues on the other hand, that institutional ethnography “assumes that observable phenomena are shaped and sustained by social structures outside the immediate setting. The researcher examines features of the local setting which show how external social organization operates in a particular setting” (p. 32). The institutional ethnographic project is to investigate how things are put together and Swift did this by examining how ideas of child neglect operated within the everyday social work practice of those involved

in child welfare agencies.

Smith's (1987) method provided the radical rethinking I needed to begin to uncover the social relationships and layered complexities of the AIDS crisis as it manifested itself in my brother's life and death, and indeed, in my own life. As she says, "individuals' accounts of their experience may disclose a level of organization beyond that experience" (p. 128). Institutional ethnography offers a way to reveal and analyse the web of relations between daily life and the wider organization of daily life through the bureaucracies, management and administrative practices of HIV/AIDS. Finally, and most importantly, it presents a method of investigation and analysis that included Jay as a knower of his everyday life in order to explore the relations that organized this daily life from his place in it. Taking Jay's journal as the starting point, I began to look at how various aspects of his living/dying were put together, by tracing the social relations of power and authority to reveal the transformative nature of the AIDS diagnosis.

There are several strategic features of institutional ethnography that emanate from Smith's social organization of knowledge, and which I will discuss below in relation to my inquiry. They are: problematic, experiential data seen as "work", and social relations discovered in textual materials. In the research proposal describing their study of the social service delivery/access connection of people with HIV/AIDS in Toronto, George Smith and Eric Mitchell [Mykhalovskiy] (1990) outline their understanding of the beliefs or premises of institutional ethnography:

....first...it is the activities of people which produce the social phenomena we are interested in studying.

Second, [...] the work of producing these phenomena is already organized before we begin our research. Our job...is to discover exactly how they are organized. To do this we do not rely on an theoretical overlay to identify internal relations within our data...Rather, we work to discover, in a purely empirical way, the social organization of social phenomena that is there to be described.

Third, when we come to explore how local events are socially organized, we find that they are usually shaped by forms of organization that go beyond the boundaries of local settings. (p.6-7).

Campbell (1998) notes:

Given these premises that Smith (1987:117-135) argues are not theoretical in the ordinary sense, but are conceptual reflections of actual relations among people, the researcher goes into any new setting to see 'how it works'. It is not to test a hypothesis, but to examine the way that the social organization is put together such that people experience it as they do (p. 59-60).

### **Problematic: a route to visibility**

Jay's journal contains an narrative of a particular time in his life, and one of my tasks has been to be ask questions that are led by Jay's account of his life. If I begin from Jay's standpoint in the world, I begin with a 34-year-old man located in a particular city in the late 1980s, involved with his work, his friends and family. Campbell (1998) notes that it is the responsibility of an institutional ethnographer to:

...search out, come to understand and describe the connections among...sites of experience. [My] sense-making is not just insightful interpretation. Nor am I looking for it to be an instance of theory. Rather, it is disciplined by the relations that organize or coordinate what actually happens...what research informants experience (p. 62).

With this project, Jay's writing about his life with AIDS is the place from which I began. It is the problematic; that is his experiences contain disjunctures that give rise to puzzles or topics for inquiry that need an explanation. The problematic, or puzzle, or "topic of

inquiry” (Campbell, 1998) arises at the line of fault between experience and a life organized or articulated to ruling structures/discourses and their conceptual frameworks. By situating the problematic in Jay’s life I then began to articulate a method of inquiry that allowed me to reveal how Jay’s world was configured by the social processes that extended beyond him; that is, how his daily life with AIDS set his feet on various paths into the wider organization of the disease in Canada—into the workings of how he chose to live with AIDS, how he might have made the decision to take his own life, how death is organized, and so forth. Smith (1987) writes that problematic is used to

constitute the everyday world as that in which questions originate....we follow a procedure of going from a social actuality to develop a conceptual apparatus disclosing and explicating its properties (p. 91).

Each analytical chapter begins with a story or stories emerging from Jay’s account of his experience, that builds or constructs the standpoint for my inquiry. Jay’s life lived after he was diagnosed with full-blown AIDS and given approximately 18 months to two years to live, “embodies” the social organization of AIDS in Canada at that time. Some journal entries are cryptic comments, cynical, humorous. Other fragments comment on the work he is doing to survive. While the entries are not a minute-by-minute account of his day, a “typical” day was often organized around at least one hospital/clinic visit, or getting out of hospital, organizing health regimens of medicines, alternative therapies, nutrition, working toward being a candidate for clinical trials, organizing money from friends, family or social assistance, attempting to work on various projects in order to maintain his self esteem, radical revision of what he used to work at for money, managing fear, agonizing about his sexuality. I saw Jay changed by his diagnosis of AIDS; I also

saw him living with AIDS and working to survive. I also see, and am involved in a world that is talking about, and organizing itself in response to AIDS. For example, after Jay's diagnosis of AIDS there was an evident rupture between his experience of himself as a gay man, and his decision to name himself with the category of "Person with AIDS" (PWA) that was produced by professionals and AIDS activists, and which he wrote about. After he killed himself there was a further rupture between his taking of his own life and the coroner's judgement of inquiry that defined his death as "suicide" because he was depressed about the fact that he had AIDS. When I found the journal after his death it contained an account that indicates he was living this disjuncture, and I found numerous expressions of disjuncture in the journal and identified their common root--the profound transformation that occurred following his diagnosis. Throughout the analysis I have identified other disjunctures that I experienced between Jay my brother the gay man and Jay the person with AIDS who killed himself and was turned into a foreign object through "ruling" practices.

Examining various entries of his journal, I was able to explore the social organization of Jay's life with HIV disease through and beyond his writing about it. How did he carry out this work? How did it converge with that of others? The journal entries--that is, his written "talk"--identifies how his life with AIDS was organized beyond the walls of his apartment and reflects the power and authority relations he became part of as a result of his diagnosis of AIDS. This talk or language makes use of words or phrases and sentences that are part of the social relations. The power relations are brought even more clearly into focus by examining his talk. Smith (1987) argues that through talk, "the

language of the setting observes the relations of its social organization” (p. 160).

Throughout his journal Jay refers to “PWAs”, “affirmations”, “sexuality”, “clinical trials”, “OIs (opportunistic infections), “suicide”, and other words and phrases that were part of the way people talked about AIDS in the late 1980s. The construct of PWA or person with AIDS for example, had, and has, various connotations for those with HIV/AIDS. Through noticing and displaying how these categories work at the everyday level, I moved to an analysis of how that work is embedded in a broader web of social relations. This work was one of pulling apart the whole and examining the relations that make it thus.

The problematic offers the place of entry into the inquiry; it is the place where the subject of the research, Jay a gay man with AIDS who took his own life, is located. In my work, the world I am examining is made up of the lives of gay men in their bodies living and dying with HIV disease; it is not a theoretical account of the nature of gay body as metaphor for the demise of a generation. When I read various journal entries I wanted to know what was organizing his experiences. His journal offered me the clues as to this experience—the dailyness of his struggle to live and his decision to take his own life. The more I began to see how much of Jay’s life with AIDS was connected to AIDS organization in Canada, the more these connections provoked questions for me. The following questions, arising from the everyday knowledge of a gay man with AIDS, are those I have kept with me as I examined my data:

What is the “work” of living with a sick body—the physical, emotional, spiritual work? What is the “work” of grieving for a lost body, for lost potential? What is the financial work of AIDS? What skills does this work take?

What is it in their living with AIDS that brings some gay men to the place of decision to take their own lives?

I began first to demonstrate how the “work” of living with AIDS was organized. How, for example, did Jay “do” or accomplish being a PWA? Secondly, I began to pull apart those work processes so I could figure out the connections--what forms did his activities take, how did he organize himself, and how was he organized?

The researcher’s traditional or conventional position has been that of objective observer. Smith’s (1990a) work shifts the researcher’s position through what she calls reflexive inquiry:

What we make here an object of investigation is what we ourselves are immersed in. The ideological practices explicated here are our own (p. 4).

This is different from more traditional ethnography in which the researcher is expected to stand back from the setting and appear not to know or understand it. George Smith (1990b) also suggests that the epistemological shift in institutional ethnography is not objective versus subjective knowledge, but a move from objective to reflexive knowledge where the researcher inhabits the world she is researching. In his view, reflexive knowledge embraces the standpoint of those outside the ruling regime; for example, the subordinate position of women in patriarchal society, of lesbians and gays in heterosexual society, or of persons living with HIV disease in a professionally-defined therapeutic environment. Campbell and Manicom (1995) argue as well that “beginning in experience helps the researcher identify ‘whose side she is on,’ while constructing an account that can be trusted” (p. 7).

What Smith and others (Jackson, 1984; Manicom, 1988; G. Smith, 1990a, 1990b) emphasize is that researchers are in a position to explore how they themselves organize concepts and practices. There is no objective/subjective or theory/practice dichotomy in institutional ethnography. Unlike the naive researcher attempting to remain distant from her objects of study, institutional ethnography requires that I know about AIDS, or find out about how AIDS treatment, or AIDS death, etc. works. Thus, I have examined Jay's journal and have undertaken research that makes his fragmentary comments meaningful. Where his talk references external events, ideas, actions, I must inform myself of what they are. From there I have revealed the ways in which how he lived, and how he died is socially organized and consequently how it too is reflexive. This has meant examining my own place in the world of AIDS, not as a social work researcher standing outside that world in the realm of professional or academic abstract social work, but as a sister, as an "inhabitant" of the lesbian and gay culture, and, a social worker who does indeed understand the professional practice that I encounter in this study. My task is to make the social relationships of power and authority he entered into more visible and to work, as Kinsman (1987, 1989, 1991, 1992a) and G. Smith (1990b) have urged, with AIDS activists in the production of knowledge that "makes more visible how these social relations that extend beyond the everyday world of PLWAs are organized" (p. 41).

### **Experiential data & textual materials**

Exploring the everyday world as problematic requires that researchers be interested in the work of living. Smith (1987) proposes that institutional ethnography employ a “generous” notion of work, and it is the analytic interest in how the work, in this case of choosing to live or die, is actually put together that distinguishes it from other forms of ethnography. She (1987) suggests that the

....concept of work is extended here to what people do that requires some effort, that they mean to do, and that involves some acquired competence. The notion of work directs us to its anchorage in material conditions and means that it is done in 'real time'--all of which are consequential for how the individual can proceed....We are not concerned so much to mark a distinction between what is work and what is not work, but to deploy a concept that will return us to the actualities of what people do on a day-to-day basis under definite conditions and in definite situations (p. 165-166).

Manicom (1988) concurs:

a central point in this examination of work processes is the way work processes intersect. It is here that we see the way the organization of the work processes in one setting provides the conditions of work in another setting, the way the accomplishment of work processes at one site provides for the accomplishment of work at another (p. 61).

The work of becoming and living as a PWA is not a passive assumption of a medical diagnosis and new identity. It can be, and was in Jay's life, a public and active struggle to work within the political frame of the term, while attempting to keep death at bay by labelling AIDS a “chronic” rather than “terminal” illness--albeit in a climate in which there was nothing available to allow those with AIDS to manage their illness. The work involved in living with HIV disease is extremely demanding. Making problematic the everyday world of a gay man with AIDS lets me examine how he (and others) were

required to spend their time, what had to be accommodated in order to carry on. His journal and notes ask questions such as: How will the rent be paid? The groceries? How can I get to the hospital? How can I understand the medical ramifications of this syndrome? Who am I, now? Such questions tell about his life and are of interest now in piecing together its social organization. For example, how in charge of his life was he, as he was living it? The inquiry is also a way of being able to explore how the work he had to accomplish, intersected with work at the hospital, with work being done (or not) by the Federal and Provincial governments regarding clinical trials or access to drug treatments, with work being done in AIDS service organizations or schools of social work about attitudes toward people with AIDS; with the work required to end one's life with or without assistance; or the work being coordinated by friends and family to support those they know with the disease, and so on. In bringing into relief the work processes of a person living with AIDS and the connection of these with other ongoing work processes, I was able to reveal that the coordination, or co-ordering of the work of living with AIDS is not neutral; it is ideological, and ordered in a particular way through the "relations of ruling".

In administrative and bureaucratic settings documents are used to "rule" and organize what goes on in a local setting. They are active and can be pulled apart to show how they have been constructed. For example, as I will show more explicitly in Chapter Seven, a coroner's judgement of inquiry document originating from the Coroners Act in BC, shapes how decisions about various kinds of deaths are determined across the province. Such a document coordinates social processes and the activities of professional

groups such as coroners, doctors, police, etc. Smith and Mitchell [Mykhalovskiy] (1991) suggest that a recursive capacity, or the “capacity to continually reproduce itself in different locations, resides in its documentary or textually-mediated character” (p. 10); and, Kinsman (1988) suggests that documents also “transmit a set of instructions which can reproduce dominant forms of social organization” (p. 39).

Dorothy Smith intends a broad use of the word document. It includes forms, assessment sheets, policy statements, academic texts, minutes of meetings, coroner's reports, and so on. In my project these documents coordinate such activities as admission into hospital, the education of professionals working in the AIDS world, the definitions of who is a person living with HIV disease, and how a death is recorded and defined. These documents are not created in abstraction; documents are practices produced by people. The form or policy or text (whatever its structure) intends a purpose, some action. Documentary practices also have a history (Campbell, 1992) and orient and organize people to their current work, as well as to future work and initiatives. Manicom (1988) argues that it is not a matter of dismissing documentary practices as so much paper work, rather:

....documents/documentary practices are integral to ruling and managing, intending particular institutional courses of action, organizing and administering daily reality into forms which are actionable within the institutional context....the coordinations of social courses of action through documentary practices are neither neutral nor random; the documents are not merely ‘things’ which facilitate record-keeping....Rather than acting in a neutral way, the documents privilege certain ways of acting, they embody particular formulations of social relationships. When work processes are coordinated through documentary practices, the work processes embody the social relations immanent in the documentary practices. Thus documents and concept and categories participate in the organization of social relations (p. 72).

The experiences of those living/dying with HIV/AIDS are “inscribed” (Kinsman, 1988) into the categories of particular documents relevant to their lives as persons living with AIDS to be more easily managed or ruled, and as Manicom suggests above, these documentary categories then privilege a particular course of action for professionals, government bureaucrats, the media, and so forth. In his work on the history of sexual regulation in Canada, Kinsman (1988, 1996) found that the documents he examined tended to focus debates and struggles within different ruling and professional groups, and were contested by gays. Similarly in the texts I examined, I saw ongoing debates among various groups regarding how one with HIV/AIDS should live or die properly.

## **The Study**

I began my inquiry from the standpoint of a gay man’s written account of his experience of living/dying with HIV/AIDS and traced the social relations that organized his experience beyond the boundaries of his everyday life; and I have explored beyond Jay’s words into the issues and events about which he spoke. As data for my inquiry I have his words, my own and my family’s experiences, remembered and/or recorded through interviews or other personal writings. I used ethnographic data-gathering methods such as unstructured or semi-structured interviews, participant observation, observation of various settings, and review of documents with a view to understanding the social relations of Jay’s life as they appear in his narrative account. Data include audio-taped interviews; other published research; professional and paraprofessional discourses;

attendance at, and organization of, AIDS conferences, demonstrations, workshops, meetings; my participation as a board member and co-chair of AIDS service organizations in two different cities; and the examination of official texts regarding HIV/AIDS such as provincial and national AIDS strategies, and a coroner's judgement of inquiry. In addition to examining personal accounts, articles and reports, I attended and presented at AIDS conferences, and am in contact with those professionals who are working with persons with HIV disease. During the writing of this dissertation, I was appointed to the Provincial AIDS Advisory Group by the Minister of Health. Using the clues in Jay's journals directed me to speak with other experts living with the disease--informants who would speak of their experience, their work within the AIDS institutions, and their own struggles with what is often called a death sentence.

I conducted in-depth interviews with three family members. I also interviewed at length, two hospital social workers--only one was able to be taped. Two in-depth interviews with a suicide counsellor were also taped. Interviews with members of the coroners service were undertaken as was an interview with a provincial government employee responsible for income assistance delivery and the development of an early AIDS protocol. I have also had informal interviews over the last four years with AIDS service organization employees and board members, government workers, income assistance personnel, senior policy advisors with Health Canada, researchers with the Centre of Excellence for HIV/AIDS at St. Paul's Hospital, family members of other persons with AIDS who killed themselves, front-line and management social workers from Canada and the United States working in various AIDS fields. I have participated in

support groups, workshops on grief and loss, spoken to students, professional and community groups and journalists about AIDS suicide.

## **Conclusion**

In this chapter I have presented the theoretical foundations for the methodological approach, institutional ethnography, through an overview of intellectual debates particularly examining critical social science and critiques of it by both postmodernists/poststructuralists and Dorothy Smith. I have pointed out that the inquiry seeks to reveal the relations of power and authority embodied in Jay's experience as a gay man living daily and nightly with AIDS and in the discourses that shaped, influenced, inscribed and ultimately transformed his life. Obviously Jay's experience as a white, middle class gay man differs in significant ways from that of a gay street youth with AIDS, a working class woman with AIDS, or a person of colour. Nonetheless, it is his standpoint which provides one entry into the organization of AIDS—that is—how concepts, institutional practices, professional discourses, intersect with the daily lives of actual individuals. It means taking seriously an explication of the social relations of living with HIV disease in a particular place and time in history—a materialist analysis. My account that follows in the next three chapters is what I have been able to piece together from various sources to make the sense of Jay's journal entries that he might have been making of his life. I cannot claim that I have captured his meaning. What I do claim however, is that in following where his words have led, these are the circumstances that

would have surrounded a middle-class gay man living and dying with AIDS in 1988 and 1989. I agree with Jackson (1991) who argues that the fundamental premise of Smith's approach to research is that the "social world has no existence independent of the activities and understandings of the people who participate in it, including the understanding and activities of the researcher" (n.p.). I am thus aiming to illuminate how Jay's struggle was waged, not "alone", and not according to rules that continually prescribed the "right way", "legitimate", "organizationally-established", etc., but as a "work" of living/dying in which he tried to stay in control of himself and be himself. I am showing a way of knowing that offers insight into how various ideologies and ruling practices penetrate into the everyday life of a man living/dying with AIDS. I have chosen to begin in the narrative experience, or written account, of a gay man with AIDS and to rely on my own experience as a participant living and working with persons with AIDS.

## CHAPTER FIVE

### The Work of Choosing to Live

*...it [the hospital] is like a  
womb I must leave. When  
I walk out these doors,  
I will be reborn. A  
different Jay than who  
staggered in that cold  
clear Friday in Feb.*

*I am Jay w[ith] AIDS  
I am a PWA  
entitled to all that is  
available to this select  
but growing company  
of people.*

*I had always wanted to  
work on an AIDS committee  
+ do home-care, etc. But I  
was scared to death of  
facing AIDS so directly.  
I wasn't ready.*

*Now that I am with + among  
them, I will lose my fear +  
feel in community w/ my  
brothers in our new metamorphosis....*

*Have had a few erotic dreams  
lately. Will my sexuality be  
lived only in my dreams, now? I'm certainly afraid of sex now --  
I was in the past, too,  
but horni-ness [sic] won out  
(Journal, March, 1988).*

*G. from AIDS Van  
 was over yesterday + he held me  
 while I cried about my  
 fear of death + loathing of my sexuality,  
 + where to find my heart....  
 ( Journal, February, 1989).*

## **Introduction**

Jay's journal has been a place to begin my inquiry into the circumstances of his decision to die by his own choice and at a time of his choosing. I spent a great deal of time with Jay through his illness, I have read the journal and thought about the tremendous personal energy he expended in living/dying with AIDS. It became clear to me that he did more than attempt to keep well. His was the arduous daily and nightly work of staying alive after being given a terminal diagnosis, and perhaps at some point, of deciding to move toward ending his life—which is also “work” that he takes on. The first excerpt gives a sense of the rupture between a gay man with AIDS and the way in which he has begun to perceive himself as a result of his terminal medical diagnosis. There is a contradiction between the illness and its label which produced fears of death, and the “hope” associated with refuting the AIDS diagnosis and its prognosis. It also acknowledges his increasing fear of sex as a result of the diagnosis. I wanted to puzzle through how becoming “Jay with AIDS...a PWA” was accomplished and to discover the social relations among the people and institutions involved in his life at this point, that established and maintained the experience of his being a “PWA”. In other words, I wanted to know how this account of himself as a gay man living /dying with AIDS was organized.

While there are probably different entry points I could have taken in order to begin to explicate the social relations he was caught up in, I wanted to begin from the standpoint of a gay man with the syndrome. The transformation from being an “ordinary” and sexual well person to one officially diagnosed with AIDS is a shocking and critical event. As I moved out from Jay’s account of his local or personal experience, a web of external, or extra-local social relations, became visible. The change in health status seemed to organize a differing relationship with his already sexualized body as mediated by the medical profession, hospitals, clinics, social service agencies, AIDS service organizations and a growing discourse regarding HIV/AIDS from AIDS activists, academics, health care professionals, and spiritual advisors. I also saw that despite the troubles he was confronting because of his terminal diagnosis, Jay was having to choose to live.

I have structured the chapter around three themes that emerged through the analysis: first, how Jay’s experience of his body and the effects of the homosexualization of AIDS may have influenced his choice to live or die. Secondly, the choices precipitated by the change in identity that Jay wrote about after his diagnosis, and how he became an “expert” AIDS patient. Finally, how “help” or support comes into a life to combine with or contradict other elements in the dailiness of making choices to live. These themes will be carried through to Chapter Six where the focus is on a further choice—whether or not suicide is, as Jay wonders, “a legitimate option”. While in a common-sense way it can be said that any experience no matter how mundane can change us, what I want to show here is the social organization of Jay’s “choice” to call himself a PWA or “Jay with AIDS”. I

will argue that his capacity to choose depends on expertise that he had already begun to acquire about AIDS as a gay man prior to his diagnosis, as well as through his time in the intensive care unit and on the ward. It is my contention that relations of power and authority coordinated his renaming of himself with the diagnosis of AIDS, and also coordinated his subsequent involvement with medical and other professionals. This chapter investigates and explicates these social relations.

**“Will my sexuality be lived only in my dreams...?”**

It was difficult to separate out Jay’s experience of himself as a gay man from the other issues he relates in the journal but because homosexuality has been a central organizing feature since HIV/AIDS first emerged, I believe it required specific analysis. I discovered that social relations of power and authority were evident in Jay’s account of himself as a sexual man once he was diagnosed with AIDS and became “Jay a PWA”.

*Have had a few erotic dreams  
lately. Will my sexuality be  
lived only in my dreams, now? I'm certainly afraid of sex now --  
I was in the past, too,  
but horni-ness [sic] won out  
(Journal, March, 1988).*

*G. from AIDS Van  
was over yesterday + he held me  
while I cried about my  
fear of death + loathing of my sexuality,  
+ where to find my heart....  
(Journal, February, 1989).*

When I read the excerpts above, I was interested in how a gay man with AIDS manages the work involved in having formerly experienced his body as a site of pleasure to one now regulated as a site of risk. Being familiar with the ways in which homosexuality is said to be a “given” when one has HIV disease, I wanted to find out how the homosexualization of AIDS might enter people’s lives—especially how it enters into the lives and experiences of gay people living with HIV/AIDS. Even if in many ways this association can be rejected on political or intellectual grounds as the so-called “face of AIDS” changes across the country (that is, in 1997 AIDS affects other than gay men), it still has a social currency and power to it. For someone who is dying from AIDS-related disorders it can be very hard not to at least take up aspects of this framing of sexuality as deviant or polluted, as a way of accounting for their deteriorating health and approaching death. It also sets up a series of contradictions/ruptures since many of these men have also experienced great pleasure and joy from gay sex.

The two journal entries above in which Jay first wonders if his sexuality is to be relegated to dreams, and later begins to loath his sexuality, are evocative of how the homosexualization of AIDS might work, and how it might then affect other aspects of living/dying with AIDS. As Adam and Sears (1996) observe, “An HIV-positive diagnosis disturbs patterns of belief about oneself and the world, as well as physical and personal relations” (p. xii). They use the work of Michael Bury (1982) who describes the impact of a chronic illness as a “biographical disruption” in which the taken-for-granted assumptions about a person’s life are forced into a reexamination, necessitating the reconstruction of one’s biography:

Making a life with HIV is an active process of developing ways of dealing with actual or anticipated changes in self or others in areas ranging from physical health to intimacy or employment. People with HIV have been 'present at their own making': individually and collectively they have challenged medicine, the state, and the common sense of the day to work out ways of living with a condition that many in society still label a 'death sentence'—with all of its punitive connotations (Adam and Sears, p. xiii).

“Biographical disruption” seems a powerfully apt term for what I saw happen to Jay following his diagnosis of AIDS. The first journal excerpt for example, in which he wonders if his sexuality will be lived only in his dreams now that he has AIDS, was written while Jay was still in hospital after receiving his AIDS diagnosis in 1988. It is part of the entry in which he also names himself as “Jay...a PWA”. He wrote the second excerpt in which he cried about his fear of death and the loathing of his sexuality, nearly one year later, a little less than three months before he killed himself: In each excerpt I saw the gap between Jay’s experience of himself as a sexually active gay man, and the way in which sexuality had become overtly linked with contagion when he was diagnosed with AIDS. During the eighteen months that the disease progressed, he came to feel his body less as a source of pleasure or eroticism and more as something loathsome, and the cause of his dying. He told me for example that he wished he had asked a former girlfriend to marry him, and that perhaps that was still an option open to him despite the fact that he was sick. In contrast to his wanting to assume a so-called “straight” life, in my interviews with family members, two brothers experienced him as more blatantly “gay” as he began for a time, to dress not just for parties but on a daily basis, in what might be termed “drag”. I saw this contradiction as a indicative of the fear and shame he felt at having AIDS.

What takes place that transforms what had once been a source of joy and often fear (legally, morally?) to a source of shame and loathing? In his account, Jay mourns what he believes may be the loss of his sexuality and wonders if it will exist only in dreams. In AIDS discourses as presented in Chapter Two, sexuality becomes equated with tainted blood, death, celibacy, not the erotic. The erotic disappears and is replaced by medical or professional versions of gay sexuality. Becoming identified with his illness was not only a rebirth as a "PWA" (which I will discuss below) but also a rebirth into a new level of stigma. As a gay man, Jay had experienced the troubles that accompany homosexuality both in families and in society. With an AIDS diagnosis these troubles were compounded. While the effects of stigma differ with individuals who have AIDS, at the time of his diagnosis the spotlight was primarily directed toward gay men. When Jay received his diagnosis the spectre of HIV/AIDS as retribution from God for a promiscuous lifestyle symbolized stigma, a theme which has been a focus for analysis in the work of Gilman (1989) and others mentioned earlier. Leaders of the religious right gleefully preached their hate toward these marked individuals, and as Sears (1992) suggests, the rhetoric of the right appeared to replace public health initiatives with calls for quarantine and involuntary testing for the virus. In becoming "Jay with AIDS ...Jay a PWA" and later writing that the "hardest thing is calling up friends and telling them", Jay shows how stigma both of disease and homosexuality is located in his talk about being diagnosed with AIDS, and the emotional work required to deal with and resist it. A medical diagnosis perhaps should not hold the power to stigmatize, and yet for a gay man, the sexual manner in which he came to have AIDS is the stigmatizing factor.

Stigma is defined as a “mark branded on a slave, criminal, etc.” or, “definite characteristic of some disease” (The Concise Oxford Dictionary, 1976), and according to Frank (1991) these marks that included ear notches and other mutilations helped others know with whom they were coming in contact. Ever since “the days of notched ears, the power of stigma has fed on seeing the body’s condition as an expression of morality, and this linkage is virtually irresistible to our thinking” (p. 96). Frank observes for example, that he learned as a cancer patient that passivity was appreciated by the various institutions who could then manage patients more easily, and that “society is obsessed with ‘health,’ but it prefers to keep ill persons on its margins, making them as invisible as possible. When people are stigmatized, they hide themselves” (p. 97). As a gay man, Jay was similarly identified as a member of a particular category of person most likely to “get” AIDS, and also to transmit the virus—an identity as constructed by centres for disease control and public health officials, and carried forward and upheld through media representations of the category (Mykhalovskiy and Smith, 1994). These repercussions illustrate perhaps more than would a definition of stigma as shame or fear. It may be the social character of stigma which is evident in Jay’s remark about how hard he found it telling friends and others he had AIDS. Ironically, while the homosexualization of AIDS continues to stigmatize everyone affected, it supports the assumption that gay men are the only ones with the disease and provides for making others invisible—for example, women and children.

It appears that Jay had taken into his own body the discourse on the relationship between sexual activity and AIDS and had begun to believe he had been the cause of his

own dying. His “loathing” of himself as a sexual man, a homosexual, was not a free-floating anxiety unrelated to his everyday life before his diagnosis. Regarding his ambivalence he wrote, “I’m certainly afraid of sex now—I was in the past, too but horniness won out”. When I read these excerpts I knew them to be “true” to one’s experience as a gay person. I recognize the social relations of sexuality in a heterosexual family. As his sister and as a lesbian, I had witnessed and been part of the familial struggles regarding sexuality. Our catholic parents reacted as many do when we “came out” that is, with fear, shock, and concern. They wanted to fix or cure, felt it was their fault that two of their children were homosexuals, and felt a deep embarrassment (saying for example, how can I talk about my children?). I have lived through experiences with the discomfort of some family members with same-sex lovers or partners during traditional “family” events such as Christmas or birthdays, and saw it slowly giving way to a general kind of acceptance. And certainly during his illness Jay felt supported by our mother and brothers. The day he was discharged from hospital he wrote: “I almost died but the love of my family + friends saved me.” Nonetheless, Jay was also dealing with the fear that entered the lives of those close to him. It was difficult for him, and for the others I knew who were ill, not to be aware of the anguish that their situation engendered. Many feared being exposed in a different way to their families. Because AIDS was and is seen as caused by unsafe sexual practices, and a promiscuous or irresponsible “lifestyle”, gay men were now actually “seen” as sexual by mothers or fathers and other family members. While parents may have had some vague notion that their sons were sexual beings, many did not want to know what that really meant. After Jay’s death for example,

my mother took part in volunteer training with AIDS Calgary. She told me later that she had only vague ideas what Jay's sexuality had been about until then.

Jay's juxtaposition of fear of death with the "loathing" of his sexuality suggests that he has internalized not only family "values" but also popular cultural condemnation of gay men by the general public, religious groups and the haze of homophobia and heterosexism pervading psychological and sociological discourse. He had been politically involved in human rights actions regarding homosexuality, had experienced police harassment, and years before had experienced the homophobia directed toward him by fellow undergraduate law students. In his stories and poems and in other moments of the journal, the responsibility of knowing so intensely that so-called abnormal sexual activity is seen as the reason for his premature death appears to be a source of deep anxiety and terror for him. Jay's experience of the "loathing" of his sexuality following his diagnosis is not idiosyncratic; it is perhaps a generalized experience that gay men with AIDS face. As I have suggested in Chapter Two, Brandt (1991) also argues for example that the AIDS epidemic is seen by some in a purely "moral" light, as a disease that occurs among those who violate the moral order. Like other sexually transmitted diseases in the past, AIDS has been viewed as a fateful link between social deviance and the morally correct.

Underlying the fears of transmission were deeper concerns about homosexuality. Just as 'innocent syphilis' in the first decades of the twentieth century was thought to bring the 'respectable middle class' in contact with a deviant, ethnic, working-class 'sexual underworld', now AIDS threatened the heterosexual culture with homosexual contamination. In this context, homosexuality--not a virus *causes* AIDS. Therefore, homosexuality itself is feared as if it were a communicable, lethal disease. After a generation of work to have homosexuality removed as a disease from the psychiatric diagnostic manuals, it had suddenly reappeared as an infectious, terminal disease (Brandt, p. 107).

This was not only Jay's experience. At AIDS conferences I have attended since 1992, both professionals and those with the syndrome still struggle with the homosexualization of HIV/AIDS and its effects. While other individuals and groups (women for example) have begun to have medical and professional attention finally focussed on their needs as persons with AIDS, the "detritus" of the syndrome's first designation as Gay Related Immune Deficiency (GRID) appears to remain foundational to many. Because these mostly gay white men had some contact with medical authorities, others who were also becoming infected and dying were ignored by what Kinsman (1996) terms the "early epidemiological gaze" (p. 349) that was focussed on homosexuals. A few years ago during my tenure as a board member of a relatively new AIDS society for example, several incidents illustrated that the conflation of AIDS with homosexuality had not diminished. Many persons with AIDS and others wanting information about HIV did not want to be seen coming into our storefront offices for fear of retaliation. Later, the search for new office space was hindered when landlords refused to rent to the society once they knew who we were. Once new space was secured however, a struggle within the membership also ensued when the then-chair reported that he had joined the society as a Christian man in order to come to terms with his own homophobia. On the other hand, the society finds that gay men in the community often do not want to use its services because the staff is primarily heterosexual women. In this same city anti-homosexual hate literature was being distributed in a local health food store and one provincial member of the legislative assembly became the target of a recent recall campaign because of his modest pro-gay stance. While those who mounted the

campaign against him suggested it was a result of not fulfilling various election promises, the process began shortly after the MLA attended a rally being held by lesbians and gays and their allies to protest a right-wing church rally featuring a “converted” homosexual woman.

The recall incident and others like it in conjunction with Jay’s life with AIDS, and his death seemed to be evidence of the social relations of power and authority organizing sexuality. Kinsman’s (1996a) analysis of the Canadian experience of sexual regulation and its effect on those with HIV/AIDS was illustrative of the relations of power and authority evident in my analysis of Jay’s journal, as well as in my meetings with others in my association as a volunteer with AIDS societies, and at professional and academic conferences. As suggested in Chapter One public health practices early in the epidemic focused on measures such as quarantine and notification of partners to stop the infection, rather than on treatment. In response, community-based gay and lesbian groups emerged, often making use of strategies from the feminist health movement. Kinsman suggests that through their educational campaigns these groups were able to curtail some of the social processes that organized AIDS-related discrimination, and exact a response from government agencies and the medical profession (p. 349). In response to the power and authority used against them, AIDS activists organized their own power to confront the medical and social construction of the syndrome as “GRID” that was taken up in the media as a gay-plague. This early social construction of AIDS as a gay disease continues to have an impact on those considered innocent or guilty victims, (Kinsman, 1996; Adam and Sears, 1996; Sears, 1991) and with State and activist agendas, “the context of making

a life with HIV is therefore a contradictory one” (Adam and Sears, p. xvi). I will examine this contradiction further in Chapter Six in relation to Jay’s use of the work of Louise Hay and her seeming ambivalence toward helping gay men.

Despite research that indicates the challenge being made to stable notions of sexuality that I discussed in Chapter Two, as well as the beginning of limited human rights and a street-level “pride” and acceptance in certain limited spaces, it is as though gay men once again epitomize lethal and stigmatized sex practices.<sup>15</sup> Beginning in Jay’s words which conflate his fear of death and sexual self-loathing, offers a way to show how the relationship between homosexuality and AIDS, worked up through the early medical and public health response to the syndrome was based on the assumption that those infected were going to die and thus organized to protect the general public from infection by homosexuals. Through these relations of dying/contagion, homosexuality becomes a category and concept that can be pulled apart and excavated to explore its history, its ideological makeup, and how it continues to be constructed in the present, in AIDS. Thus, Jay experienced himself as a homosexual man with HIV disease who expected that his sexuality was to exist in dreams or was something to be loathed. His sexuality was in a certain sense obliterated by definitions and ideas about him in relation to AIDS, and *may* have been a contributing factor in the choice to take his own life, as I begin to explore in the next section.

---

<sup>15</sup>While it appears that lesbians and gays are media darlings at the moment with Ellen Degeneres “coming out” on her prime-time television show in 1997, and the fact that several series have positive lesbian or gay characters, the overall public response is a clear reminder of the depth of homophobia and heterosexism in North American society evidenced in violence or silence, or in British Columbia and Alberta, openly political opposition in 1997-98.

## **Becoming “Jay with AIDS...a PWA”– an expert AIDS patient**

Ebaugh (1988) reflects that, “Each time an individual enters or exits a role, self-identity is threatened” (p. 22). Jay acknowledged in his journal the profound changes he experienced after he was diagnosed with AIDS and discharged from the intensive care unit. His description of himself as “Jay with AIDS”, Jay “a PWA”, indicates the work of that transformation--albeit, not of his own choosing. Here I argue that the diagnosis of a fatal disease officially provided by a medical doctor precipitates his rebirth into a person with AIDS (PWA) and into a “patient” and brings into relief the new relations of power and authority that reorganize his life and his self-identity. Regarding their interviews with a number of persons with AIDS, Adam and Sears (1996) remark that the experience of shock was extremely intense for people whose diagnosis was associated with imminent death (p. 19). The men and women with whom they spoke described the “collapse of one’s sense of future” (p. 20) and the loss of any long range perspective. What they also found was that thoughts of suicide were indicative of the most severe reaction to a diagnosis.

After being released from intensive care where he had not been given much chance of survival, Jay felt hope for his recovery as well perhaps in the fact that there was something available to PWAs such as himself. He wrote:

*When  
I walk out these doors,  
I will be reborn. A  
different Jay than who  
staggered in that cold  
clear Friday in Feb.*

*I am Jay w[ith] AIDS  
I am a PWA  
entitled to all that is  
available to this select  
but growing company  
of people.*

*I had always wanted to  
work on an AIDS committee  
+ do home-care, etc. But I  
was scared to death of  
facing AIDS so directly.  
I wasn 't ready.*

*Now that I am with + among  
them, I will lose my fear +  
feel in community w/ my  
brothers in our new metamorphosis....*

He had nearly died but was alive and felt supported. However the “different Jay” has in a sense been captured and colonized by his diagnosis and is being transported through a new territory (Dreuilhe, 1988; Frank, 1991)—the terrain of health and social professionals who have the ability to read the map of HIV/AIDS. Jay’s use of the term “PWA” (today the term is PLHIV/AIDS, person living with HIV or AIDS) illustrates that he was aware of the social arrangements of AIDS that were already in place before he was diagnosed with pneumonia and subsequently AIDS; and, he was accomplished at making that conceptual leap in using the available label. I see in the excerpt words showing his struggle in attempting to come to terms with his “new” identity as a man with AIDS, how that work is done and how it intersects with the work of his doctors, AIDS activists, social workers, and other support both in and outside of the hospital. Jay’s admission to the intensive care unit for example, precipitated the involvement of those physicians and

nurses who were not only used to working with acute care critical patients, but who were becoming more familiar with HIV disease. Hence, as they investigated the cause of Jay's collapse, they were able to attach to him their diagnosis of pneumocystis carinii pneumonia (PCP) which is an opportunistic infection indicating full-blown AIDS. One month later as he walked out the hospital door as a person with AIDS, he had the distinctive talk of AIDS that had been in place prior to his being diagnosed with the disease. He was learning the new terrain, and had a preliminary sense of how to read the map. It is the kind of distinctive talk that forms the basis of the analysis of this work, and is a way of talking that calls up particular concepts about the syndrome such as: PWA or AIDS, legitimate death, or clinical trial or "O.I", t-cell count, stigma, fatal illness. It is the "talk" that, as other researchers (Campbell and Manicom, 1995; Smith, 1990a, 1990b) have observed in other instances, drags histories of discourses, psychological and medical concepts of sexuality, administrative and managerial procedures of keeping track of those who are ill, the protocol of clinical trials and so on, into the everyday/everynight business of living as a PWA.

When I read the excerpt above, I was struck by Jay's use of the word "reborn" upon his discharge from the hospital almost a month after nearly dying from pneumocystis carinii pneumonia, as well as his description of taking on a new identity. The understanding of being reborn is usually located in the context of a religious conversion, having one's current paradigm radically altered, a spiritual rejuvenation or awakening, a feeling that all is well, that one is "saved" or being given a new chance at making life better. There is also a sense that one is "new", "pure" "young in spirit"; or,

certainly within the Christian framework, that one is forgiven for the follies and sins of the old life and has been offered hope to carry on with life in a new way. It is the beginning of a new spiritual journey. However, it is also found to be commonplace in other illness narratives (Ellis, 1993, 1995; Frank, 1991). Frank for example, talks about his identity change through cancer in which the “hospital had created its own version of my identity. I became the disease, the passive object of investigation and later of treatment” (p. 52). This seems to be similar to Jay’s experience; for example, he wrote “...it [the hospital] is like a womb I must leave. When I walk out these doors I will be reborn...”

What is the death that has occurred prior to Jay’s “rebirth”? What was wrong or ill with his previous “birth”? My brother had been expected to die by the doctors who admitted him when he “stumbled in [to the hospital] that cold clear Friday...” I heard this expectation myself when I spoke to the attending physician many times while Jay was in the ICU, and later on the ward. During the seven days in which the intensive care unit became both “womb” and “tomb”, his rebirth followed a diagnosis of full-blown AIDS and several weeks in the hospital. Jay renamed his process of rebirth “terminal” through having been diagnosed with AIDS-related PCP. “Rebirth” appears to have been his name for moving in and out of delirium, having his lungs pumped out, choking on secretions, being tied to the bed so as not to rip out tubes, hooked up to life supports unable to move, hallucinating, having his meagre life signs set off alarms bells and flashing lights that brought nurses and doctors running to restabilise him. The organization of the medical personnel and machines put in place in the hospital to cope with AIDS worked to make

his transformation a reality. I saw for example, that his name was entered into their charts as someone with an opportunistic infection indicative of AIDS. I was told that he may not survive; and when he was transferred from intensive care to a ward, a sign on the door to his room indicated his infectious status. It seemed to me that we were all--medical professionals and family--caught up in facilitating, almost as "midwives", Jay's rebirth.

In some religions, rebirth is accompanied by a new name. A catholic infant for example, is baptized or christened during a ceremony in which he or she is named after a saint the parents may have chosen. Jay's rebirth also confers a new name, "PWA, person with AIDS", through a diagnosis of a terminal illness. Instead of being saved or being offered hope of a cure however, he is reborn through medical technology and intervention, a form of regulatory power that provided him with life on the one hand, and a death sentence on the other. As a result of machines providing oxygen, keeping the heart pumping, draining urine...a new birth occurs through the canal of tubes. It was a birth into death, as the diagnosis was seen in 1988. The "different Jay" has been re-named as a category of illness, reborn into a category that is still in 1998 called "AIDS victim" or "AIDS patient". The primary significance of this categorization is that it tends to re-make a person into the social problem "AIDS". The function of categorization for example, as it applies to "single mother" has been discussed throughout Griffiths's (1995) and Smith's (1987) ongoing analysis of schooling. Smith observes that:

A child's problem in school, when it is made accountable in terms of the concept of the single parenthood of her or his mother, marshals procedures entering child, parent, teacher and school administration into courses of action specialized to this category of 'problem' (p. 168).

I see the category “person with AIDS” operating in similar ways. The rebirth into a PWA was bestowed as the result of an AIDS diagnosis. The journal excerpt about his new identity is an instance of how the social organization of AIDS is present in the “talk”, or in this case, the jottings on paper, of someone who is living with it. Writing about his rebirth, Jay acknowledged his transformation into “Jay with AIDS” by having his near-death experience aligned with a medical regime instituted to manage the ever-growing numbers of people with HIV disease. In the naming of himself as a PWA, Jay was also however, working with a political mantle by aligning with “a select but growing number” of others with an AIDS diagnosis, his brothers in metamorphosis. Together PWAs in North America and Europe have created the burgeoning political movement organized in what is often construed as an “unruly” response against the domination of the medical establishment and other professionals to control their lives.

This contradictory sense of transformation parallels the notions of identity I discussed in Chapter Three (Adam and Sears, 1996; Patton, 1990). In many ways the mantle “PWA” seems to have replaced a stigmatizing identity while at the same time opening up a political space for those with HIV disease. On the other hand, it may also reinforce the stigma since those who used the term during the time Jay was ill, were primarily gay men. Even then however, there were gay men who did not want to be called PWAs, nor did they want to avail themselves of the services slowly opening up for PWAs.

The term “PWA” is one that Jay would have been familiar with having read magazines such as Canada’s now-defunct gay publication, “The Body Politic”, hearing

about gay men dying of some unknown “plague”, knowing men who were being tested, or perhaps sick, and so on. He would have known that someone with an AIDS diagnosis would be called a “PWA”, and that like other epithets applied to gays--faggot, queer, etc.--the term was being reclaimed by those with full-blown AIDS as a political tool against biomedical and sexual regulation.<sup>16</sup> Jay and other gay men with full blown AIDS had begun to interrupt this type of management of their disease and their role as dying patients, by taking the label “person with AIDS” as a rallying cry. The emerging activists’ organizers refused the designation “victim” and created their own label in the face of those who defined them only as carriers of disease. They formed coalitions and support groups throughout North America, lobbied governments for access to drugs, and with supporters they fought for access to housing and health and social benefits (Mykhalovskiy and Smith, 1994). The political term “Person With AIDS” provided, if not protection against the ongoing deterioration resulting from the illness, at least support in the face of being labelled “other”, and in many cases stigmatized, scapegoated, ridiculed, killed, experimented with, written about, denied housing, and often medical services. As well as attempts to take back their lives, those involved in PWA organizations at the time, did provide one another with a measure of support. An early

---

<sup>16</sup>“PWAs at the 1983 lesbian and gay health conference held in Denver issued the ‘Denver Principles’, the ‘founding statement’ of people with AIDS...movement. In extract the statement reads: ‘We condemn attempts to label us as ‘victims,’ which implies defeat, and we are only occasionally ‘patients,’ which implies passivity, helplessness, and dependence upon the care of others. We are ‘people with AIDS... We recommend that health care professionals...always clearly identify and discuss the theory they favor as to the cause of AIDS, since this bias affects the treatment and advice they give... We recommend that people with AIDS...form caucuses to choose their own representatives, to deal with the media, to choose their own agenda, and to plan their own strategies... People with AIDS have the right...to die and to *live* in dignity.’” (Cindy Patton, 1990, quoting Callen, M. (1988) (Ed.). *Surviving and thriving with AIDS: Collected wisdom, Volume II*. New York: People with AIDS Coalition).

newsletter from one such group provides for example, information on various drug therapies, conferences, and upcoming talks by AIDS experts. There are also announcements of a talk by two men who are healing themselves of AIDS, times of ongoing workshops and groups such as a healing circle, discussion group, tai chi, and reasonably priced haircuts.

As I continued to sort through Jay's papers, the information he had gathered about drug treatments, the notes he kept while organizing retreats for the persons with AIDS Society, I was impressed by the work he tried to do for others who had AIDS, having initially not wanted to be involved prior to his diagnosis. He had brochures from across the country regarding AIDS workshops, information from AIDS Action Now! regarding drug treatment actions, and articles about self-healing. There were forms he had completed regarding a workshop he planned for "nurses who are just being introduced to the idea of AIDS care". He had written that the focus of the workshop was "How a PWA feels about the care they got in hospital. General care issues for PWAs. Emotions upon diagnosis, etc." Jay was attempting to create choices for himself, and other PWAs, against the powerful biomedical barrage of the late 1980s through advocacy work with the Persons with AIDS Society, as well as through organizing retreats for other gay men with AIDS. For example, in an article for the Person with AIDS newsletter that he wrote about the retreat, and in a schedule of daily activities he had prepared, he described a weekend of good food, talk with others, meditation, being outdoors, healing touch and massage. Jay and other PWAs were attempting to manage their condition through what Sears (1992) calls "health from below"--a "politics...that locates the struggle for health as

part of the fight for control over our bodies and our lives” (p. 31) rather than “health from above” in which the state is the primary organizer of the experience. In essence, persons with AIDS were keeping themselves alive through self-help activism, while simultaneously being defined as terminally ill by the medical establishment, whose definitions were taken up in various forms by the media. The “face of AIDS” at that time, that is representations of persons with AIDS, was a gay man, and sometimes a drug user. Jay had seen this “face” in various American magazines and told me how lucky he felt not be living in the United States where so many of those with HIV disease were homeless.

Prior to being admitted into the intensive care unit and assuming the role of a hospital patient, Jay’s identity as a person with AIDS did not exist. Being defined by the medical profession as having full blown AIDS gave Jay “official” permission to assume a new identity. The relations of medical authority and power were evident to Jay and to me not only in his rebirth into a PWA but in the implications of AIDS as a fatal disease. Not only was he Jay the PWA, he was simultaneously Jay the AIDS patient. To reiterate, in the late 1980s there were two conflicting views regarding living/dying with AIDS. The most prominent was that because AIDS was terminal, all resources should go into end of life care. On the other hand, there was evidence among those close to the disease that people with HIV disease were living longer and thus fighting to have resources placed in treatments that could aggressively attack it. Thus, the work of being a PWA, as well as a “patient” with a so-called terminal illness, was and is a complex and contradictory task of activist in the struggle for adequate knowledge of the syndrome and its treatment.

Following his diagnosis--his rebirth as a PWA--Jay needed to learn how to do AIDS, or to become an "expert" in being an AIDS patient. The patient role requires that a PWA learn to act in particular ways to make himself available for various treatments--this requires knowing who to talk with, and how to talk with them. A PWA who wants to live is also required to understand medications, to learn about clinical trials, diet, and non-allopathic methods for example. There is an assumption that somehow even in the midst of being told of terminal illness a person should be able to make informed decisions about his or her life by assessing all options. The contradiction extends to the subtle coercion by professionals working with various therapies and attempting to provide support and create choices or plans on how to work to live in this context--living in the context of dying.

Jay challenged this assumption PWAs were offered by the medical profession. Among his papers, I found a sheaf of handwritten notes he had titled "AIDS World Tour" that seemed to have been jotted down quickly and were intended as his response to ideas put forward at an international conference panel focused on AIDS:<sup>17</sup>

*[it's] a bit difficult talking about my impending death in public. I felt it wouldn't be too hard to do...but today, I'm very tired and find the discussion raises my grief, fears, and I catch my breath.*

*Have to choose to live and as this can be a very unloving world at times, it makes the choice difficult. Why stick around? Hostility, violence, etc. Instead, I am challenging myself and my doctors: AIDS is a chronic condition that I must deal with (day to day year to year) similar to other chronic illnesses.*

---

<sup>17</sup>The conference was: The Body as System, A Weekend Colloquium in Association with ISISSS 88 (International Summer Institute for Semiotic and Structuralist Studies).

*But let's not nail the coffin prematurely, ok? We are all alive and dying alive and living. ANGER. Just getting it together and now I have to deal with a serious condition...[and] attitudes of govt/med/society/family/friends [sic]*

*Although medical establishment defines me as a person with AIDS, I have my doubts. OK [I'm] HIV+ and [had] a near death experience [and] OK, PCP and 1 month in hospital and 7 days on life supports and respirators in I.C. But if I accept I have "AIDS" as a diagnosis, I will accept the prognosis, which is death within, as my doctor said, "6 months to 2-4 years, several years..." No one knows. So why colour my wishes/hopes/plans by saying, "you're dead"? (August, 1988)*

While Jay was on the one hand finding it difficult to talk about his illness publicly, he also wrote in the "AIDS World Tour" notes about struggling to cast aside the ruling of his condition as fatal by challenging his doctors to rethink the power their diagnostic role has for an individual's ability to stay well, and to acknowledge the expertise he has as someone living with HIV disease. His doctors did not know when he would die, but as experts they nonetheless provided a time frame of six months to four years in which this dying might occur. The power and authority to define comes from their expertise. In the excerpt above, Jay attempted to interpret and publicly refute the ambivalent instructions he had been given by the medical establishment, and that appeared to be taken up by academics at the conference. According to the conference program attached to his notes, under the conference title "The Body as System" was an afternoon devoted to two separate and sequential sessions entitled "The Rhetoric of AIDS". In response to such papers as "How can we think AIDS?" and "AIDS, Culture, and Biomedical Discourse: the Politics of Sexual Difference" Jay wrote that at that point he has to "choose to live" in an unloving world that makes the choice a difficult one.

His notes address an occasion in which Jay is publicly struggling with the choices

he is facing as a gay man with AIDS. It reveals the contradiction between being diagnosed as terminal and the fears and responsibilities of patienthood associated with it, versus the hope associated with not accepting the fact that he has been told he will die. He is trying to sort through for himself and for others with his AIDS World Tour notes, decisions that he is trying to make as a PWA. The notes illustrate the social relations operating between a person living with AIDS and the medical profession, and those existing between the medical establishment and an academic panel. They also reveal another aspect of the AIDS crisis—a class issue. Jay as an educated middle-class man knew how to gain access to an academic conference being held at a university. Although their discussion “raised his grief, fears...” he could nonetheless grapple with the academic theorizing about his life and the life of other PWAs. What seems important here though, is that he wanted to use the skills he had to engage in the intellectual debates regarding AIDS. I see him challenging the panellists who, like his doctors, were perhaps attempting to “use” his life for their own purposes. If they were going to do so, he wanted them to know what it was like, and that he knew what they were doing. The mental and emotional “work” to respond to the various presentations required that he try to ignore his own symptoms for the duration of the panel in order to talk about his experience. However, he indicates to the panel that he is grieving and tired. In his recent work on AIDS narratives Kruger (1997) quotes from a fictional character who speaks to this dilemma offered to a newly diagnosed person with AIDS. Clearly, the struggle is not one that only affected gay men in the late 1980s:

Dr. Fillgrave had a fixed, bland expression beneath which percolated a bilious loathing, and he treated Eddie as if he were just another cadaver. 'You'll last a good two weeks, don't worry, two years, maybe six years if you're lucky,' he offered helpfully, when all the blood rushed out of Eddie's face and he thought he was going to faint, 'unless of course you don't have health insurance, in which case the quicker the better, eh?' He actually said that, like a bad stand-up comic doing 'the doctor from hell.' But doctors, Eddie thought, if they didn't kill you with their ignorance, they would surely try to kill you with their knowledge. That he, indeed, did not have medical insurance seemed to him merely an additional argument in favor of alternative treatments, like suicide, perhaps, or--what? (Wier, 1991 as quoted in Kruger, p 168).

Like Eddy, the choices Jay made were negotiated and challenged in the context of a 1988 diagnosis which continued to suggest that it was a terminal disease. Even so, a perceived inability to make the correct choice can be seen to have fatal consequences. Choosing to live appears to mean casting aside the diagnosis of AIDS, and instead, taking up what might be seen as an "unruly" identity, that of living outside the ruling and defining nature of the diagnosis that has been applied to the terms of existence. With the acquisition of a new identity comes decisions that must be made regarding staying healthy, and knowing how to do so. The longer a person can stay healthy, the longer they can remain employed, maintain a home, and not have to reorganize their lives in conjunction with medical treatments and other indignities.

After examining Jay's journal entries and his AIDS World Tour notes I found evidence of what several political activist ethnographers (G. Smith, 1989; Kinsman, 1992a, 1996; Sears, 1992, 1995) describe as the lack of a policy response in Canada. Jay's talk of himself as "Jay with AIDS" and his rebirth into "a PWA" while at the same time challenging his doctors that he wanted to be someone with a chronic condition rather than a terminal illness, is illustrative of the social organization of AIDS in Canada at that

time. During the 1980s the lack of a federal response and the failure to provide access to treatment resulted in a response determined by public health and palliative care (Kinsman, 1992a; 1996; Sears, 1992, 1995). As I mentioned in chapter One, efforts during these years consisted of sporadic funding to community AIDS groups for education and support. These expressions of policy oriented to public health and palliative care would have informed Jay's experience. The power of the AIDS diagnosis under these circumstances offered guidelines to persons with AIDS regarding choices about how their living or dying should be managed. The message at that time appeared to be "prepare for your death". A crucial factor in the social organization of AIDS death (discussed more fully in Chapter Six) is the power, actual or not, of medical practitioners; power such that a definition/diagnosis has the ability to confer a death sentence on those who may want to define themselves differently—as having a chronic illness and thus be "living" with rather than "dying" of AIDS.

Someone diagnosed with HIV disease must attempt to make sense of the treatment available, decisions need to be made about how to investigate what is necessary, and how to get it. In his journal, Jay experiences a fleeting sense that he has control of his life "at this moment" and that ultimately all the treatments, both traditional and alternative, will work toward health and healing. As part of a longer entry written the day he was released from hospital having been diagnosed with AIDS Jay says:

*Thanks to the doctors +  
nurses at OGH. They helped  
save me, too...*

*(Journal, March 16 1988)*

Later however, anxiety about the progress of the disease, while seemingly interspersed with moments of calm and well-being, is actually an illustration of the burden he felt trying to “do” health as he was dying.

*...My medications are failing me....  
Had a bone marrow test last week  
+ if it indicates an O.I. [opportunistic infection]  
including TB, then I can't do the a.penta-  
midine clinic, which I have been  
working toward for 6 months on  
the double blind study. SHIT.  
I cried in IDC[infectious disease clinic] today  
in front  
of the gentle Dr. F.  
So what do I do?  
I'm looking for another doctor  
to review my case...*

*(Journal, sometime in January, 1989)*

In the late 1980s the idea that AIDS could be treated as a chronic condition was just beginning to be discussed. While he has researched what he “should” be doing to keep his immune system functioning, his medications are not working and further tests have had to be endured. The medications such as AZT available in 1989 exacted a physical toll, since taking them in conjunction with other medications caused further ongoing discomfort. One of my brothers for example, recalled that Jay would occasionally stop taking his AZT because they made him feel so sick. Because of the numerous opportunistic infections, each had to be treated with a different form of medication. This was burdensome and disrupted one’s life. The timing of various medications was crucial and many of the men I knew used timers or “beepers” throughout the day and night to remind themselves to take a pill. How can one keep death at bay

through bouts of pneumonia, candida, possible TB, and other recurring infections?

During the time that Jay was diagnosed, Kinsman (1996a) argues that the “hegemony of AIDS as universally fatal” (p. 351) pointed to a major tension

between the knowledge that there were various treatments that could extend people’s lives and continuing State, professional and corporate practices standing in the way of this access. There was both a possibility of survival but also its denial (p. 351).

Thus, AIDS forced a person into becoming an expert in personal medical treatments. On numerous occasions for example, my brother like all those with AIDS, was required to make his way to hospital again for another test, or appointment or admission. If he had an infection which he had been trying desperately to keep at bay, he would not be able to be part of a clinical trial for a new drug, despite having been part of the double blind study for six months. The clinical trials and treatment process held out hope for prolonging life—the pentamidine study that Jay mentions in his journal in 1988 was to help those susceptible to pneumocystis pneumonia. For those with HIV/AIDS at the time, a great deal of effort and work went into keeping “fit” for clinical trials, and in the early days of this study the “subjects” did not know whether or not they were receiving pentamidine. Either way, it meant trips to the hospital, time spent taking the drug or placebo, feeling hope that perhaps they were feeling better because of it, or maybe imagining it because perhaps it was the placebo, hoping to be chosen to continue on the real thing if other infections did not occur. Jay is desperate that he may not be “fit” for this trial, despite his efforts to keep himself well for it. A person must be able to travel to the hospital, be available at particular times, and avoid certain other infections to maintain eligibility as a

clinical trial subject. I remember being at the hospital on one occasion during the time that Jay was part of this study, and experiencing a sense of great discomfort that people so ill with AIDS, and who could possibly benefit from the drug, may have been on the placebo. While millions of dollars were being spent on investigating AZT, the only access to the promising aerosol pentamidine was through the placebo-based trials.

Kinsman (1996a) argues that in reaction to this activists began to challenge both how trials were organized, as well as the ethical problems associated with “clinical endpoints”—that is, that death or an opportunistic infection would determine how the drug worked.

In Jay’s excerpt he writes that while in for another appointment at the AIDS clinic, he cries in front of one of the doctors in his frustration at being ill once again. There is tremendous fear and frustration in working so hard to live and in trying to figure out all the options, or in attempting to make the right decisions regarding treatment so as to coordinate one’s illness to the medical research, or to hospital routines. Like others with the disease, his journal indicates that he experienced a moment-by-moment roller coaster of “yes I can beat this disease,” or “no, it is overtaking me.” Behind the words “I must do more work in this area” and “what else can I do that I am not doing?” lies the process of anxiety that includes fear of perhaps not making the right choices about health, and the need and urgency to feel in control, have the power to fight, and to manage the disease process.

In a weekly reminder that Jay kept for various appointments, the week of February 1, 1989 lists thirteen different meetings with his doctors, a social worker,

alternative therapists, friends, homemakers, a community health nurse and meals on wheels. The month of February indicates that he had scheduled close to fifty appointments related to his health in one way or another—some involved phone calls to make the appointments, others indicated various practitioners or service providers were to come to his apartment. During the eighteen months that Jay had AIDS his journal refers to the medications and treatments he used such as sepra, AZT, pentamidine, dextran sulphate, citrotien, xylacane, benadryl, dapsome, trimethoprim, nizorac, ketokonizal, nystatin powder, halcyon. Jay was prescribed halcyon to help him sleep, but it appeared to cause considerable problems. After Jay killed himself, one of my brothers believed that “those pills played a big role.” Jay had described hallucinations but my brother said he knew so little about halcyon then, he thought they were part of having AIDS.

When he was unable to eat because of thrush in his throat he tried liquid food such as Ensure. He underwent various procedures and treatments such as several bronchoscopies, module T scan, lumbar punctures, heart scan, calcium scan, blood transfusions and had been on heart monitors and oxygen machines. Throughout the journal and in other notes Jay talks about various alternatives to AZT and pentamidine. He made use of, and arranged for others with HIV/AIDS to have access to: reiki, massage, crystals, visualization, nutritional advice, acupressure, counselling, prayer, faith healers, vitamins, diet, exercise. In Chapter Six I will discuss in detail yet another so-called alternative approach to taking care of himself that Jay mentions repeatedly in his journal. I want to reiterate here that Jay’s account indicates his struggle with medical power and authority conferred through a terminal diagnosis while he asserts his own

individual power to work toward his own definition of AIDS as a chronic condition.

While the notion of AIDS as a manageable condition was taken up by PWAs through treatment information and access to alternatives, advocacy, lobbying and so on against the hegemony of the medical establishment labelling their lives terminal, the idea of AIDS as a chronic condition was later taken up by professionals and academics as well. However, despite well-meaning intentions in the professional iteration of manageability of the disease, the responsibility for their own condition was placed on those patients with HIV disease at a time when there were no treatments to keep it manageable (G. Smith, 1990; Kinsman, 1992a, 1997; Sears, 1992; Adam and Sears, 1996). For instance, in 1990 almost one year after Jay's death, I attended a federal government conference with my mother who had been invited to speak of her experiences of Jay's illness and death. The conference, called Caring Together was, from my perspective, a forum to offer support to caregivers in helping those with HIV disease die better. In a way, the conference was a supportive environment for those working with HIV clients or family members, as well as those present who were HIV positive or living with full-blown AIDS. But I see it now as an example of the effort and money focussed on end of life support, rather than on treatment efforts, as well as an illustration of the power to define how HIV disease is to be approached.

There was work to be done while one waited for death. As I moved back and forth through Jay's journal I also recalled the talks we had about how he was managing money, appointments, and his fears and worries. His daily work of living with an AIDS diagnosis consisted of a myriad of daily and hourly choices to be negotiated regarding the

physical and emotional work of keeping well and deciding whether or not to continue. Jay's experience as a gay man with AIDS was fraught with contradictions. As "terminal illness", living with AIDS appears to have made it difficult to make choices/plans on how to work to live in this context--living in the context of dying. In their study of persons with AIDS and the relations of hooking up to social services Mykhalovskiy and Smith (1994) show how many individuals had to reorient their lives to government income support programs once they became ill. Jay had been working on a contract basis sporadically for several years, had little savings, was ineligible for unemployment insurance and had no pension or long-term disability benefits. Consequently, he too "hooked up" to social services. As an educated middle-class man having previously advocated for others, he did know how to access the welfare system. Nonetheless, the amount he received (as written in his journal with other expenses and income) was insufficient to keep an apartment, buy food, and purchase vitamins or any other non-medical health-related items. In May 1988 for example, he wrote:

*\$400 over budget per month  
-maybe get food from AIDS Vanc.  
-Vitamins....*

*July (From savings)*

*At \$300 expenses over  
welfare, I can live for  
6 months: July-Dec ...*

I was familiar with the provincial system Jay and other persons with AIDS were attempting to access. In an interview I conducted with a government worker who had helped create a protocol in the late 1980s, I discovered that early on in the epidemic, line

workers in government agencies did not know how to assess those with AIDS and their needs. At the same time, and not surprisingly, those with AIDS were unsure of how to describe themselves to government workers, and how the illness was affecting them. This official told me that it was not until she had talked with several young gay men and asked them to describe for her exactly what they did during the day and what they used, that she realized why her workers were not granting these individuals a crisis grant under the then (1988) legislation. She described a situation in which a client tried to tell her that while he sometimes needed extra food, a cheque was easier for him to manage than a food voucher, particularly if he had to get some items from a health food store or a pharmacy. Workers would more often than not turn down a request for extra bed linens or pyjamas until they learned about the effects of night sweats and the amount of laundry that needed to be done.

While Jay had to make a case regarding crisis grants for vitamins and other supplements, some of these were able to be obtained through the local persons with AIDS society, family and friends. In Jay's case, extra food or other so-called non-essentials were often purchased by family and friends who contributed ongoing amounts. Any extra money had either to be acknowledged or hidden from social services. Jay faced fears about having to give up his apartment because he could not pay the rent. While he had been in tight spots financially over the years, he knew he would be able to find work, travel, create projects and work again. Now, however, being sick drastically shifted that dynamic and he was anxious about not being able to re-enter the work force, or even to take on some freelance work. Jay told me that one of his primary worries was that the

person he was renting from would discover he had AIDS. When his landlord did arrive unannounced Jay would tell him he had the flu or a cold. Deceit, or impression management (Ferguson, 1984) was a strategy, not just Jay, but others learned to use to access services. In order to obtain additional assistance such as home care or homemakers through social services, men told me they often cried in order to elicit both sympathy, and the assessment of “needy” that the professional first had to make.

The fear of dying, for instance the pain involved, and the fear of death itself (the unknown) presents the question of whether death would be better than ongoing pain and fear. Full-blown AIDS still carries with it a sense of fatality despite the fact that in the 1990s those diagnosed often live longer. The “fact” of dying as an outcome of the diagnosis of AIDS, while perhaps not as imminent today because of combination therapies, still remains. At the same time the PWA label carries the other meaning--the death sentence. As Alonzo and Reynolds (1995) observe,

The ‘normal’ identity of the individual is essentially worn down and the stigmatic AIDS identity becomes fixed by multiple opportunistic infections, repeated hospitalizations, physical changes, weakness, dependence on others, increased contact with medical practitioners, and sometimes either increased contact with estranged family and friends or essential rejection and increased social isolation (p. 311).

The work of becoming a PWA is not a passive assumption of a medical diagnosis and new identity. It can be, and was in Jay’s life, a public and active struggle to work within the political frame of the term, while attempting to keep death at bay by labelling AIDS a “chronic” rather than “terminal” illness--albeit in a climate in which there was nothing available to allow those with AIDS to manage their illness. I have talked about the notion

of “unruly” in relation to the way I saw Jay living with AIDS, and in the way the journal is written. His choices were based on his daily/nightly experiences of living with full-blown AIDS; yet he struggled against how AIDS was being managed or “ruled” and seemingly ignored his own experience during that time. Throughout this section I have shown that Jay’s diagnosis of a fatal disease officially provided by a medical doctor led to what he termed his rebirth into a person with AIDS (PWA), and into a “patient”. This rebirth brings into relief the relations of power and authority that reorganize his life and his self-identity. Despite his “terminal” illness, Jay attempted to maintain his definition of AIDS as chronic, and to see himself in solidarity as a Person with AIDS who had some control over the disease.

## **Family, friends and professional “care”**

*Mom is still here, maybe till the  
end of March. She is my rock that  
is sustaining me.*

*(Journal, March Monday 1988)*

*...the social worker has  
agreed to see me for some counselling....  
Again, I am overwhelmed by  
my friends' and family's response.  
I see from this that we have all  
pulled closer, + even when they  
cause me pain in some way,  
I know they do it out of love...*

*(Journal, January 1989)*

*I have breath, life, a loving mother  
 + family helping me.  
 I choose to change my mind,  
 + live + accept my life.  
 (Last entry, March 1989)*

In the foregoing sections I have shown Jay struggled with his fear of death and the loathing of his sexuality against the power of stigma, and also how he struggled against the power of medicine to confer a death sentence upon him. There was a further struggle articulated in his account that I saw as the relations of power and authority of caring or caregiving. I was witness to my brother's "rebirth" into a "PWA", and was determined, as were his friends and other family members, to make sure that he would not succumb to another near-death episode. In a more subtle way we too were perhaps transformed or reborn, as we simultaneously fought against his diagnosis while not quite believing it to be the chronic, rather than fatal condition, that Jay wanted it to be. It seemed to us that Jay had made a miraculous recovery--he had nearly died, but he was, although extremely weak, feeling hope that he would survive for a long time. Our fear subsided for a time, yet I found myself alert for signs of recurring pneumonia or other infections. Because HIV disease, particularly AIDS, requires consistent medical attention, the "victim/patient" designation is one that is taken on and put off regularly as persons with AIDS are continually entered into the medical administration of the syndrome. The so-called technical/medical assistance required to overturn a diagnosis of death was outside the realm of those of us who could work with Jay to get well. Throughout his hospital ordeal and his medicalization from an "anonymous" gay man to a person with HIV disease, Jay wrote that he felt supported by family and friends who stayed with him: "I

almost died. But the love of my family + friends saved me”. As he left the hospital several weeks after his diagnosis, in a wheelchair laden with flowers and medications accompanied by his mother and a woman friend, he felt hopeful and relieved, that somehow the death sentence would or could be retracted. He had done an enormous amount of physical and emotional work to continue living, and he would balance the death sentence against the new hope he was feeling through the rebirth. Nonetheless, he began to act in a manner that suggests a different, less hopeful understanding as he left his job, relinquished his apartment and began to make plans for his life as a PWA “entitled to all that is available to this select but growing company of people”. “All that is available” to Jay in 1988 was very little in the way of treatment or support that would allow him to see himself in any other way but terminally ill.

Jay’s account is filled with names of friends, family, relatives, AIDS care workers, doctors and social workers who offered support, or were approached for support following his diagnosis. As “Jay the PWA” enduring the ups and downs of various opportunistic infections, the effects of medications, and day-to-day worries, he was often in a position in which he had no choice about the help he needed in order to survive. Some of it was in the form of intrusive medical procedures such as lumbar punctures or bronchoscopies, transfusions, being a participant in a clinical trial hoping that he was receiving aerosol pentamidine rather than the placebo. Help also came by way of ongoing friendships through visits, calls, letters, meals, or just being touched. In the excerpts above another aspect of help or caring is revealed—that of the ambivalent nature of support or being taken care of as an adult gay man in the late 1980s. The excerpts point to

a rupture between his appreciation of the support he was receiving and the reality of the inability of his family and friends who did not have AIDS, to perhaps understand what he was going through.

Gay men with AIDS who have been on their own since they were teens, face the prospect of having to rely on the families they may have good relationships with when each can come and go, or when each lives in different cities. In many situations lovers or family members work and cannot provide daily care. Much of the informal AIDS care has been taken up by volunteers, friends, and relatives if there is no lover. When a gay man is single, the day-to-day support is often provided by mothers according to professionals with whom I spoke. For the ten months after Jay was diagnosed he managed without live-in help. Friends and family members provided financial, physical and emotional support, and Jay sought out physicians, alternative therapies, counselling and other professional support as well. He also provided support to others by organizing events through the PWA society and speaking out about HIV/AIDS. Yet, for a man whose schedule was determined as much as possible by his own needs, the involvement of so many others in his day to day life was itself a tension to be coped with. This was particularly so when he was discharged from hospital on several occasions and wanted and needed someone in the apartment, but on the other hand felt uncomfortable having anyone in the small space that was his. His need for assistance during certain parts of the day meant that he gave up privacy. Not only was any companion he had necessarily attuned to his needs, but he had also to be aware of the other--perhaps not listen to a piece of music he wanted, make a phone call, have someone over. Family members who stayed with him commented that

he often went off to his room for hours at a time, for privacy. I was told by other gay men (personal communication; 1989, 1992; 1995; 1997) that they are adamant that no strangers will take care of them, and that they leave cleaning or other errands until a day when they are feeling well. In these situations part of the “work” is learning how to be clients, and how to negotiate the system in different ways on their own, or through advocacy groups (Mykhalovskiy and Smith, 1994). It is also learning how to live with being “helped”.

In the entries above, Jay acknowledges the support he felt from our mother during his illness, and yet both of them also felt the strain involved. She was the constant presence during his near-death hospitalization, and almost a year later arrived to take care of him after he was discharged from hospital in early March 1989. While there was a homemaker who cleaned the bathroom and kitchen and did the laundry, and friends and family who visited and took on various tasks, our mother shopped, cooked, did banking, picked up his medications, accompanied him to doctors’ and hospital appointments if he was unable to go by himself, and generally did all the routine daily tasks. She said a couple of things that indicated the ambivalence of support:

I didn’t want Jay to see me upset. I didn’t want him to see me cry...but when he went to bed at night I would just lie there thinking, ‘what must it be like for him?’ What thought would he be going through, you know. His whole life going down the tubes...and it would break my heart and I felt so helpless. And so many times I wanted to go in and talk with him but his door was shut...It’s hard to know what to do...

I think the fact that I was there may have bothered him...to think his mother had to be there looking after him. That was the last straw.

Less than a year after Jay's death she was asked to speak about her experiences as a mother coping with her son's illness and suicide, at a conference called Caring Together/Entraide: A National Conference for the AIDS Caregiver sponsored by Health and Welfare Canada and the Federal Centre for AIDS. She told the participants:

He was in hospital for several weeks and I visited him daily—sharing his fears, suffering along with him and giving him all the support I could. I think this was my initiation into the role of caregiver although at the time I didn't know the meaning of the word—I was just being a mother.

My mother's use of the term "caregiver" indicates that she had become aware of a form of "taking care" that had professionalized something she had taken for granted—"mothering". Yet it was her mother role that she suggests may have distanced her from Jay; perhaps both felt that he was becoming an infantilised adult son. The discourse of caring is pivotal to the professions and AIDS service organizations involved with persons living with HIV/AIDS. A person with AIDS is taken care of by medical professionals, social workers, home support workers, nurses, those from AIDS groups, "buddies", friends, family, and so forth. Often those involved in health or social service work are said to be members of a "caring profession". However, as Hugman (1991) suggests, the "idea of caring carries a multidimensional and even ambiguous set of meanings" (p. 9). Some of these meanings attempt to distinguish between caring about and caring for.

Distinguishing between caring as commitment and caring as a task...begins to identify 'caring' as an issue in the claim to professionalism of particular occupations. While occupations such as medicine, law or architecture (all predominantly masculine historically) may be said to 'care about', it is occupations such as nursing, the remedial therapies and social work (all predominantly feminine historically) which 'care for' to differing degrees as well as care 'about', often acting on the pronouncements of the 'masculine' professions (p. 11).

Hugman suggests that family carers (whom he does not indicate are primarily women) may begin to use the professional language--perhaps as my mother did in calling herself a caregiver--yet resent the professionals' use of the term "caring". He argues that:

....caring becomes an aspect of power in which other people (professionals, the cared-for, wider society, the state) define the lives of those who are doing the caring work informally. This occurs through the design and implementation of policies and practices which are overtly designed to care, expressing concern and at the same time taking charge through the control of social structures within which daily life takes place. Caring is 'taking over', but it may be the carer who is taken over as much as the person who is cared for (p. 12).

I attended the conference at which my mother spoke. She was among a handful of non-professional "care-givers". While professionals were discussing burnout, the workshops I attended in which participants included family members were struggling with concerns such as the ignorance, anxiety and confusion they felt from interactions with some health professionals, financial burdens, putting one's life on hold to care for someone else, trying to be a counsellor, a nurse and a dietary expert, and coping with one's own emotional and physical exhaustion, as well as the ups and downs of the person with AIDS. An issue that I also recognized was that of the person with AIDS resenting the caregiver as his dependence became greater. Being taken care of versus maintaining a sense of privacy illustrates the "costs" of personal support. My mother described for example, knowing that Jay wanted and needed her help, while at the same time not wanting her to be there. Other family members recounted that instead of visits in which Jay had formerly recounted his numerous projects or adventures he retreated into long silences. On the other hand, Jay's anxiety about the progress of the disease is interspersed with moments of feeling able to cope and knowing that the physical and emotional

support from doctors, friends, family and other persons with HIV disease is there--“Again I am overwhelmed by my family and friends’ response. I see from this that we have all pulled closer.” He seemed to struggle with loving us despite the fact that we were usurping his autonomy.

In his note above, about seeing the social worker for some counselling for example, Jay suggests that not all his needs could be met by friends and family. That this was included in the same entry as his dilemma regarding whether or not he should move toward his death (to be examined in the next chapter), led me to hear it as his need to use the social worker as a sounding board to talk through his worries, and perhaps his options. Seeing Jay’s struggle to live well on his own terms, and knowing that my mother had met with the social worker on several occasions, led me to speak with professional social workers who worked on the so-called front-lines with people living and dying with HIV disease. I assumed that they would have been counselling people with concerns like Jay’s. His weekly reminder indicates that he had an appointment with her the day after this journal entry was written. At first I was curious why he would have chosen to speak with a social worker rather than with someone from the persons with AIDS group, or his friends and family, but within the context of the entire entry, it appears that Jay was trying to process his dilemma on many levels and by gathering several points of view, both professional and informal. It may indicate his attempt to maintain his independence from his family over his final life decisions.

As a social worker I was interested in my profession’s role with HIV/AIDS and in how the relation between “patients” and social workers was organized. Again, I am not

claiming that these relations were always true for Jay himself, but they were the social relations of living and dying with AIDS at that time. According to one social worker I spoke with, in 1987 social workers were asked to be part of the AIDS care team at St. Paul's Hospital, as several physicians who had been doing both medical care and counselling for people with HIV/AIDS could not continue with both roles. The social workers provided what she described as "continuity of care" within the hospital for those with AIDS, and were responsible to the head of the social work department. Since most persons with AIDS had a primary physician and often several specialists, social workers were the common link among all the professionals. They covered all the wards including emergency, intensive care unit, palliative care, the infectious diseases clinic, medical short-stay. At the time that Jay was diagnosed with AIDS everyone with HIV/AIDS was referred to the AIDS care social worker. They accepted referrals from physicians in the community, as well as self referrals. Jay was seen by a social worker on each of his admissions to the hospital and had access to counselling as an outpatient. My contact while Jay was sick was primarily with two social workers whose caseload consisted of patients, partners, lovers, and family members. One woman, now a social work clinical specialist, told me that most of the work tended to be crisis intervention, dealing with peoples' reactions to testing positive for HIV, patients in crisis, family counselling, and keeping statistics.

The social workers I have spoken with formally and informally seem to be ambivalent regarding their professional affiliation. They are proud and competent professionals who, because they work so closely with those affected by HIV/AIDS have

gained tremendous expertise regarding its medical and social complexity. Yet, they are critical of what they see as a conservatism within their profession when it comes to HIV/AIDS, and the issues of sexuality still attached to it. My sense of AIDS social workers is that practice what I would call compassionate activism--as opposed to what the profession calls "client self-determination". This phrase--and practice still taught in schools of social work and part of the social work Code of Ethics--harkens back to the modernist sense of subjectivity in which every individual, regardless of circumstance, is the author of his or her own fate. When Jay made the decision to see a social worker for counselling he was seeing someone who could guide him in his labyrinthine emotional and physical upheaval, not placate or minimize his experiences of illness or pain. While the profession works within the relations of power and authority, I saw (and continue to see) HIV/AIDS social workers creating space within the terror and fear of a diagnosis and its aftermath, in order to assist people to make choices on how to live and how to die. In Chapter Six I will analyse these relations more fully in the discussion of what constitutes a proper death.

## **Conclusion**

In some ways attempting to separate the work of living and the work of dying is artificial, and I have struggled in this analysis not to remake Jay's life into discrete segments that appear to illustrate a logical progression from a diagnosis of AIDS to the taking of his own life. In this chapter I have shown instances of the relations of power and authority

that organize Jay's (a person with AIDS) work of living with the syndrome. I discussed the "loathing" of sexuality organized by the power of stigma and homophobia, as well as the relations of dying/contagion against which persons with AIDS including Jay have made political counter-attacks. I also illustrated how his "re-birth" to a new identity was organized by the power and authority of medical professionals who determine life/death and patient/victim, and Jay's political and intellectual response. The relations of power in caregiving were also seen as contradictory--despite the loving, support and a special effort to do the work differently provided by families and professionals, a person with AIDS feels, or is made, dependent.

What was so immediate on first reading his journal was the tremendous amount of work he expended in figuring out how best to live as a gay man with AIDS, as well as the continued negotiation regarding both how to live well, and how to die. What I have begun to explicate, and will continue in Chapter Six, is how he tried to make the right decisions about being "healthy". I saw in the writing he did about his "work life" with AIDS, the relations of power and authority that took up his life revealing a story about change and the resultant choices to be negotiated as a result of the change. The knowledge that Jay gleaned from medical and other sources about how to live with AIDS was contradictory. As a PWA, "living" with the syndrome is what Jay learned about, expertly, as an insider. This knowledge takes him to a place of knowing he must die.

## CHAPTER SIX

### Unruly Death: “Is suicide a legitimate option...?”

#### Introduction

*But my dilemma:*

*a) Love myself, heal myself--this is one approach. I'm not sure what love is--how do you love yourself. This I must work on. Louise Hay et al.*

*b) Stephen Levine, and Emmanuel's Book seem to encourage you to accept death-- "the removal of the tight shoe". If I am truly dying (which contradicts the fact that if I choose to change I need not die), --should I move towards it + embrace it?  
 --when will it happen?  
 --will I be scared; I have lots of fear about this now, esp[ecially] with such low hemoglobin.  
 --will it happen quickly?  
 --should I will it quickly?  
 --is suicide a legitimate option if things get too out of hand (I don't want to suicide--I want to go naturally)*

*(Journal Entry, Late January, 1989)*

Jay's words in the journal excerpt above reference the challenge he was making to the rules for living and dying that are taken for granted and enforced in variety of ways

particularly in Anglo-Canadian culture. Taking his dilemma as the problematic, or puzzle, it is my argument that coroners, health and social service professionals, families, and the ill themselves “work” at maintaining a proper stance and behaviour vis-a-vis dying. Jay’s dilemma, and that of others who may be “truly dying” and wondering how death will happen, is intertwined with and shaped by the authoritative relations of dying that exist in discourse—in this case a discourse shaped by psychiatry, psychology, sociology and suicidology as manifestations of expert rather than experiential knowledge (Prior, 1989; Griffith, 1995; Smith, 1990). Whether he was conscious of it or not, Jay’s journal reflects I argue, the social science discourse that suggests there is a correct and proper way to die - a discourse that organizes an individual’s experience—in this case the experience of trying to figure out how to die the good or natural death, and then the act of killing oneself. My task was to seek out this discursive organization by exploring questions such as: How is death legitimated and by whom? Who has the authority to say when death is illegitimate? What are the rules that Jay must conform to in order to die a legitimate death? I wanted to explore what was behind that tension or dilemma which illustrates that “legitimacy/illegitimacy” is central to his thinking. Even before his official diagnosis of AIDS, Jay, perhaps like so many gay men of his generation, was worried about dying. For example, in a journal entry written in December 1987, two months prior to being diagnosed with AIDS he wrote:

*Don't feel it's worthwhile to make plans, as I fear death by AIDS.*

I began to analyse these data by remembering as Campbell (1998) notes, “that a specific social organization coordinates” what I saw and heard as well as what Jay has written in trying to figure out his “options.” In the journal entry at the outset of this chapter Jay writes about various activities, both physical and mental on which he is drawing—alternative or complementary therapies and techniques, his fears and questions about death, ideas about the legitimacy of suicide, and finally, the notion of “going naturally”. These concerns were evident before his diagnosis, but are heightened post-diagnosis. Family conversations also illustrate how others experienced his dilemma.

### **“But my dilemma...”**

Asking “is suicide a legitimate option” is one side of Jay’s dilemma. In his words there seems to be a tension about not performing the task of dying in the right way. As if arguing with himself he writes, “I don’t want to suicide—I want to go naturally”. There is a further tension between being able to choose how and when one wants to die, and the means through which the dying process and the naming of a death is ultimately controlled. The entry however, hints at his struggle to come to terms with fear of death, his hope associated with various therapies, and what kind of death would entail a “legitimate option”. As the analysis in Chapter Five indicated, Jay became a “PWA” and thus subject to the interpretation of his illness as terminal by medical professionals. Like most young persons living with AIDS, he struggles to make sense of his dying and to let into his consciousness the enormity of what his doctors have told him. These relations are

evident in several instances in his journal as he tries to sort through if he truly has AIDS, which in the late 1980s is a diagnosis of death; or, whether it is merely a chronic condition which can be managed through his choice of treatments, and willing himself not to die. If he agrees that he is dying what route should he take--acceptance or taking control? In other words, he has, or "should" have, the power and ability to transform himself in the way he needs. Jay sees himself able to choose life or to will death. He writes for example "...if I choose to change I need not die..". As I will illustrate later in the chapter, what is not immediately evident, but what he wrote and what both of us know is that suicide is not considered a "legitimate option" even if "things get out of hand."

The journal excerpt at the chapter beginning was written almost three months before Jay killed himself, and it seems that he is very torn about what direction to go regarding living or dying. The entry shows a young man attempting to deal with the progress of his disease, how death might occur, and how he might deal with it. Some days he does not believe he is dying--that AIDS can somehow be overturned through his choosing it not to be so. In the late 1980s the idea that AIDS could be treated as a chronic condition was firmly espoused by those familiar with non-traditional healing practices, but was just beginning to be discussed by the medical establishment. While Jay feels support and love from family and friends as he contends with ongoing infections and intrusive medical procedures, he tries to work through what he calls my "dilemma". His words reflect frustration that he cannot be given concrete answers about his health, or lack of it. As part of the same journal excerpt he wrote, "What else can I do that I am not

doing?” From my visits and telephone calls I was aware that he had been attempting as much as possible to eat well, querying his doctors about treatments, and long-term prognoses. One brother recalled that he and Jay did not talk about death, instead, they talked about his survival, and at one point Jay asked him if he would mind buying him a book about heroes, that he had seen a reference to. But he also remembered that it “seemed like the escape hatch was starting to close...life was closing down” for Jay. Another brother felt that after Jay’s trip to Asia to seek support for his video law project he came home much sicker. He couldn’t eat certain things, wasn’t taking his medication as regularly and Jay told him that he was “depressed, guilty and pissed off—he said, ‘did I bring this [AIDS] on myself?’” When I visited Jay in hospital toward the end of February 1989, we talked about him having made a conscious decision to live after his near death experience the year before. He told me that he wondered now if that had been the right thing. It was also after this hospitalization that our mother came out to stay with Jay while he recuperated. More than once he said to her, “I wish I could just sleep away. I am out of control of my life. I’m just a burden.”

Jay also continued to confront the perception, even by those familiar with terminal illness, that AIDS was somehow different and alien. For example, he was trying to sign up for a cancer workshop through the Hope Society but was at first deemed ineligible until his doctor wrote the organization explaining that kaposi sarcoma was a form of cancer. He had been given concrete information from his doctors about low hemoglobin accompanied by changes in weight, throat infections, ongoing lung infections, and the beginning of kaposi’s sarcoma, that prompt him to ask himself, “should I move towards

death + embrace it?”

To be feeling one's body undergoing changes due to illness is terrifying—he wonders if he will be scared as his death comes closer, and is fearful now because of his blood count. Attempting to negotiate what one should be like when confronting death seems to illustrate a general lack of knowledge about it. I propose that Jay's words implied there is a right way to die, that somehow being “scared” is internalized as the wrong choice. While some who were seropositive were found to be living long, most persons diagnosed with full blown AIDS in the late 1980s were living less than two years. In addition, people generally assumed as one of my brother's remembers his own reaction, that AIDS immediately conjured up death. In feeling that he is moving toward death—or the end of his life, Jay's query about whether he will be scared is indicative of a pervasive fear that he was experiencing, and that is reflected in his family, society, and the medical profession as well.

His fear of the dying process is made more vivid when he has been told his hemoglobin is low... “ Will I be scared; I have lots of fear about this now...” Fear of dying, the pain involved, and the fear of death itself presents the question of whether death would be a better option. How can one keep death at bay through bouts of pneumonia, candida, possible TB, and other recurring infections? While Jay was in a better position than many with HIV as far as knowing that support was available through local persons with AIDS organizations, or hospital social workers (“...the social worker has agreed to see me for some counselling.” ), and had friends and family who helped with some aspects of care, he nonetheless kept up a frantic pace of attempting to make

sure he was doing all the right things.

### **“Going Naturally”: a good death?**

Jay’s fear that he is dying, fear of the unknown, trying to determine how his dying will proceed, when it will happen and what it might look like contrast with messages about the proper course of action to be followed in dying that are available throughout society. Accordingly, what is to be known about how to move toward death or how to embrace it? What are the rules, the etiquette of dying, and how does one come to learn them? His fears are warranted in a time in medical science when a “vision of death as itself pathological” and as “an abnormal transition of being” persists (Prior, 1989, p. 128) and is ultimately something to be treated. As mentioned in the previous chapter, in following the rules about being an AIDS “patient”, it seems as though a person like Jay must thus accept a diagnosis of death; and following that, must learn how to die legitimately and naturally. This was influenced too, by the public health response insisting that AIDS was terminal and thus promoting the emphasis on palliative care.

The rules about “going naturally” are all around us and are understood and enforced ideologically, that is, through everyday ways of “doing” death. People have learned that despite the fact that they do not each live out their lives to die peacefully surrounded by loved ones, this is nonetheless maintained as the ideal, and as normal. Indeed, many are surrounded by machines rather than loved ones, and death occurs to children and adults of all ages, through random accidents, violence, disease, natural

disasters, and so on. The so-called traditional good death is atypical except in very few circumstances, generally when the very old die and it can be said that they had a “good long life.” I realized how I had internalized notions of good death. I remember for example feeling a surge of anger at Jay following the death of my friend Stephen three months after Jay killed himself. Stephen died at home with his lover and two of us with him. This to me, was “going naturally” and I realized that it was what I had wanted, and perhaps needed, from Jay.

Jay’s talk of suicide as a legitimate option versus “going naturally” into a good death is not a concept he pulled out of the air. Kellehear (1990) points out that the concept of “good death” has appeared in various iterations through time. As “euthanatos” it broadly means good death or dying well, not however, as in our modern notion of euthanasia. Active euthanasia has meant the voluntary ending of one’s life, while its passive form has meant “simply to die with dignity at a moment when life is devoid of it” (Mannes, 1976 as quoted in Kellehear, 1990). Regardless of our experiences with death—loss of family or friends—there does seem to be an etiquette for dying a proper and “good death” (Charmaz, 1980; Prior, 1989; Kellehear, 1990) that Kellehear suggests we are all aware of, and which “reduces the social impact of the death by controlling and channelling behaviour outwardly towards others” (p. 58). A proper death is one that is transformed into a set of manageable problems coordinated for example by a palliative care team in which dying is accepted, loose ends are tied up and the family is quiescent. The palliative care discourse presumes an acceptance of the terminal illness and the expertise of a professional team to manage it (Miller, 1997). This suggests that

there is also the idea of “good” death meaning “acceptable”—a kind of disciplined dying. In his examination of the last year in the lives of cancer patients for example, Kellehear (1990) adopted the idea of good death as the “social life of the dying person, who is aware that he or she is dying...It refers to social interactions by a person or persons with the central institutions of the wider society” (p. 33). Ironically however, having noted that it is important to understand the social experience of dying outside the psychiatric and social problem perspectives, he suggests five features of “the Good Death” that were evidenced in the deaths that he followed. These features are noteworthy, because even in their innocuous presentation as features that ultimately reveal themselves in idiosyncratic ways, they still appear to formulate propriety: an awareness of dying; social adjustments and personal preparations; public preparation for death; perhaps leaving work if one was employed outside the home; and finally, saying goodbye. It appears that even in attempting to illustrate that people should not be bound to particular ways of arranging their deaths, readers are left with new procedures. “Good” is an interesting adjective in relation to death and has been used for years in various forms. The Victorians for example, called it *ars moriendi*, or the art of dying well.

Vestiges of the medieval and later European ideas and social practices regarding “good death” can be seen in contemporary views about the proper kind of death. As a child raised in a catholic home and attending catholic schools, I grew up listening to stories of brave and courageous saints. In these terrifying tales women, children and men had their tongues cut out, were thrown to the lions, boiled in oil, endured disease, rape and other unspeakable tortures. I knew I could never survive something like that, and my

worst fear was, not being abducted by strangers or aliens like children today, but contracting leprosy or being burned at the stake like the saints. My mother assured me that God gave them the grace or strength to endure these atrocities and I took that to mean that they did not feel any pain. Theirs was a good death; and in my child's mind, this type of death was natural.

Knowledge about how dying should be accomplished emerges and is coordinated through various sources in western society—professional, medical, religious, new age knowledge, television, newspapers, the Internet, film, literature and so on. These ideas are held, and carried in professional practice by experts, and exist as well in what we all know about death as a matter of what might be called common sense. Perhaps because of the commonly shared assumptions regarding proper ways of dying, debates regarding the right to die, or the right to live, various moments of choice in the patterns of beginnings and endings of life seem to construct the fact of death, or illegitimate ways of dying as a social problem—one that can be regulated or managed. By this I do not mean to imply that the “expert” discourses provide “norms” that operate independently of those who are dying. The resistance to the regulatory stance is evidenced for example in the lives of those who have been attempting to take back control of their own dying (Ogden, 1994a, 1996) and are challenging both through the legal system and often in conjunction with activist medical professionals, how they want to die. Ogden (1994a) a social worker and criminologist presented groundbreaking and controversial research on euthanasia, assisted suicide and AIDS for example that has opened up this debate generally and within the profession of social work. He is correct I believe, in assuming that the

experience of those assisting persons with AIDS to die, has pushed both the legal and medical professionals to confront the issues of death and dying.

Jay states, "I don't want to suicide--I want to go naturally." I was curious about what it might mean to "go naturally" when he had a stigmatizing and so-called terminal illness. In my interviews with some family members, in excerpts from my own journal, and in early discussions with Jay's doctors, there seemed to be an assumption that he would die, that it would be a painful death, but that it would happen as the disease progressed. In a stark description of the progression of AIDS, Dean (1995) observes for example that, "People with AIDS and their caregivers often engage in intensive fights for life. The natural course of the illness is characterized by alterations between relatively normal daily functioning and serious disability, until death occurs either from the treatment, suicide or disease processes" (p. 32). The assumption of what kind of death to expect from HIV disease is evident even in this quote as late as 1995. In contrast to this desperation however, one brother told me that he never discussed death with Jay, and somehow assumed that "Jay would beat it--we talked about his survival".

Going "naturally" and "good death" appear synonymous to me. In wanting to "go naturally" Jay's words are for example, linked to contemporary practices that can be traced through historical references to the good death found in the middle ages and throughout western culture, where much about middle-class death and dying has been recovered from diaries, letters, civic documents, popular writings, novels and literature of the *ars moriendi*, or the "craft of dying" (McCray Brier, 1989). In the seventeenth century for example, dying was social and the death-bed, contrary to our usual hospital practice of

allowing one or two family members in the room at one time, was the hub of activity. Our hospital procedures contribute to the notion that death should be private, and as Thomas (1991) suggests, “[T]here is something faintly indecent, wrong, about dying in full view of the public...” (p. 57). According to McCray Beier, people were kept reminded of their own mortality as they attended births, illnesses and deaths in an era when visiting the sick “was a religious and social duty” (p. 44). For Victorians, the ritual of dying and death included many women and other neighbours or relatives who shared responsibility for laying out the body. In her view, contrary to contemporary usage, a natural death differed from a “good death”. A natural death involved infants and the aged, and “[I]t was also natural for people to die of wounds, epidemic diseases, childbirth, and certain chronic disorders...Even death from minor ailments could be regarded as natural if the symptoms were unusually severe” (p. 45). The “good death” on the other hand referred to the duties that were expected both of the dying and those around the death-bed. In her analysis of death in the Victorian family, Jalland (1996), through the use of memoir, diaries, and various religious tracts of the time also observes that features of a “good death” included a specific etiquette:

Death ideally should take place at home, with the dying person making explicit farewells to each family member. There should be time, and physical and mental capacity, for the completion of temporal and spiritual business, whether the latter signified final Communion or informal family devotions. The dying person should be conscious and lucid to the end, resigned to God’s will, able to beg forgiveness for past sins and to prove his or her worthiness for salvation. Pain and suffering should be borne with fortitude, and even welcomes as a final test of fitness for heaven and willingness to pay for past sins (p. 27).

In detailed journals kept by the dying themselves or by their caregivers, Jalland found an

intense piety and resignation to death particularly if the ill person had been a devout Christian who believed in purification through suffering and death. Books written by clergymen on deathbed piety and etiquette influenced families coping with numerous child deaths and the death of young adults. These texts suggested that a painful death indicated punishment for a sinful life as well as a test of one's Christian faith. Jalland found that a good death "could display the power of true Christianity with its assurance of ultimate victory over death in the knowledge that the contrite Christian was 'gone to glory'" (p. 51). In examining documents from the later Victoria period, she found that the notion of a good death shifted from an emphasis on a person's spiritual state, to one detailing physical suffering. A good death became one in which the dying did not suffer physical pain, and it was a time in which the medical profession was gaining a certain ascendancy over the Church. With a shift from the more spiritual to secular approach, Jalland notes that Victorians and Edwardians became less familiar with death and wanted to avoid the earlier deathbed rituals of their parents and grandparents--an attitude which she suggests has carried into the twentieth century.

Much like the features outlined by Kellehear (1990) above, dying well presumed that one's earthly affairs were ordered, and this order was learned as one visited and cared for others who were sick and dying. Interestingly, while visiting included taking care of business, nursing care or housework, certain diseases precluded visits, and were clearly outside the "social"--those who were dying of plague or from syphilis. Neither of these would have been considered good or natural deaths. "Plague terrified not only with its killing power but with the alienation it produced" (McCray Beier, 1989, p. 56); while

syphilis was viewed with shame and horror because of its connotations. She notes as well that “Good death was pious and prepared. Bad death was unregenerate and, with the possible exception of suicide, unprepared” (p.61). Suicide negated the good death.

The response to these illnesses is not unlike the responses to HIV disease which is always associated despite its origin, with sexual promiscuity or other moral lapses such as drug addiction. As with inheriting ideas about the right way to die, Nelkin and Gilman (1991) have suggested that those with AIDS inherit the “unclean image of the patient with a sexually transmitted disease” (p. 43) They argue that the blame for being ill is not ascribed to a retrovirus but to a lifestyle—an individual is at fault so society has no responsibility. Nor perhaps is the response to suicide any different. The social conventions of the Victorian period may appear humorous or macabre; however, the legitimacy of a death in twentieth-century Canada is as rigorously controlled, albeit perhaps not as overtly. Indeed, the notion of preparing for one’s death and getting affairs in order is in stark contrast to the seeming unpreparedness and unruliness of an illegitimate death such as suicide. A senior federal policy advisor in the area of HIV/AIDS suggested in a conversation with me that until we can understand how spirituality may shift in the face of such a devastating illness, we will never be able to comprehend a decision such as suicide. That is, in his view, a young individual’s sense of self and his [sic] relationship to a god, or cosmos shifts radically following an AIDS diagnosis (1995, personal communication). Our social conventions are not, for all of us, prompted by specific religious injunctions; nonetheless, religious or at least spiritual moral codes appear to feature in their control.

For Jay and others who are seriously ill, and for their friends and family should they be around, often one way of attempting to seek advice or guidance regarding various choices (legitimate or otherwise), or what might be expected as one gets closer to death, is to talk with a professional, someone outside family or friends who is also working with others in similar situations. This gives prominence in directing a contemporary “good death” to professional social workers and nurses, whose work often locates them in hospitals, palliative care units or hospices. Generally when a person is admitted to hospital, services in addition to medical treatment are set in motion—social work services, or chaplaincy for example. This person may often be the first contact regarding what the ill person may expect. Often as in Jay’s case, counselling services may be available once the person with AIDS is discharged.

As a social work practitioner and educator who has witnessed the dying process and deaths of persons with HIV disease and cancer, I wanted to discover what the profession had to say about a good death and what it might consider a “legitimate option”. When I began my research, little was written or discussed by the profession specific to AIDS death, and little was available regarding AIDS suicide (Ogden, 1994a; Ogden and Young, 1997). Generally, I found a dissonance between what was being written and taught about dying and death, and the actual daily practice of social workers involved with persons with HIV/AIDS. One social worker who has worked extensively with persons with AIDS and their families told me,

How do you call it a perfect death when someone’s 22 years old?...Young people struggle with all they’ve got till the very end—some die angry. They’ve got a right

to die angry...We don't have to take control of someone's death...People literally rot with this disease and they have a right to say 'I've had enough.'

Her words suggest that those with HIV disease should be able to choose how they wish to die, and also perhaps choose their own form of a "good death." Nonetheless, working within a hospital setting can catch a social worker up in the institution's approach to death. The "we" to whom she is referring, could be those within the institution who have the implicit or explicit power to direct a particular kind of dying. It is difficult for example, for a hospital to pretend it is unaware of assisted suicide or to not have aggressive preventative measures put in place for patients deemed at risk for suicide. Also implied in the social worker's remarks is the suggestion that she has seen her clients' angry deaths, and that other professionals view dying angry as an unfortunate ("unruly"?) rather than good or natural death.

As someone educated in a Canadian school of social work, this particular clinical social worker told me that her knowledge of HIV came from those with the disease and their families, as well as from physicians; it did not from her formal social work studies. This is not a remarkable fact. Most social work practitioners, even those Master's prepared, find that their education provides an overview to policy and research but is often lacking in specifics--in this case, education regarding the issues of HIV/AIDS (CASW report, 1995). What I heard in her comment was a stance of rebellion against standard social work approaches toward dying and death. For those social workers employed in AIDS service organizations, hospitals, or hospices many have learned about AIDS on the job, and many like the social worker referred to above, have learned from

their clients with HIV. At a social work and AIDS conference I attended in 1994 for example, a 21-year-old gay man with AIDS related in a small discussion group that several social workers he had encountered could not deal with his issues regarding death and dying. He described one situation during which, in his opinion, the social worker tended to dismiss his fears about dying as well as his attempts to talk about it. He told us that he wanted her to know that he was not in denial about his death, rather he wanted an opportunity to talk about it in his own way and in his own time. In his experience, not only were social workers not trained in death and dying issues, but they were not prepared to deal with this in conjunction with sexuality.

In the early years of AIDS in Canada the profession was criticized for the same issues. It had neglected to take into account issues of sexuality or death and dying, and was ill prepared to respond to an AIDS health crisis (Clarke, 1989). Examining AIDS and the ways in which people think about it, social worker Kerry Baisley (1989) stresses that health care professionals must look inward at their personal perspectives regarding AIDS itself and those who have it. Conversely they must look outward at their professional practice with those individuals and families involved in the complex of experiences which occur when someone is subject to a life-threatening condition. Social workers who become involved with AIDS have also had to come to terms with their own ease of acceptance in being labelled "deviant", since the fear, panic and hatred toward persons with AIDS has often been directed toward professionals involved with individuals and/or groups. A recent Canadian study suggests that the accumulated findings of social work practitioners' attitudes and knowledge about AIDS indicates a clear need to incorporate

AIDS-related content into basic professional education programs (Frankel, Frankel and Grosser, 1992). After a survey of the Canadian schools of social work the Canadian Association of Schools of Social Work has recommended that in order to meet accreditation standards, social work education programs will be required to include AIDS related material.<sup>18</sup>

The social work profession may be faulted for its lack of response and its own practices, as described by the young man I met at the AIDS conference. However, during the late 1990s the Canadian Association of Social Workers produced two reports that indicate a shift, at least by those social workers directly involved with HIV/AIDS; and through my work and research I have learned that most social workers directly involved in the everyday lives and health of those with AIDS want to be able to work on the side of their clients. They learn to interpret life and death matters locally rather than in accordance with discourse-driven practices that construct and organize the choices regarding differing approaches to dying as a social problem. While social workers are generally perceived by both media and the public as colluding with the state against “clients” or alternately colluding with clients against the state (certainly in their role as child protection workers or probation officers for example) those working on the front-lines with persons with HIV disease are for the most part perceived as radical advocates within the hospital setting, AIDS service organizations, and/or as members of more vocal AIDS activist groups outside their “professional” roles.

---

<sup>18</sup>Section 1.7 of the Canadian Association of Schools of Social Work’s Educational Policy states that: Each school’s curriculum shall provide evidence of the ongoing identification and critical evaluation of contemporary social issues, including but not limited to HIV/AIDS.”

As are those who work in the frontline with abused women and children, with poor families, street youth and so on, social workers whose primary role is with HIV disease are among the “experts” who work on behalf of those living/dying with AIDS without transforming them, or their concerns, into social problems. Some of the professional literature however, focuses on the AIDS “patient” as a social problem, and conceptualizes the professional challenge posed by persons with AIDS as adjustment disorders, neurologic disorders, or maladaptive coping, rather than issues of life and death. I was critical of the notion “maladaptive coping” as illustrated in the following definition of coping responses:

Because AIDS is a terminal, catastrophic illness, persons with AIDS are considered to proceed through four stages of response. Once medical authorities disclose the diagnosis of AIDS, a period of shock, numbness and disbelief is often experienced initially. Although the length of this period may vary, critically ill persons generally recognize the seriousness of their illness immediately and must quickly contend with fears of dying, fears regarding potential losses in dependence and mobility, and fear of becoming neurologically and cognitively impaired. Consequently common manifestations are anxiety, anger, and depression *which are seen as maladaptive as tension and frustration increase* [emphasis mine] (Nyamathi and van Servellen, 1989).

As I read this work in conjunction with Jay’s journal and realized the tension he experienced between days of hope and others of anxiety and fear, it was difficult to approach it within the frame of maladaptive coping. In this type of literature there seems little room for someone with AIDS to voice his fears about what to do about dying, or to be able to talk through “is suicide a legitimate option”. Instead for example, under “Nursing intervention for suicidality” Nyamathi and van Servellen argue that:

Suicidal gestures are the ultimate means of ‘giving up’ and must be attended to quickly and effectively. Although some persons with AIDS view suicide as

justifiable, the health professional must not accept this justification (p. 120).

Although the authors offer ideas to nurses regarding making assessments and working so that “the patient may be allowed to explore a full range of feelings without fear of repercussion” (p. 120), their proposed interventions seem unlikely to provide a person with AIDS the opportunity to discuss choices. Their comments illustrate how a judgmental “morality” can be carried in professional discourses and practices. Certainly it raised questions for me about professional positioning in relation to how death is regulated, or made legitimate, that I will address more fully in the next chapter. One of the social workers I spoke with shared her response to this professional labelling:

Maladaptive coping! I'd like to take some researchers and stick them in a chair when they were 22 years old and say, 'congrats, you've got AIDS.' I really wonder what they mean by maladaptive behaviour...Someone's behaviour today in a crisis may be totally different a month from now. A lot of people when they're told they're HIV do strange things. I've done some bizarre things too!

Professional perspectives add a particular bent to the social organization of AIDS as an epidemic; it appears that there are “proper” interventions, particularly vis-a-vis suicide. In their discussion of HIV-related mental health nursing issues Hall, Koehler and Lewis (1989) note that “those recently tested as HIV positive, those who are first experiencing pain and/or loss of function, and those at the final stage of illness are also at greater risk of suicide” (p. 281). Hall *et al.* in writing about the nurse's role in suicide assessment or intervention seem to suggest that if a professional becomes too closely entangled in the messiness of dying she may sympathize with a client's wish to take his own life:

The dilemma experienced...may result from identification with the patient, a perceived conflict with the usual advocacy role of nursing, or a belief in the rights of individuals to terminate their own lives (p. 282).

The AIDS social workers with whom I have talked and worked, struggle with the tension in their own roles as advocates often working in traditional medical settings, and several have commented on the difficulties inherent in a multidisciplinary setting in which conflicts emerge among professionals about what approach to take with clients with HIV disease. While working within a professional discourse that often appears heavily weighted toward psychology and discourses of control, AIDS social workers appear to move often within a frame of “care” coupled with political advocacy. The emancipatory political movements and politics (feminism, anti-racism, post-colonialism, politics of disability, and self-empowerment with regard to health practices) have provided encouraging changes in social work practice as well. Many social workers are also gays or lesbians, or members of other marginalized groups such as women or people of colour and bring a critical analysis of the health care system, power, heterosexism, and the relationship of professionals to “patients” and clients. Many have HIV diseases themselves, or lovers, friends, or family are HIV positive. Nonetheless, the profession is situated within its own “ruling relations”— a history of middle-class charity work emerging from the industrial revolution, professional organizations, schools, curricula, legislation, codes of ethics, values, and various theories and practices regarding how counselling should be accomplished.

Although individual instructors may teach and write from critical perspectives, the profession itself, as well as schools of social work, were late to formally adopt critical analyses of race, gender, sexuality, class, and so forth. Having been a faculty member in two schools of social work since 1989, and thus attending numerous national and

provincial meetings, I have been aware that lack of attention to these issues in curricula, hiring practices and support to minority students has created divisions in schools of social work across Canada. While the value of client self-determination is a cornerstone of social work theory and practice (Mullaley, 1993, 1996) ironically with AIDS work, social workers may be perceived by their professional colleagues as taking notions of self-determination or empowerment too far as they advocate for clients in opposition to professional groups and organizations particularly in end of life decisions. For example, in its Comprehensive Guide for the Care of Persons with HIV Disease(1997) the Canadian Association of Social Workers has included a statement entitled “CASW Principles on Euthanasia and Assisted Suicide.” The fifth principle states that: “The various positions of professional and other interest groups need to be balanced with the needs of fundamental stakeholders in this issue. The stakeholders include the ill persons themselves, their family (as defined by the ill persons) and other caregivers” (p. 130). While it attempts to restrict professional interference in end of life decisions, the person with HIV/AIDS as a “stakeholder” appears positioned in potential conflict with family and others.

These first generation social work “AIDS experts” have however, along with persons living with AIDS, community groups, and other professionals working in this area, opened the way for HIV/AIDS practice, policy and research issues to be examined, and thus are in a position to transform the profession. Through working groups and task forces, the Canadian Association of Social Workers (CASW) and the Canadian

Association of Schools of Social Work (CASSW) began extensive work with their colleagues and students in the late 1980s which continues to the present, to examine HIV/AIDS from a social work perspective. The impetus for such an examination came from students, from those whose family and friends were affected by HIV, and from those who had begun to work with persons with HIV/AIDS in various settings. The documents prepared by these organizations provides an historical context within which to view the progress of the profession as it deals with issues of terminal illness, grief and loss, homosexuality, ethics, curriculum demands, and so on. I examined these documents in order to discover what social workers are learning about dying and death, and also, because as Smith (1990a) notes,

texts are seen as constituents of social relations and...by exploring our own knowledge of how to operate the interrelations among them, we explicate both own practices and a segment of the social relations in which those practices are embedded and which they organize (p. 149).

In early 1988, close to the time that Jay collapsed and became "...Jay with AIDS. Jay a PWA," the CASW submitted a proposal to the Federal Centre for AIDS to "undertake a study of the ways in which Canadian schools of social work were, and could be, responding to the AIDS pandemic" (CASSW, 1988, p. ii). A working groups of faculty members and community representatives produced a discussion paper prefaced with these comments:

We have seen our task as the stimulating of the social work teaching community to make the maximum possible contribution to the control of this pandemic and the suffering that flows from it. In the process we became convinced that the AIDS crisis has come to play a key role in social work and, therefore, social work training (p. iii).

The authors of this report believed that social work education had an important contribution to make and that

If we are dealing with the ethics of social work, individual versus public rights and questions of confidentiality, poverty issues, issues related to women, the understanding of human sexuality and sexual expression, the meaning of family, social work and health care, dying, death and bereavement, minority and disenfranchised groups, issues of discrimination or human rights and legal responsibility, it is no longer possible to teach or study these topics without involving the AIDS phenomenon as a key reference point (p. 3).

The report recognized the contentious issues surrounding death, and the fear that these may engender in both new and experienced professionals:

....there is...the question of how they should counsel and, in a special sense, empower the client in relation to the quality of remaining life and the impending death, the right to refuse life supports, and the rights and duties of lovers and families and the contemplation of suicide and the euthanasia 'option' (p. 10).

So while the working group was advocating attention to these issues in social work curricula across Canada, one of the social workers I spoke with said that in her experience, not many social workers want to work with HIV/AIDS. She described a situation in the early 1990s when five in-patient social workers quit.

BH: What does that say about our profession, or social work education?

SW: On the whole, social workers tend to be fairly homophobic in my experience.—certainly at school and at work. It's a different job, not bankers' hours—you have to make a commitment...And we have no education. When I went to school there were never courses on human sexuality. I took them outside the university. Not even a basic AIDS 101! And there's not a social worker alive in this country who's not at some point dealing with someone who is HIV positive!

Her comments point to a dilemma most likely faced in all schools of social work, that of homophobia and heterosexism. While professional reports can advocate for changes in curriculum, it is individual faculty and students within a slow-moving institution, who

can actually support, or thwart such initiatives. The working group however, also acknowledged that social work education specific to HIV/AIDS alone would not enable people to deal with dying and death issues unless they had "...an opportunity to be firm in their own self-awareness and self-questioning stance on death, dying, suicide and euthanasia, [they] will be much less ready to serve a human purpose at the bedside" (p. 11).

In a recent document prepared by the Canadian Association of Social Workers (1995) seven ethical dilemmas were revealed in an analysis of respondents' narratives regarding various aspects of their work with HIV disease. The dilemma most cited was that regarding end of life decisions by persons with HIV disease, while the least problematic was working with other professionals; although among the issues was "coping with the denial within the social work profession about the connection between HIV and gay men" (p. 15). This report also noted that:

Just under half of our respondents indicated that the knowledge component of their professional education was least beneficial in preparing them to work in the field of HIV/AIDS. The majority of responses suggest that it is more beneficial to gain knowledge on the job, where you are in close proximity to the client population and have access to updated information....many noted an array of topics that their educational content did not include, such as death and dying, medical issues, health promotion, sexuality, drug use, addictions and cultural diversity. According to social workers, professional training is most lacking in the area of human sexuality (p. 17).

Most of these professionals remarked that they found clients to be the "experts and teachers; that they are living the experience on every level which makes them the expert guides in this journey" (p. 18). The recurring issues of education regarding dying and death, and sexuality, in conjunction with the ongoing comments that those with HIV

disease are the experts and teachers in the field appears relevant today even as it was in 1988 and 1989. On the other hand the actual cumulative collective knowledge from years of working directly with persons with HIV and their families and friends is evident in the recent CASW guide for the care of persons with HIV disease:

Every person who is dying will approach the last stages differently. As helpful as Kubler-Ross's four stages of death and dying are, not everyone will follow that journey. Some choose to 'rage' literally or chemically. Some fight to the last breath and seek out every possible treatment. Some set limits around what they will do, and try to protect their independence and their sense of quality of life. Some may consider ending their lives at a certain time, so they can have some control over their life and death (p. 128).

The same guide suggests that while the "'good' death may be a myth", social workers can advocate with nurses, doctors and others to make sure a person's death is as painless as possible, and that they have choices regarding the process of dying. As I read these documents it was evident that professions are not monolithic in their approaches, and are revising their educational policies, curricula and practices. Social workers such as those I spoke with have also learned about dying and death through their contact with people like Jay who raged into an "unruly" death despite the support and expertise they were able to provide. The idea of legitimate or illegitimate options appears, at least in policy, to be challenging formerly held notions of professional expertise. An additional form of expertise was strongly evident in Jay's journal however, one that as I will show in the following section, was more influential in many ways than the professional discourse.

## **“Love myself, heal myself...”: An approach to AIDS**

The word “proper” is often used in conjunction with etiquette, manners or moral behaviour. In everyday talk for example, we describe dying individuals we have known as being “brave”, “strong”, and “courageous” in the face of death. We have only to peruse the obituary column in the newspaper to see how pervasive such notions are. Phrases like “valiant battle”, or “faced death with dignity”, perhaps ease the stress of the living. Indeed, the pioneering work of therapists such as Kubler-Ross (1969) suggests ways in which death can (often read as “should”) be approached. Thus, through ways of supposedly helping someone through the journey of approaching death, rules about how this can be accomplished become entered into the discourse (and are uttered by the dying) and begin to construct a case regarding legitimate death—the right, good and natural death. Someone who does not conform to his or her society’s way of doing things is seen as improper or non-conforming. However, rather than improper, I found that the word “unruly”, defined in *The Concise Oxford Dictionary* (1976) as “not easily controlled or disciplined, disorderly”, to be more precise with regard to death. “Unruly” behaviour in Jay’s case was his choice to end his life rather than to continue living/dying with AIDS and entering into a manageable “good death.” It was a decision made by a man needing and trying to stay in charge of his life while other forces, such as family and societal expectations, ideas about what a death should be like, and what an AIDS death should look like, operated to redefine and take away that control. In this section I present an example of the work Jay attempted in taking back some control he felt had been usurped

as his illness progressed.

Weighing the options and the idea of taking his own life appears to have been on Jay's mind throughout his illness and even prior to his official diagnosis. Perhaps it is not surprising, given research suggesting that suicide is common place among those with HIV/AIDS (Adam and Sears, 1996; Sherr, 1995b; Sherr et al., 1991) that ideas about taking one's own life were entered into the journal of a gay man who was fearing for his life. In the following excerpt he writes about an approach by which he may be able to heal himself of AIDS.

*a) Love myself, heal myself--this is one approach. I'm not sure what love is--how do you love yourself. This I must work on. Louise Hay et al.*

*(Journal, Late January, 1989)*

Self healing at the time Jay was ill, was a prevalent approach used by gay men to manage HIV/AIDS. According to Canadian researchers (Pawluch, Cain and Gillett, 1995) alternative therapies such as acupuncture, chiropractic, massage, spiritual healing, and so forth--have been growing in popularity and "between 30 and 50 percent of people living with HIV and AIDS are using some form of alternative health care to deal with their condition" (Stine, 1993 as cited in Pawluch et al., p. 64). Their work challenges various assumptions regarding why people seek out alternative health approaches, such as that ill people only turn to these approaches out of desperation, or have lost faith in Western medicine. In contrast, they found that those with HIV/AIDS sought out alternative approaches as part of a deliberate strategy. The respondents in their study "had a way of

thinking about their HIV infection and about health and illness that rationalized their use of alternative therapies” (p. 65). They did this by redefining AIDS as chronic and manageable, and defining health holistically—that is, in emotional, spiritual, mental, and physical terms, and often combining both mainstream and alternative approaches in a complementary way. For some persons living with HIV and AIDS the transformation from internalized self-hatred to self-love through positive affirmations appears to work, at least in terms of their reconciliation to the disease. The experience of self, the reformation of one’s identity as contamination and contagion, and the strength and ability to steel oneself against the moral and religious barrage that reinforces this image has spawned a response to gay identity and to HIV disease termed “immune discourse” (Yingling, 1991). Those with HIV/AIDS are struggling with the failure of their immune system—the more vulnerable the immune system, the more a person is susceptible to opportunistic infections.

The possibility of choosing life or death is evident in many of the practices/alternative therapies that I know Jay engaged in during this time. However, it was Louise Hay’s (1988) approach that figured most prominently in his journal. She is perhaps the most well-known among many immune discourse proponents and has had a profound effect. Hay describes herself as a metaphysical counsellor, teacher and healer whose method of healing from AIDS is to combat self-hatred and stigma through self-love. In his book on various holistic healing approaches to AIDS which Jay had and read, Serinus (1987) talks of Hay as a “source of inspiration and hope” who has “worked individually and collectively with thousands of people diagnosed with AIDS...The love

she puts into her work is palpable to anyone allowing themselves to truly listen...For many men, it has been Louise's wise and healing voice that has led them to their own healing power" (p. 322). Serinus observes:

Louise believes that almost everyone on this planet suffers from self-hatred and guilt to some degree. Gay men in particular, she finds, often carry a heavy load of rejection and oppression from parents and society. Her work involved accepting oneself and embracing the totality of one's being with self-love. By helping people to dissolve the hatred and oppression within them and to absolve themselves of all guilt, Louise helps her clients get in touch with the healing power of love. As she explains, 'When you love yourself, everything in life improves and you strengthen yourself inwardly. I teach people that there is nothing wrong with them--that we are all wonderful beings. I do this with everyone who comes to me, regardless of the imbalance or dis-ease' (p. 322).

In The AIDS Book: Creating a Positive Approach (1988) which Jay was given, Hay sets out her program for healing. She tells her readers that: "I see AIDS as a message from the body, the final attempt of one's own consciousness to communicate--at the point when you can't just take a pill and keep going. Now, you have to listen" (p. 19). The program involves the recitation of "affirmations" such as "I love myself and accept myself".

Jay's journal excerpt mentions "Louise Hay et al." and the influence she and others have in the lives of terminally ill people.<sup>19</sup> What this, and other journal entries prompted me to do, was explore how his experience of his specific dilemma regarding legitimate/illegitimate death was organized in reaction to her work. I was interested in examining for example, what Jay meant when he wrote "Love myself, heal myself..." and how Hay's work came to influence him in this quandary. I found a tape among Jay's

---

<sup>19</sup>In a journal entry written the previous year shortly after he had been in intensive care, Jay noted the following title: Serinus, J. (Ed.). (1987). Second Edition. *Psychoimmunity & the Healing Process: A Holistic Approach to Immunity & AIDS*. Berkeley: Celestial Arts. Other books he read at the time were several by Stephen Levine, an American, whose work on meditation as well as work with the dying is very popular.

collection labelled only “Louise Hay”, which may have been given to him by a friend who copied it from the original. The first side is an explanation of her approach, while side two is a guided meditation incorporating her philosophical ideas.<sup>20</sup> On side one Hay says to her listeners:

We don't want to be ill and yet we need every disease we have. It's the body's idea of telling us that we have a false idea in consciousness. We are being told we are on the wrong track and need to change the way we think. Every illness is a lesson for us to learn... We need to eliminate the cause of the disease and for that we need to go within ourselves where the process of illness began. It is my belief that we are each 100 percent responsible for every experience in our lives...

I am sure that those using Hay's approach agree with the ideas she presents above about illness being a lesson through which an individual can be transformed. Having been raised catholic, and familiar with the use of repetitive prayer, I nonetheless found them chilling, and was interested in the urgency with which Jay wrote out affirmations in his journal. I wanted to understand how metaphysical or psycho-immune approaches worked and how they may have contributed to his dilemma regarding a legitimate death. On the one hand, Jay's dilemma as he wrote about it appears to be one of taking responsibility for healing himself of AIDS by loving himself, versus accepting the fact that he is going to die. If he accepts his death or the fact he has an illness seen to be terminal, part of his dilemma is “If I am truly dying (which contradicts the fact that if I choose to change I need not die)—should I move towards it + embrace it?” “Affirming” life and maintaining hope in the midst of negotiating treatment options, points to a complex issue. Jay's words

---

<sup>20</sup>By examining Hay's work in the context of Jay's struggle I am not suggesting that alternative therapies can not or should not be used by those with serious illnesses. I am not in a position to criticise their effectiveness since I have used, and continue to use at various times in my life, guided meditation, counselling, reiki, acupuncture, massage and other approaches to stress reduction and health—some reminiscent of Hay.

suggest that he has learned that if he can love himself enough he can heal himself of HIV disease. The subtext is that in order to enact this healing, he must first know what love is. Alternatively, he can accept death. This option appears to suggest that acceptance may be the preferred route for those who cannot learn to love themselves because they refuse, or they do not know how to “love”. There is a tension in trying to figure out how to love before it is too late. What does it mean? What is the “trick” or the key to knowing how to love so he can live? If someone knows how to do it, where are they? Jay appears to be caught regarding his ability to live and/or die. In an earlier portion of the same excerpt he writes:

*I love + accept myself exactly as  
I am  
I let go of fear  
I let go of anger  
I let go of delusion*

A list of similar affirmations about loving the self is initially invoked and threaded through the entire journal account (see Chapter One). These seem to provide the backdrop or foundation upon which the everyday/everynight of trying to resolve his dilemma is enacted. The work of negotiating treatment choices, finding doctors, or alternate health options becomes an individual struggle despite the doctors, counsellors, reiki master, faith healers, family and friends, and other persons with HIV disease with whom Jay had contact.<sup>21</sup> Within the context of greater technological approaches to saving and prolonging life, and perhaps in conjunction with it, exists a panoply of alternate

---

<sup>21</sup> Appointments with various people such as massage therapists, doctors, and other healers were noted in both his journal and a weekly reminder date book.

approaches to terminal illness. While each strategy may not make claims for its efficacy as the sole hope in the face of death, nonetheless each implicitly points to the idea that there is a right choice to be made, or to be found, that will result in staying alive. If the right strategy can be discovered in counselling therapies or practices involving healthy eating, affirmations of self-love, meditation, visualization, healing touch and so on, then death can be avoided. Behind this is the unspoken/implicit threat that if you die, it could be because you entered into a wrong choice or decision; and certainly, since some persons with AIDS do live longer, others may see this as indicative of the right lifestyle choice.

It is easy to recognize in Jay's journal Hay's approach to disease management through self-love. Throughout February and March, 1989 he wrote:

*I love myself + accept myself  
exactly as I am.  
I love + appreciate all of myself,  
and accept myself exactly as I am.*

*I love myself  
I forgive myself  
I forgive all the others + release them.*

*I am well  
I am becoming strong  
I have a better appetite.*

His last journal entry states:

*I have chosen renewal + life!  
I can heal myself  
I love myself + accept myself  
I forgive myself + all + I release  
the past, + live in this very  
moment.*

*I am healing  
The process has begun.*

He believed he “must work on” how to love himself in the way Hay suggests. She has said that:

Healing comes from a willingness to change inside. I can almost tell when people first come to me if they’re going to make it or not. I look at their attitude toward themselves and their willingness to commit themselves to whatever they must do to heal themselves. We have to be willing to fight our fear, which dissolves when we allow the love that is within all of us to surface (Hay quoted in Serinus, 1987, p. 322).

Indeed, in her 1988 book she says that what she has seen in the lives of the person’s with AIDS she works with is “lack of love”....which has... “ played a large role in the acquiring the dis-ease” (p. 31).

AIDS to me is a dis-ease of love, the lack of love. AIDS shows us how incredibly un-loving we can be. Look at how we treat people with AIDS. They are often rejected, abandoned, isolated and even denied the assistance they so sorely need” (p.31).

There are a number of implications in Hay’s messages that need to be made explicit. One that stands out is that the lack of love by those who do not have AIDS is due to the fact that those with AIDS are homosexuals whose experience of hatred has left them vulnerable to disease. For those steeped in traditional religions in which guilt is the spectre that infuses one’s life particularly in areas of sexuality, Hay’s method can perhaps increase guilt. The implication inherent in her work intimates that those who are not able to slam the door in the face of death obviously do not love themselves enough. Jay writes, “I’m not sure what love is--how do you love yourself. This I must work on...” Do people who do not love themselves--however that is measured or defined--deserve to die?

Perhaps Hay is also implying here that those caring for persons with HIV/AIDS are not loving them enough.

While persons living with AIDS should be able to choose whatever healing methods work for them, Hay's approach seems to reinforce the individual or private response to AIDS--that is, that the illness exists independently of its social or political context. The technique of repeated affirmations suggested in the health and spirituality literature of people like Hay, acts almost as a personal shield against the medical and professional regulations practised on/against the gay body. Loving oneself according to Hay, stabilizes the fractured gay body/identity. For the person with AIDS, her challenge may make sense in the face of the goliath of traditional medicine in which an AIDS patient, depending on his or her ability, is often granted little control or information. Jay struggled with this.

*If I am truly dying  
(which contradicts the fact that  
if I choose to change I need  
not die), --should I move towards it  
+ embrace it?*

Being able to overthrow death and disease through "affirmation" or "prayer", to invite a miracle into one's life is a powerful tool in the hands of a "patient". However, "choosing" to change appears to push a person with AIDS toward a position of individual blame. Hays' critics contend that she neglects to take into account the "collective dimension of AIDS as a death which is at least in part an act of political regulation" (Yingling, 1993, p. 305; Kinsman, 1995).

There is another unacceptable implication in Hay's teaching. If a gay man is

choosing to change, he must have also made an earlier choice to live in a particular way so as to invite retribution, to invite AIDS because of his behaviour, or “lifestyle”. Hay suggests that men like Jay do choose their disease:

If we choose dis-ease, can we choose to cure it? Remember our so-called ‘choice’ of dis-ease is seldom done on a conscious level. It comes out of our deep-seated beliefs and our habitual ways of thinking, speaking and acting. These belief habits create negative actions and an atmosphere where dis-ease can flourish. Let us examine our behavior and what we can do to change our options (p. 41).

According to Hay, Jay can now choose not to have AIDS by drawing on a love within himself. Change begins for gay men when they receive an official diagnosis of AIDS and become, through this disease classification, transformed into persons-living-with-HIV/AIDS. When a young man first accepts his gay identity it can be both exhilarating and traumatic. The new gay identity often precludes all else—this is the way he is “seen” by family, friends, or co-workers—as solely homosexual, rather than in the complexity of traits of which sexuality is only a part. Then the gay man gets AIDS and is seen to “become” the disease in the same way—the change from person to patient with a death sentence is accomplished with the diagnosis. Later he may be introduced to the work of Louise Hay and undertakes her “therapy”. In the same dramatic way as the previous transformation of self, her prescription calls for yet another personal revolution: the AIDS “patient” must accomplish a transformation that transcends the beliefs of the medical profession and indeed, generally held views of society. In this social context, choosing to change by learning to love oneself in order not to die is hard work. I have some sympathy for the point of view expressed by a woman from the activist group, ACT UP (AIDS Action to Unleash Power) who is “angered by the common supposition that

you can control your health by positive self-images” (Martin, 1994, p. 135). She believes that people are being blamed for their HIV status and that an approach such as Hay’s “plays on the ways in which we have already been trained to feel guilty” (p. 135).

While Hay may not intend it, in the midst of illness the individual is implicitly presumed to be at fault. First of all for being ill with this particular disease which still tends to be associated with risk groups rather than risk behaviours (in this case the risk group ‘homosexual’) and one’s membership in a group as defined by others. Secondly, one is blamed for not knowing, or actively discovering how to heal oneself. The process of attempting to live within this frame appears to involve intense anxiety, frustration, fatigue, and depression. Somehow a person should know what choice or direction is best. Moulton et al. for example (1987 as cited in Alonzo and Reynolds, 1995) found that “attributing the cause of AIDS to one’s self was positively correlated with dysphoria (a combined measure of depression, anxiety and negative mood)” (p. 311).

For gay men raised in religious homes, Hay’s exhortations may have a familiar yet ominous ring. While wanting to be saved, one must admit to having “sinned” or at the very least, to have chosen badly. Testimonials from gay men at her gatherings (called “Hay Rides”) who have held AIDS at bay through her approach may offer a beacon of hope. For men who become more ill, the alternative, death, seems to reflect on them. Not having the ability to transform oneself back into a healthy man, not being able to stop one’s immune system from closing down appears to mean that an individual did not love himself enough—was not doing it right, was not sincere enough, cannot work miracles, is somehow wrong. Juxtaposed with a stigmatized and one-dimensional identity of being

gay, as well as having a stigmatizing illness, is now the failure of being unable to heal and accept oneself. Forgiveness is not at hand and one is banished from the social realm of the living.

Jay may see himself teetering on the brink between hearing from his doctor that he has 18 months to live and thus must be dying, versus the ability to choose to defy his dying by changing through affirmations and visualizations of self-love. Since many of the men dying of AIDS are young, the ability to choose to change and therefore not to die is a form of salvation. As young people they do not believe in death. They will be the first ones to live forever, or at least to beat the odds and not die young, at least not this young. AIDS is a terrifying push in the face of their mortality. Hay (1988) states:

Living with AIDS is a big lesson in 'accepting what is.' It may not be an experience we consciously want at all. However, AIDS is here, and we may have it. After we have gone through the initial steps of fear, denial, anger and hopeless resignation, then we need to move into a more positive phase. AIDS is a learning time. What can we learn from this dis-ease, and how can we improve our health? We can be angry at the dis-ease and use this anger to motivate us to do everything we can to eradicate it. We do not want to be angry at ourselves. Even if we see clearly how we contributed towards our illness, we do not want to compound our problems by self-anger (emphasis mine) (p. 111).

Hay's reference to the initial steps of fear, denial and anger, echoes the work of Elisabeth Kubler-Ross (1969) whose work on death and dying became a touchstone in the 1970s and 1980s. Kubler-Ross's stages of dying offered a way for the dying and their caregivers to perhaps understand what people may go through as they approach death. What happened instead was that these various stages were interpreted as a way that people "should" die (Kellehear, 1990). The notion of disease as a life lesson is a macabre approach and as Canadian sociologist Arthur Frank (1991) observes regarding his own

journey as a relatively young man with testicular cancer:

Cancer personality theories will persist because they have a payoff for everyone. On the one hand the ill person is accused, but on the other she is comforted. Perhaps by changing her personality she can recover; it is never too late. Those around the ill person can rest assured he got cancer because he was that sort of person, different from themselves. ...The genius of the cancer personality argument is that it means nothing has to change. The fault and fear are safely contained, locked up inside the cancer patient...Only the ill are left to feel guilty (p. 112-113).

I am unsure where Jay may have first come in contact with Hay's writings and her approach. However, during the time he was ill, several men I met were also using her methods in their own lives. With a friend who had AIDS, I attended healing circles that were run by the local persons with AIDS society. While I was not aware that Hay's methods were used in the group, after one session we were invited back to the home of another HIV positive man who also offered counselling to other infected men. He wondered if we had heard of Louise Hay and invited us to stay and watch a video tape of her "working" with a large audience of people with AIDS and their supporters.

The video of Hay working with hundreds of gay men showed a charismatic figure—a middle-aged woman who draws on her own struggles and experience with cancer, and transforms it for others to use. It was a scene reminiscent of an evangelical revival with men testifying, for example, to having been cured of a terminal illness. She was a warm and nurturing mother or aunt figure who, while medical researchers search for a cure, appeared to offer life after a diagnosis of death. Her words seemed to inspire healing, where medical words might inspire fear. She seems to offer a route away from death, an opportunity to begin to choose differently. Given the network of persons with

HIV/AIDS in Vancouver at the time, and the fact that the city has an active and growing number of healers and so-called alternate approaches to health and wellness, it is no surprise that the HIV/AIDS community would attempt various ways to stop the disease, or at least manage it using all existing approaches and philosophies.

Ultimately, however, I am left with the question as to whether such approaches do offer hope. What I see in Jay's journal is a frantic hope to be able to heal himself, or to die the good and natural legitimate death, and what I have discovered about his contradictory text offers me some way of reflecting on the ways in which Louise Hay and other practitioners were part of his conundrum. On the one hand they offer a message of hope through self healing, while on the other, their words are a kind of torment which may lead the person attempting to self heal to believe that he has also caused his own fate and must face that terrible responsibility.

## **Conclusion**

"Fearing death by AIDS" as Jay wrote in 1987 seems a normal reaction. The work of living with fear of death from any disease would seem to be a tremendous burden. Add to that having a stigmatizing disease, being a member of a stigmatized sexual minority, being young, sexual, unable to support oneself, and fearing increasing dependence. The progression of death by AIDS meant lost choices and potential, the loss of some lovers and friends, loss of his body, loss of image and sexual attractiveness. All the support in the world does not alter the fact that a terminally ill person is engaged in a journey on

which we on the other side of the divide cannot partake or understand. The fear that lay ahead with AIDS was the fear of knowing how others had suffered, that as the disease progressed, more frequent opportunistic infections, including those affecting the brain, had to be dealt with. Because of his own involvement with a local persons with AIDS organization, Jay had also lost friends to AIDS and knew what they had experienced.

It appears that Jay's only "legitimate option" would have been to die as a result of an opportunistic infection--this is "going naturally" when a person has AIDS. In this kind of death "nature" has been allowed to take its course. Ironically, while every type of medical intrusion is deemed natural or legitimate in prolonging life, a person's own hand in the ending of his life is not. Interrogating the tension between phrases such as "is suicide a legitimate option" versus the "longing to go naturally", leads us into an area of major debate about death and dying in our society. I have examined the influences that I found traces of in Jay's journal. There are other ways of thinking of legitimate death. Do we hold persons with AIDS accountable because they choose not to move through various stages of dying and choose to ignore what we the living need in participating in the perfect death? Jay finally decided that for him, going naturally meant taking his own life. The good and proper death and the discourse that penetrates into everyday life brings me to a discussion, in the next chapter, of how his act came to be authorized or "ruled" a suicide.

## CHAPTER SEVEN

### Defining Death: AIDS, Suicide and the Coroner

*I find his death to be suicidal and although no writings were left by way of explanation, it can be surmised that James Herringer took his life while in a depressed state of mind due to his diagnosis of AIDS (From Coroner's Judgement of Inquiry).*

#### Introduction

For reasons that will probably never be clear, many gay men with AIDS choose to take control of their lives, by self-killing. In official terms however, as in the words of the coroner stated above, Jay did not “take” his own life or kill himself; he committed “suicide” because he was depressed about the fact that he had AIDS. Alternatively, the taking control of his life/death as an act of autonomy if that was the case, could not be entered into the record because there is no language with which to describe it officially. Several weeks after his death I received, having requested it, the coroner’s Judgement of Inquiry with her conclusion that Jay had committed suicide (See Appendix Two). What I saw as I read the report was how Jay’s taking of his own life had been interpreted or “read” in a different way than experienced by his family and friends; and it did not seem to reflect, except in a superficial manner, his own struggle with AIDS. It was extraordinary to read in three brief pages the objective documentation of what happened that day, and I was unprepared for the shock, sadness and anger it evoked.

At the time of course, it did not occur to me that this official interpretation of the

life-transforming event I had experienced entirely differently a few short weeks earlier, would become “data”. I am sure that client reports I wrote years ago to fulfill my agencies’ mandates, and student reports I construct today are experienced much the same way by their recipients as part of the organizational practices that I, along with clients/students, are caught up in. For me the classification “suicide” had no meaning; it held no relevance to the anxiety I felt or to the daily struggles I had witnessed as my brother lived with AIDS.

As I read the Judgement I remembered the morning that Jay killed himself. Family and friends rushed to the hospital as they received news that he was dead, or dying, we were not sure. Once there however, we could not see Jay’s body until the doctor had officially pronounced him dead. When the attending physician met with us just outside the emergency room doors with the his news, one of my brothers and I wanted to see our brother’s body and were not allowed to be in the room alone with him. A nurse was required to be there with us. This was the hospital’s policy as determined by the coroner. Much later I learned that Section 12 of the Coroners Act states:

A person who has reason to believe that a person died in any of the circumstances mentioned in Section 9 [note: which includes suicide] shall not interfere with or alter the body or its condition in any way until the coroner so directs.

This requirement entered Jay’s body into a chain of events by which he became the property of the state through the coroner, rather than being able to be attended by those who loved him. While his “act” of dying was uninhibited by regulation, his family and friends in a sense came to be regulated as a result of it. Whether it was rational and autonomous decision, irrational, the result of depression or dementia, a spur of the

moment decision, or the result of “maladaptive coping” to his terminal diagnosis—no one will ever know the reasons why Jay killed himself. However, when I read the coroner’s report, she seemed so “sure” of how to get to her judgement of what had happened. I had been at the hospital shortly after Jay died. Later I received the coroner’s judgement of inquiry that outlined her reasons for concluding that what Jay did was “suicide”, and why it was able to be categorized as such. As I attempted to reconstruct an account of what happened I realized that I needed to know how the coroner reached found her way to that conclusive decision.

This chapter examines the Judgement of Inquiry I received from the Coroner’s office. My analysis of it supports the argument that the work of the coroner transforms and orders the experience of a gay man taking his own life into an official and legitimating account; that is, it shapes the actual event into something that happens on paper. Jay’s death challenges the rules for dying that are understood and enforced in a variety of ways through coroners, and health and social service professionals among others, who “work” at maintaining a proper stance and behaviour regarding death. “Unruly” or un-ordered behaviour in this case, was a choice made by a man needing to stay in charge by taking his own life, while the state’s ruling apparatus operated to redefine and take back the control. This happens, as I will show, in routine practices of coroners and other professionals whose practices are linked through knowledge of suicide. I am treating this knowledge work as problematic or the topic of inquiry here.

While I do not want to impose an alternative authoritative version of my own here, I do want to create a discursive space for perhaps a different interpretation that will

challenge the factually constructed one evident in the Judgement of Inquiry. As Smith (1990a) has shown in her analysis of suicide

At the point of someone's suicide, there is the sharpest sense of disjuncture between any formal account of that death and how that death has been experienced by those involved (p. 142).

The work of the coroner, through text-mediated practices, continually opens up for my analysis, how her local practices are connected to and ruled by extra-local ones. I suggest the possibility that my brother (as perhaps others have done) was taking control of his life/death as an act of autonomy--an "unruly death". If that was the case it would constitute a disruption of how society, as upheld by the law ( illustrated for example, in contested notions of "going naturally" vs. assisted suicide and euthanasia), health and social service professionals and perhaps even friends and family, expects or even demands one to die.

I want to make this argument by first demonstrating that the coroner's work throughout history has been and continues to be to constitute order by *ruling* on particular modes of death. Secondly, I intend to show how the work of constituting this particular death into a semblance of order (the coroner's conclusion of "suicide"), required that Jay's autonomous decision was rendered officially irrelevant, even trivialized, through the methods of accounting for the action taken by medicalizing, psychologizing and otherwise reconstituting it in discourse that authorizes it "appropriately".

## The “Crown’s” Work & Responses to Suicide

The time I first read it, and even now, I am both dismayed and fascinated by the coroner’s conclusion of suicide in Jay’s death. In our culture we call the taking of one’s own life “suicide”, despite the fluidity of the idea and definition of self-killing throughout history. Through my analysis of the Judgement of Inquiry I came to see how the document worked to maintain the resilient notion of suicide as an unnatural act. I began to see as well, the centrality of depression within coroner policy as a possible cause of the resilience. In order to gain an understanding of the Judgement of Inquiry and the work that the coroner engages in to constitute *order* from an *unruly* death, I wanted to find out more about the coroner’s historic role in relation to the state, and in relation to self-killing as understood by the state. Current notions of determining the cause of death and keeping of reports and records about numbers and types of deaths, are rooted in the historical administrative function of the coroner. The coroner, whose task was to “protect the financial interest of the Crown in criminal proceedings” (Secretary of State for the Home Department, 1971) also required him to know how to read a death in a political/social environment. As Marshall (1991) observes, “the historical roots... penetrate so deeply that the institution cannot be described without reference to its historic background” (p. 2).

Coroner law and practice is located within a history of authority and meaning as far back as the tenth century (Forbes, 1978). Forming itself in the stew of Anglo-Saxon, Roman and Norman law it emerged in the chaotic landscape of England and Wales as an

unpaid elected position with allegiance to the King (Forbes, 1978; Hunnisett, 1961; Thurston, 1980; Granger, 1984). It is a position that has always been one of delegated authority to the Crown, as seen in the derivation of the word coroner: “custos placitorum coronae” or keepers of the pleas of the Crown, became “coronater”, then crowner, and finally, coroner. For those of us who loved the stories of Robin Hood who constantly outwitted King John and the Sheriff of Nottingham while England longed for the return of Richard the Lionheart, the coroner played an early role. Richard was apparently desperate for money to continue his crusades and while Sheriffs were in place to ensure, among other things, that the crown received its due from nobles and serfs alike, their duties were onerous and the funds did not always reach the King’s coffers. Forbes (1978) describes the coronership as “providing a mechanism both for administering justice and for insuring that the royal interest in certain sources of revenue was recorded, protected and exploited” (p. 5).

Officials were put in place to keep the “King’s peace”, but as all the historians writing about this office suggest, it was the financial rather than the judicial task which seemed to prevail. Individuals convicted of crimes were not only jailed or executed, but were required to hand over to the king’s representatives, all their possessions. The coroner’s jurisdictional role is an interesting one as it placed responsibility on the community to maintain law and order. In the eleventh century, not unlike in contemporary jurisdictions, fines and the confiscation of property for law-breaking were a great source of revenue. Crime or death for example, were not viewed as solitary acts; they were the responsibility of the community. If communities failed to keep law and

order, they too were heavily fined or amerced, and profits given to the king by way of the coroner. Among the coroner's duties as instructed by the crown, was to hold inquests on dead bodies that would have been discovered in his jurisdiction. Often in the case of an unidentified body or a suspicious death, the body may have been moved from one county to another so communities could avoid fines.

The position of coroner created by Hubert Walter, Archbishop of Canterbury, has been transformed through the centuries from that of a collector of revenues for the king, to its contemporary role as "ombudsman for the dead". While local officials performed various judicial and administrative tasks prior to the tenth century, according to Thurston (1980) Walter introduced the office of the coroner in 1194. He ordered under what was known as the Articles of Eyre (periodical circuit court justices) that "three knights and a clerk be elected by freeholders as 'keepers of the pleas of the Crown' in each county" (p. 2). Because of their independent wealth knights were considered able to investigate crime and death without accepting bribes. The coroner's obligations however, appear to have been more than jurisdictional or completely sublimated to the will of the Crown. Partially this is because the Monarch was often unable to keep abreast of the details in every county or "hundred" of his or her entire land, and thus local custom often took precedent in the interpretation of criminal law. While the coroner's numerous duties were entered into various law books in the Middle Ages, according to legal historians (Forbes, 1978; Hunnisett, 1961; Thurston; 1980) records from the time indicate that his primary duties included:

...the appraisal and recording of goods and chattels of persons committing

homicide and suicide, outlaws, confessed felons, and abjurors of the realm....By far his most important duty was to hold inquests upon dead bodies, specifically the bodies of persons who had died from other than natural causes... (Forbes, 1978, p. 6).

In addition to inquests and abjurations, crown pleas were “kept” in several ways according to Hunnisett (1961) :

...attaching or arresting witnesses, suspects and others, appraising and safeguarding any lands and goods which might later be forfeited, and by recording all the details (p. 1).

The use of the terms “keeping” and “holding” pleas is important. Granger (1984) notes that “‘Keeping’...implied taking all necessary actions to ascertain and preserve such pleas and to enable them to be brought to trial, where appropriate...It did not include judicial determination of crown pleas, which was meant by the term ‘holding’” (p. 10).

As I read the history of the coroner and kept in mind the investigation and Judgement of Inquiry into my brother’s death, I was interested in descriptions of early inquests. When most duties of the office of coroner were eroded beginning in the 1300s, his duty to attend to dead bodies was seen as the coroner’s most important function. If someone found a body (apparently not uncommon) he or she, as “first finder” was obligated to “raise the hue and cry” and to summon the coroner (Secretary of State for the Home Department, 1971, p. 108) and could be heavily fined if they did not. Needless to say, many did not bother to report their discoveries or moved dead bodies from their jurisdiction to another. They could also be fined if they buried the body before the coroner had viewed it. To avoid losing access to Crown revenue generated from fines, the coroner tried to reach and view the body as soon as possible. According to Granger

(1984):

On receiving information that the body had been discovered, the coroner had to proceed post-haste to view the corpse in question. Speed was essential in order to allow for a rough and ready 'post-mortem' examination of the body to ascertain cause of death before decomposition and to improve the chances of apprehending any suspects in the case of felonious death (p. 15).

Medieval inquests required that once a body was found, and before he viewed it, the coroner ordered a bailiff to summon a jury of men (anyone over age 12) from the four surrounding counties as well as twelve freemen from the area. The jurors were sworn to speak truthfully about what they knew about the body and were seen as witnesses to the investigation. Thurston (1980) describes early inquests as the jurors and coroner sitting around the body to survey the corpse for wounds and other clues to the death. The inquest and burial were public "rituals of interpretation" (MacDonald and Murphy, 1990 p. 223) during which the coroner and his appointed jury would attempt to decipher what the deceased's actions and words prior to death might have meant. The jurors were also expected to answer questions from the coroner about what they knew about the body. As today,

Of primary concern would be establishing whether the death had occurred naturally, by misadventure or feloniously and, if feloniously, whether it was homicide or suicide (Granger, 1984, p. 17).

At the conclusion of the inquest, MacDonald and Murphy (1990) claim that the verdict often "represented the community's collective 'reading' of the physical evidence, the events that preceded the death and the words and actions of the dead" (p. 223). Through this collective interpretation, family and relatives often helped determine whether the death was a suicide or not; although MacDonald and Murphy note that juries had great

difficulty trying to determine on physical evidence alone, how a person died.

Since the circuit justices may not return to jurisdictions for a few years, the coroner's inquest may result in someone's arrest for homicide. It seemed however, that the Crown was ultimately more interested in obtaining fines, and people could be "attached" or bound over to make their appearance at the next eyre. The person who had found the body for example, witnesses, or kinsmen--virtually anyone connected with the death in any way, had to put up a kind of bond or surety. If they did not return for the court, they would lose the bond, and could be fined yet again. Once the inquest had terminated, the coroner's task was to create a detailed record of the proceedings.

According to Granger (1984) this included

...detailed reference to all amercements, lands, chattels, deodands [note: animals or objects which 'moved'] and the names of all persons and groups attached. All such information was entered upon his Rolls, the official record of his activities for presentation in due course to the justices of eyres (p. 18).

Eventually the coroner's only duty was to hold inquests into violent deaths; and once the fines against the jurisdiction in which the body was found were abolished, it became difficult to have anyone carry out these remaining tasks. An intriguing incentive was established. The coroner was "to receive a fee of 13s. 4d. for every inquest held...but if he failed to do so, he would be fined 100s" (Secretary of State for the Home Department, 1971, p. 112).

The position of coroner in Britain languished somewhat until the nineteenth century when two pieces of legislation were enacted requiring investigation of deaths. The first was called the Births and Deaths Registration Act (1836) which obligated the

coroner to report to the local registrar deaths, and the particulars of a death if an inquest was held. The second required that medical witnesses at coroners' inquests be paid. It was not until the late 1800s that a coroner's act was proclaimed. It was this act which became the basis for the law which governs modern-day coroners. The consolidatory legislation confirmed that the primary function of the coroner was no longer to protect the financial interests of the Crown, but to provide a means for investigating the circumstances in which deaths took place and the causes of death in situations where this was desirable for the benefit of the community in general (Granger, 1984, p. 29).

Granger argues that while the nineteenth century British coroner system had been created to investigate and draw conclusions regarding "causes and circumstances of unusual death, coinciding with the compiling of accurate death records and the detection and investigation of criminal activity" (p. 31), the twentieth century refined these functions. Through the enactment of new legislation regarding coroner duties and the registration of births and deaths throughout the 1920s and 1930s the coroner's office became less concerned with investigating suspicious deaths and bringing criminals to justice, and more concerned with establishing causes of death and conducting public inquiries. Granger, a lawyer, observes that Canadian coroner functions paralleled those emerging in Britain however, Canadian Criminal Code abolished the indictment function of the coroner's role almost eighty years before Britain.

Today in British Columbia the Coroners Service is established as an independent operating agency under the auspices of the Ministry of Attorney General. The 1994-1995 annual report from the Ministry relates the following:

The BC Coroners Service investigates sudden and unexpected death to ensure that no death is overlooked, concealed or ignored. The service's mandate is especially directed to the protection of those who are dependent on others for their care and custody.

A coroner's investigation may result in either an inquest or inquiry. An inquest is an independent public hearing involving a jury and the examination of witnesses under oath, required when deaths occur in prison or police custody. Inquests are also held at the coroner's discretion where it serves the public interests, when there is a need to clarify evidence, or when it is required to address family or agency concerns. An inquiry comprises a full investigation and formal report of the facts and coroner's findings. A coroner's inquiry or inquest determines the identity of the deceased and clarifies facts about the death.

The Coroners Service operates with 'lay coroners'—carefully chosen individuals from various fields of expertise—under the direction of the Chief Coroner. The Chief Coroner has a staff of approximately 147 people... (p. 47-48).

The report presents statistic highlights for the year. In 1994-95, of the 9524 deaths reviewed by the coroners service, more than 4300 inquiries were undertaken. "Of the 2283 unnatural deaths, 1483 (65 percent) were classified as accidents, 501 (or 22 percent) as suicides, 192 (8 percent) as undetermined, and 107 (5 percent) as homicides" (p. 48). Legal and social historians (MacDonald and Murphy, 1990; Granger, 1984; Thurston, 1980; Secretary of State for the Home Department, 1971; Forbes, 1978; Hunnisett, 1961) observe that many of the early coroners' duties survive today including holding inquests into sudden, violent or unnatural death, or when a body was found in the open and the cause of death was unknown, and also, when a death occurred in prison. These are not unlike the duties outlined in the BC's Coroners Act.

The compilation of records specific to suicide tended to note the manner in which persons killed themselves. According to MacDonald and Murphy (1990) self-killing in Tudor England was not unlike the crime of murder and those found guilty of "felo de se"

(felon or murderer of the self) by a coroner's jury heaped punishment not only on themselves but also on their families. Like other convicted felons, all they owned was confiscated by the Crown or its representative. The corpse itself was not permitted a Christian burial:

The night following the inquest, officials of the parish, the churchwardens and their helpers, carried the corpse to a crossroads and threw it naked into a pit. A wooden stake was hammered through the body, pinioning it to the grave, and the hole was filled in. No prayers for the dead were repeated; the minister did not attend (p. 15).

The clash between secular and religious attitudes and actions toward *felo de se* was apparent in both the manner in which the body of a suicide was dealt, and in the confiscation of the individual's property. MacDonald and Murphy (1990) suggest that juries had little problem with a verdict of *felo de se*, but did not like to disinherit the suicide's heirs:

Reverence for the rights of inheritance is the central value of any agrarian society. The law of self-murder pitted that powerful sentiment squarely against the demonic horror of the crime (p. 78).

In some respects the shift toward a more secular attitude regarding self-killing is reflected in decisions of coroners' inquests to gradually bring forward verdicts that did not place blame on individuals but which considered them "non compos mentis" (not in the right mind), rather than *felo de se*. Through his analysis of inquest documents however, Forbes (1978) suggests that while superstitions regarding the murdering of self had lessened somewhat by the end of the eighteenth century, "*felo de se*" continued to be dealt with cruelly.

Bringing forward a verdict of suicide in the medieval or Tudor eras meant that

because of limited investigative techniques in uncovering physical signs of self-murder, the coroner and jury were reliant on other strategies. As will be seen later, contemporary “signs” of suicide used to draw conclusions in suicidal deaths often parallel earlier indicators. Through the 1500s and 1600s the “signs of self-murder” to be sought by the coroner at an inquest might include: “a solitariness, ‘a strange change in outward behaviour’, speeches and actions implying that something important was going to happen, leaving notes, previous attempts, melancholy, madness, ‘words or gestures that implied depressed moods’ ...” (MacDonald and Murphy, 1990, p.227-231). An important clue to the resilience of ideas of what might constitute a major suicidal sign appeared to be melancholia. In their research MacDonald and Murphy found that both laymen and doctors recognized the symptoms of melancholy--“a man very sad, who having his arms wreathed up, and his hat pulled downe in his eyes, goeth up and down in a discontented manner” (MacDonald and Murphy, 1990, p. 230). In their testimony at coroner’s inquests then, witnesses would describe the deceased as having appeared melancholy. Regardless of their education, they were, according to various inquisition records able to demonstrate an “informed awareness of the traditional scientific explanations for the disease and its symptoms” (MacDonald and Murphy, 1990, p. 231). Even then, people were cognizant of the words necessary to produce the necessary stereotype, or sign for a particular outcome.

As I described in Chapter Three, suicide as madness has been used to argue that a person cannot be rational and take his or her own life. Like melancholy, madness held particularities that could be invoked at inquests, and it became a proof that someone had killed himself. Emanating from this, physical pain associated with various illnesses was

thought to have caused a “mad” person to take his or her own life. MacDonald and Murphy (1990) argue however, that while inquest witnesses may have been able to provide these various signs as proof of suicide, they also provided testimony of what they saw as more subtle changes recognized as the result of living with the deceased or being in the same community where behavioural changes were apt to be noticed:

We monitor ourselves, playing out the roles that we ourselves and others have fashioned for us, drawing on a common ‘script’ and understood by members of our culture. The signs of suicide in early modern England were expressions, gestures and actions that seemed to imply a foreshortening of time and discontinuity of identity (p. 236).

Coroners’ judgements in self-killing of “felo de se” or “non compis mentis” were based then on a number of factors that included physical evidence, perhaps obtained through a post-mortem, as well as secular and religious signs and motives.

For the purposes of my inquiry, the juxtapositioning of an independent coroner system with the establishment of an administrative system to compile accurate death records and investigate criminal activity can be seen as an important regulatory strategy and another step in modern bureaucratic capitalism. It is also perhaps, as it was in medieval and early modern England, a measure of cultural and social change. With the historic information in mind I turned first to coroner’s policy on suicide and to the Judgement of Inquiry, as I began to figure out how much of the past influences current judgements and conclusions.

## **Suicide and the Work of the Coroner**

I am arguing throughout this chapter that the work of the coroner transforms and manages the experience of a gay man who killed himself, into an official account. In other words it shapes the act into something that happens on a government document. However, before I begin to describe the analysis of the judgement of inquiry, and how Jay's death challenges the rules for dying that I saw embedded in this official account, I want to return briefly to the discussion I took up in Chapter Four regarding the role of documents within Smith's approach to the social organization of knowledge. When I began to examine the Judgement of Inquiry as an official record of Jay's death, I found it to be an excellent example of Smith's (1990a) argument that:

in organizations concerned with processing people, there are characteristic forms of coordinating work processes focused on the individuals who are their objects...Individuals are known as *cases* under the interpretive aegis of their records (1990a, p. 89).

A document is not an inert bureaucratic form; it "does" a particular type of work. A document such as the Judgement of Inquiry for example, organizes the daily work that officials have completed. It maps a flow of ideas; and as I will show, people like Jay become shaped by the documentary form and are organized in relation to it. Kinsman (1995) observes for example, that "texts are actively used within ruling relations to organize and coordinate social relations" (p 82). I am not suggesting that our complex bureaucracies could function without standardization. However, to understand the power inherent in documentary order it seems necessary and useful to examine how so-called idiosyncratic experiences become translated and organized to fit a particular official

interpretation of those experiences.

Practising textual analysis as Smith suggests, enabled me to begin to see how particular interpretations of a document are made, and for what purposes they are intended. When I began to examine the Judgement of Inquiry document I became aware of its ideological nature; that is how the coroner's practices or the way in which she was mandated to work to complete the document as part of her job and the state's requirements in enumerating a death, helped ensure the resilience of notions of suicide and depression.

I know how much activity most social workers and academics face regarding the administrative requirements of our work. In the course of our careers we may complete hundreds of case files, fill out thousands of forms, reports, and documents, record meetings or interviews and so forth. We take for granted our work as professionals and the documents we complete "on" other people such as "student profiles" or "risk assessments" or "surveys" that transform what we observe and record in our daily work to particular administrative requirements. After awhile we may take the information on these documents for granted as we tick off the boxes or provide brief commentaries under various headings. The accumulation of our "ticks" and "comments" are often collected and forwarded to the administration and changed into statistics about various aspects of our work--profiles of clients or students, categories of risk, numbers of births or deaths, and so on.

The Judgement of Inquiry is just such a common-place document, on which a government representative--the coroner-- after the work of investigating the

circumstances of a death, “ticks” the appropriate box to indicate the manner in which an individual died or was killed. One such box is “suicide”. As I mentioned above, the collection of official statistics has long been associated with coroners’ work (Forbes, 1978). They forward data to official repositories on the numbers of deaths they have classified in various categories within their jurisdictions. Regarding “suicide” for example, these statistics are compiled in publications such as those produced by Statistics Canada (1996), and may be used by others to argue for particular services or programs for target populations; for example, suicide prevention programs for gay youth or aboriginal communities. The data collected may also be employed to create finely-tuned assessment tools or training programs, by agencies working with those who consider themselves, or are considered by others to be suicidal. Twentieth century bureaucracies rely on a complexity of standardized files, records, and forms to connect to one another across various sites. The Judgement of Inquiry document has a specific purpose as do most government reporting forms. It might be thought of as the “conversation” or “currency” of the state, and functions as a link among professionals in bureaucratic sites—pathologists, hospital physicians, coroners, police. More than linking, however, the accounts produced construct a particular version that becomes the official or authorized account of the death.

## **Doing Judgements: Making Death into an Official Account**

Information about how the coroner works to classify a death is found in the British Columbia Coroner's Service Policy and Procedures Manual (1991) and is used to complete the Judgement of Inquiry. In Chapter 2, under the heading Judicial Services, the preamble states that:

**The coroner is charged with determining the manner and cause of every reportable death. This determination is registered with Vital Statistics via the Coroner's Medical Certificate of Death (Section 1, subsection C).**

This section then provides definitional guidance to the coroner regarding five classifications of death:

- 1) The coroner or jury shall classify the manner of a death and record it on the Coroner's Medical Certificate of Death, Judgment of Inquiry and Verdict of Coroner's Inquest as follows:
  - a) **NATURAL:** Death primarily resulting from a disease of the body and not resulting secondarily from injuries or abnormal environmental factors;
  - b) **ACCIDENT:** Death resulting from an action or actions by a person causing death to himself, or a death that results from the intervention of non-human agency;
  - c) **SUICIDE:** Death resulting from self inflicted injury, with intent to cause death;
  - d) **HOMICIDE:** Homicide is a neutral term and is used to classify a death that resulted from injuries caused directly or indirectly by the actions of another person, without imputing blame or fault to that person;
  - e) **UNDETERMINED:** Death which, because of insufficient evidence or inability to otherwise determine, cannot reasonably be classified as natural, accident, suicide, or homicide.

Authority for these “Classifications of Manner of Death” emanates from the Coroners Act and the Vital Statistics Act. In sub-section G of the policy, “Types of Deaths” the preamble provides the coroner with a description of the classification of suicide:

A suicidal death is the result of an intentional destructive act. Although often planned it may be an impulsive or irrational action. A motive may be present but is not always determined despite investigation which may result in family’s denial of suicide (Chapter 2, Section 2, Sub-section G).

Section 2 also guides the coroner in how to investigate death that may be a possible suicide:

- 6) The coroner shall obtain medical and psychiatric histories
- 7) Suicide investigations should include, but not be restricted to, the following areas:
  - a) current life stresses
  - b) loneliness as well as more concern with interpersonal stress, financial problems and health
  - c) family stresses and loneliness
  - d) in young persons (under 25 years), suicidal behaviour becomes prevalent and predictable phenomenon during mid-adolescence
  - e) any sign of severe depression followed by an air of well-being
  - f) recent writing of a will or giving away treasured possessions
  - g) talk about going “away” or going on a long “trip”
- 8) The coroner will consider utilizing the services of a behaviouralist

In determining how the death should be classified, such phrases as “current life stresses” (a) or “severe depression” (e) show how various indicators given to the coroner through the Coroner’s Act and policy, direct the investigation to a reliance on psychiatric and psychological expertise. The policy directive above illustrates a connection to psychiatric work and the work of other professionals who create definitions of depression and of suicide. These definitions get worked up in authoritative texts such as the Diagnostic and Statistical Manual (DSM-IV, 1994) and find their way into professional textbooks and various training materials. The relationship between the coroner’s policy stated above

(Chapter 2, Section 2, Subsection G) and the work of other professionals is evident in printed materials given to me by a coroner. One handout (with no other designation of the place of its origin) entitled “Operational Criteria for Determination of Suicide (OCDS)” reads:

**I. Self-Inflicted:** There is evidence that death was self-inflicted. This may be determined by pathological (autopsy), toxicological, investigatory, and psychological evidence, and statements of the decedent or witnesses.

**II. Intent:** There is evidence (explicit, implicit, or both) that at the time of injury the decedent intended to kill himself or herself or wished to die, and the decedent understood the probable consequences of his or her actions.

**A. Explicit verbal or nonverbal expression of intent to kill self.**

**B. Implicit or indirect evidence of intent to die such as the following:**

- ▶ Preparations for death inappropriate to or unexpected in the context of the decedent’s life.
- ▶ Expression of farewell or the desire to die or an acknowledgement of impending death.
- ▶ Expression of hopelessness.
- ▶ Expression of great emotional or physical pain or distress.
- ▶ Effort to procure or learn about means of death or to research fatal behavior.
- ▶ Precautions to avoid rescue.
- ▶ Evidence that decedent recognized high potential lethality of means of death.
- ▶ Previous suicide attempt.
- ▶ Stressful events or significant losses (actual or threatened).
- ▶ Serious depression or mental disorder.

A small note at the end of the criteria states that:

These criteria were developed by a working group of persons representing the Academy of Forensic Sciences, American Association of Suicidology, Association for Vital Records and Health Statistics, Centers for Disease Control, International Association of Coroners and Medical Examiners, National Association of Counties, National Association of Medical Examiners, and National Center for Health Statistics.

I am providing the criteria as outlined by this American group as an example of how the coroners service makes use and sense of professional discourse. The need to have explicit classifications and definitions of death, even one called “undetermined”, makes sense in light of the orientation of the classifications toward the recording of vital statistics regarding numbers and types of deaths in a province or country. During his investigations, one coroner I spoke with told me that:

I always worked with my own personal definition [of suicide]. I sat down and I'd look at the type of investigation I would do around a suicide and I had it written there. And what I had written was 'suicide is a term that I would apply to a death where directly or indirectly by their own negative or positive actions caused their own death and where there is evidence to support that'. Let's say you're using medication and you decide you want out and you know that not taking it...I looked at all of those aspects even in an elderly person...You have to talk to a lot of people, sometimes, to get all the facts. And then you might not even be able to make a judgement.

His remarks indicate how he tried to make sense of this classification despite policy guidelines. According to a coroner with whom I spoke, two further handouts used in skills training for suicide prevention counsellors collapses several items from lists<sup>22</sup> entitled respectively, “How to Recognize a Depressed Person: Signs and Symptoms of Depression” and “How to Recognize a Suicidal Person”. While the policy presented above asks coroners to seek reports of any sign of severe depression followed by an air of well-being, one handout says that a suicidal person will “have been very upset and agitated but suddenly become calm and cheerful (the decision has been made).” Again, the policy directs coroners to examine whether or not the person who has killed him or

---

<sup>22</sup>There was no reference cited on this two-page handout, although an attachment related to another aspect of training made reference to E. Schneidman's (1985) work.

herself has talked about going away, or going on a long trip. The handouts tell us that a suicidal person is making plans for death or absence. While the handout states that the suicidal person will be giving away prized belongings, making a will, and getting their affairs in order, the policy directs coroners to investigate whether the individual was engaged in the “recent writing of a will or giving away treasured possessions.” The coroners I spoke with were often involved in training people who would eventually counsel those who were contemplating “suicide”. The investigation into a death, often able to be presumed by the position of the body and the means by which it appears the person died, is oriented toward states or definitions of mental health already inscribed in official discourse as in the examples above. It is evident that official records rely for background facts on the lived experience of those involved.

In Jay’s case, the facts or “particulars” about his state of mind were gathered by the coroner from one of his doctors who revealed two previous hospital admissions. When Jay was discharged on the last occasion the coroner writes that “he was felt not to be suicidal although he remained in a state of depression.” Case notes from other professionals comprise the record and these become entered into the official record as facts which contribute to the particulars of the case. As was done historically, how family members or doctors or neighbours who witnessed his death, or who know certain facets of his life, make sense of it, and then respond to questions about it from the investigating officers or coroners is recorded on bureaucratic documents to stand as facts about the actual cause of death.

During their investigation which requires that coroners attempt to determine the

“suicide’s” mental state, policy suggests that if necessary, they may call on the skills of a behaviouralist to assist them in constructing a psychological profile. A coroner I spoke with told me that, “If I had real difficulty with it [classifying the death] then I’d ask for a behaviouralist to do an investigation; to do an in-depth investigation--almost a psychological profile--enough to find out.” Again, the coroner’s use of the discourse on suicide and depression appears to be that informed by the disciplines of psychology and psychiatry. The multidisciplinary field of suicidology is influential in this regard. Oriented specifically toward preventing suicide, the contributors are primarily psychologists whose research provides the background information leading to an assessment that will determine whether a death will be classified as suicide. I was seeing the re-construction of a life to accomplish official purposes.

### **“In a depressed state of mind...”**

During an interview, an AIDS social worker told me that she sees a great deal of what she would call depression in those with HIV/AIDS, and considers it normal. “It drives me crazy when a patient’s in hospital and someone says ‘he’s really depressed’. No shit! He’s 27 years old and dying of AIDS. I’d be depressed.” In her work on how violence against women is socially organized, Walker (1995) examined a series of reports which she treats “as moments in a conceptual process bringing into being a ‘social problem’” (p. 65) The coroner’s conclusion that Jay “...took his life while in a depressed state of mind due to his diagnosis of AIDS” treats the term “depression” in a similar manner by assuming

common-sense knowledge of the word “depression”, as well as its taken-for-granted links with suicide and with AIDS.

The coroner’s work process following official procedures is accomplishing a cause of death definitively. I am arguing that this is a ruling relation. According to the Judgement of Inquiry, one of the investigative tools used by the coroner to determine the cause of Jay’s death, was the post mortem—both physical and psychological. In understanding the relationship among depression, HIV disease and death classification within relations of ruling it is critical to begin to see the relationships also, between the psychiatric establishment and its hegemonic grasp on disease definitions and diagnosis. Most clinicians whether they be social workers, psychologists, or psychiatrists diagnose depression according to measures developed by the American Psychiatric Association.

In Canada the marriage of depression and AIDS is evident in a document I examined entitled Depression: An Overview of the Literature (1995) produced by the Canadian Mental Health Association. The preface states that the overview was prepared in association with the AIDS Care, Treatment and Support Unit of Health Canada with funding under the National AIDS Contribution Program of the National AIDS Strategy of Health Canada. Authors of the report indicate that they have attempted to balance both the medical and psychological understanding of the “illness” of depression; and while they do not offer what they term a “critical evaluation of the topic”, nonetheless one of their hopes is that the overview “...will stimulate further investigation of depression and its relationship to other disorders, including HIV/AIDS” (p. 7). This document acknowledges that clinicians require more than merely knowing how to recognize and

treat depression. Yet while stressing that the broader social context within which an individual's depressive state arises must be taken into account, they nonetheless observe that:

Depressive disorders form a category of clinical or medical diagnosis and fall under the general heading of affective or mood disorders. The system of criteria found in the Diagnostic and Statistical Manual of Mental Disorders--Fourth Edition (DSM-IV)...is widely accepted by mental health professionals as a standard of clinical diagnosis (p. 10).

While they are not necessarily considered mental health professionals, Coroners might be considered among the professionals or user groups of knowledge about depression.

Without thoroughly analysing the types of depression or the range of factors, types of assessment and prevalence associated with it, coroners appear to know how to construct the relationship between depression, AIDS and suicide and they must do so in order to undertake their official work. This Canadian Mental Health Association overview of research into depression acknowledges that the ability to diagnose depression in people with HIV disease is not simple because of the factors connected to the syndrome. These include issues concerning whether depression is caused by medication used to treat the disease, or if it results from the symptoms associated with HIV/AIDS such as fatigue, sleep disruption, weight change and so on. Whatever answers may be discovered, HIV is said to have a significant impact on mental health. Factors such as having a terminal illness, changes in quality of life, fear of dying, stigma, homophobia, discrimination may lead to feelings of isolation, fear and rejection that could heighten the stresses already associated with the disease. One of the studies by Catalan (1988) presented in the overview suggests that psychiatric disorders are said to be

prevalent with a diagnosis of full-blown AIDS. Citing further research on HIV/AIDS and depression, authors of the overview note that:

A 1984 retrospective study of the patient charts of 52 AIDS patients hospitalized during an acute illness revealed that 17% exhibited severe depression [using the Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM-III)]. An additional 65% had some form of mood disturbance (Perry and Tross, 1984). While the results must be interpreted in light of the retrospective nature of this study, this study highlights the emotional and psychiatric needs of persons living with AIDS (Johnson, 1987) (Canadian Mental Health Association, 1995, p. 40).

Although the methodology of the quoted study is not reported, we have to assume that the authors found, as data, the comments that knowledgeable reporters, themselves using official diagnostic categories, would have been making. All of this “knowing” is socially organized, and is the topic of considerable debate, as the following discussion begins to suggest. The overview also suggests that research exploring the relationship between AIDS and suicide is inconclusive. While some work indicates its prevalence among persons with AIDS, other work refutes such a conclusion.

The inscription of earlier struggles and debates to define, categorize or philosophically come to terms with self-killing is reflected in two additional contemporary Canadian reports that I examined. In 1987 the Report of the National Task Force on Suicide in Canada was published by the department of National Health and Welfare. According to the chair of the report, the Task Force was established after an international conference for suicide prevention focussed attention on suicide in the Canadian context. In 1994 an update was prepared by members of an expert working group on suicide, whose mandate was to make “...the information appropriate for the current time frame” (Health Canada, p. xi). The role of the original Task Force was to

present current knowledge on the epidemiological nature of suicide, its causes, how it can be addressed through various stages of intervention, recommendations to be taken up at local, provincial and federal levels, further areas for study, and how to provide their findings to Canadians. Both reports have as an organizing feature, pages of current statistics regarding aspects of suicide in Canada. The 1994 update provides no definition of suicide; neither is there a discussion on how definitions come to be used as common-sense parlance. This may suggest that there is an assumption that those making use of the term incorporate the same meaning across professions, cultures, and jurisdictions, and are thus taking definitional knowledge for granted.

Despite what I saw in the Judgement of Inquiry into Jay's death, the Task Force on Suicide reports that it tries not to assign causal significance to various possible contributors to suicide such as psychiatric disorders. Yet as indicated in the 1995 overview on depression discussed above, those with depressive disorders are found to be at higher risk for suicide, with rates of depression as high as 70% among suicide completers (Barracough, Bunch, Nelson and Sainsbury, 1974). A further study cited in the depression literature overview (Tanney, 1992) suggests that since it is difficult to distinguish between depression as a mental disorder and depression as a symptom, it is not easy to assert depressive disorders as a factor in suicide. Nonetheless, 27-39% of people who had completed suicides had experienced stressful life events such as losses or interpersonal conflicts within the six weeks prior to their attempt (p. 19). Of high risk groups, gays and lesbians were more than two to six times more likely to attempt suicide; however, Tanney (1992) considers this evidence 'too thin' in light of what he considers

scarce and over-interpreted data.

Surveys conducted by members of the Task Force on Suicide within faculties of Medicine, Nursing, Social Work and Psychology revealed a limited level of suicide education in all disciplines. They comment that, “In many programs, suicide was not treated as a separate issue and was subsumed under the general topic of depression” (emphasis mine, p. 63). While the Task Force agrees that evidence does link some mental disorders to suicide, they caution that “...[T]he problem arises in seeing all suicides as irrational, and in drawing a direct causal link between mental disorder and suicide (p. 2). Despite this mild rebuke, there appears to be a general consensus among mental health professionals that most suicidal behaviour is the result of irrational mental states brought on by mental illness.

In a brief discussion of suicide and those with terminal illness, researchers whose work is included in the task force document suggest

....that it would be unreasonable to presume that a terminally ill person’s expressed desire to die can be dismissed as irrational, impulsive, poorly thought out, inconsistent with his or her values, or symptomatic of psychiatric disorder. However, as with other suicidal persons, the likelihood of ambivalence must always be recognized, as well as the possibility that treatable depression or other factors amenable to change are influencing the person in the direction of suicide. To assume that terminal illness is, in itself, sufficient justification for suicide, and that every expression of suicidal intent by a terminally ill person should be taken at face value, would be to devalue the lives of these people and to neglect opportunities for making their final days more meaningful and comfortable (p. 80).

Despite appearing to remove the link between terminal illness and suicide, the linking of terminal illness and depression appeared to organize the particulars surrounding the conclusion of Jay’s death as “suicide”.

In the Task Force report, suicide and HIV disease is given only brief mention, but my examination of both reports provided an example of what Smith (1987) calls an ideological circle. An indication of the relationship of the two comes from information on suicide prevention centres that report numerous calls from AIDS patients considering suicide. The arguments and cautions presented in each of these reports certainly seems to direct attention to the complexity of the act of self-killing and reflects the underlying stance of what might be termed “the sacredness of life” philosophy, regardless of political positioning. The 1994 Task Force document states that most of the factual data collected to determine factors leading to suicide, comes from official statistics. The statistics themselves, are drawn from medical and other officially organized forms and documents from hospitals, coroner’s reports, police records, or social work client reports, which name particular subjective ways of being in the world-- “depressive”, “phobic”, “suicidal”. These terms are drawn from sources such as the DSM-IV (1994) whose manner of research and classification is under scrutiny from psychiatrists, clinical social workers, and psychologists concerned with the sex and cultural biases inherent in such as classification scheme (Kutchins and Kirk, 1989).

### **“I find his death to be suicidal...”**

Coroners function in their day-to-day roles as organizers of a particular professional knowledge about death and how it is to be classified, certified and registered. Among the various labels they have the authority to assign to a lifeless body is that of “suicide”. Individual coroners cannot say anything about the broken body or the distraught family because they cannot redefine the terms or categories by which they are authorized through their legal and professional roles to classify a death. For the purposes of record keeping and administration the terms “suicide” and “AIDS” are categories rather than traumatic experiences affecting numerous people including lovers, families, AIDS workers, health professionals, physicians and others involved in actual lives. These categories function as a kind of impersonal shorthand in which the work of complex bureaucracies keep track of the beginnings (birth certificates) and endings (death certificates, coroners’ reports) of its citizens. For example, the actual events leading up to a birth—the new parents’ anxiety, joy, and perhaps fear; or those surrounding a death—the excruciating grief, disbelief, sadness, horror—are obliterated in official documents. The categories, part of the administrative work in which the beginnings and endings of life are officially accomplished, thus write over the human interactions, feelings, and meanings that these experiences create. An act of taking one’s own life is transformed through administrative textual practices into a particular kind of death—a “suicide”—that is then understandable and reportable.

Yet the category “suicide” in the coroner’s Judgement of Inquiry can be seen as

an active world in itself. In it exists an order and a language and a set of blueprints that guides the structuring of events and provides ways for a coroner to act that fit with the discourse surrounding the category. In Swift's (1995) discussion of the category "child neglect" for example, she has examined a similar kind of discursive responsibility carried by child welfare professionals and observes that, "Categories....contain within themselves implicit social 'instructions' for their understanding, instructions that allow specific instances and experiences to be appropriately matched to them or discarded" (p. 67). As with social workers whose "child welfare work is organized around the problems of identifying and categorizing the experience of clients to determine its 'fit' with specific social categories" (p. 68), the coroner's work is organized around classifying a death through the incorporation of ideas put forward in the contemporary definitions of "suicide" that carry with them the detritus of the category.

Situating AIDS and depression in the context of the Judgement of Inquiry provides particular social instructions about how "suicide" is to be read. The coroner's investigative work and the statistics produced from that work, contribute further to professional and psychiatric discourses. These discourses, which drew on particulars obtained from coroners' reports in the first place, became in turn, the sources from which the local coroner was able to provide the definition of suicide and depression that she used to label the case. The instructions, or the schema for how to read the death as "suicide" can be located in the coroner's conflation of AIDS and depression, and the coroner's policy that conflates suicide and depression. As seen in the excerpt at the outset of this chapter, the coroner's work in investigating a death and in being able to

conclude it was suicide ultimately conflates the discourses of depression, suicide, and AIDS.

The work process of being able to assign an “x” to the box “suicide” in the section of the document entitled “Classification of the death” begins in the twentieth century, as it did in the time of the medieval coroner, with the discovery of an apparently lifeless body. One coroner described to me his initial involvement:

Someone would first become aware of the death—and I presume it’s a sudden and unexpected death. They would probably dial 911, phone the ambulance or police—the ambulance or paramedic would activate the police, who in turn would activate the coroner. In other words, section 9 of the coroner’s act imposes on anybody who has reason to believe that someone has died in suspicious [sic] circumstances is bound under the law to report to the coroner. At that stage you’d go out and attend the scene—the scene should not be disturbed until the coroner gets there. Once the implication of criminal procedures has been negated the coroner combs the scene. In the criminal investigation the scene belongs to the criminal investigators—but the body, the legal/medical end of it is always under the jurisdiction of the coroner. Regardless—we decide on the removal of the body, we decide on the autopsy procedure, we have continuity on the body with the police then the police attend the autopsy. We’re the ones that determine the cause of death, we’re the ones who verify that cause of death.

It is this discovery of the body that activates ambulance, police, perhaps other emergency response teams. If police or medical authorities have questions regarding the circumstances of the death, the coroner whose authority comes from the chief coroner by virtue of his/her appointment by Lieutenant Governor of the province, becomes involved. With this authority, and with accountability to the Attorney General, coroners must issue warrants for the possession of the body and for the investigation of the circumstances of the death. They can inspect any place that the deceased person was, can seize anything believed to be material to the investigation, and can obtain information from any records

relating to the deceased. He or she investigates a death in order to come to some conclusion about how an individual died, and defines the death according to one of five classifications mentioned previously. The work of ordering this death into its proper frame on behalf of the state begins as the coroner completes the documentary work.

The Judgement of Inquiry is formal and official and is identified as such by the Province of British Columbia Coat of Arms in the top left-hand corner of the document. The first page provides a face sheet (hereafter referred to as Part 1) to be completed through the typing in of short responses, and is signed by the coroner as the government representative. It provides a summary of demographic data--name of deceased, address, place of death, and so forth-- as well as noting how a death is classified. The second part of the document (hereafter referred to as Part 2) is entitled "Circumstances and Recommendations as a Result of the Inquiry" and is divided into four major sections: summary of events; medical history and background; post mortem examination; and conclusion. It too is signed and also initialled by the coroner, and includes the deceased's name and case number. Each part of the document depends on the other for completion. That Part 2 carries official status as a formal piece of the Judgement of Inquiry is indicated by the Provincial Coat of arms in the upper left-hand corner. Parts 1 and 2 depend on one another for their completion as will be seen.

**PART 1:** The coroner notes where in the province the coroner's court is held. In the upper right hand corner of the form is space for the coroner to apply her case number. Because the police were involved early in the investigation of the death in question, the police case number, too, has been typed in beneath that of the coroner. These case

numbers illustrate the link between the institutions of Attorney General, and the city or regional police force, and the coordination of work between the two. Jay is a “case” both for the coroner and the police as indicated by the corresponding numbers each employs to track him through their systems. Re-creating Jay as a possible “suicide case” requires the coroner to assemble facts about his death in concert with the police who also have official responsibilities for such a death. Smith (1990a) notes that:

As professions and professional discourses have been established, case histories and case records have become part of the knowledge basis of the professional discourse, as well as of professional administrative practice. Methodical procedures for writing them are developed, ensuring that records are collected in standardized ways and not as idiosyncrasies of individuals or particular hospitals or clinics (p. 90).

In the case of a coroner’s report an understanding of the Coroners Act and the discourses related to the assignment of a particular classification of death (how suicide and depression may be linked for example) help both police and coroner in this regard, and evidence may be gathered that supports a given approach to the taking of one’s life.

Two closed rectangles provide space for the surname and given names of the person who is the subject of the Judgement of Inquiry; and immediately below is space for the subject’s address. The format of Part 1 requires that the coroner state his/her name after the name and address of the deceased, presenting up front her authority and the “fact” that she has looked into this death that was reported to her on a particular date. The reporting or telling of information to the coroner comes, as noted above, from a variety of sources which are explained more fully in the narrative sections in Part 2 of the Judgement of Inquiry.

The coroner must also record the age, sex, date of birth and whether the deceased is Native. She then completes the place of death (the address at which or near which the death took place) and the estimated time of death. The simple recording of the time sets up a legal responsibility—date and time of pronounced death. The time of death was pronounced by a doctor at the hospital to which the body was taken. Once the emergency workers deliver the body to the hospital it becomes entered into procedures set up for “unnatural” deaths in hospital. Death is entered into the official record at the hospital and “time of death” is then officially provided to the coroner for entry into her report. The doctor must also be the authority to tell the family of the death, and he or she pronounces the body dead. The circumstances of the death are often further determined by an autopsy. The document thus also reflects the link between the coroner and hospital staff and hospital procedures. It also indirectly outlines procedures for determining a variety of actions, for example, who can have access to the body, nursing/doctors practices, the role of chaplain, organization of the trauma room and its regulations, when someone is officially dead, and when family can claim the body. As in the creation of birth records that Smith (1990a) describes, hospital practices in the case of a sudden death correspond to various forms and achieve the same “order”:

....even though for the hospital each birth differs, it responds with a standardized record-keeping routine. Thus hospital and medical practices anticipate and provide for the conceptual structure of the birth certificate and the demographer’s count; their routine practices also constitute birth as merely birth (p. 87).

Part 1 asks for the type of premise at which the death occurred, by what means the body was identified at those premises, and by whom. Immediately following this information,

the coroner indicates to whom the body was released, and on what date. In the document I am analysing this may have been one of the last pieces of information entered, since in the case of this report regarding Jay's death, his body was not released to a memorial services agency until two days following the death. In the case of death that appears to be a suicide, the coroner requests a post mortem. On the document it must be indicated if there was a post mortem, as well as when and by whom it was conducted. "Yes" or "no" must also be checked off next to "toxicology examination". Again a date and by whom it was conducted must be indicated. Relevant findings are listed in the space provided.

A major section in Part 1 is the Medical Cause of Death. There are two subsections: immediate cause of death; and other significant medical causes contributing to death. Although Jay's death was classified as suicide, this is not the cause of death. The "immediate cause of death" was "massive deceleration injuries...due or as a consequence of a fall". Written in the space "Other significant Medical Causes Contributing to Death" was "AIDS". The coroner's investigation had involved a discussion with another family member as well as Jay's doctor. Had a member of the family perhaps not been in Jay's apartment to inform the police that he had AIDS, this may not have been included in the official record. However, it may have been revealed through post-mortem testing or through medical records or other interviews with his doctors. Nowhere on the document, except in her conclusion, is depression suggested as a cause or contributing fact to the death.

Toward the end of the document is the "Classification of Death". By putting an "x" in the box beside the word "suicide", the coroner classifies this particular death. The

work of the investigation – interviews to determine identity of the body, state of mind of prior to death, pronouncement of death by a medical doctor (also certified and able to make such pronouncements); an autopsy with its dates and conclusions and toxicology examination (in Jay’s case, not conducted until 16 days following the death)--has led to this conclusion. The date that the report is completed, and the coroner’s signature concludes the first of the three page Judgement of Inquiry.

**PART 2:** The narrative portion of the Judgement of Inquiry also indicates where in the province the coroner’s court was held. The case number is inserted in the upper right-hand corner. The police case number is not included. The upper left-hand corner has the provincial coat of arms, but nothing else to indicate that the work involved in producing the document is under the aegis of the Ministry of Attorney General. The head of the document reads “Circumstances and Recommendations as a Result of the Inquiry into the Death of.....”. Two closed rectangles provide space for the names of the deceased. Below the names, space to write the narrative report is provided within a thin-lined box.

The “Summary of Events” section states that the coroner’s investigation was activated by a neighbour who heard a “bang on her balcony railing ...” and called the police who gathered preliminary facts in the parking lot. The Summary also reports that the building manager met the police and told them who the dead man was, that the police searched Jay’s clothing and found official identification in the form of a drivers’ licence that verified the building manager’s visual identification. Once this was complete, they arranged to have the body transported by ambulance to the hospital, and continued to interview neighbours, and locate family members.

The medical history section provides confirmation of an AIDS diagnosis and a brief description of previous hospital admissions for depression. The post mortem section describes the results of the physical autopsy and the toxicology report. These findings are also entered into Part 2. It is in the “conclusion” to this section of Part 2 of the document that all elements of the coroner’s investigation are drawn together.

The categorization of a death, in this case the ruling or conclusion that the death was “suicide”, is made because the definition of it and the descriptors of the death fit the schemata used by coroners’ service in British Columbia. The coroner has to determine how, when and under what circumstances the body came to be a corpse. Jay did not leave a note explaining his action, but he apparently left clues that the coroner could follow, clues that could be fitted into the definition of suicide. The investigation, carried out through interviews and an examination of the body, assisted the coroner in reading these clues to capture the distinction between a homicide, suicide, or so-called natural death. One such clue for example, was provided by doctors the coroner interviewed who related not only that Jay had AIDS but that he was “depressed” prior to his death. The answers the coroner received throughout the investigation were reshaped when she returned to her office and was required to dis/embodiment the life once again, by placing information about his life and death into an organizational format. As illustrated above, a coroner’s location within the medico/legal arena does not permit him or her to engage in work without relying on social science categories and concepts about depression, suicide, or HIV disease. The Judgement of Inquiry documents the work of the coroner and stands as an official account of how she worked to reach the conclusion that Jay killed himself

because he was depressed about the fact that he had AIDS. The coroner's version is the official pronouncement and certification of his death as suicide and provides an indication of how the relations of power and authority surrounding the definitions of death are made visible.

### **Conclusion: What the Coroner's Work Accomplishes**

Jay struggled to come to terms with fear of dying, how to live with mounting health problems, and increased dependence on others. That he killed himself is interpreted as something that can happen when a person has AIDS because he is depressed about being terminally ill. Not all professionals agree with this interpretation; nonetheless, the common-sense relationship between the two allows (as demonstrated above) for capturing the unruliness of taking one's own life and fitting it back into a manageable category--suicide. Despite what I as a sister or friend may know about a gay man with HIV disease who killed himself, the story of the death that I know about is disrupted by an "official story" created through the selection and arrangement of various facts that have emerged through the telling of the story by family and doctors and other witnesses. The lived connections of the story--a gay man's anger at dying so young, the increased loathing of his sexuality, fear of what death will feel like, fear of pain, dependency, and so on are the kind of "particulars" that the coroner is after in her investigation. I am contrasting here, her procedures for making sense of a death, and Jay's own determination of how to live and die. Other interpretations about his living and dying had

to be subsumed to produce the official version. There is a difference it seems to me, between the need to determine a “cause” for which evidence can be marshalled from discourse, and noting that Jay had decided to end his life on his terms. The latter does not need “depression” as a cause, nor any other of the “particulars”. The coroner’s investigative work and the statistics produced from that work, contribute further to the professional and psychiatric discourses which can now draw on the “particulars” she noted as the basis for defining suicide and depression in the case. The instructions, or the schema for how to read the death as “suicide” can be located in the coroner’s conflation of AIDS, depression, and suicide, and the coroner’s policy that conflates suicide and depression.

In the Judgement of Inquiry that I examined, the coroner’s assemblage of facts about Jay’s death from witnesses and ancillary reports is recorded on the document so that it is logical to understand the act as suicide. Not unlike the nineteenth century application of the term melancholia to gestures and postures of those deemed suicidal, it seems evident that the coroner easily conflated AIDS with depression, which itself has been described as a series of other indicators that can result in suicide. She could “see” Jay’s death to be suicidal and “surmised” that AIDS leads to depression which subsequently led, in this case, to suicide. The “sign” of depression is integral to a suicide investigation. To a certain extent the decision makes sense. Coroners, as well as other professionals, carry ideas of who persons with AIDS are. The AIDS-as-imminent fatality construct provides the assumption that persons living with HIV/AIDS are not expected to live very long despite new evidence to the contrary. In his description of himself, in my

conversations with family members, in our sorting through what happened after Jay killed himself, we too conflated various combinations of these terms such as “depression” to try to make sense of the progression of the illness, and his death.

A person may “take” his or her own life, but the reality of the act whether of desperation, defiance, or refusal to be taken over by disease, is squeezed back into a ruled form, such as that required in a coroner’s judgement. Once the coroner learned first, that Jay had AIDS, and furthermore by obtaining, as policy says, “medical and psychiatric histories” that indicated he had been diagnosed as “depressed” by his doctor, she could then begin to draw conclusions about the nature of the death and how to classify it into a suitable and understandable ending of a life. A “depressed state of mind”, or depression itself is not defined in the Coroners Act or policy, but through training that teaches the socially constructed “common sense” of depression, it is assumed that the coroner will know what this means. Evidence can then be put together in ways that makes “AIDS/depression = suicide” a factual matter. Her intervention solidifies that understanding into textual reality. As Atkinson (1978) argues, “...*all or most of the ‘causes’ cited by suicidologists are indeed ‘involved in the very description’ of suicide--to the extent that even such mundane factual reports as are found in the columns of local newspapers bristle with theoretical interpretations and possible explanations of the suicides they report*” (p. 172).

Why isn’t suicide a “legitimate option”? A body is found in so-called unnatural circumstances. An official accounting must be done. It is not any longer a personal event but a public one. The accounting requires that the death be recorded as a particular kind

of death on a specific organizational document which, for instance, sets in motion the cessation of government “benefits” and responsibilities. Thus, “suicide” appears in a coroner’s report as part of a discourse that literally transforms the act from “taking one’s own life” by applying particular criteria to a death that matches what is known about it.

This argument is an illustration of how experience comes to be administered; that, despite perhaps the caring nature of an individual coroner or related professional, the “unruly” life and death of the gay man with HIV disease is ultimately submerged or ruled. In so doing, the coroner by virtue of the process he or she is mandated to follow by legislation and policy, eliminates the subjectivity of the person with HIV/AIDS disease who is trying to make sense of his life and act accordingly. The questions the coroner asked in the investigation into the circumstances of Jay’s death may have been ordinary queries, empathetic to the feelings of those she interviewed. Nonetheless, the stories gathered from them were reshaped when she returned to her office and was required to dis/embody the life once again, by placing information about a life and death into an organization format so that it could be entered into the state statistics. In this discursive practice, suicide becomes professionally acceptable if not a “successful” professional outcome; for at least professionals such as coroners recognize such deaths as an accepted part of the discourse related to depression, suicide or HIV disease. Thus, how suicide is constructed organizationally is laid over the body like a shroud, covering the nakedness of the personal act.

The coroner’s report appears in sharp contrast to my family’s and friends’ experience of Jay having killed himself. It categorizes the death; its task is not to name

the everyday experience of a death as experienced or lived through, by lovers or family-- their anguish, profound grief, guilt, fear, rage, sadness. Bureaucratically, his "suicide" was entered into provincial vital statistics after causes and motives were investigated and determined; personally the "taking of his own life" is entered into the lives of his family and friends as an unbearable loss. The two forms of knowing about this kind of death are extremely different. While one illustrates a ruling account, the other knows death as unruly, uninhibited by regulation, propriety, morality and professional efforts. For Jay perhaps taking his own life was a personal and unknowable statement about his condition; for his family and friends his death was an unruly state of grief unable to be regulated by forms, categories or bureaucratic requirements.

Coroners' work is a ruling practice that has been established to maintain order over the centuries, and preserves a ruling perspective on death, and the right or proper way to die in our society. Jay's self-killing might have disrupted that order but for the procedures that professionals followed to return his personal act to its proper and legitimate category. My goal in this chapter has been to show the context of the coroner's decision, and to begin to create discursive space for other interpretations.

## CHAPTER EIGHT

### Conclusions

My inquiry into the social organization of AIDS suicide was provoked by my own experience of Jay's illness and death and by what I saw as the contradictions in knowing that had their impetus in his journal. I had expected to find some "truth" in his words about AIDS, but instead, I discovered the narratives of medical, professional, immune and self-help discourses interjecting, defining, categorizing and being reflected in his words and actions. Early on in the investigation I began to term his act an "unruly death". Prompted not only by the coroner's accounting and definition of his death, but also by my own sense of Jay's act as one of autonomy, I sought to figure out how AIDS suicide works in contemporary society for some people. As I examined his journal and moved out from it to the wider organization of AIDS it was not my intention to create a rationale for suicide; instead, I wanted to understand how a gay man with HIV disease in the late 1980s may have come to the decision to take his own life.

As I mentioned in Chapter One, it took me a long time to realize the extent of Jay's "capture" by HIV/AIDS—both the disease itself and the discourse surrounding it. I attempted to find him as a subject in his own life and death decisions rather than accepting as "truth" the various discursively organized accounts. Yet what I did find, is a subject whose own knowing/acting seems to have been taken over (even after death)—to an extent almost unimaginable—by such socially organized practices. Once Jay wrote

about what was happening to him as he lived with AIDS, once it became his journal “text”, it was as much socially organized as the coroner’s report (Chapter Seven).

When I began my inquiry, I had hoped that somehow his journal was the “real” thing; that somehow I could offer to others and perhaps to myself, a true picture of what living/dying with AIDS was like. That somehow the journal would make sense of his suicide. Taking his life was in an odd way perhaps, the “real” thing (until it too was officially labelled). I became aware that in Jay’s narrative there were no clear-cut explanations or revelations regarding his struggle with AIDS. His life and its narrative telling were enmeshed in the language and organization of contemporary AIDS discourses available to him. What I had suspected regarding the authority of cultural, professional and medical knowledge about HIV/AIDS, and at the time of his illness the lesser influence of AIDS activism, was revealed as I examined the relations of power and authority evident in his writings. Yet in showing the context and complexity of AIDS suicide, I also realized that explicating this complexity can perhaps begin to transform it (Kinsman, 1988; Campbell and Manicom, 1995; Swift, 1995).

What does Jay’s story reveal for the present? First of all I discovered that AIDS suicide says as much about life as it does about death, and in that sense is more than a final act. In undertaking this inquiry I found that Jay’s own transformation as a result of his AIDS diagnosis, alerted me to ongoing contradictions. While I have been aware in a general way of how knowledge is created and how pivotal language is to contemporary society’s acquisition and dispersion of knowledge, this inquiry has shown me how quickly discourses about HIV/AIDS emerged, how quickly and deeply they can be seen

to seep into an individual's experience, and how professions, sciences and individuals participate in their reproduction. HIV/AIDS discourse has a language of its own, acronyms, billions of words in print, in cyberspace, in curricula, film and other media. The language of science, medicine, professions, media, religion creates a moveable knowledge about HIV/AIDS, and a roster of experts that often makes it difficult for those with HIV/AIDS and others working in various "fields" to actually "know". I saw evidence of this not only in Jay's writings, but was alerted to it in interviews with family and professionals. It was quite jarring to become conscious of how all of us talked in categories and concepts of AIDS discourse without problematizing it or even being aware of it at the time. Our common-sense knowledge helped us comprehend the newly emerging discursive terms and to understand various documents such as a Judgement of Inquiry in which the definition of Jay's final act was officially determined.

Despite a kind of discourse of urgency, nine years after Jay's death the HIV/AIDS crisis still looms large in British Columbia; and, while the impact of HIV/AIDS on other individuals and populations is becoming more widely known and addressed, stigma and the fear of homosexuality prevail. There are now drug therapies available that appear to prolong the lives of some with HIV/AIDS; nonetheless, others decide as did Jay, to take their own lives. The British Columbia government is poised to release an AIDS Strategy and prepare for its implementation by various regional health authorities across the province. The fact that this document has taken so long to produce speaks to the contradictions, controversies and competing agendas inherent in such a "socially" constructed syndrome, and I suspect it will take more than ten or fifteen years to replace

the embeddedness of ideas regarding homosexuality or what constitutes proper death as they relate to HIV/AIDS.

Those who die a proper or “ruled” AIDS death, who have listened to the experts’ advice about the way to live and die with AIDS have much to teach society about what it is like to die as a result of a stigmatizing disease. But in examining the context in which, whether consciously or not, individuals such as Jay have eschewed the regulation of their bodies in life and in death, perhaps reveals to professionals, researchers and helpers harsh lessons about what constitutes a good life when one is confined within the concept and the practices of terminal illness. With the focus on keeping persons living with HIV/AIDS accountable for their living and dying, there appears no urgent need to question the authority that regulates these taken for granted, or unquestioned, expectations. What it also brought into relief for me was the terrible numbers of persons with HIV/AIDS in Canada and globally for whom the disease is perhaps one other additional burden and who have no choice about the conditions of their lives or their deaths. In many ways our contemporary privilege of being able to decide to debate issues of the right to die points to the work required to come to terms with our need to control death by ideological, legal, religious, medical or professional regulation. If we turn attention to these issues it will mean attempting to create policy and practice responses in a climate of contradiction. Canadian governments for example, are reluctant to deal with issues surrounding the right to die—much as they have continued to have difficulty with pro-choice debates. As well, there seems to have been a lull in public and government responses to HIV/AIDS in the late 1990s with the emergence of new drug therapies. Yet

the urgency of the policy vacuum is felt by those with the syndrome as well as by community agencies. I suspect this vacuum may be filled by a renewed activism on the part of persons living with HIV/AIDS and their allies; indeed, the movement toward recognizing the necessity for social sciences research based in and working with affected communities, may be a starting place.

Since Jay's death AIDS activists have influenced knowledge-making and the professional discourse regarding treatment, education, prevention tactics, right to die issues, marginalization, research and scholarship. In my experience, not all AIDS activists are located at the community level. The rhetoric of partnership and community put forward often in provincial and national strategies has been seen to dilute AIDS actions (Kinsman, 1997); nonetheless, there are activists everywhere: persons living with HIV/AIDS, scholars, medical and other health/social professionals, community people and care-givers, working at various levels to create and shift knowledge about HIV/AIDS. This activism invites contradiction. The so-called "expertise" needed by community-based activists in their relationships with funders or treatment experts for example, often requires specific scientific knowledge that may move them away from the standpoints of those they initially intended to work with/for. There is a term for this now-capacity building--in which grassroots organizations must have mechanisms by which they can "keep up" with the ongoing medical/technical trends in HIV/AIDS, as well as the increasingly complex accountability measures required by government.

For lesbian and gay health and community activists/academics/professionals there are contradictions as well. This project supports observations made by others about how

our professional work has often contributed to the replication of practices that obscure what those with HIV/AIDS need and want (Kinsman, 1988, 1996; G. Smith, 1995). Kinsman (1988) for example, argues that lesbian/gay professionals educated with various “proper” credentials and trained in the official discourses of their disciplines become the respected representatives of what I would call a formerly “unruly” grassroots organizing impetus. We can be seen to be supporting the state against those with HIV/AIDS and moving community groups toward a government or professional agenda. However, during the time of the AIDS crisis in Canada there have also been significant shifts in human rights advances for gays and lesbians. While religious leaders and groups maintain a vitriolic barrage against this extension of rights, nonetheless, particularly in British Columbia, policy and legislation are advancing—at least as Kinsman noted ten years ago, “...on an abstract and formal level” (1988, p. 494).

Having begun this project in Jay’s journal, from his standpoint, it seems that what he needed from those involved in his life as a result of AIDS was support to remain “Jay” without changing his identity, without becoming a “case” or someone who was perceived as coping in a maladjusted manner because he did not always follow expert advice. I drew on information from the Canadian Association of Schools of Social Work and the Canadian Association of Social Workers regarding shifts in curricula for both continuing professionals and current students. In my view, education that would reexamine professionalism within the context of critical analysis is required. Persons struggling to live with HIV/AIDS who may become increasingly reliant on professional help or caring, deserve a professionalism that would deconstruct ideas and concepts of caring and make

so-called caring practices subject to scrutiny and analysis. Persons living with HIV/AIDS require an activist professionalism that does not lose itself in a liberal notion of social work practice in which “client self-determination” becomes a mechanism to disengage, or to hold power over others. Uncovering and understanding relations of ruling, or what Swift (1995) calls hidden realities, seems to point to a deep and ethical responsibility on the part of those practising in the areas of suicide, AIDS, education, mental health, and so on, to show how AIDS works. It means asking questions about local and extra-local health and social policy, and about who controls health care. Those of us who are lesbian or gay professionals/academics must struggle as well against the tyranny of our own expertise that we often unwittingly dispense without taking into account that those who are ill may already know what they need, or may only be seeking information from us on how to understand the system in which they have become entangled.

Throughout the analysis I also became more aware of the work that is required by social scientists to try to understand the larger concepts involved in any research project, and how easy it is perhaps, to rely on already-established categories and concepts to provide the context for our analysis. To attempt to understand how knowledge about HIV/AIDS has been and is being discursively created I have become more aware generally about how social science research about HIV/AIDS is put together, what data it relies on, what expertise is recirculated and recycled across Canada and globally. I have discovered, myself, how important it is to be able to illustrate and unravel the context in which people with HIV/AIDS are living and dying, and, how important it is for social scientists to challenge themselves and those who use their work not only for policy and

planning, but most importantly, for activism. G. Smith (1995) observed for example, that investigating administrative regimes is “an ordinary part of the day-to-day work of challenging and transforming a ruling apparatus” (p. 32). Writing research that has emerged from such a personal narrative has been a contradiction for me, as both professionally and scientifically there is a subtle curb to omit the personal and the messy. And yet, if we are to understand the full impact and the implications of HIV/AIDS in society, social science research which can rigorously present a life or lives, is as essential as basic and clinical research.

This analysis points to ways in which all those affected by HIV/AIDS might understand the socially organized context in which their decisions to live and die take place, and begin to be aware of the insidiousness of the proper and accountable way to die. Perhaps this project can contribute to the work on assisted suicide, as well as to work engaged in providing comfortable, compassionate, reasoned approaches and opportunities to explore options regarding end of life decisions. It can also provide an illustration of how those relations we take for granted, actually work. It can reveal for example the intricate stitches that have created the context in which AIDS suicide exists.

HIV/AIDS is not only a syndrome but a textually mediated process influenced and shaped by professional, religious, cultural and media discourses. Jay’s final choice could be read as a triumph—an “unruly” choice—in which he asserted final control over the regulation of his life and death. However, those working in this field are left with the web of discourse and practice that provides us with profound questions about the nature of this “choice”. He disrupted the official order with his act; yet as presented in

documentary form, his death cannot be framed as liberation/autonomy-- it is framed outside of him. This project has attempted to make visible from an account of a person who lived with HIV/AIDS and those caring for him, what could never be made visible from the standpoints of professional experts. While it is individual people with AIDS who will decide whether to take their own lives, depending on the circumstances in which they find themselves, I have attempted through this inquiry, to articulate how these decisions are fully social. As my research progressed, I discovered how my brother's death by his own act was turned from an attempt to take charge of his life--an unruly act--into conformity with official rules.

I have shown what it means to say that his death, as well as his life with AIDS, was discursively organized and ruled. I suspect however, that Jay was aware of how he had been colonized by AIDS and its discourses, and how he participated in the discursivity of his life. His responses to the semiotics conference on AIDS and the body for example, and his challenge to doctors to keep their diagnoses of death to themselves are evidence of this. I doubt that I have "reclaimed" Jay, or freed his journal account from the sticky web of discourse. But I understand more fully how his life and death were socially organized. I saw evidence of Jay's resistance to the discourse, and while he may have been caught up in it, his life and his journal illustrate a powerful contestation that moves toward a deeper social analysis of HIV/AIDS and the possibilities of movement and transformation. As I read Jay's words--the partial narrative of his life as it was marked by AIDS--and reflect on them as one voice in the burgeoning text of homosexual history in the age of AIDS, I am moved once again by his determination to embrace and

be embraced by life. While it is indeed socially organized, his last journal entry written in early Spring 1989 nonetheless reads like a song of hope:

*I have chosen renewal + life!  
I can heal myself  
I love myself + accept myself  
I forgive myself + all + I release  
the past, + live in this very  
moment.*

*I have breath, life, a loving mother  
+family helping me.*

*I choose to change my mind, +  
live + accept my life.*

## BIBLIOGRAPHY

- Adam, B. D., & Sears, A. (1996). Experiencing HIV: Personal, family and work relationships. New York: Columbia University Press.
- AIDS Action Now! (1993, October). Confronting the HIV research crisis: Treatment activists' perceptions of the Canadian AIDS society. Toronto: Author.
- AIDS Alert. (1989). Suicide and AIDS: What Health Providers Should Know. 4(5), 77-79.
- Alonzo, A., & Reynolds, N. R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. Social Science Medicine, 41(3), 303-315.
- Altman, D. (1987). AIDS in the Mind of America. New York: Anchor Books.
- American Psychiatric Association. (1994). Diagnostic and statistical manual of mental disorders (4th ed.). Washington, DC: Author.
- Atkinson, J. M. (1978). Discovering Suicide: Studies in the Social Organization of Sudden Death. London: MacMillan Press Ltd.
- Baisley, K. (1989). AIDS: Social construction and implications for social work. Unpublished Master's Thesis. University of British Columbia School of Social Work, Vancouver, British Columbia.
- Barraclough, B., Bunch, J., Nelson, B., & Sainsbury, P. (1974). A hundred cases of suicide: Clinical aspects. British Journal of Psychiatry, 125, 355-373.
- Battin, M. P. (1994). Going early, going late: the rationality of decisions about suicide in AIDS. The Journal of Medicine and Philosophy, 19, 571-594.
- Baumgartner, G. H. (1985). AIDS: Psychological Factors in the Acquired Immune Deficiency Syndrome. New York: Charles C. Thomas.
- Beck, A. T., Steer, R. A., Beck, J. S., & Newman, C. F. (1993). Hopelessness, depression, suicidal ideation, and clinical diagnosis of depression. Suicide and Life-Threatening Behavior, 23(2), 139-145.
- Bergeron, J. P., & Handley, P. R. (1992). Bibliography on AIDS-related bereavement and grief. Death Studies, 16, 247-267.

- Boldt, M. (1988). The meaning of suicide: Implications for research. Crisis, 9(2), 93-108.
- Boswell, J. (1980). Christianity, social tolerance and homosexuality: Gay people in western Europe from the beginning of the Christian era to the fourteenth century. Chicago: University of Chicago Press.
- Boys, W. F. A. (1894). A practical treatise on the office and duties of the coroners in upper Canada. Toronto: W.C. Chewett and Co., Law Publishers.
- Brandt, A. M. (1991). AIDS and metaphor: Toward the social meaning of epidemic disease. In A. Mack (Ed.), In time of plague: The history and social consequences of lethal epidemic disease. New York: New York University Press.
- British Columbia Centre for Disease Control. (1997). AIDS update quarterly report (Fourth quarter). Vancouver: Author.
- British Columbia Centre for Excellence in HIV/AIDS. (1996). HIV/AIDS research in British Columbia: A ten year retrospective. Vancouver: Author.
- British Columbia Coroners Service Policy and Procedures Manual (1991). Victoria: Author.
- Brodribb, S. (1992). Nothing matters: A feminist critique of postmodernism. Melbourne: Spinifex.
- Bury, M. (1982). Chronic illness as biological disruption. Sociology of Health and Illness, 8(2), 137-169.
- Cain, R. (1993a). AIDS service organizations in context: An interim report. Hamilton: McMaster University, School of Social Work.
- Cain, R. (1993b). Community-based AIDS services: formalization and depoliticization. The International Journal of Health Services, 23(4), 665-684.
- Cain, R. (1994). Managing impressions of an AIDS service organization: Into the mainstream or out of the closet? Qualitative Sociology, 17(1), 43-61.
- Campbell, M. (1992). Administering child protection: A feminist analysis of the conceptual practices of organizational power. Canadian Public Administration, 35(4), 501-518.

- Campbell, M. L. (1998). Institutional ethnography and experience as data. Qualitative Sociology 21 (1), 55-73.
- Campbell, M. & Manicom, A. (Eds.). (1995). Knowledge, experience and ruling relations: Studies in the social organization of knowledge. Toronto: University of Toronto Press.
- Canadian AIDS Society. (1989, September). Working together: Towards a national AIDS strategy in Canada. Ottawa: Author.
- Canadian AIDS Society. (1997, September). More issues and questions: A companion document to Health Canada's "tell us your views". National AIDS Strategy Phase III. Ottawa: Author.
- Canadian Association of Schools of Social Work (n.d.). AIDS and social work education: A discussion manual and a video. Ottawa: Author.
- Canadian Association of Schools of Social Work. (1988/89). AIDS and social work training in Canada. Ottawa: Author.
- Canadian Association of Schools of Social Work. (1990a). HIV/AIDS and social work education: A curriculum guide. Ottawa: Author.
- Canadian Association of Social Workers. (1990b, November). Preparing for HIV and AIDS: Resource kit for social workers. Ottawa: Author.
- Canadian Association of Social Workers. (1995). Social work practice and practice wisdom in the field of HIV/AIDS: Research report. Ottawa: Author.
- Canadian Association of Social Workers. (1997). Comprehensive guide for the care of persons with HIV disease. Module 6: Psychosocial care. Ottawa: Author.
- Canadian Mental Health Association. (1995). Depression: An overview of the literature. Ottawa: Author.
- Canadian Public Health Association. (1993, March). HIV/AIDS: A public health perspective. Ottawa: Author.
- Cass, V. C. (1979). Homosexual identity formation: A theoretical model. Journal of Homosexuality, 4, 219-235.
- Cass, V. C. (1984). Homosexual identity: A concept in need of definition. Journal of Homosexuality, 9(2/3), 105-126.

- Cass, V. C. (1990). The implications of homosexual identity formation for the Kinsey model and scale of sexual preference. In D. P. McWhirter, S. A. Sanders, & Reinisch (Eds.), Homosexuality/heterosexuality. New York: Oxford University Press.
- Charmaz, K. (1980). The social reality of death: Death in contemporary America. New York: Random House.
- Clarke, R. (1989). Professional dissonance in this time of AIDS: A value critical evaluation of social work training with a view toward radical change. Unpublished Master's Project, Carleton University, Ottawa, Ontario.
- Clough, P. T. (1993). On the brink of deconstructing sociology: Critical reading of Dorothy Smith's standpoint epistemology. The Sociological Quarterly, 34(1), 169-182.
- Coleman, E. (1987). Assessment of sexual orientation. Journal of Homosexuality, 14(1/2), 9-24.
- Coleman, E. (1990, November). Expanding the boundaries of sex research. The Journal of Sex Research, 27, 473-480.
- Coroners Act of British Columbia (1975).
- Costa, P. T., & VandenBos, G. R. (Eds.). (1990). Psychological aspects of serious illness: Chronic conditions, fatal diseases and clinical care. Washington: American Psychological Association.
- Cote, T., Biggar, R. J., & Dannenberg, A. L. (1992). Risk of suicide among persons with AIDS. Journal of the American Medical Association, 268(15), 2066-2068.
- Crimp, D. (1988). How to have promiscuity in an epidemic. In D. Crimp (Ed.), AIDS: Cultural analysis/cultural activism. Cambridge, MA.: MIT Press.
- Crimp, D. (1992). Portraits of people with AIDS. In L. Grossberg, C. Nelson, & P. Treichler (Eds.), Cultural Studies. New York: Routledge.
- Dean, L. (1995). The epidemiology and impact of AIDS-related death and dying in New York's gay community. In L. Sherr (Ed.), Grief and AIDS. Chichester: John Wiley and Sons, Ltd.
- De Cecco, J., & Shively, M. G. (1983/84). From sexual identity to sexual relationships: A contextual shift. Journal of Homosexuality, 9(2/3), 1-26.

- D'Emilio, J. (1992). Making trouble: Essays on gay history, politics, and the university. New York: Routledge.
- D'Emilio, J., & Freedman, E. (1988). Intimate matters: A history of sexuality in America. New York: Harper and Row.
- DePaul, E., & Liberman, M. (1986). Facts on AIDS for the Public. Ottawa: Canadian Public Health Association.
- Devor, H. (1993a). Sexual orientation identities, attractions, and practices of female-to male transsexuals. The Journal of Sex Research, 30(4), 303-315.
- Devor, H. (1993b). Toward a taxonomy of gendered sexuality. Journal of Psychology & Human Sexuality, 6(1), 23-55.
- De Wachter, A. (1991, November/December). The Dutch and the dying. The Hastings Centre Report, 22, 2.
- Diamond, T. (1993). Making gray gold: Narratives of nursing home care. Chicago: University of Chicago Press.
- Douglas, J. D. (1967). The social meaning of suicide. Princeton: Princeton University Press.
- Dreuilhe, E. (1988). Mortal embrace: Living with AIDS. (L. Coverdale, Trans.). New York: Hill and Wang.
- Duberman, M. (1991). About time: Exploring the gay past. New York: Meridian.
- Dynes, W. R., & Donaldson, S. (Eds.). (1992). Homosexuality and psychology, psychiatry and counselling. New York: Garland Publishing, Inc.
- XI International Conference on AIDS. Abstracts, Volumn Two. Vancouver: Author.
- Ebaugh, H. (1988). Becoming an ex: The process of role exit. Chicago: University of Chicago Press.
- Eccles, P. (1992). Service delivery from the Ministry of Social Services to clients with HIV/AIDS. Unpublished manuscript, College of New Caledonia, Prince George, BC.
- Ellis, C. (1995). Final negotiations: A story of love, loss and chronic illness. Philadelphia: Temple University Press.

- Ellis, C., & Flaherty, M. (1992). Investigating subjectivity: Research on lived experience. Newbury Park: Sage Publications, Inc.
- Epstein, S. (1988a). Moral contagion and the medicalizing of gay identity: AIDS in historic perspective. Research in Law, Deviance and Social Control, 9, 3-36.
- Epstein, S. (1988b). Nature vs. nurture and the politics of AIDS organizing. Out/Look, Fall, 46-53.
- Epstein, S. (1991). Democratic science? AIDS activism and the contested construction of knowledge. Socialist Review, 21(2), 35-63.
- Epstein, S. (1994). Comments on e-mail list.
- Escoffier, J. (1990). Inside the ivory closet: The challenges facing lesbian and gay studies. Out/Look, 10(summer), 40-48.
- Farangis, J. (Ed.). (1993). Readings in social theory: The classic tradition to post-modernism. New York: McGraw-Hill, Inc.
- Felthous, A. R. (1983). Patient's choice to suicide v. treater's duty to prevent suicide: Some changing clinical dilemmas. Behavioral Sciences and the Law, 1(4), 95-99.
- Ferguson, K. (1984). The feminist case against bureaucracy. Philadelphia: Temple University Press.
- Forbes, T.R. (1978). Crowner's quest. Transactions of the American Philosophical Society, 68, Part 1. Philadelphia: the American Philosophical Society.
- Forecast. (1993). Journal of the B.C. Centre for Excellence in HIV/AIDS. 1(2).
- Frank, A. W. (1991). At the will of the body: Reflections on illness. Boston: Houghton Mifflin Company.
- Frankel, H., Frankel, S., & Grosser, S. (1992). Social work students' knowledge and attitudes regarding AIDS ( Final Report). Faculty of Social Work, University of Manitoba: Child and Family Services Research Group.
- Fuss, D. (Ed.). (1991). Inside/out: Lesbian theories, gay theories. New York: Routledge.
- Giddens, A. (Ed.). (1971). The sociology of suicide: A selection of readings. London: Cass.

- Giddens, A. (1971). Introduction. In T. G. Mazaryk. Suicide and the meaning of civilization (W.B. Weist & R.G. Batson, Trans.). Chicago: University of Chicago Press.
- Gilder, E. (1989). The process of political praxis: Efforts of the gay community to transform the social signification of AIDS. Communication Quarterly, 37(1), 27-38.
- Gilman, S. (1988). Disease and representation: Images of illness from madness to AIDS. Ithaca: Cornell University Press.
- Gilman, S. (1989). Sexuality: An illustrated history representing the sexual in medicine and culture from the middle ages to the age of AIDS. New York: John Wiley and Sons.
- Gilmore, N., & Somerville, M. (1994). Stigmatization, scapegoating and discrimination in sexually transmitted diseases: Overcoming 'them' and 'us'. Social Science Medicine, 39(9), 1139-1358.
- Glass, R. (1988). AIDS and suicide. The Journal of the American Medical Association, 259(9), 1369-1370.
- Granger, C. (1984). Canadian coroner law: A legal study of coroner and medical examiner systems in Canada. Toronto: The Carswell Company Limited.
- Griffith, A. (1995). Mothering, schooling and children's development. In C. Campbell, & A. Manicom, Knowledge, experience and ruling relations: Studies in the social organization of knowledge. Toronto: University of Toronto Press.
- Gross, L. (1993). Contested closets: The politics and ethics of outing. Minneapolis: University of Minnesota Press.
- Grover, J. Z. (1992). AIDS, Keywords and Cultural Work. In L. Grossberg, C. Nelson, & P. Treichler, (Eds.), Cultural Studies. New York: Routledge.
- Hall, J. M., Koehler, S. L. & Lewis, A. (1989). HIV-related mental health nursing issues. Seminars in Oncology Nursing, 5 (4), 276-283.
- Hall, J. M., & Stevens, P. E. (1988). AIDS: A guide to suicide assessment. Archives of Psychiatric Nursing, 1(2), 115-120.
- Halperin, D. M. (1990). One hundred years of homosexuality and other essays on Greek love. New York: Routledge.
- Harding, S. (1990). Feminism, science and the anti-enlightenment critiques. In L. Nicholson (Ed.), Feminism/postmodernism. New York: Routledge.

Hay, L. L. (1984). You can heal your life. Santa Monica: Hay House.

Hay, L. L. (1988). The AIDS book: Creating a positive approach. Santa Monica: Hay House.

Health Canada. (1994a). Suicide in Canada: Update of the report of the task force on suicide in Canada. Ottawa: Minister of National Health and Welfare.

Health Canada. (1994b, May). National AIDS strategy toward building private sector partnerships: A discussion paper. Ottawa: National AIDS Secretariat.

Health Canada. (1994c, November). National AIDS Strategy: Towards a national HIV/AIDS research planning process. Ottawa: Author.

Health Canada. (1996, April). Quarterly surveillance update: AIDS in Canada. Ottawa: Bureau of HIV/AIDS & STD.

Health Canada. (1997a, August). Quarterly surveillance update: AIDS in Canada. Ottawa: Bureau of HIV/AIDS & STD.

Health Canada. (1997b, September). Towards a Canadian strategy on HIV/AIDS: A discussion paper. Ottawa: Author.

Health Canada, Laboratory Centre for Disease Control Division of Epidemiology. (1994). Proceedings of the 3rd annual HIV/AIDS epidemiological research meeting. Ottawa: Author..

Health and Welfare Canada. (1989). Federal Centre for AIDS Report for 1988. Ottawa: Minister of Supply and Services.

Health and Welfare Canada. (1990a). HIV/AIDS: Canada's blueprint. Ottawa: Minister of Supply and Services.

Health and Welfare Canada. (1990b). Building an effective partnership: The federal government's commitment to fighting AIDS. Ottawa: Minister of Supply and Services.

Health and Welfare Canada. (1990c). Review of the literature on HIV infection and mental health. Ottawa: Minister of Supply and Services.

Health and Welfare Canada. (1990d, March). Caring together/Entraide: A National Conference for the AIDS Caregiver (Conference Report). Ottawa: Federal Centre for AIDS.

- Health and Welfare Canada. (1990e, March). Federal Centre for AIDS Resource List. Ottawa: Author.
- Health and Welfare Canada. (1991). National AIDS Strategy: Progress Report 1991. Ottawa: Minister of Supply and Services.
- Health and Welfare Canada. (1992). Ending the isolation: HIV disease and mental health in the second decade. Ottawa: Minister of Supply and Services
- Health and Welfare Canada. (1993a). National AIDS Strategy: Phase II Building on progress. Ottawa: Minister of Supply and Services.
- Health and Welfare Canada. (1993b). AIDS community action program funding guidelines. Ottawa: Minister of Supply and Services.
- Heap, J. L. (1995). Foreword. In M. Campbell & A. Manicom (Eds.). Knowledge, experience, and ruling relations: Studies in the social organization of knowledge. Toronto: University of Toronto Press.
- Herd, G. (1992). Gay culture in America: Essays from the field. Boston: Beacon Press.
- Herringer, B. & Solomon, R. (1988). AIDS and social work. Paper presented at University of British Columbia School of Social Work, Vancouver, British Columbia.
- Herringer, B. (1989). Never-married and childless women in midlife: An exploration of the issues. Unpublished Master's Thesis, University of British Columbia School of Social Work, Vancouver, British Columbia.
- Herringer, B. (1994). A clash of knowledge(s): The social organization of AIDS suicide. Paper presentation at the Sixth Annual Conference on Social Work and HIV/AIDS, New Orleans, Louisiana.
- Herringer, B. (1996a). A clash of knowledge(s): Toward an analysis of AIDS 'suicide'. Canadian Social Work Review, 13(1)
- Herringer, B. (1996b, July). Unruly death: Toward an understanding of the social organization of AIDS suicide. IX International Conference on AIDS, Vancouver, 2. Abstracts We.D. 246.
- Herringer, B. (1996). The Twenty-fourth monday in ordinary time. In R. Elwin (Ed.). Countering the myths: Lesbians write about the men in their lives. Toronto: Women's Press.

- Herringer, B. (1997). AIDS, suicide and the coroner: Making death into an official account. The Social Worker, 65(3), 66-76.
- Hillman, J. (1964). Suicide and the soul. New York: Harper and Row.
- Hogg, R. S., Strathdee, S. A., Braib, K. J., O'Shaughnessy, M. V., Montaner, J. S., & Schechter, M. T. (1994). Lower socioeconomic status and shorter survival following HIV infection. The Lancet, 344, 1120-1124.
- Horowitz, P. (1988). Beyond the gay nation: Where are we marching? Out/Look, Spring, 7-21.
- Houlbrooke, R. (Ed.). (1989). Death, ritual, and bereavement. London: Routledge (In Association with the Social History Society of the United Kingdom).
- Hugman, R. (1991). Power in the caring professions. Houndsmills Hampshire: Macmillan.
- Hunnisett, R. F. (1961). The medieval coroner. London: Cambridge University Press.
- Irvine, J. M. (1990). Disorders of desire: Sex and gender in modern American sexology. Philadelphia: Temple University Press.
- Jackson, N. (1984). Work and education: the case of business education. Paper presented at the Learned Societies Conference, Guelph, Ontario.
- Jackson, N. (1991). Qualitative research methods: Why there are no recipes. Monograph.
- Jacobs, S. E., & Cromwell, J. (1992). Visions and revisions of reality: Reflections on sex, sexuality, gender, and gender variance. Journal of Homosexuality, 23(4), 43-69.
- Jalland, P. (1996). Death in the Victorian family. Oxford: Oxford University Press.
- John, L. H. (1994). Borrowed knowledge in social work: An introduction to post-structuralism and postmodernity. In A. S. Chambon & A. Irving, (Eds.), Essays on postmodernism and social work. Toronto: Canadian Scholars' Press Inc.
- Kellehear, A. (1990). Dying of cancer: The final year of life. United Kingdom: Harwood Academic Publishers.
- Kimmel, M. S. (1993). Sexual balkanization: Gender and sexuality as the new ethnicities. Social Research, 60(3), 571-587.

- Kinsman, G. (1987). The regulation of desire: Sexuality in Canada. Montreal: Black Rose Books.
- Kinsman, G. (1988). Official discourse as sexual regulation: the social organization of the sexual policing of gay men. Unpublished doctoral dissertation, University of Toronto.
- Kinsman, G. (1989). Their silence, our deaths: What can the social sciences offer to AIDS research? In D. Goldstein (Ed.), Talking AIDS: Interdisciplinary Perspectives on Acquired Immune Deficiency Syndrome (ISER Research and Policy Papers No. 12). Newfoundland: Institute of Social and Economic Research, Memorial University.
- Kinsman, G. (1991). 'Homosexuality' historically reconsidered challenges heterosexual hegemony. Journal of Historical Sociology, 4(2), 91-111.
- Kinsman, G. (1992a). Managing AIDS organizing: "Consultation," "partnership," and the national AIDS strategy. In W. K. Carroll (Ed.), Organizing Dissent: Contemporary Social Movements in Theory and Practice. Montreal: Garamond Press.
- Kinsman, G. (1992b). Queer 'nations.' queer spaces: Academic institutionalization and queer activism. Paper presented at the Sociology and Anthropology Society Conference (Learned Societies), Charlottetown, P.E.I.
- Kinsman, G. (1993, January/February). Making homosexuality the problem once again. New Maritimes, 17-19.
- Kinsman, G. (1995a). The textual practices of sexual rule: Sexual policing and gay men. In C. Campbell & A. Manicom, Knowledge, experience and ruling relations: Studies in the social organization of knowledge. Toronto: University of Toronto Press.
- Kinsman, G. (1995b). "Character weaknesses" and "fruit machines": Towards an analysis of the anti-homosexual security campaign in the Canadian civil service. Labour/Le Travail, 35, 133-161.
- Kinsman, G. (1996a). The regulation of desire: Homo and hetero sexualities. Second Edition, Revised. Montreal: Black Rose Books.
- Kinsman, G. (1996b). 'Responsibility' as a strategy of governance: Regulating people living with AIDS and lesbians and gay men in Ontario. Economy and Society, 25(3), 393-409.

- Kinsman, G. (1997). Managing AIDS organizing: "Consultation," "partnership," and "responsibility" as strategies of regulation. In W. K. Carroll (Ed.), Organizing dissent: Contemporary social movements in theory and practice. Second Edition. Toronto: Garamond Press.
- Kirk, S. A. & Kutchins, H. (1988, June). Deliberate misdiagnosis in mental health practice. Social Service Review.
- Klein, F., Sepekoff, B., & Wolf, T. J. (1985). Sexual orientation: A multi-variable dynamic process. Journal of Homosexuality, 10(3/4), 35-49.
- Krueckl, J. (1987). Psychosocial impact of AIDS on the person, his lover and the family (Major paper). University of British Columbia, School of Social Work, Vancouver, British Columbia.
- Kruger, S. (1996). AIDS narratives: Gender, sexuality, fiction and science. New York: Garland Press.
- Kubler-Ross, E. (1969). On death and dying. New York: Macmillan.
- Kushner, H. I. (1989). Self-destruction in the promised land: A psycho cultural biology of American suicide. New Brunswick: Rutgers University Press.
- Kutchins, H. & Stuart, A. K. (1988, May/June). The business of diagnosis: DSM-III and clinical social work. Social Work, 215-220.
- Kutchins, H. & Kirk, S. A. (1989). DSM-III-R: Conflict over new psychiatric diagnosis. Health and Social Work.
- Laane, H-M. (1995). Euthanasia, assisted suicide and AIDS. AIDS Care, 7 (Suppl. 2), 163-167.
- Laqueur, T. (1990). Making sex: Body and gender from the Greeks to Freud. Cambridge: Harvard University Press.
- Lather, P. (1991). Getting smart: Feminist research and pedagogy with/in the postmodern. New York: Routledge.
- Lester, D. (1988). Suicidal individuals: Two types of research or two types of people? Crisis, 9(2), 130-34.
- Lester, D. (1992). Why people kill themselves: A 1990s summary of research findings on suicidal behavior (3rd ed.). Springfield: C.C. Thomas.

Lopez, D., & Getzel, G. S. (1987). Strategies for Volunteers Caring for Persons with AIDS. Social Casework, 68(1), 47-53.

Lorber, J. (1994). Paradoxes of gender. New Haven: Yale University Press.

Lyotard, J. F. (1984). The postmodern condition: A report on knowledge. Minneapolis: University of Minnesota Press.

Mack, A. (Ed.). (1991). In time of plague: The history and social consequences of lethal epidemic disease. New York: New York University Press.

Macdonald, L. (1994). The politics of postmodernism. A talk presented to the International Green Left Conference, Sydney, Australia. (On e-mail list).

MacDonald, M., & Murphy, T. R. (1990). Sleepless souls: Suicide in early modern England. Oxford: Clarendon Press.

Magove, C. R., & Frankish, E. R. (1940). Boys on coroners. A practical treatise on the office and duties of coroners in the provinces of Canada and the North-West Territories and Newfoundland. Toronto: Carswell Company, Ltd.

Maj, M. (1990). Psychiatric aspects of HIV-1 infection and AIDS. Psychological Medicine, 20, 547-563.

Manicom, A. (1988). Constituting class relations: The social organization of teachers' work.

Unpublished Doctoral Dissertation, University of Toronto, Department of Education, Toronto, Ontario.

Mann, S. A., & Kelley, L. R. (1997). Standing at the crossroads of modernist thought: Collins, Smith, and the new feminist epistemologies. Gender and Society, 11(4), 391-408.

Marshall, T. David. (1991). Canadian law of inquests (2<sup>nd</sup> ed.). Toronto: Thomson Professional Publishing.

Martin, E. (1994). Flexible bodies: Tracking immunity in American culture - from the days of polio to the age of AIDS. Boston: Beacon Press.

Martin, J. P. (1991). Making terminal care decisions. Focus, 6 (6), 3.

Marzuk, P. M., & Perry, S. W. (1993). Suicide and HIV: Researchers and clinicians beware. AIDS Care, 5(4), 387-390.

Marzuk, P. M., Tardiff, K., & Leon, C. (1994). Increase in fatal suicidal poisonings and suffocations in the year "Final Exit" was published: A national study. American Journal of Psychiatry, 151(12), 1813-1814.

Marzuk, P. M., Tierney, H., Tardiff, K., Gross, E. M., Morgan, E. B., Hsu, M., & Mann, J. J. (1988). Increased risk of suicide in persons with AIDS. Journal of the American Medical Association, 259(9), 1333-1337.

Masaryk, T.G. (1970). Suicide and the meaning of civilization (W.B. Weist & R.G. Batson, Trans.). Chicago: University of Chicago Press.

Maynard, S. (1991). When queer is not enough: Identity and politics. Fuse, (fall), 14-18.

McCray Beier, L. (1989). The good death in seventeenth-century England. In R. Houlbrook (Ed.), Death, ritual and bereavement. London: Routledge, in Association with the Social History Society of the United Kingdom.

McDonnell, J. R. (1993). Judgements of personal responsibility for HIV infection: An attributional analysis. Social Work, 38(4), 403-410.

McManners, J. (1981). Death and the enlightenment: Changing attitudes toward death among Christians and unbelievers in eighteenth-century France. Oxford: Clarendon Press.

McWhirter, D. P., Sanders, S. A., & Reinisch, J. M. (Eds.). (1990). Homosexuality/Heterosexuality: Concepts of sexual orientation. New York: Oxford University Press.

Mills, S. (1997). Discourse. London: Routledge.

Ministry of Attorney General. Annual Report 1994-1995. Victoria. Author.

Minton, H., & McDonald, G. J. (1983/84). Homosexual identity formation as a development process. Journal of Homosexuality, 9(2/3), 91-103.

Money, J. (1988). Gay, straight, and in-between: The sexology of erotic orientation. New York: Oxford University Press.

Morton, N. (1986). The journey home. Boston: Beacon Press.

Mullaly, R. P. (1997). Structural social work: Ideology, theory, practice. (2nd ed.). Toronto: Oxford University Press.

- Murphy, T. F., Poirier, S. (Eds.). (1993). Writing AIDS: Gay literature, language and analysis. New York: Columbia University Press.
- Mykhalovskiy, E., & Smith, G. (1994). Hooking up to social services: A report on the barriers people living with HIV/AIDS face accessing social services. Ottawa: National Welfare Grants, Health and Welfare Canada.
- National Advisory Committee on AIDS. (1986). AIDS in Canada: What you should Know. Ottawa: Health and Welfare Canada.
- National Task Force on Suicide in Canada. (1987). Suicide in Canada. Ottawa: Minister of National Health and Welfare.
- Nelkin, D., Willis, D. P., & Parris, S. V. (1991). A disease of society: Cultural and institutional responses to AIDS. New York: Cambridge University Press.
- Neron, C. (1996). Euthanasia, assisted suicide and HIV/AIDS: Implications for social work. The Social Worker, 64(4), 129-136.
- Neuman, W. L. (1991). Social research methods. Boston: Allyn and Bacon.
- Newton, E. (1988). Of yams, grinders and gays: the anthropology of homosexuality. Out/Look (spring), 28-37.
- Nicholson, L. J. (1990). Feminism/postmodernism. New York: Routledge.
- Nunokawa, J. (1991). All the sad young men: AIDS and the work of mourning. In D. Fuss (Ed.), Inside/out: Lesbian theories, gay theories. New York: Routledge.
- Nyamathi, A., & van Servellen, E. (1989). Maladaptive coping in the critically ill population with acquired immunodeficiency syndrome: Nursing assessment and treatment. Heart and Lung, 18(2), 113-120.
- O'Brien, C. (1994 Winter). The social organization of the treatment of lesbian, gay and bisexual youth in group homes and youth shelters. Canadian Review of Social Policy 34, 37-57.
- O'Dowd, M. A., Freedman, J., Kaplan, I., Bernstein, G., & McKegney, F. P. (1992). Characteristics of HIV+ patients attempting suicide while attending a psychiatric clinic. International Conference on AIDS, 8(2), B186.

Office of the High Commissioner for Human Rights and UNAIDS. (1988, February 18). Joint Press release by the Office of the High Commissioner for Human Rights and UNAIDS: Guidelines on HIV/AIDS and human rights published. [Online]. Available: <http://www.us.unaids.org/highband/press/hrpren.html> [03/28/98].

Office of the Provincial Health Officer. (1993, November). Public health guidelines for managing difficult HIV cases. Victoria, BC: Author.

Ogden, R. D. (1994a). Euthanasia, assisted suicide and AIDS. New Westminster: Peroglyphics Publishing.

Ogden, R. D. (1994b). Palliative care and euthanasia: A continuum of care? Journal of Palliative Care, 10(2), 82-85.

Ogden, R. D., Young, M. & Johnson, A. (1995). Euthanasia and assisted suicide: A survey of registered social workers in British Columbia.

Ogden, R. D. & Young, M. (1997). Survey on euthanasia and assisted suicide: BCASW member's views. Perspectives, 19(2), 1-2,8.

Ontario Law Reform Commission. (1995). Report on the Law of Coroners. Toronto: Author.

Orr, D., O'Dowd, M. A., McKegney, F. P., & Natali, C. (1990). A comparison of self reported suicidal behaviors in different stages of HIV infection. International Conference on AIDS, 6(1), 141.

Padgug, R. (1989). Gay villain, gay hero: Homosexuality and the social construction of AIDS. In K. Peiss, C. Simmons, & R. Padgug (Eds.), Passion and Power: Sexuality in History. Philadelphia: Temple University Press.

Parga, F. (1989). Suicidal thoughts and acts in HIV infection suspects. International Conference on AIDS, 5, PG 804.

Paske, G.H. (1989). AIDS, taboos, and U.S. sensibilities. Journal of Moral and Social Studies, 4 (3), 213-229.

Patton, C. (1989). Sex and Germs: The Politics of AIDS. Boston: South End Press.

Patton, C. (1990). Inventing AIDS. London: Routledge.

Patton, C. (1993). Tremble, hetero swine! In M. Warner (Ed.), Fear of a queer planet. Minneapolis: University of Minnesota Press.

- Paul, J. P. (1993). Childhood cross-gender behaviour and adult homosexuality: The resurgence of biological models of sexuality. Journal of Homosexuality, 24(3/4), 41-54.
- Pawluch, D., Cain, R., & Gillett, J. (1995). Ideology and alternative therapy use among people living with HIV/AIDS. Health and Canadian Society, 2(1), 63-84.
- Plummer, K. (1992). Modern homosexualities: Fragments of lesbian and gay experience. London: Routledge.
- Prior, L. (1989). The social organization of death: Medical discourse and social practices in Belfast. New York: St. Martin's Press.
- Pritchard, C. (1995). Suicide - the ultimate rejection? A psycho-social study. Buckingham: Open University Press.
- Pugh, K., O'Donnell, I., and Catalan, J. (1993). Suicide and HIV disease. AIDS Care, 5(4), 391-400.
- Rayside, D. M., & Lindquist, E. A. (1992). Canada: Community activism, federalism, and the new politics of disease. In D. L. Kirp & R. Bayer (Eds.), AIDS in the industrialized democracies: Passions, politics, and policies. Montreal: McGill-Queen's University Press.
- Remien, R.H., Rabkin, J., Katoff, L., & Williams, J. (1991). Suicidality and psychological outlook in longterm survivors of AIDS. International Conference on AIDS, 7(1), 50.
- Richardson, D. (1984). The dilemma of essentiality in homosexual theory. Journal of Homosexuality 2, (2/3), 79-90.
- Rogers, J. R., & Britton, P. J. (1994). AIDS and rational suicide: A counselling psychology perspective or a slide on the slippery slope. Counselling Psychologist, 22(1), 171-178
- Rosa, V., Espinosa, R. Vidal, C., Cruz, M., & Angulo, J. (1992). Depression, aggression and suicide in patients with HIV seropositive. International Conference on AIDS, 8(3), 129.
- Rosen, M. (1992). Coming to terms with the field: Understanding and doing organizational ethnography. Journal of Management Studies, 28(1), 1-24.
- Rosenau, P. M. (1992). Post-modernism and the social sciences: Insights, inroads, and intrusions. Princeton: Princeton University Press.

- Roy, D. J. (1988). Is dying a matter of ethics? Death Studies, 12, 137-145.
- Roy, D. (1981). Biomedical Power Equals Moral Authority? In Staum, M.S. and Larsen, D.E. (Eds.) Doctors, Patients and Society: Power and Authority in Medical Care. Waterloo: Wilfred Laurier Press.
- Rubenstein, D. (1981). Marx and Wittgenstein: Social praxis and social explanation. London: Routledge & Kegan Paul.
- Schneider, S. G., Taylor, S. E., Kemeny, M. E., & Hammen, C. (1991). AIDS-related factors predictive of suicidal ideation of low and high intent among gay and bisexual men. Suicide and Life-Threatening Behaviour, 21(4), 313-328.
- Schneider, S. G., Taylor, S. E., Hammen, C., Kemeny, M. E., & Dudley J. (1991). Factors influencing suicide intent in gay and bisexual suicide ideators: Differing models for men with and without human immunodeficiency virus. Journal of Personality and Social Psychology, 61(5), 776-788.
- Schneidman, E. S. (1985). Definition of suicide. New York: Wiley.
- Schneidman, E. S. (1985, April). Ten commonalities of suicide and their implications for response. Paper presented at the Conference of the American Association of Suicidology.
- Schneidman, E. S. (1993). Some controversies in suicidology: Towards a mentalistic discipline. Suicide and Life-Threatening Behavior, 23(4), 292-298.
- Schmidt, G. (1985). Allies and persecutors: Silence and medicine in the homosexuality issue. Journal of Homosexuality, 10(3/4), 127-140.
- Sears, A. (1992). 'To teach them how to live': The politics of public health from tuberculosis to AIDS. Journal of Historical Sociology, 5(1), 61-83.
- Sears, A. (1995). Before the welfare state: Public health and social policy. Canadian Review of Sociology and Anthropology, 32(2), 169-188.
- Secretary of State for the Home Department. (1971). Report of the Committee on Death Certification and coroners. London: Her Majesty's Stationery Office.
- Sedgwick, E. K. (1993). How to bring your kids up gay. In M. Warner (Ed.), Fear of a queer planet: Queer politics and social theory. Minneapolis: University of Minnesota.
- Sedgwick, E. K. (1990). Epistemology of the closet. Berkley: University of California Press.

Serinus, J. (Ed.). (1987). Psychoimmunity & the healing process: A holistic approach to immunity & AIDS. (2nd ed.). Berkeley: Celestial Arts.

Sherr, L. (Ed.). (1995a). Grief and AIDS. Chichester: John Wiley and Sons.

Sherr, L. (1995b). Suicide and AIDS: lessons from a case note audit in London. AIDS Care, 7(Suppl. 2), 109-116.

Sherr, L., Davey, T., McCreaner, A., Green, J., & Hedge, B. (1991). Anxiety, depression and suicide prevalence and health care worker's [sic] response needs. International Conference on AIDS, 7(2), 282.

Sherr, L., Hankins, C., & Bennett, L. (Eds.). (1996). AIDS as a gender issue: psychosocial perspectives. London: Taylor and Francis.

Shively, M. G., & De Cecco, J. P. (1977). Components of sexual orientation. Journal of Homosexuality, 3(1), 41-48.

Shively, M. G., Jones, C., & De Cecco, J. (1983/84). Research on sexual orientation: Definitions and methods. Journal of Homosexuality, 9(2/3), 127-136.

Simon, W. (1989). Commentary on the status of sex research: The postmodernization of sex. Journal of Psychology & Human Sexuality, 2(1), 9-37.

Simon, W. (1994). Deviance as History: The future of perversion. Archives of Sexual Behavior, 23 (1), 1-20.

Skeggs, B. (1991). Postmodernism: What's all the fuss about? British Journal of Sociology of Education, 12(2), 255-267.

Slome, L., Moulton, J., Huffine, C., Gorter, R., & Abrams, D. (1992). Physicians' attitudes toward assisted suicide in AIDS. Journal of Acquired Immune Deficiency Syndrome, 5, 712-718.

Slome, L., Mitchell, T. F., Benevedes, J. M., Charlebois, E., Mandel, N., Townley, D., & Abrams, D. I. (1996). Physician's attitudes toward assisted suicide in AIDS: A five year comparison study. XI International conference on AIDS, Abstracts We.D 244.

Smith, D.E. (1987). The everyday world as problematic: A feminist sociology. Toronto: University of Toronto Press.

Smith, D.E. (1990a). The conceptual practices of power: A feminist sociology of knowledge. Toronto: University of Toronto Press.

Smith, D.E. (1990b). Texts, facts, and femininity: Exploring the relations of ruling. London: Routledge.

Smith, D.E. (1991). Writing women's experience into social science. Feminism & Psychology, 1(1), 155-169.

Smith, D. E. (1993). High noon in textland: A critique of Clough. The Sociological Quarterly, 34(1), 183-192.

Smith, D. E. (1996). Telling the truth after postmodernism. Symbolic Interaction, 19(3), 171-202.

Smith, G. (1990a). Policing the gay community. In W.K. Carroll (Ed.). Organizing dissent: Contemporary social movements in theory and practice. Toronto: Garamond.

Smith, G. (1990b). Political activist as ethnographer. Social Problems, 37(4), 629-647.

Smith, G. (1991). Policing the gay community. In R. Ng, G. Walker, & J. Muller (Eds.), Community organization and the Canadian state. Montreal: Garamond Press.

Smith G. (1994). Palliative care in Toronto for people with AIDS: The impact of class on poor PWAs. Journal of Palliative Care, 10(2), 46-50.

Smith, G. W. (1995). Accessing treatments: Managing the AIDS epidemic in Ontario. In M. Campbell & A. Manicom (Eds.). Knowledge, experience, and ruling relations: Studies in the social organization of knowledge. Toronto: University of Toronto Press.

Smith, G., & Mitchell, E. (1991). Getting 'hooked up': An organization study of the social-service delivery/access connection for people with HIV/AIDS. Toronto: A Research Proposal prepared for National Welfare Grants.

Snitow, A., Stansell, C., & Thompson, S. (Eds.). (1983). Powers of desire: The politics of sexuality. New York: Monthly Review Press.

Stanley, L. (Ed.). (1990). Feminist praxis: Research, theory and epistemology in feminist sociology. London: Routledge.

Stanley, L. & Wise, S. (1990). Method, methodology and epistemology in feminist research processes. In L. Stanley (Ed.), Feminist praxis: Research, theory and epistemology in feminist sociology. London: Routledge.

Starace, F. & Ogden, R. (1997). Suicidal behaviours and euthanasia. AIDS Care, 9(1), 106-108.

- Starace, F. (1995). Epidemiology of suicide among persons with AIDS. AIDS Care, 7(Suppl. 2), 123-129.
- Steinbrook, R. (1987). Ethical issues in the AIDS epidemic. Focus, 2(4), 1-4.
- St. Paul's Hospital. (n.d.). Social work department HIV psychosocial assessment. Vancouver: Author.
- Swift, K. (1991). Creating knowledge: A study of the production of knowledge about child neglect. Unpublished doctoral dissertation. University of Toronto, Toronto, Ontario.
- Swift, K. (1995). Manufacturing "bad" mothers: A critical perspective on child neglect. Toronto: University of Toronto Press.
- Thomas, L. (1991). Science and health--possibilities, probabilities and limitations. In A. Mack (Ed.), In time of plague: The history and social consequences of lethal epidemic disease. New York: New York University Press.
- Thurston, G. (1980). Coronership. London: Barry Rose.
- Townsend, E. (1998). Good intentions overruled: A critique of empowerment in the routine organization of mental health services. Toronto: University of Toronto Press.
- Treichler, P. A. (1988). AIDS, homophobia, and biomedical discourse: An epidemic of signification. In D. Crimp (Ed.), AIDS: Cultural Analysis/Cultural Activism. Cambridge, Mass.: The MIT Press.
- Trussler, T., & Marchand, R. (1993). Taking care of each other: Health promotion in community based AIDS work. Vancouver: AIDS Vancouver.
- Trussler, T., & Marchand, R. (1994). More reflections on taking care of each other: Health promotion in community based AIDS work (vol. 2). Vancouver: AIDS Vancouver.
- Tullis, E., Y, D-G., Rawji, M, Rachlis, A., Hyland, R., & Chan, C. K. The long-term effects of aerosol pentamidine on pulmonary function. Clinical Investigative Medicine, 15(1), 42-48.
- Vance, C. (1988). Social construction theory: Problems in the history of sexuality. In D. Altman, et al., Homosexuality, which homosexuality? International conference on gay and lesbian studies. London: GMP Publishers.

- Vancouver/Richmond Health Board. (1997, November). HIV/AIDS and injection drug use in the DTES. Vancouver: Author.
- Vlasak, G. (1975). Medical sociology. In S. Perlin (Ed.), Handbook for the study of suicide. New York: Oxford University Press.
- Wagenhouser, J. (1990). Safe sex without condoms. Out/Look, 11(winter), 65-70
- Walker, G. (1990). Family violence and the women's movement: The conceptual politics of struggle. Toronto: University of Toronto Press.
- Walker, G. (1995). Violence and the relations of ruling: Lessons from the battered women's movement. In M. Campbell & A. Manicom (Eds.), Knowledge, experience, and ruling relations: Studies in the social organization of knowledge. Toronto: University of Toronto Press.
- Warner, M. (Ed.). (1993). Fear of a queer planet: Queer politics and social theory. Minneapolis: University of Minnesota Press.
- Watney, S. (1989). Policing desire: Pornography, AIDS and the media (2<sup>nd</sup> ed). Minneapolis: University of Minnesota Press.
- Watney, S. (1994). Practices of freedom: Selected writings on HIV/AIDS. Durham: Duke University Press.
- Weedon, C. (1987). Feminist practice and poststructuralist theory. Oxford: Basil Blackwell Ltd.
- Weedon, C. (1997). Feminist practice & poststructuralist theory. Second Edition. Oxford: Blackwell Publishers.
- Weeks, J. (1985). Sexuality and its discontents: Meanings, myths and modern sexuality. London: Routledge & Kegan Paul.
- Weeks, J. (1988). Love in a Cold Climate. In P. Aggleton, & H. Homans (Eds.), Social Aspects of AIDS. London: The Falmer Press.
- Weeks, J. (1989). Sex, politics and society: The regulation of sexuality since 1800 (2<sup>nd</sup> ed). London: Longman Group Ltd.
- Weinberg, T. S. (1978). On 'doing' and 'being' gay: Sexual behaviour and homosexual male self-identity. Journal of Homosexuality, 4(2), 143-156.

Weinberg, T. S. (1985). Biology, ideology, and the reification of developmental stages in the study of homosexual identities. Journal of Homosexuality, 10(3/4), 77-84.

Weitz, R. (1990). Living with the stigma of AIDS. Qualitative Sociology, 13 (1) 23-38.

Yingling, T. (1991). AIDS in America: Postmodern governance, identity, and experience. In D. Fuss (Ed.), Inside/out: Lesbian theories, gay theories. New York: Routledge.

Yufit, R. L. (1991). American Association of suicidology presidential address: Suicide assessment in the 1990's. Suicide and Life-Threatening Behaviour, 21(2), 152-63.

# APPENDIX ONE

## Jay's Journal

kyolic  
Golden Seal  
Vit C  
Lecithin  
Tylonol [sic]  
cough syrup  
tofu  
soups  
rice  
noodles  
fruit  
juices  
bread

### December 1987

Reasons for living  
The beauty of the earth, summer,  
winter, spring and fall/north +  
south

Reasons for not living

Politicians are corrupt

I can't see a picture of my life 6  
months from now--fearful of this  
future block.

Depressed. Can't relate well to  
people; don't want to interact.  
Tired, sleep all the time, no  
energy for anything.  
No excitement for things.

Don't feel it's worthwhile to make  
plans, as I fear death by AIDS.

Maybe death is a welcome relief.  
On to the next chapter.

**December 1987**

Is death the great liberator?  
Will it release us from the pain of  
this world?

**Dream February 28, 1988**

Ottawa Gen[General] Hospital

Jay is looking at the ads for  
adventurous gay men to hike and  
canoe across Canada. One meets me  
in the wilderness. We laugh and  
play in the water in the  
wilderness.

Scene moves to Montreal tenement  
[sic] slum. Broken windows, howling  
cats + chaos.

**Thoughts March 1, 1988**

Still can't believe this is happening.  
I feel so weak and scared +  
freaked out. the 1st 4 days in  
Int. care was a nightmare of tubes  
down the lungs, hands restrained,  
heart machines + oxygen. I was so  
out of it. Rosemary and Terry came by,  
thought it was an hallucination.  
Don't know when, but Mom,  
Barb, Steve and Chris came --  
I was so overwhelmed with care + love.  
It still brings tears to my eyes  
that they would drop their schedules  
to see I was o.k.  
They want me to move back west, which I  
am very happy to do.

Early retirement I call it!

### **March Monday week 2.2**

I can't tell dates anymore.  
Altho' this was the possible  
day of my release. Unfortunately  
I have been running a  
high fever, along with  
nausea -- I used to eat  
ravenously, but now must  
force myself. Threw up the  
other day. Drinking lots of  
liquids. My weight is still  
down. Must start eating  
more fresh fruit w/ sugar.  
Pears, grapes -- refreshing.

I am disappointed about  
the days of fever, as they have  
laid me low. But I have been  
getting encouragement from  
many channels. Cathy called + it  
was hard but she has faith. Paula  
walked in the room in tears for 20 minutes  
hugging me and saying how  
unfair. When she calmed down  
we were able to look at the thing  
more realistically.

Mom is still here, maybe till the  
end of March. She is my rock that  
is sustaining me.

I try not to worry about the  
worldly/material stuff I have  
to deal with. As things are  
working out so well.

I will stay w/ Terry + Ed  
till I go west -- no questions  
asked. Bless them.

**Tuesday**

Day 5 of feeling shitty. I can't eat because of nausea, + throw up sometimes. The sight of food makes me almost throw up. Fevers have been 38-40+ which have rendered me washed out. Only a few hours a day am I feeling energetic

They gave me a lumbar puncture late in the aft 2 days ago. My back is a screaming pain zone. Cannot get comfortable. The procedure was not pleasant +now the after-math.

This is all discouraging me very much.

**Thurs[day]: Feelings today**

despair  
pain  
separation of mind + body/whose body is this anyway  
frustration  
fear

**AIMING FOR**

hope  
improvement  
bringing my mind to help body during this crisis  
encouragement

The orange balloon  
with multicoloured  
dots

Became my mandala

The Sound of women  
laughing is a happy sound

Dr. Ross AIDS the Challenge of the  
Future  
Psycho-immunity + the healing  
Process, Jason Serius [sic]

Housecleaning:  
Friday Mar 18

Needed:  
3 large moving co. Cartons  
celluloid tape  
marker

**March 14**

I have been pre-occupied with  
worrying today. What is going to  
happen. I am scared.  
Called Ken + Michael + got  
cheered up -- this after crying  
for awhile -- pent up tears.

Barb was here this p.m. Here w/  
Joan as her attendant  
for a conf on women + power.  
It was so wonderful to  
see her + talk. We walked the  
halls. She carried gifts from  
George, Steven + other greetings.

I have to keep reminding  
myself to keep a slow pace --  
and concentrate on getting well.  
The worrying only fights  
against you.

I get released on Wed! I'm  
excited + scared. I've been

here for ? 3 ½ weeks? Can't  
remember. Now it is like a  
womb I must leave. When  
I walk out these doors,  
I will be re-born. A  
different Jay than who  
staggered in that cold  
clear Friday in Feb.

I am Jay w/ AIDS  
I am a PWA  
entitled to all that is  
available to this select  
but growing company  
of people.

I had always wanted to  
work on an AIDS committee  
+ do home-care etc. But I  
was scared to death of  
facing AIDS so directly.  
I wasn't ready.

Now that I am with + among  
them, I will loose my fear +  
feel in community w/ my  
brothers in our new metamorphosis.

Have I yet in all my life been outside  
of Plato's cave, where you only  
see the shadows of life?  
I think I have, for  
moments at a time

In a world of complacency,  
+ tastelessness for real  
life, the shock of mortality  
+ AIDS brings you back from  
such complacency. There is  
no more time for such  
things.

P.B. called this a.m. I  
told him that he was my best  
friend + why couldn't we be  
closer dammit. We ended up  
crying and finally saying  
choked-up good-byes.

I look like a refugee victim  
from a concentration camp.  
I am down from 200 lbs.  
to 162! I haven't been  
162 since on the way up!  
or at weight watchers in  
high school. Drawn, hollowed out  
face -- emaciated legs (they used to  
be so big + muscled)  
my ribs showing. I still have a  
stomach tho'! I'll probably  
look great in my clothes that  
haven't fit for years!  
Weird way to lose weight.  
Now I have to concentrate on  
putting it back on! What a  
switch for me.

Had the IV taken out today. Feels  
good not being attached to a  
couple of plastic bags, tubing  
+ a wheeled pole!

Also showered myself today,  
will victories never cease?

Have had a few erotic dreams  
lately. Will my sexuality be  
lived only in my dreams, now?  
I'm certainly afraid of sex now --  
I was in the past, too,  
but horni-ness [sic] won out.

**Tuesday [March 15]**

call OHIP (Ontario Hosp Ins Plan)

I've decided to pack my  
red mini, because I will  
become, with appropriate cow-boy hat:  
Elizabeth Manley,  
Queen of the Ice, sweetheart  
to the Olympic masses!  
I need more sequins tho.  
Can hardly wait for my  
debut!

**Wednesday**

I have been released!  
I checked out of Ottawa General  
about 1:30 p.m. w/ the help  
of Paula and Mom. They loaded  
me onto a wheelchair, + covered  
me w/ flowers + wheeled me  
right out of that tomb/womb  
hospital. I felt like a  
bridesmaid, w/ daisies +  
orchids + lovely spring floral  
arrangements in my arms.

I am getting flashes of the  
horrible time in I.C.  
Mom showed me the notes  
I wrote while in I.C. +  
under "the tubes" writing  
is like a 2 year old + the  
messages range from the  
mundane (will you scratch  
inside my ear?) to the  
mystical ("the Shaman  
woman..kissed my tender  
sides...") Even some hallucinatory  
Spanish. I was a bit freaked  
out when I saw these notes  
today + realize how out of

it I was. Mom said it was  
70/30 death/life  
for a couple of days.

I almost died.

But the love of my family  
+ friends saved me.

Now I want to hug everybody  
even Sister J at the  
hospital.

Thanks to the doctors +  
nurses at O.G.H. They helped  
save me, too, + I hug them.

M.H. was over last  
nite, my last night at OGH, +  
he said he thought I had changed,  
that there was a peace/calm  
in my eyes. I guess I have  
calmed down a bit. I hugged him  
+ told him I love him.

Now, I love everybody!

**Sat. March 19**

Late nite. Can't sleep. Off  
sleeping pills. Mind going around  
like a top -- things to do; Mexico  
last year; fear of the future.  
Have to get back some  
humour in my life. Things  
are too serious.

Am at A[untie] R's apt.  
I have a little room in the  
basement--a suite. I go upstairs  
for meals which have been  
excellent. Tonite, pasta, salad  
+ garlic bread. I bought

wine for the occasion + a bottle of vodka for mom. She was quite tipsy tonite which was fun, altho' at one point we were crying and hugging because she was so scared about losing me. She said she cried more than while Dad was ill. Biological link vs. married emotional link. I was very moved, + glad I stayed alive.

Auntie R is so funny. She is so full of energy, always on the move. Lots to say, great dresser, + very good to mom + I.

Got the stuff out of the apt. Of L and P on Fri. Thank goodness. Joe, Claude + Ken helped. It was quite the effort and I was exhausted. Some plants looked dead -- hope they revive w/ the watering.

Almost wanted to drive car out west w/ junk, but really don't have the energy + fear snow storms (always in spring time) + car fucking up. Better to sell car + ship stuff + take the plane to Calgary. Really looking forward to Chris and Claire's wedding.

Lots to do but must take it slowly. No hurry Jay. Slow down, Slight fever tonite.

Got a letter from Jan H.  
 w/ photos of her daughter Jacobie  
 + Rick in Damascus. Read  
 Katherine's travel letter in the  
 bath today. Incredible, she  
 was teargassed in a riot in  
 Jerusalem --what an adventurer!  
 Wish I could visit Rick in  
 Damascus.

One big pain about this  
 illness is that travel will be  
 curtailed, altho' I'd love to  
 go to Peru to visit Rick  
 when he goes there. He  
 should be in Canada/B.C.  
 in June--really looking  
 forward to seeing him.  
 I'm very happy for him.  
 Married + travel career. I'm  
 a bit jealous, esp, now that  
 I don't know how long I  
 will live. Here is Rick,  
 my almost twin, + he will probably  
 live till 65 + have an interesting  
 life. Well, I guess my experiences  
 are unique too, esp. near death  
 + now on this journey  
 w/ AIDS.

What is to become of me? I go to  
 Vanc. + live on welfare. Maybe  
 get some freelance work. Going  
 to the west coast to die? Going  
 home to die? What is death?  
 Will it be 1 year, 2, 3, 4, 5,  
 or 10? How do you fight this  
 thing. Hardest thing is  
 calling up friends + telling  
 them.

Must get humour back  
 in my life. Jan H. says that's

my greatest asset + weapon.  
But haven't felt too humorous  
lately.

Feel really weak. Must gain  
strength. Must take it easy.  
Relax, Jay.

(List at end of entry:  
take stuff day early  
walk outside  
insurance  
dimensions of rack in compartment  
electrical outlets  
cancellation insurance)

#### **Thurs, March 24**

Sold the car to Richard tonite!  
\$650; it passed safety inspection.  
Whew! I'm so relieved. That, other  
than getting well, moving  
etc. was my biggest worry.

P. took me to hospital  
today for my "nuclear"  
heart scan. She told me I  
was glowing! Yuk! The technician  
showed us the computer  
generated heat graphics.  
...Hope the  
test is a positive one.

G.M. in town  
for a conference. Hope to  
have cocktails w/ him, + S  
+ co. On Sat. Aft.

#### **April 13**

En route, en VIA.  
Train just pulling into  
Thunder Bay. Beautiful day.

Blue, crisp + clear. The sleeping  
Giant floated over the lake ice.

Mediocre dinner in dining car.  
Salmon was delicious but  
everything else bad. But nice  
chat with Australian  
man + Torontonion woman.

1 hour from Winnipeg;  
we've just left the trees +  
rocks of Ont + entered the  
flatlands of Manitoba.  
Have seen several  
hawks. One huge one sitting on  
fence post, watching us go  
by.

Ron will meet me in Winnipeg.  
Our ½ hour rendezvous.

Slept very well last nite. Hope  
for the same tonite. I'm just  
getting used to life on the  
train + tomorrow noon will  
see it end. I should take  
the Patagonian Express to  
S. America!

Things I'd like to do in Alberta:  
-go to Banff/Cave +Basin + Hot  
Springs  
-drive the foothills  
-Glenbow/Arts Centre

In B.C.  
-Long Beach  
-Hornby

-Go to Peru

**May 88****Budget May 88**

\$700	running shoes	60
	thesis	250
	binocs	75
	Banff	50
	Food/eat out	50
	shows/ent	50
	clothes	50
		<u>\$600</u>

	June	
\$250	Via (?)	120
	Food	100
	Ent	50
		<u>270</u>

	July	
\$400	Rent	400
	Food	200
	Vitamins	50
	Gas	50
	Ent	100
		<u>800</u>

**\$400 over budget per month**  
 -maybe get food from AIDS Vanc.  
 -Vitamins

**July (From savings)**

\$400	expenses	Savings: \$3000 C.U.
\$800	car	
\$350	insur	

\$1550

3000-1500=1500

1500/300 = 5

At \$300 expenses over  
welfare, I can live for  
6 months: July-Dec  
on \$3000 from C. U. savings  
+ car + insurance.

**July 30 or August 1/88**

In Smuggler's Cove Sunshine  
Coast across the Strait from  
Hornby Island. I can hear  
Tribune Bay calling. Don't know  
my route there yet, but maybe via  
Lasqueti Island.

I don't know why but I've  
started smoking cigarets + dope  
like there's no tomorrow. Ha!  
Maybe there isn't! No! No!  
Must be positive. But why  
am I doing this -- it's self-  
destructive and I know it.  
Do I want wish to self-destruct?  
Maybe I'm just nervous on  
board. I'm close to tears. I feel  
out of place, except I ran  
into N, B, and 2 of their  
friends at Buccaneer Bay this  
afternoon. Their 2 friends  
just arrived out of the woods from  
their cabin about ½ hour walk  
to Smuggler's Cove.

I do love N and B. I  
am very honest with them. It's  
hard being honest. Try being  
honest w/ yourself, my dear!

**November-mid December, 1988  
Beijing, China**

[Since Jay does not mention anything about AIDS I am not including excerpts from this trip as it is more a travel journal]

**No date (sometime in January 1989)**

I love + accept myself exactly as  
I am

I let go of fear  
I let go of anger  
I let go of delusion

Right now I focus on the  
moment. I am in the moment.  
I am focussing on me.

I will try to be gentle with  
myself + do things that I enjoy.

I will enjoy my life, each day  
of my life. I will continue to  
attempt to focus on the  
very moment I am in. How do  
I feel. At the moment calm,  
content + cocooned in my apartment  
feeling OK at this moment.

But, under this calm exterior is  
still a lot of fear. My medications  
are failing me (except for the  
thrush in the throat, thank god!)  
Had a bone marrow test last week  
+ if it indicates an O.I. [opportunistic infection],  
including TB, then I can't do the a.penta-  
madine clinic, which I have been  
working towards for 6 months on  
the double blind study. SHIT.  
I cried in IDC today in front  
of the gentle Dr. F.

So what do I do?  
I'm looking for another doctor  
to review my case--perhaps  
Dr. J.  
W. the social worker has  
agreed to see me for some counselling.

Joe has asked his faith healer friends  
to include my name in their prayers  
+ he may visit as he has some  
healing powers too.

The Reiki treatment helped  
a lot, relaxed the throat--but  
what pain in just laying on of  
hands, Also opened my bowels!

Doing a lot of affirmations:

I love + accept myself  
exactly as I am

I must do more work in this area.  
Will visit K. Thurs. for a  
healing hands on treatment.

What else can I do that I am  
not doing? I'm sure I'm  
on the right track -- feel positive  
about your power to change this  
crisis into a manageable regime  
again.

Again, I am overwhelmed by  
my friend's and family's response.  
I see from this that we have all  
pulled closer, + even when they  
cause me pain in some way,  
I know they do it out of love.  
And I love them. Like the day  
of the bone marrow test. I was  
a wreck. They all kept calling + I  
was in tears for 2 days, which,

with my bad throat was agony.  
 But Bob, Steve + Chris came  
 over + I cried in their embraces  
 which felt good.

But my dilemma:

a) Love myself, heal myself -- this  
 is one approach. I'm not sure  
 what love is -- how do you  
 love yourself. This I must work  
 on. Louise Hay et al.\*

b) Stephen Levine\*, + Emmanuel's Book\*  
 seems to encourage you to accept  
 death -- "the removal of the tight  
 shoe". If I am truly dying  
 (which contradicts the fact that  
 if I choose to change I need  
 not die), -- should I move towards it  
 + embrace it?

--when will it happen?

--will I be scared; I have

lots of fear about this now, esp.  
 with such low hemoglobin.

--will it happen quickly?

--should I will it quickly?

--is suicide a legitimate

option if things get too out of hand  
 (I don't want to suicide -- I want  
 to go naturally)

**Thurs. Feb. 2/89**

Feeling so much better in my spirit  
 today + yesterday.

Bone marrow tests are normal! No TB or O/I. Thus  
 I can pursue A. Pent (aerosol pentamidine) soon.

11 a.m.

In the IDC getting a blood transfusion  
 -- finally. My hemoglobin has gone

to 85% – too low for  
 comfort. Now being energized!  
 Barb brought me in as she came  
 to town to see me + as she had  
 heard Steve D. is in ICU.  
 I send him my love + the new  
 energy I am gaining.

G. from AIDS Van  
 was over yesterday + he held  
 me while I cried about my  
 fear of death + loathing of my sexuality,  
 + where to find my heart. He said my ability to cry  
 and feel emotion was on the right  
 track towards self healing. What a  
 beautiful man!

Re transfusion: In middle of  
 meditation receiving this gift of  
 blood I had a sudden flashes  
 of colour, red, + warmth that  
 spread throughout my body.  
 Mandalas of red health.

I love myself + accept myself  
 exactly as I am.

I am healing  
 The process has begun.

**Monday Feb 6/89**

I love + appreciate all of myself,  
 and accept myself exactly as I am.

I certainly have more energy,  
 after having slept 2 days  
 following transfusion.  
 Day 3 I leapt out of bed  
 at 8:30 a.m. and took in a good  
 breakfast, a walk, + a show  
 with Chris H. (Rain Man)  
 till 4:30. Loved the show.

Had supper +crashed about  
9:30 –Quite a day for  
a former anemic old  
fart.

Hope hemoglobin stays  
about 100 for awhile +  
that I gain more energy  
as days go by.

Barb spent time w/  
me in the hospital as did  
Steve – I love them so much.  
Steve D. is in intensive  
care cardiac unit; his body is  
freaking out, so Barb spent  
time between him + me. She  
made a special trip for  
Steve + me! Afterwards George,  
Barb, Chris + Claire came over  
for a lovely dinner Barb  
prepared.

We are all being taken  
care of. Let go of the fear  
of this illness, no-one will  
let you go -- you have lots  
of support.

They love me  
I love them  
I love me + accept me  
exactly as I am!

**Wed Feb 8/89**

I love myself +accept myself exactly  
as I am.  
I am part of the universal design.

My 'heart' I am discovering is more  
than just 'me' or 'Jay' -- it is a

spiritual envelope that interacts with  
 + includes others. Thus, when I hug  
 Bob + we tell each other we love each  
 other, our 'hearts' or spiritual envelopes  
 meet + actually the energy grows  
 stronger. I would like to read auras  
 to see this heart that surrounds people.

I have such a sense of well being  
 today! It's such a good feeling.  
 Yes! Here it comes! Health + a new  
 loving Jay.

**Tues. Feb. 21/89**

I love myself  
 I forgive myself  
 I forgive all the others + release them.

I am well  
 I am becoming strong  
 I have a better appetite.

Last week felt I was having an  
 attack of PCP. On drugs for that.  
 Developed ulcer between stomach +  
 esophagus; makes eating difficult,  
 painful.  
 Went to see Dr. W., he will  
 do gastroscopy brushings next week  
 "to see what we may see".  
 Nice guy.

Then over to Dr. C.'s, head of  
 infectious diseases on St. Paul's  
 AIDS team. He has something up  
 his sleeve for this candida.  
 Tells me I need more weight!  
 Down to 156! Definitely need to  
 get some flesh on my bones.

While leaving hospital found a  
 great old wooden cabinet + a

great chair for computer work.  
 Spent all Monday nite re-arranging  
 the furniture -- what energy!!  
 Looks great + I'm very happy  
 + secure in my home

I feel so positive, and have  
 lots of fun stuff to do -- having  
 movie nite potluck supper  
 using my new TV + VCR, courtesy  
 of Mom, bless her.

Great having even this 30%  
 energy boost.

Yes, it looks like Spring is around  
 the corner. Keeps me going. I  
 plan to plant a small garden in  
 the garden boxes on the balcony.  
 What fun! A little gardening!

Will start water colouring soon,  
 learn to express myself thru Art.  
 There us an Art therapist at PWA  
 that will hold sessions. Must call  
 him.

I am well  
 I am strong  
 I LOVE AND APPRECIATE MYSELF

--My medications + procedures + diet  
 + vitamins ARE WORKING!

**Feb 28/89**

Well, here we are for round 2:  
 emergency, nose piece +the  
 needles + IV tortures. I felt  
 like Christ last night pinned  
 to the cross.  
 As Stephen D. is here too we  
 play "Upstairs/Downstairs" with our

visitors.

This really makes you focus  
moment to moment, usually  
on where the pain is now, or  
which pain you're going to  
or decide to experience.  
Sometimes they all hit  
at once for a time.

But feeling much better  
today, but still trying  
to stand up from this "stumble"

Feeling more joy  
and  
colouring on an  
art pad  
After an afternoon  
of thoughts of death  
and  
what it means  
and  
if I want to let go  
and  
dive into the cool  
waters of the next world  
I dream  
of water flowing  
I can jump  
in anytime

**The next day: (March 1/89)**

Had a wonderful dream about  
being healthy + more energy. This  
has given me a new outlook  
today. It was as if my "wise self"  
had counselled me out of my  
dark hours of yesterday.

I am learning to change.  
This is merely a chronic

condition that requires  
maintenance, and yes, special  
care. I am learning to change  
+ willing to change.

Back to life!!  
I am healing!!

(Entry is followed by a sketch of his apartment  
and where his computer, telephone and various  
other items might be placed)

**Last entry (sometime in March/89)**

I have chosen renewal + life!  
I can heal myself  
I love myself + accept myself  
I forgive myself + all + I release  
the past, + live in this very  
moment.  
I have breath, life, a loving mother  
+family helping me.

I choose to change my mind, +  
live + accept my life.

**Notes on the back pages of the journal**  
**No Dates**

shower and gown  
wheel chair  
nutritionist: Ensure Vanilla

---

Brian (doctor)  
light head --blood pressure --suggestions  
effect of xylocaine  
constipation  
is head cleared? Stop treatment?  
Spetra  
xylocaine  
benadryl (caps 25 or 50 mg)  
or liquid only for bad rash

kerri oil for bath  
moisturizer for skin

-picture framing nails  
-look for recipe book holder  
--bind recipes for Canadida book  
--call the women re her diet/suggestions  
-Toronto has a cookbook?  
Lots of info on control  
--toilet washable rub and bath mat

Clare to buy a foamy  
B re flannel sheet  
A has flannel sheet  
A has good cook book

Marco's recommended book  
Banyan

--Crystal: amethyst, Barb + Banyan Books

--Chris: watercolours; where to get pad of paper  
--Marg for ideas art therapy  
--A re cassette tapes

FIND A nutritionist re how lng leftovers can be used  
body flesh(?) Building for Candidas  
i.e. no sugar or wheat

--contact Toronto (PWA office)

--meditation retreat weekend. Bob?  
--Hope Foundation--where are their books to read

Candidas AMPHOTERICIN

Dapsone 1x  
Trimethoprim 4x  
Nizorac ?/Ketokonizal 2x

Gastroscopy NYSTATIN POWER ORAL USE?  
biopsy/brushing

Treated AIDS patients  
 10:45, 11:45, 12:45, 2 p.m.  
 GO TO ST. PAUL'S ADMITTING

Reduce AZT (½?)

Consult with Dr. W. Once results are in from Gastroscopy

Bronchoscopy  
 Calcium Scan

Deficiencies in Ying--nourishing  
 therefore little (Yang) energy present  
 more +fluids, no spicy foods  
 re, orange OK foods yams squash carrots  
 soups

Linseed oil on salads, in fridge  
 KS --note for Hope Foundation

HALCYON

If below 97, transfusion

Quest Super Once a Day minerals  
 Caprilic \$30  
 Ecomer \$50

E. D. Acupressure \$30.00

Counsellor

Meals on wheels

St. Pauls' IDC[infectious disease clinic] phone number  
 Social workers: phone numbers

Home Care -- AIDS--City Health --MSS--approval form

Treatment--hemoglobin below 87%  
 off AZT  
 jeopardizing bone marrow--TB  
 pentamidine

'B' trials  
So I'm freaking out  
possible to review my case  
w/ appt w/ Dr. C.

Dr. D. West Broadway  
Ear, nose + throat

Hemoglob 85  
platelets 186

No TB  
RETICS bone marrow indicator

Hope Cancer Foundation  
Women's Health Collective  
Candida Research and Info Foundation  
Clinical Ecologist

# **APPENDIX TWO**

## **Judgement of Inquiry**



CORONER'S COURT OF BRITISH COLUMBIA  
HELD AT BURNABY B.C.

CASE NO  
Vancouver Pol  
Case #

JUDGEMENT OF INQUIRY  
Into The Death Of

**HERRINGER**  
SURNAME  
Address: #901

**JAMES ANTHONY**  
GIVEN NAMES  
Vancouver, B.C.

I, \_\_\_\_\_, a Coroner in the Province of British Columbia  
have inquired into the death of the above stated which was reported to me on the 24th day of  
April 1989 and as a result of such inquiry have determined the following facts:

Age: 35 Sex: M  F  Native   
Date of Birth: December 15, 1953 Est. Date of Death: April 24, 1989  
Place of Death: Vancouver Est. Time of Death: 1030 hours  
Place of Injury/Illness: Vancouver, B.C. Date and Time: As above  
Type of Premise: Private residence Code   
Identification Method: Visual  Other:   
Identification By: Mr. \_\_\_\_\_ building manager.  
Body Released to: First Memorial Services, Vancouver, B.C. Date: April 26,  
POST MORTEM EXAMINATION: Yes  No  Date: April 25,  
Conducted By: Dr. \_\_\_\_\_ pathologist  
TOXICOLOGY EXAMINATION: Yes  No  Date: May 10, 1989  
Conducted By: Provincial Toxicology Centre, Port Coquitlam, B.C.  
Relevant Findings: Blood: Ethyl alcohol - 0.02% Vitreous Fluid - Ethyl alcohol - not detected  
Triazolam - not detected alcohol - not detected.  
Basic drug screen - none detected detected.  
Acidic drug screen - none detected  
MEDICAL CAUSE OF DEATH: Opiates - none detected. Code   
(1) Immediate Cause of Death: (a) Massive deceleration injuries  
DUE TO or as a consequence of Code   
Antecedent Cause if any: (b) DUE TO or as a consequence of Code   
Giving rise to the immediate cause (c) Fall  
(2) Other Significant Medical Causes Contributing to Death: A.I.D.S. Code

BY WHAT MEANS: Jump from 23rd floor of apartment building. Code   
CLASSIFICATION OF THE DEATH: Natural  Accidental   
Homicide  Suicide   
Undetermined

Dated this 14th day of June 1989

\_\_\_\_\_  
Coroner



CORONER'S COURT OF BRITISH COLUMBIA  
HELD AT BURNABY B.C.

Case No.89.

CIRCUMSTANCES and RECOMMENDATIONS as a RESULT of the INQUIRY  
Into The Death Of

HERRINGER

JAMES ANTHONY

SUMMARY OF EVENTS:

At 9:45 a.m. on April 24, 1989, James Anthony Herringer was found lying in the parking lot on the west side of a Vancouver apartment block. It was obvious he had suffered a fall from a height. A tenant on the eighteenth floor had heard a bang on her balcony railing followed by the sound of impact. She looked over the balcony and saw the subject lying below. She immediately summoned the Vancouver City Police who were met at the scene by the building manager. He identified the subject as James Herringer, a tenant on the ninth floor. Identification in the jacket pocket confirmed this.

Attendance was made to suite 901 where  
was informed of the circumstances.

explained that James was an AIDS patient who had left the apartment to attend the AIDS Clinic at St. Paul's Hospital at about 9:30 a.m. stating that he would return in the afternoon.

It would appear that, instead, James went to the roof of the building (equivalent to 23 floors) and jumped from the west side. There is unrestricted access to the roof. No suicide note was located on the roof or in the apartment. EHS transported James to St. Paul's Hospital where death was pronounced shortly thereafter at 10:30 a.m. by Dr. -

MEDICAL HISTORY AND BACKGROUND:

Dr. confirmed the diagnosis of AIDS although James' condition was not severe at this time and death was not imminent. He was markedly depressed about his disease and had two recent admissions to St. Paul's Hospital in a catatonic state. On his admission from April 10 - 14, 1989, the admitting diagnosis included questionable overdose of Halcion. On discharge he was not felt to be suicidal although he remained in a state of depression. Dr. saw him regularly and had



CORONER'S COURT OF BRITISH COLUMBIA  
HELD AT BURNABY B.C.

Case No. 13

CIRCUMSTANCES and RECOMMENDATIONS as a RESULT of the INQUIRY  
into The Death Of

HERRINGER

JAMES ANTHONY

MEDICAL HISTORY AND BACKGROUND - Cont'd:

last seen him four days previously. His prescription medication included Azidothymidin for AIDS, Halcion for sleep, and Ketoconazole for candida and Septra.

POST MORTEM EXAMINATION:

The body was moved to Vancouver General Hospital for autopsy performed by Dr. April 25, 1989. Massive deceleration injuries were evident with multiple fractures of skull, ribs, pelvis, and long bones combined with laceration of aorta, lungs, spleen, bladder and heart.

Toxicology analysis was positive for only a minute amount of alcohol (0.02%) and no other agents were detected on full screen.

CONCLUSION:

I find that James Anthony Herringer, 35 years of age, came to his death on April 24, 1989, in Vancouver, B.C. from unnatural causes to wit: Massive deceleration injuries secondary to a fall.

I find this death to be suicidal and although no writings were left by way of explanation, it can be surmised that James Herringer took his life while in a depressed state of mind due to his diagnosis of AIDS.

89/06/16

Coroner