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**NARRATIVES OF IDENTITY AND RESISTANCE:
GAY AND BISEXUAL MEN LIVING WITH HIV AND AIDS**

by

ALAN NICHOLAS PACKWOOD, B.A.Hons.

**A thesis submitted to
the Faculty of Graduate Studies and Research
in partial fulfillment of
the requirements for the degree of**

Master of Arts

Department of Sociology and Anthropology

**Carleton University
Ottawa, Ontario
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NARRATIVES OF IDENTITY AND RESISTANCE:
GAY AND BISEXUAL MEN LIVING WITH HIV AND AIDS

submitted by Alan Nicholas Packwood, B.A. Hons.

in partial fulfilment of the requirements for
the degree of Master of Arts

Thesis Supervisor

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June 25, 1993

Abstract

This thesis brings together stories told by gay and bisexual men living with HIV and AIDS. These stories are interpreted with an understanding that social narratives have articulated a relationship between contagion and "homosexual bodies" in the context of a medical model of "AIDS-as-disease." Opposed to the medical model of AIDS is a myth of healing imbedded in the stories told by AIDS-affected men. This myth of healing is illuminated through a structural analysis of the story of AIDS as it is told by mainstream medicine and by HIV-positive gay and bisexual men.

Acknowledgements

I would like to thank the members of my committee, Brian Given and Bruce Cox, for their advice and support both intellectual and emotional. I would like to thank Glenn Rockett and Angela Favretto of the AIDS Committee of Ottawa for giving an academic the chance to do something in "the real world." I would like to thank Douglas Ivison and Kathryn Payne for their patience and their friendship. I would especially like to thank the men who took the time to share their stories with me.

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Chapter One: Introduction

This paper surveys "stories" told by and about gay¹ and bisexual men living with HIV² and AIDS³. I examine stories which posit contagious associations for the category of "the homosexual⁴." I move on to explore the story⁵ told about AIDS in the conventional disease model advanced by mainstream medicine. I discover a response to this story in the form of a classical myth⁶ of healing which is given a contemporary articulation in the experiences of men living with HIV and AIDS. In the course of this investigation I argue for the implications storytelling has for the construction of experience and identity. I shall begin by telling part of my own story.

I have been interested in several interconnected phenomena as the focus of my research. I shall outline the reasons for my interest so that I can make these clear. I am unconvinced of the theoretical validity, or intellectual honesty, in telling anyone that my connection with HIV/AIDS arises "as a gay man." I am particularly concerned with the

¹ Please see Appendix A for a definition of this term.

² Please see Appendix A for a definition of this term.

³ Please see Appendix A for a definition of this term.

⁴ Please see Appendix A for a definition of this term.

⁵ Please see Appendix A for a definition of this term.

⁶ Please see Appendix A for a definition of this term.

politics of such a statement. "As a gay man I have such and such to say about HIV/AIDS and blah blah blah..." If I make such a statement I have positioned myself as oppressed and somehow virtuous. The corollary of this attitude is generally unstated: "As a gay man (you better not disagree with me or you are a homophobe) blah blah blah..."

Here I am not trying to remove politics from the sphere of research. Representations of "the Other" in anthropological research have been used for purposes outside the interest of that "Other." The excesses of the discipline should remind us of the potential misuses of ethnographic research. These misuses would not have to be as heavy-handed as the bombing of Evans-Pritchard's informants by the Royal Air Force! Short of that we still need to take care. While I am not trying to ignore the potential political implications of my research I am attempting to avoid situating myself as having some form of unassailable virtue. I am not undertaking my research "as a gay man" but as myself.

Me...

I am, however, a gay man. I have grown up into a community being devastated by AIDS (Acquired Immune Deficiency Syndrome) and living in fear of HIV (Human Immunodeficiency Virus) which is the virus, or more precisely the retrovirus, suspected to cause the breakdown

of the immune system. This paper is the end result of an attempt to understand the experiences of some members of this community. In the course of this attempt I have tried to come to terms with my own relationship to AIDS.

In chapter three I shall outline my methodological aims and assumptions. An important method I have employed is that of a mutual telling of stories. By this term I mean not only a recognition that my research consisted of interchanges with my informants but a form of ethnographic practice. I engaged in conversations that were very personal to the men whose stories inform this research. I felt it was necessary that these conversations take the form of an exchange. This research is not based on a whim but emerges from my life. I shared my motivations for this work with men who have become my friends. It is as necessary that I explain these motivations in this written context as it was in those many conversations.

I am now twenty-four years old. This is an accident of timing which makes me luckier than had I been born a gay man into an age group only a few years older than myself. When gay men began to die in the years following 1978 a critical period of time passed where the causes of "gay cancer", as it was then termed, were not understood. I am a member of the first generation to know enough about the transmission of HIV to protect myself if I am careful.

This is a fact of vital importance to this paper and

the way I have lived my life. In the five years between my first test for the presence of antibodies to HIV in my blood and my second test in February of 1992 I was able to avoid thinking about AIDS. I found it hard enough to grow up dealing with a sexuality⁷ I have been, for the most part, ashamed of, to simultaneously face the deaths of tens of thousands of other gay men.⁸ I had always felt powerless in the face of this plague and engaged in my share of wishful thinking. "Perhaps," I thought, "if am careful and keep my fingers crossed someone will solve this problem and it will all go away."

I could no longer maintain this illusion after the autumn of 1992. Freddie Mercury died that November. Freddie Mercury was the lead singer of the British rock group Queen and was one of my heroes as a teenager. It would be difficult for me to describe the grief I felt at his passing and the implications of his death to the rest of my life. I have had many of my heroes die of AIDS. Andy Warhol, Robert Mapplethorpe, Keith Haring and Hervé Guibert are four gay artists who come to mind. Most of the theory upon which I ground my work stems from my reading of Michel Foucault. He died of AIDS in 1984.

⁷ Please see Appendix A for a definition of this term.

⁸ By this I do not mean to imply that gay men have been the only constituency affected by AIDS. I mean that this is the only constituency affected by AIDS to which I belong. I shall, however, argue in the following chapter that gay men are constructed in a particular intertextual relationship to HIV and AIDS.

The death of Freddie Mercury was altogether different. This is partially a result of a different relationship I have to rock music than I do to other forms of art. Mr. Mercury had a far greater influence on me than the other men I have mentioned. This difference, however, only accounts for part of the hurt Freddie Mercury's death allowed me to feel.

Many of my gay male⁹ friends are in their thirties and are in an unfortunate age group which is now beginning to test positive, become sick and die.¹⁰ It was only last year that AIDS became something affecting my life in anything but a vicarious way. It was only that autumn when I came to the realization that more of my gay friends were HIV-positive than are not. With the death of Freddie Mercury everything became very real to me.

I decided to do something about it.

I set out to speak with adult HIV-positive gay men in Ottawa and Toronto about their relationship to their bodies and to HIV/AIDS. I intended to relate those discussions to their experiences of the medical apparatus¹¹. When I began my research I had engaged in informal conversations and read

⁹ Please see Appendix A for a definition of this term.

¹⁰ I must point out that not every gay man this age is testing positive and that not everyone testing positive is a gay man in this age group. These men are, however, in the last generation to have grown up and come out before AIDS.

¹¹ Please see Appendix A for a definition of this term.

gay writing on the subject which lead me to believe that I would find a conflictual relationship between gay men and their bodies and gay men and the medical apparatus. I had no idea what I was getting into.

I set out to research a paper with a focus on alternative therapies. I hoped to engage in a critique of what I imagined to be a monolithic medical system. While this remained my intention it is only now, looking back on my fieldwork, that I can make some sense of what I actually managed to research. I feel that my intended aims are consistent with what I actually accomplished but that I reached my goal in a way I had not anticipated.

The Red Stocking movement of the early 1970s provided contemporary feminism with one of its most important tenets: "the personal is the political." I believe that for anthropologists "the personal is the ethnographic." Professor John Cove put this to me another way when I was enroled in an undergraduate class in field methods. Cove described living as an anthropologist by saying that "the tape-recorder is always going." I discovered this for myself when I started seeing Jake.¹²

I met Jake several years ago but I only became involved with him a short time before I began my research. Looking back at that time I realize that I have become reconciled to

¹² "Jake" is not his name. I have assigned false names to my informants in order to protect their confidentiality.

the death of Freddie Mercury, my teenage role-model, but that I have yet to sort out my feelings for the other man who motivated this paper. Jake is the only man I have ever really fallen in love with. He is a truck-driver, a motorcycle mechanic and a very hot man. Jake is now my "ex." He is HIV-positive.

I have spent the last year wondering why I took the risks I did. I am probably one of the better educated people in this city in terms of safer-sex practices because of my friendship with HIV and AIDS educators. I could have taken care and been at insignificant risk of exposure to HIV. I almost always did. There is a minimum waiting period of three months before it can be determined that blood which has been exposed to the virus will test positive for the presence of antibodies to HIV. Any test before three months have elapsed following a potential exposure cannot conclusively determine someone to be HIV-negative. My relationship with Jake ended abruptly. I was left to wait out the three months on my own.

Do not mistake an error in judgement for an attempt at "verstehen." I cannot claim to "understand" what it is like to live with HIV. At the end of a very long three months I was tested and found to be "negative." I can, however, claim to have thought very carefully about the implications testing "positive" might have had for my life. The ethnographic had - abruptly - become personal.

This experience left me with a puzzle. Last summer I was terrified. I was terrified that I had made a terrible mistake which could dramatically shorten my life. I was confronted with my mortality in a way more fundamental than I had imagined possible. This despite having been in situations far more directly threatening. I took a lot of chances as a teenager which, in retrospect, seem foolish. In many ways I am surprised to find myself alive and, at the age of twenty-four, an adult. The chances I took as a teenager could have ended my life much more abruptly than AIDS and yet none of my experiences had prepared me for the wait I had to endure. I discovered that I very much wanted to remain alive. I realized that there were many things that I desperately wanted to do. I had failed to take care of myself. I had done something very stupid.

For months I could not tell anyone what had happened. I was embarrassed and ashamed. I did not want anyone to worry when there was nothing anyone could do. It was only in the weeks just before I was due for my blood-test that I finally told anyone. For the most part I waited on my own.

I was not quite on my own. I had my books. One of these - the Meditations of Marcus Aurelius - came to be one of my only sources of comfort. The Meditations would also prove to be the source of my puzzle. Part of me tried to avoid thinking about the possibility that I might be HIV-positive. Part of me tried to avoid thinking about HIV or

AIDS at all. This is difficult for anyone who watches the news or reads the paper. This was particularly difficult for me as another part of me was engaged in reading and preparations for research with the AIDS Committee of Ottawa. In the middle of this the Meditations could somehow impart a serenity I could not find anywhere else.

It turned out I was not the only person to have felt this way. I have already mentioned Hervé Guibert as one of my heroes who has died because of AIDS. Guibert was a French writer who is known for his autobiographical novels. In one of these - To The Friend Who Did Not Save My Life - Guibert tells a story of his friend, a philosopher who was dying with AIDS, whom he calls "Muzil":

"Mancini had been buried, at his request, with his paintbrush and the Manuel of Epictetus, which follows the Meditations of Marcus Aurelius in the yellow Garnier-Flammarion edition. I had a copy of it, covered in glassine, that Muzil had plucked from his library shelf a few months before his death to give to me, as one of his favourite books; he suggested that it might comfort and calm me at a time when I was particularly upset and unable to sleep." (Guibert, 1991: 66)

"Muzil" is, of course, another hero I have lost to AIDS: Michel Foucault. My puzzle was this: Why the Meditations of Marcus Aurelius? Here I was reading about a small event in the months before Foucault died. An event in the life of the man whose philosophy has underpinned my work over the past three years and which constituted the theoretical basis upon which I had begun my research. Why had Foucault and I turned to the same work of classical

philosophy to confront HIV and AIDS? If I had this thesis to write again this would be the question I would want to ask.

It was another "small event" in life which provided me with a clue. A few days after I had tested HIV-negative I spent the evening at the house of my supervisor, Brian Given. We sat on his porch smoking cigars. I told him something of what had happened and that I had been lucky. I always find it hard to know when it is better to say something rather than not say anything at all. He responded with some simple, and important, advice: it was important to allow people living with HIV or AIDS whatever romance there is to be found when faced with terminal illness but that I had to take care of myself. I did not realize at the time that this "romance", when understood as an association with my informants' experience of what they termed "unconditional love", would be important to understanding the stories I would be told about living and coping with HIV and AIDS.

This clue has turned out to be the key to the story which underlies those told me over the past year. I believe it is this clue which might also solve my puzzle:

"When Muzil gave me his copy of the Meditations, he told me that Marcus Aurelius had opened this work with a text praising his elders, different members of his family, his teachers, in which he thanked each person in particular, the dead first of all, for what they had taught him and the way they had changed his life for the better. Muzil, who was to die a few months later, remarked that he planned to write something similar soon about me -- and I wondered how I could have ever managed to teach him anything." (Guibert, 1991: 67)

Guibert and Foucault are both dead now. So is Freddie Mercury. So is my old friend Pierre. I hope this paper thanks all of them in a small way. I learned from all of them. I also have to thank all of the men who have spoken to me over the past year. They are all most definitely living with - and not dying of - HIV and AIDS.

I shall return to my puzzle at the conclusion of this paper.

My paper...

When I began my research I believed there were two immediate levels of conflict for an HIV-positive gay or bisexual man in understanding his body. The first of these was his battle with HIV and the second his fight for control of the care of his body. With this in mind I set out to advance a model by which the body of "the homosexual" might be understood in relation to the body of a corporate State. From this base I went on to examine the structure through which the story of AIDS-as-disease is told. This analysis makes up the following chapter.

The third chapter outlines the methodological base of my research. I believe anthropological method, particularly that of participant observation, to be of unique potential in contributing to the lives of gay and bisexual men with HIV and AIDS. It was the purpose of this research to pull together stories of gay men in their struggles with HIV and

in the medical system such that other gay men who test HIV-positive might learn from the experiences of those who have come before them. I realized that this was no longer the primary focus of the academic component of my research as I spoke with more and more men. I began to perceive a story which underlay the idiosyncrasies of each individual story. In this sense, I believe, an anthropological analysis of myth can also make a contribution to the lives of HIV-positive gay men.

Anthropology is uniquely suited to this task in the privilege it places on the voice of "the Other." I believe the best way to learn from HIV-positive gay men in order to help other HIV-positive gay men is to speak with gay men who are HIV-positive and listen carefully to what they have to say.

I not only believe that anthropological method and analysis is valuable to helping HIV-positive gay men but that this research fills a niche in ethnographic research. Aside from a single addition of Contemporary Ethnography only limited material concerning HIV/AIDS has arisen from the discipline of anthropology. This absence parallels a scarcity of anthropological research concerning "homosexuality" and gay men.¹³ I feel this is an important gap as it cedes the debate to psychology, and less

¹³ With the exception of Gilbert Herdt's oft-cited work in Melanesia.

frequently sociology, which sometimes fail to appreciate sexuality through a cross-cultural frame. The psychological literature concerning homosexuality commonly fails to apply such a frame in making universalizing assertions. This literature proposes models of experience which are demonstrably inadequate with the simplest of cross-cultural comparison.

The analysis which I undertake through the course of this paper is grounded in anthropological approaches to the study of religion. This focus may seem far afield from more typical attempts to understand the experience of AIDS through the lens of medicine or sociopsychology.¹⁴ I believe this approach offers a new way of conceptualizing healing responses to AIDS through an alternative model of healing. It is for this reason that I believe this research to be of interest to anthropology and to the social sciences in general.

The fourth chapter is a re-telling of the stories I have been told by men living with HIV and AIDS. My conversations with these men illuminate a critical response to conventional medical understandings of AIDS. These conversations also challenged my initial assumptions which focused my research towards an analysis of institutional practices. The stories told by gay and bisexual men living

¹⁴ It is perhaps for this reason that I know of only one other source of comparable analysis. James Miller's work was an inspiration for this paper.

and coping with HIV and AIDS offer a critique more fundamental than anything I had imagined. They offer a response based upon a commitment to "love under all conditions."

... and Style

I would like to conclude this introduction with some notes concerning style. My research has been with both gay and bisexual men who are HIV-positive or who have AIDS. I often simply refer to gay men rather than "gay and bisexual" men. This is intended to make my prose less cumbersome and not to exclude the experiences of the bisexual men with whom I spoke. These experiences are in some ways distinct as, for example, bisexual men are often constructed in media representations as "plague vectors" from the gay community to the mainstream. These distinctions are, however, beyond the scope of this preliminary examination and constitute a worthwhile subject of future investigation.

I have also chosen to refer to men who are "HIV-positive" rather than as "having AIDS." While the former is a necessary condition of the latter¹⁵ many of the men with whom I spoke had not "progressed" to full-blown AIDS.

Becoming HIV-positive, however, is the starting point from

¹⁵ Though not necessarily a sufficient condition. There are an increasing number of people who have been HIV-positive for ten years or more who have yet to develop AIDS. The reasons for this are unclear and of obvious medical interest.

which the story of this progression is told. This thesis represents the experience, and rejection of, this story as it is told by allopathic¹⁶ medicine.

My use of personal pronouns in this paper often takes the masculine "he" or "his." My use of these terms does not intend to assert these masculine pronouns to be gender-neutral. My use of these gendered pronouns is the result of my research focus on the experiences of a group of men with HIV/AIDS.

¹⁶ Please see Appendix A for a definition of this term.

Chapter Two: Theory

This chapter begins with a discussion of the construction of the homosexual body as a contagious site. I explore the implications of this narrative¹⁷ in its prefiguration of AIDS narratives which are readily mapped onto this site. In the second section of this chapter I explore the implications of the discursive/subject positions of the positive and the negative as a means of structuring stories of HIV.

From this discussion I move on to an articulation of the dialectical narrative form through which progressive HIV infection is understood. This discussion links the notion of a contagious homosexual site with a sequential binary logic. This structure underlies the narrative form utilized in medical discourse¹⁸ and in the stories told by men living with HIV/AIDS about their lives.

The first section of this chapter employs a poststructural analysis of narrative and government. The second and third section turn to a structural analysis of the story told in medical constructions of AIDS. I close by suggesting that the experience of AIDS is mediated by an ancient myth of mortal illness and healing.

¹⁷ Please see Appendix A for a definition of this term.

¹⁸ Please see Appendix A for a definition of this term.

The Homosexual Body as Site of Contagion

In this section I will illustrate the narrative with which our culture surrounds gay men and other marginal groups as sites of contagion. These lie within broader narratives concerning the social body. It is important to understand this narrative of contagion as it pre-dates and underlies later narratives concerning HIV/AIDS.

This excerpt from the medical journal of the German physician's association in June 1935 serves as an excellent example of what might be termed a discourse on purity in the social body:

"The comparison between Jews and the tuberculosis bacilli is a telling one. Almost all people harbour TB bacilli, almost all nations on earth harbour the Jews - a chronic infection, which is difficult to cure. Just as the human body does not absorb the TB germs into its general organism, so a natural, homogenous society cannot absorb the Jews into its organic association; at most they suffer them as parasites."
(cited in Ben-Sasson, 1976: 1019)

Ben-Sasson cites this as an example of how "old, established German institutions adopted Nazi concepts and methods towards the Jews at a more rapid pace than could have been anticipated." (Ben-Sasson, 1976: 1019) Ben-Sasson is surprised at the rapidity of the acceptance of Nazi doctrine concerning the Jews after only two years of Nazi rule. What this citation reveals, however, is not limited to the deployment of a Nazi discourse on the Jew. It reveals the relationship which is constructed between a

scapegoated constituency and the "health" of a "social body."

This quote serves further to underline a construction outlined by feminist biologist Donna Haraway in what she terms the "informatics of domination." (Haraway, 1990: 203) Haraway posits a "movement from an organic, industrial society to a polymorphous, information system." (Haraway, 1990: 203)

Haraway grounds her model in a transformation of the modern understanding of "Biology as clinical practice" into a postmodern¹⁹ construction of "Biology as inscription." (Haraway, 1990: 203) Ben-Sasson cites an example of signifying practices engaged in by Nazi era German medicine which compared a specific community to tuberculosis in a body. The "jews" could be understood by a metaphor²⁰. This metaphor represented a healthy social body "infected" by a marginal community understandable through the metaphor of "Microbiology, tuberculosis." (Haraway, 1990: 203)

It is important to note that in discussing "the jews" as metaphor I am not discussing Jews as a social and historical fact. Following Lyotard:

"I am not thinking of a nation... neither a figure not a political (Zionism), religious (Judaism), or philosophical (Jewish philosophy) subject... I use quotation marks to avoid confusing these "jews" with real Jews. What is most real about real Jews is that

¹⁹ Please see Appendix A for a definition of this term.

²⁰ Please see Appendix A for a definition of this term.

Europe, in any case, does not know what to do with them: Christians demand their conversion; monarchs expel them; republics assimilate them; Nazis exterminate them. "The jews" are the object of a dismissal with which Jews, in particular, are afflicted in reality." (Lyotard, 1991: 3)

This is an important distinction. The practice of government in Nazi Germany was not responding to Jews but to a story told about "the jews." This story made sense of forcing populations of actual Jews into ghettos as a practice of quarantine. This logic made sense of separating the "unhealthy" part of the social body from the "healthy" part. It later made sense of an attempt to eradicate "the jews" as a doctor would attempt to eliminate an infection from a body.

Haraway posits "transitions from the comfortable old hierarchical dominations," such as the relationship of "the jew" to Nazi Germany, "to the scary new networks." (Haraway, 1990: 203) The metaphor of clinical practice presented by tuberculosis and "the jew" is superseded by the inscriptive practice of "Immunology (and) AIDS." (Haraway, 1990: 203) This model underlies what Paula Treichler characterizes as an "epidemic of signification" (Treichler, 1989: 32) concerning HIV/AIDS where "AIDS is a story, or multiple stories, read to a surprising extent from a text that does not exist: the body of the male homosexual." (Treichler, 1989: 42)

This assertion rests upon a specific understanding of the relationship of narrative constructions of the world to

the "real world." Haraway subscribes to the view in which stories about the world are held to be impositions upon a chaotic and meaningless reality. I differ from Haraway's view in some significant ways which become evident in the changing focus of the following sections of this chapter. Story-telling and the "life world" shall be discussed in the following chapter concerning method.

I subscribe to Treichler's assertion in so far as the model of the "homosexual body" originating in biomedical stories of sexuality is not one which is experienced by "homosexual" men in their variety of self-identifications (Packwood, 1991). I refer to "homosexuals" in the same way that "the jews" are referred to by Lyotard. I am not referring to an actual community but a fiction. It is this fictive "homosexual body" which is addressed in governmental operations. It is this "body" to which we shall return. It is self-understandings of the body that I wish to derive from the stories HIV positive gay men tell about themselves.²¹

My implicit comparison of Nazi era German medicine with the contemporary medical apparatus may seem harsh to anyone who has not lived a gay life in relation to that medical

²¹ I must stress that this discussion is focused upon a fictive male homosexual body. Lesbians and "lesbian bodies" have a different relationship to a construction of gender, sexuality and the specific case of AIDS. Penelope Ironstone engages in a discussion of narratives which frame "lesbian bodies." (Ironstone: 1991)

apparatus. While it is important to illustrate this relationship in greater detail by work in the field it is possible to demonstrate my reason for this comparison:

"It is the sense of a totalized threat to a biologized identification of the self with the nation that characterizes both Nazi medical politics and modern familialism. Thus Jews, antifascists, gypsies, and "degenerates" (including, of course, large numbers of lesbians and gay men) were postulated as intrinsic and self-evident threats to the perceived unity and very existence of the German Volk, and the policy of killing them all "as a therapeutic imperative" only emerged in relation to the deeply felt danger of Volkstod, or "death of the people" (or "nation," or "race"). It is precisely this sense that people with HIV infection, usually misdescribed as AIDS carriers, are widely understood to threaten the equally spurious unity of "the family," "the nation," and even "the species." (Watney, 1989: 74-75)

The comparison of Nazi Germany in the 1930s to North America of the 1980s may seem harsh. Consider telling quotes chosen for an instillation entitled Let the Record Show... created by ACT UP (the AIDS Coalition to Unleash Power) which appeared at New York's New Museum of Contemporary Art in November of 1987:

"The logical outcome of testing is a quarantine of those infected.

-Jesse Helms, US Senator

It is patriotic to have the AIDS test and be negative.

-Cory Servaas, Presidential AIDS Commission

We used to hate faggots on an emotional basis. Now we have a good reason.

-anonymous surgeon

AIDS is God's judgement of a society that does not live by His rules.

-Jerry Falwell, televangelist

Everyone detected with AIDS should be tattooed in the upper forearm, to protect common needle users, and on the buttocks to prevent the victimization of other homosexuals.

-William F. Buckley, columnist"

(Crimp, 1989: 8)

With the exception of the anonymous surgeon these sources represent influential opinions to the ruling right-wing of American politics throughout the 1980s. These are not the opinions of a disenfranchised fringe but of the mainstream of political power in the first decade of the AIDS epidemic. Here the intertextual²² relation of narratives of HIV/AIDS and the "homosexual body" are evident. The body serves as an important site for the inscription of social meanings. The inscription occurs in operations of government and between individuals. Meaning, however, is also produced at the level of the sub-individual (borrowing the term from Foucault, 1980: 208). By this I mean an individual's struggle with his own body which has been infected by HIV.

I have argued that the pre-war German conflation of "the jew" and the tuberculosis bacilli was not entirely a result of Nazi doctrine but an intersection of Nazi ideology concerning "the jew" with pre-existent narratives of contamination and the social body. Similarly, AIDS is not the cause for understandings of the homosexual as source of physical and moral contagion. "AIDS," becomes a convenient story to superimpose over existing understandings of "the homosexual."

It is possible to demonstrate a narrative of the contagious "homosexual" by examining literary

²² Please see Appendix A for a definition of this term.

representations of "homosexual" desire which pre-date the AIDS epidemic. Mishima Yukio and William Burroughs both address this subject, their own troubling desire, in novels published in the late 1950s.

In his thinly disguised autobiographical novel Confessions of a Mask Mishima Yukio describes a fascinating relationship of his adolescent protagonist to the body of his object of desire - a boy named Omi - and through this mechanism towards his own body:

"As he began the pull-up, the muscles of his arms bulged out hard, and his shoulders swelled like summer clouds. The thickets of his armpits were folded into dark shadows, gradually becoming invisible. And at last his chest rubbed high against the iron bar, trembling there delicately. With a repetition of these same motions, he did a rapid series of pull-ups. Life-force - it was the sheer extravagant abundance of life-force that overpowered the boys. They were overwhelmed by the feeling he gave of having too much life, by the feeling of purposeless violence that can be explained only as life existing for its own sake, by his type of ill-humoured, unconcerned exuberance. Without his being aware of it, some force had stolen into Omi's flesh and was scheming to take possession of him, to outshine him. In this respect the power resembled a malady. Infected with this violent power, his flesh had been put on this earth for no other reason than to become an insane human-sacrifice, one without any fear of infection. Persons who live in terror of infection cannot but regard such flesh as a bitter reproach....The boys staggered back, away from him." (Mishima, 1958: 78-79) (my italics)

Here Mishima describes an infectious and dangerous power that resides in the homosexual body/desire. The unattainable and unequivocally masculine²³ Omi embodies

²³ Please see Appendix A for a definition of this term.

this desire as it is inscribed by the gaze of Mishima's protagonist and of the other boys. Omi's physicality, however, transcends this infectious power in a fashion that is impossible for the lesser and feminine homosexual body of Mishima's protagonist. The violent assertion of a "natural" masculinity transforms the protagonist's feeling of impotent desire into feelings of jealousy and self-hate in its "bitter reproach" of his lesser homosexual body. This complex interaction of ideas of infection and "the homosexual" are to be found in a novel written two decades before the onset of the AIDS epidemic.

A parallel articulation of this intertextual relation of the homosexual body to contagion may be found in William S. Burroughs' novel Naked Lunch, first published in 1959:

"Carl Peterson found a postcard in his box requesting him to report for a ten o'clock appointment with Doctor Benway in the Ministry of Mental Hygiene and Prophylaxis...
 "You know of course that we are trying. We are all trying. Sometimes we don't succeed." His voice trailed off thin and tenuous. He put a hand to his forehead. "To adjust the state - simply a tool - to the needs of each individual citizen." His voice boomed out so unexpectedly deep and loud that Carl started. "That is the only function of the state as we see it. Our knowledge... incomplete, of course," he made a slight gesture of depreciation... "For example... for example... take the matter of uh sexual deviation." The doctor rocked back and forth in his chair. His glasses slid down onto his nose. Carl felt suddenly uncomfortable." (Burroughs, 1959: 186-188)

Burrough's attempts to make the connection between "prophylaxis," the prevention of disease, which is

ostensibly physical and that which is moral. Desire which is "deviant" is desire which is diseased. Two decades before AIDS Burroughs chooses to make his point by having Dr. Benway compare deviant sexuality with another illness:

"We regard it as a misfortune... a sickness... certainly nothing to be censored or uh sanctioned any more than say... tuberculosis... Yes," he repeated firmly as if Carl had raised an objection... "Tuberculosis. On the other hand you can readily see that any illness imposes certain, should we say obligations of a prophylactic nature on the authorities concerned with public health, such necessities to be imposed, needless to say, with a minimum of inconvenience and hardship to the unfortunate individual who has, through no fault of his own, become uh infected... That is to say, of course, the minimum hardship compatible with adequate protection of other individuals who are not so infected... We do not find obligatory vaccination for smallpox an unreasonable measure... Nor isolation for certain contagious diseases... I am sure you will agree that individuals infected with hurumph what the French call "Les Maladies galantes" heh heh heh should be compelled to undergo treatment if they do not report voluntarily." (Burroughs, 1959: 186-188)

Here again are representations of the homosexual body in its relationship to the State and the medical apparatus. Burroughs' Dr. Benway articulates rationales of hygienic and moral safety which "inconvenience" those infected by deviant sexualities. The homosexual body, like the tubercular body, is posited as a source of contagion to the "public health" of the State. Naked Lunch, like Confessions of a Mask, precedes the AIDS epidemic by twenty years. Can't we assume that narratives of HIV/AIDS are based in these pre-existent understandings of the homosexual body.

Cultural understandings of HIV/AIDS are neither

arbitrary and accidental nor entirely the result of a rational and objective description of the transmission of a virus within an identifiable demographic risk group. Stories told about HIV/AIDS are grounded in wide assumptions about homosexuality and purity within the social body:

"The HIV virus enters a kind of Noddy-land of narrative meaning, where it takes on particular characteristics, goals and functions - even "preferences". On the other, however, it joins the morass of unthinkability in which homosexuality is already (for many people) placed, a Gothic territory where fears are flung out into a sort of mental wasteland beyond the castle walls of the ego."
(Williamson, 1989: 70)

It is important to illuminate the perceived relationship of contagion to "the homosexual" as it underlies practices of government in the face of HIV and AIDS. The poststructuralist theory which I have applied in this analysis is effective for this task. This analysis is, however, inadequate to the task of understanding the perception of HIV and AIDS by those directly affected.

Thus, I believe it is necessary to ground a discussion of survival and resistance²⁴ within HIV positive gay men's own understandings of HIV and their relationship to their bodies. Specific categories of understanding can only come to light in carrying out that investigation. In theorizing this relationship I shall turn to a structural analysis.

²⁴ Please see Appendix A for a definition of this term.

The Positive and the Negative

This paper is centred around two apparently simple questions posed to men inside and outside formal interview situations. They are also regularly posed inside and outside the formal governmental apparatus deployed to engage the epidemic: Are you HIV-positive? How did you find out or, more tellingly, come to understand yourself to be HIV-positive?

This is a question which is asked in both anonymous HIV testing systems and clinical or hospital-based testing practices. This is a question asked of people who are offering to donate blood both directly and indirectly through questions which attempt to reveal the identity of a donor or through questioning of behaviour which places an individual at greater risk of exposure to the virus. This is a question which was asked of some of the men with whom I spoke as they attempted to enter the United States for medical treatment unavailable in Canada.

Many personal advertisements specify the HIV status of the person placing the advertisement and the status of a desired partner. This is a question asked of any man picked up in a bar. This interrogation may be a direct question. It may also take the indirect form of a search for clues: Does he look too thin? Does he have any blemishes? Does he look tired? The suspicion of HIV will often discourage an encounter.

AIDS has changed the gay community:

Jim: That's the thing about Montreal. It's like AIDS never happened there. The boys don't play safe. So people come from all over... But you go to Chicago or San Francisco it's like you see it in the faces. People just walking around. AIDS has wiped out neighbourhoods. And it's not like there was tight community. Family or something. You stop seeing a face... even a trick you might know and it's like "oh they moved or maybe they dropped out of the scene or something". Or maybe they're dead.

What I intend to suggest is that HIV and AIDS has had a more subtle and invasive effect on the gay community and the experience of a gay life. HIV/AIDS is not only evident through its creation of absences but in the new field of self-understanding upon which it insists a life be premised.

When I first outlined this project to Glenn Rockett at the AIDS Committee of Ottawa he warned me that I would face disapproval from some HIV-positive men: "What do you know Negative Boy?" While I have yet to encounter this attitude in my research the question begs another: Am I "negative boy"? Is my self-understanding predicated upon the fact of an absence of HIV? This question allowed for another perspective on the question I asked HIV-positive men. The men with whom I spoke not only had insight into the experience of being HIV-positive but of becoming HIV-positive. This is a question particularly suited to the disciplinary interests of anthropology for here was an instance of transformation from one kind of being to another complete with a highly ritualized process by which this transformation was observed.

These two states are known by two opposing terms. These terms indicate a stark division in which a person is either positive or negative. One is either positive or one is not. This much seemed evident in the warning I received which indicated the presence of a politics predicated upon the experience of being HIV-positive. This experience was privileged in the sense that it posits the experience of an HIV-positive "us" as distinct from and HIV negative "them". This politics arises in part from a sense of frustration at a gay community often indifferent to the situation of men with what one informant referred to as "the plague."

Jim: I used to think it happened somewhere else you know like New York or San Francisco or maybe to Haitians. I don't shoot drugs... poppers and shit and maybe that's not good for you..

I think poppers (amyl nitrate) are immunosuppressants like coke or alcohol...²⁵

Jim: Yeah. Well now it's like the teenagers don't give a shit like they think AIDS just happens to us older guys. Like they're immortal or something.

I would not have been surprised to find men in this environment who would be militantly "positive" in an attempt to claim a unique knowledge which could not be shared with those outside the experience of living with HIV. I have instead encountered a consistent articulation of the experience of becoming HIV-positive and being HIV-positive as distinct from being HIV-negative. In the next chapter I shall elaborate on the process of self-articulation through the telling of stories.

²⁵ My comments and questions are in "bold" font.

The distinction between these polar states would seem to be clear and easily defined. It would seem that an individual could only be positive or negative. It is at the points of failure for these categories to constitute absolutes that the operation of becoming positive is revealed.

The first of these points happens every time an individual who understands himself to be negative engages in an activity that might facilitate transmission of the virus:

Paul: It drove me crazy! I couldn't stand using condoms because it reminded me of the risk I was taking. I just used to cross my fingers.

Paul seemed to ask himself a litany of questions: Was it safe? Was he positive? Am I positive now? Many of the men with whom I have spoken played what one referred to as a "numbers game." This refers to a calculation of the perceived odds of encountering an HIV-positive sexual partner in a given number of sexual partners and, more specifically, of the risk of transmission of the virus through particular sexual behaviours. Even when the odds of having been exposed to the virus were perceived to have been low these men expressed a sense of having felt uneasy. This unease expressed itself in varying ways. One man, a medical technician, feels certain he has been exposed to the virus:

Are you HIV-positive?

John: Yeah. I am.

You said that you had never been tested? Is that right?

John: No I haven't. Look it's never been established that this virus can do any of the things it's been

suggested it does. They keep changing their story because none of them work. But I know I'm positive. I've been with (HIV-positive lover) for two years and we don't use condoms. I like the parks too. If something is going around then I've got it.

I spoke with John about his stance of indifference to HIV, AIDS and the risk that most of the medical community, AIDS service organizations and the gay community would feel he is taking. He did not agree that his stance was one of studied indifference. I found it difficult to reconcile this disagreement with his simultaneous sense of certainty that he had been exposed to the virus despite his refusal to acknowledge its presence in his body, or his life, through a test. HIV has a presence in his life despite this refusal in so far as John has adopted an unpopular position which he finds he has to defend.

This reaction may be contrasted with that of Sean. Sean is an HIV negative gay man who has himself tested for antibodies to HIV every three months even though he has virtually no chance of exposure to the virus:

Sean: I never have sex and I don't use drugs. I drink a little but that's O.K. I guess I just decided to wait it out. It isn't worth the risk even if it is very small.

An interesting aspect of John's coping strategy, never tested, and considers himself HIV-positive and also Sean's, tested regularly, abstains, is that neither accepts conventional wisdom concerning the practice of "safer sex." In fact, neither accepts a medical model of illness in which one may determine whether or not one is at risk of

developing AIDS through a test for the presence of antibodies to HIV in the bloodstream. Both John and Sean are, by this standard, ultimately uncertain of their HIV status and thus may be considered to have a sense of self in the "interstice", or the place between clearly defined categories.

The practice of testing for antibodies to HIV assumes a ritual form. Here I am following Victor Turner's use of the term ritual as a "transformative performance revealing major classifications, categories, and contradictions of cultural processes... through its liminal processes, it holds the generating source of culture and structure." (Turner, 1986: 157, 158) The HIV-antibody test may constitute a rite of passage in one form of Arnold van Gennep's typology. The long wait for test results may be characterized as a "liminal" or transitional (Gennep, 1960: 11). Gennep cites the example of rituals concerning passage from one age group to another as transitional (Gennep, 1960: 11). The HIV-antibody test may similarly mark the transition from one category of being to another.

While experiencing the two-week waiting period between having blood drawn and the disclosure of results an individual is neither positive nor negative but exists in a liminal state between categories. This practice assumes the form of a rite of ordeal in that the individual experiencing this transitional period cannot know whether or not he will

pass from one state to another. Here an individual must pass through a rite of initiation much like the ordeals of entrance into a secret society.²⁶ This ordeal is unlike that experienced by a prospective Freemason in that the candidate hopes they shall finish the ordeal without having passed into a new category of being.

This situation of this individual is distinct from that of John or Sean in that this individual, provided he does not risk exposure to the virus in the interim, is going to be relatively certain of his HIV status. Even with recourse to a blood test, however, another version of the "numbers game" is played out. Certainty is tempered by the knowledge that between one and ten per cent of tests regularly indicate a false positive calling for a secondary test. It must also be understood as conditional upon the timing of the test in relation to the time of risk of exposure and the means of possible exposure. The presence of antibodies to the virus is only thought to be detectable some three months following possible exposure. A blood test conducted before three months have elapsed cannot determine an individual's negative HIV status. If an individual was potentially exposed to the virus through unprotected "passive" anal

²⁶ I say that these ordeals are similar but not that they are identical. The self-consciously performative dimension of, for example, a Masonic rite of passage would seem to be missing in the ritual surrounding an HIV-antibody test. A separate study examining potential performative aspects of this procedure would make an interesting outgrowth of this research.

intercourse the waiting period is considered to be six months because of what the local testing counsellor characterizes as "one in a million" cases of late production of antibodies.²⁷

The medical characterization of the HIV status of a body would seem to betray many ambiguous states somewhere short of absolute. In the three month period of latency the virus may be held to be present in a body though this presence is undetectable. Here a medical model of illness, and a rational understanding of the world, asks that an individual believe in the potential presence of an agent of illness which neither that individual nor the medical practitioner can detect. After a three month latency period a test may be made, not for the presence of HIV, but for clues to its presence in the form of antibodies. Upon the inference of this presence the individual must understand their body to be potentially mortally ill despite the outward appearance of health. In this operation HIV has an agency which possesses the body. This possession is indiscernible to an individual except in the actions of those who have authority to determine its presence or absence.

The positive and negative states are interesting in that one state represents health and the other the certainty

²⁷ This information constitutes the contemporary accepted HIV risk model as it was represented to me by Claudine Gai, the regional anonymous testing counsellor for Ottawa-Carleton.

of fatal illness. This ascription inverts the colloquial understanding of the positive as the constructive or beneficial and the negative as that which is destructive or unpleasant. This inversion would support a frame in which the positive and the negative exist in a relationship of binary opposition despite any ambiguity entailed in determining the state of a particular body or in the transition from one state to another. The interaction between these signs, however, may be demonstrated to be more complex than a simple opposition.

AIDS Narrative as "Walter Reed Dialectic"

The story of AIDS is told, and experienced, within a dialectical structure. Here the dialectic is understood to be the process by which contradictions in a state of being interact in order to bring about a synthesis in the form of a new state of being. This process is understood to occur through time and may be termed a historical movement. The dialectic is a term for both this movement through history and for the operation by which this movement comes about.

This understanding of the dialectic is drawn primarily from Hegel's Logic of Science. (1951) and from critical commentaries of Hegel (Bottomore, 1983; Gadamer, 1976; Levi-Strauss, 1963; Lukacs, 1968; and, Pinkard, 1988). I am transferring the use of the dialectic from the context of social history to that of personal history as it is

structured by myths of experience. The dialectical structure of myth is not neutral but is deployed in order to tell specific kinds of stories.

It is necessary to bring together concepts of ritual, liminality and myth in order to elucidate the application of a dialectical model to an anthropological context. It is worthwhile to repeat Victor Turner's definition of ritual as a means of elucidating a dialectical relation. Turner understands ritual to be:

"...a transformative performance revealing major classifications, categories, and contradictions of cultural processes... through its liminal processes, it holds the generating source of culture and structure."
(Turner, 1986: 157, 158)

I have already elaborated on the importance of this definition in its emphasis upon transition between categories of being and the liminal process by which this transition operates. This definition, however, is still more important in its understanding of ritual processes as revelatory of contradictions within categorical arrangements. A dialectical relation is one in which the resolution of contradictions is the dynamic by which culture and structure are generated and re-generated. Indeed "for the dialectical method the central problem is to change reality." (Lukacs, 1968: 3)

This method is one means of accounting for a diachronic narrative structure rather than the static synchronic structure of a single binary pairing of positive and

negative. A Hegelian structure of identity, difference and opposition finds its dynamic in the process of thesis, antithesis and synthesis (Hegel, 1951: 35-66). This is an understanding of the relation between categories in opposition which Hegel discusses in terms of the Positive and of the Negative (Hegel, 1951: 52) In order to understand the experience of one state it is necessary to understand this state in relation to its binary opposite as:

"the Positive is not an immediate identity, but is partly a term opposite to Negative, having significance only in this relation and therefore containing the Negative in its concept" (Hegel, 1951: 63)

This concept is elaborated in the social sciences through the structural anthropology of Levi-Strauss. Levi-Strauss was concerned with transferring the method of structural linguistics to the study of systems of myth and kinship. In making this transference Levi-Strauss was interested in the use of this form of linguistics in its ability to account for synchronic phenomena through a diachronic analysis. Levi-Strauss cites the structural linguist N. Troubetzkoy to assert that in the "evolution" of a phonemic system, and by extension other systems of classification such as kinship, "at any given moment is directed by the tendency toward a goal." (Troubetzkoy cited in Levi-Strauss, 1963: 34)

This form of movement is dialectical in structure. Levi-Strauss comments at some length on the relationship of dialectics to structure. In this analysis the interaction

of myth and ritual are understood to have a dialectical relation (Levi-Strauss, 1963: 232-241). The influence of Hegel is evident in Levi-Strauss' definition of the purpose of myth as a means "to provide a logical model capable of overcoming a contradiction." (Levi-Strauss, 1963: 229) This definition of myth is synonymous with the operation of the dialectic.

Levi-Strauss' dialectical model of myth and ritual is dependent upon the structural relationship of these elements (Levi-Strauss, 1963: 240). The story of progressing from health to death finds its structure in a progression of concepts which resemble binary pairs:

HIV negative... to HIV positive

HIV positive... to HIV disease/AIDS related complex

HIV disease... "full blown" AIDS

AIDS... death

It is this story which is initially experienced by an individual who has been exposed to HIV. This story is constantly referred to by physicians in understanding and representing such an individual's relative state of health. This structure is drawn immediately from the Walter Reed Classification System which "charts the course of patients from exposure to HIV (WR0) and the onset of infection (WR1) through stages of progressive immune dysfunction."

(Redfield, 1989: 67) I intend to suggest that this structure, while charting stages of infection, does so in a

manner suggestive of stories which predate the epidemic. This story is told in the precise structure which Levi-Strauss elaborates upon in order to explain sequential duplication in mythic structures:

"The function of repetition is to render the structure of the myth apparent. For we have seen that the synchronic-diachronic structure of the myth permits us to organize it into diachronic sequences (the rows in our tables) which should be read synchronically (the columns). Thus, a myth exhibits a "slated" structure, which comes to the surface, so to speak, through a process of repetition." (Levi-Strauss, 1963: 229)

It is just such a slated structure which is evident in the Walter Reed Classification System and in the experience of HIV which is concomitant with practices of treatment which follow this system. This system of classification, and the stories told alongside this system, closely replicate a mythic structure. That is not an accident.

This story takes the form of a descending relational dialectic in its articulation of a series of states which unfold through history. In this instance the history is specific to an individual. It is the descending structure of this history which provides the clue that this story is based upon a much older one. It is necessary to pull together some final ideas before this link is made.

To test positive, regardless of the possibility and concern for re-infection, is a conclusive change of state. This change of state invariably entails a transformed self-understanding. To test negative, even in the event this result entails a change in behaviour to deter risk of

exposure to the virus, is necessarily to remain in a state in potentia. Once one has tested positive one becomes and remains positive. To test negative does not mean that one shall forever remain negative.

The HIV negative state resembles the "unrealized" condition of Christian eschatological models of being. This resemblance is not coincidental but a result of a parallel construction of judgement and realization of the self. This characteristic of uncertainty is not limited to the sphere of the negative. The story is not a simple one in which one moves from state to state in clearly defined steps. Uncertainty and partiality characterize every state of being:

Event:	Perceived result of this event:
Unsafe Sex	May be exposed to HIV...
Blood Test	May test Positive...
Positive	May develop AIDS...
"Full blown AIDS"	May die

At each step a new kind of certainty as the story progresses to its conclusion in death. This synthetic state finds in itself a new seed of uncertainty in anticipation of the next transition. Each synthesis finds in itself a new relation of thesis and antithesis culminating in a new state of being. Even the certainty of death may be mitigated by hope for new treatment which will prolong life - a "magic bullet."

Hegel understands the dialectic as the impetus behind shifts from state to state. This understanding finds its reflection in Turner's understanding of ritual, Gennep's understanding of liminality and Levi-Strauss' understanding of myth. The second meaning Hegel attributes to the dialectic is the term for pattern of transformations from state to state. Hegel "unites two ancient strands of dialectic, the Eleatic idea of dialectic as reason and the Ionian idea of dialectic as process." (Bottomore, 1983: 122) The Ionian idea takes an ascending form or a descending form. The latter is a structure of reason in which divine "manifestation in the phenomenal world is explained." (Bottomore, 1983: 122) The descending dialectic is one which argues for the immanence of the divine.

This venerable narrative structure is repeated in the Walter Reed dialectical form. This would suggest that the story through which HIV and AIDS are experienced is one which entails an experience of immanence. This experience has been suggested in work concerning popular understandings of the experience of AIDS. James Miller discusses the representation of people living with HIV or AIDS as victims. Miller illuminates representations of victims as "guilty, innocent, disenfranchised" with his most telling observation of people with AIDS as victims with a "sacrificial" character (Miller, 1991: 55). In this final story people living with HIV/AIDS are martyrs. Miller characterizes this

story of AIDS as "Acquired Immanent Divinity Syndrome" (Miller, 1991: 55). That is a "hagiographical mutation of AIDS that we can only diagnose from its luminous symptoms" (Miller, 1991: 60).

Miller addresses the representation of the experience and perception of "victims" of AIDS in Randy Shilts' novel And the Band Played On: Politics, People and the AIDS Epidemic. (Shilts, 1987) This work has become the centre of what might be termed a growing canon of AIDS culture and fiction. In this work Randy Shilts dramatizes the heroic transformation of a gay man with AIDS:

"In the harrowing tale of Gary Walsh, for instance, Shilts pushes the victim role to new heights by describing the public apotheosis of a "typical" plague-victim into a healing saint. Walsh, a San Francisco therapist, was diagnosed with AIDS in 1983, and in the year following his diagnosis lesbian activist Lu Chaikin watched adversity transform her friend by stripping away the pretensions of personality "layer by layer, until (his) altruistic essence was all that remained." No diet prescribed by the Church Fathers could have a more ascetic effect on Gary than the Gay Plague... Now that he offered his friends "unconditional love", people come away from conversations with Gary "like pilgrims leaving a holy shrine."" (Miller, 1991: 60)

In this story AIDS has a redemptive function. To test positive for the presence of antibodies for HIV is a practice of diagnosis²⁸ and dia-Gnosis²⁹. This apprehension of a redemptive operation is not unique to AIDS but "just as the physician might say that there lives

²⁸ Please see Appendix A for a definition of this term.

²⁹ Please see Appendix A for a definition of this term.

perhaps not one single man who is in perfect health, so one might say perhaps that there lives not one single man who after all is not to some extent in despair" (Kierkegaard, 1954: 155).

This "sickness of the spirit" (Kierkegaard, 1954: 155) may be termed a sickness of the spirit or pneumapathology (Doran, 1990: 48). Kierkegaard closely ties this form of illness to any state other than that of a "perfect Christian" (Kierkegaard, 1954: 155). In Christian narratives of history and salvation this is a very difficult condition of being to experience. Robert Doran elaborates on this model of history:

"Without a healing that originates beyond the distortions of the dialectical processes of history, history itself would be purely and simply a matter of cumulative and progressive fatalistic determination. Healing must originate beyond the upwardly directed world-constitutive and self constitutive creative vector of human consciousness... The incapacity for sustained development on the basis of our own resources is simply reinforced if there is not solution from beyond the immanent dynamics of the human developmental process." (Doran, 1990: 242)

Doran articulates a model of being in history which is dependent upon a dynamic of illness and healing. In this history the process of healing must, however, originate from beyond the closed system of human action. Indeed "the required healing agency is not a function of the upwardly directed dynamics of the creative vector... The agency is an unconditional love that lets our victimized darkness rest in being loved." (Doran, 1990: 242)

The experience of AIDS is paradigmatic of this structure of history and the divine:

"As an AIDS victim, Gary will outgrow the traditionally second-rate Catholic role of the martyrus in spiritu (martyr in spirit): the unspecified hurts of his pre-AIDS life will appear as nothing compared with the transfiguring torments of the disease. These offer him an opportunity to become a first-rate witness to the therapeutic glories of Love Triumphant, a true martyrus in corpore (which was the privileged role for an early Christian because it entailed death in the arena). It is an opportunity he gladly takes. Dispatching his pilgrims with a zap of unconditional love, he finds the strength to exclaim to Lu before snuffing out his little candle in the darkness of the Flesh: "I got it, I finally got it!.. I am love and light, and I transform people just by being who I am."" (Miller, 1991: 60)

Here the "AIDS victim" is transformed into an embodiment of love, a "Person Living With AIDS." AIDS becomes a vehicle of divine immanence in the world of the material and in doing so tells a story of healing in the face of worldly suffering. This relationship of the individual with a terminal illness to a universal healing constitutes a structural inversion the binary paired concepts of sickness and healing.

Miller makes a valuable contribution in his observation of the narratives of immanence asserted in stories told about AIDS. This observation is particularly interesting in that it is congruent with the descending dialectical structure of the AIDS story-as-myth. The association of contagious illness and death with concomitant narratives of immorality and redemption form a close parallel text to narratives of the homosexual body. These associations are

then played out in a series of descending steps composed of binary sequences of certain to uncertainty to certainty.

Miller regards Acquired Immanent Divinity Syndrome as a romanticization of what he admits to be a "valiant effort" to assert humanity in the face of ostracism and death (Miller, 1991: 55). He argues that:

"unfortunately, not all people with AIDS have what it takes to be People With AIDS. Someone may have the minimal requirement, HIV disease, with none of the other essential PWA qualifications - faith in the democratic process, commitment to activist aesthetic practices, loads of political energy, gay-positivity, community spirit, guts, and hope. Perhaps a great many people with AIDS simply have no place in the heroic activist picture, because the picture itself, an idealistic vision of social and sexual liberation, tends to gloss over the harsh realities of their weakened physical state. It pressures them to be what they may not or cannot be, social paragons, at a time when society is willy-nilly turning them into pariahs. It may even make them feel guilty for not living up to the high ideal of Living With AIDS." (Miller, 1991: 59-60)

There is an imperfect fit between the mythic implications of refuting what I have termed the "Walter Reed dialectic" and the experience of living with HIV and AIDS. This myth closely matches the experience of some HIV-positive men while standing in contrast to the experience of others. This is an important distinction. Miller asserts that seropositivity is not concomitant with "sainthood." This is certainly the case for many HIV-positive men. I had expected to find many cases which would refute the romantic characterization portrayed by Randy Shilts. I was to be surprised.

What I failed to anticipate was that the men I spoke with did not understand themselves to be "AIDS victims" but characterized themselves to be "Living With HIV or AIDS." Men who had not come to terms with HIV did not respond to my flyers advertising my research. I had inadvertently introduced a bias into sample, only men with a "positive attitude" were eager to share their stories. The disposition of these men, however, refuted the somewhat cynical vision which I initially shared with James Miller.

The men I spoke with left me with an impression not dissimilar to the vision Shilts imparts in his fiction. My informants were living out a myth which serves to address the ills of the spirit in the face of death in the body. This myth structures the stories told by men living with HIV and their experience of that life. The relationship of this particular narrative structure and the wider subject of narrative as practice to experience are the subjects of the following chapters.

Chapter Three: Method

In this chapter I shall address issues of method and methodology alongside epistemological concerns. This will involve a discussion of the research techniques, or methods, which were used and the methodological concerns of this approach (Harding, 1987: 2). I shall conclude this chapter with a discussion of narrative in order to explain my decision to ground this research in the stories HIV+ gay men tell about themselves.

Methodological Problems

I am struck by a sense of the improbability of ever producing a fair representation of my experiences "in the field." William James writes of the "ineffability" of mystical experience. I believe that fieldwork may also be characterized as ineffable because of this knowledge of wordless experience and the inability to translate an this experience into words.

This problem of representation is as old as the discipline of anthropology. The first example which comes to mind is the case of Malinowski's diary in the Trobriands. In this source Malinowski reveals an ambivalence towards the people with whom he lived which was not evident in his formal work. A contemporary expression of this dilemma comes from John Cove's meditation upon his experience of the

field. He speaks of his ambivalence towards representing this experience:

"This book presents a lie... Although the results are as honest as I can make them, how they were reached bears virtually no relationship to the process of inquiry to be described. The research was motivated by reasons which are not a necessary part of the analysis. Similarly, the question and approach taken were not worked out prior to the investigation; rather, they were by-products of it. What actually occurred was more like a series of accidents, with few if any connections among them worthy of the label logical." (Cove, 1987: 1)

I have attempted to make my motivations for undertaking this research as clear as I could in the introductory chapter. I feel that despite this there remains an aporia, a gap, which Cove describes between those motivations and experiences and the possibility of translating them into words. John Cove calls this disjunction a "lie":

"In a sense, the lie is unavoidable. Communication, even within science, does not require honesty. That quality would more likely inhibit the process if the objective is to present a set of conclusions. Anyone who has done exploratory research has almost certainly faced the same dilemma. What is amazing is how seldom it is recognized. Once caught up in the attempt to communicate the activity takes on its own reality, and the author winds up believing that the form of argument is actually what happened. It is only when one pauses and reflects that the fiction becomes apparent." (Cove, 1987: 1)

This fiction stems from an imperative towards a "literary" coherence in ethnography. This imperative does not match an often confusing and chaotic experience of the field which defies orderly ethnographic representations of such experience. I am reminded of conversations I have had with Karen Richter over the course of her fieldwork with the

Ottawa Police Department (Richter, 1992). Richter often expressed an impression of the "surreality" of the anthropology department and the "reality" of her life in police cruisers. I have felt the same sense of separation from my ostensible role, and role specific identity, as a student of anthropology in the context of my work with the AIDS Committee of Ottawa. I often felt that the "real me" was a person establishing an alternative form of community outreach programme. The "other me" who was a student engaged in Master's research was at best partially real and at worst a form of nuisance in the way of my "real" pursuits.

This separation was disturbing in itself but was also a source of concern for me as an individual trying to carry out work which would be both scientifically rigorous and ethically tenable. This concern arose because I had failed to anticipate the sense of the surreality of my primary role as researcher. This failure stems from traditional forms of representation which inadequately articulate the practice of fieldwork.

This particular problem points towards broader concerns of the practice of anthropology and social science:

"Science is now a bit more insecure regarding what it's on about. Science has come to view the process of inquiry itself as problematic, and has produced at least two principal trends from this revolutionary adjustment of view: (1) a shift from a fragmented, mechanistic, non-purposive conception as, for example, in systems theory, and (2) a shift from concern with objectivity to a concern with subjectivity - that is,

with the role perception and cognition play in scientific inquiry." (Laughlin, 1989: 17)

I understood Laughlin's characterization of changes in the discipline alongside the "New Ethnography" of James Clifford and George Marcus' Writing Culture. In this work the perspectives of cultural theory and textual criticism (Clifford, 1986: vii) are deployed to critique traditional ethnographic writing. I was forced to ask myself how I could carry out and represent work in light of "postmodern" concerns outside a practice of navel gazing.

A response to a critique of positivist social science does not have to take the form of an exclusively subjective reading in which the researcher throws up her or his hands at the prospect of adequately, honestly or fairly apprehending the world outside of herself or himself. This response does not have to take the form of treating informants as objects to be passively studied.³⁰ An attempt could be made to listen carefully to the views of informants and take care to include the opinions of the researcher (Maguire, 1987: 104). The context in which this kind of interaction can take place may be one in which both the researcher and the informant have a common interest in a project (Maguire, 1987: 103-104).

It was through this observation that I linked concerns of representation with another possible source of research

³⁰ I am reminded of Charles Laughlin's characterization of this position: "My God! Their all dots!"

paralysis: the question of ethics. I needed to find a way to make sure that my research would be relevant to the people who would act as informants and to the AIDS service organizations which would facilitate my research. I felt it was necessary that some form of reciprocity be forthcoming on my part if I was to conduct research which would result in my earning a degree. I also felt that the circumstance of the men with whom I was speaking was such that I had to offer a tangible reason for their participation. While I was already beginning to understand John Cove's warning that a thesis was not "a warm human experience" I still had faith in Sandra Kirby's claim that "doing research can be empowering and fun." (Kirby, 1989:170)

I shall elaborate on how a participatory research strategy answered the methodological problems of my research. I set out in the spring of 1992 with a number of assumptions. I wanted to employ an entirely inductive method in my attempt to privilege the voices of HIV-positive gay men over medical models of their experience. I would first speak with gay men and rely upon their description of their experience before introducing a general model of, for example, the relationship of a HIV-positive gay man to the medical establishment.

This hope was compromised by the theoretical model upon which my questions were premised. I had already deployed a deductive method in so far as I had chosen to ground my

investigation in understandings of the body as a site of the operations of power and resistance. I found it difficult to communicate this understanding to people involved in counselling or AIDS outreach work. This lead me to question the appropriateness and applicability of academic knowledge in the "real world" of the field. This failure to communicate between the world of the university and the world of the field served to underscore the surreality of my role as graduate student.

I decided that it was necessary to make my research relevant in this "real" context. I set out with the hope of putting together a collection of stories and ideas which could be useful to HIV-positive gay men. It seemed obvious to me that I must be careful not to achieve the opposite of my goal. I ran the risk of intruding on the lives of HIV-positive gay men or doing damage to them in their representation in the final document of my thesis. The most fundamental obstacle I encountered in initiating my research was one of meeting a group of HIV-positive gay men interested in participating in this research while simultaneously not intruding on their privacy or placing this privacy at risk.

It was my original intent to begin a discussion of gay men's strategies of resistance to the medical apparatus and struggles with HIV. I was going to survey HIV-positive gay men who were refusing standard medical care practices such

as the prescription of AZT³¹. From any initial survey responses I would attempt to narrow down to a small number of gay men who would have signalled a willingness to speak to me face to face. In this sense the initial survey was to be a means to the end of in depth conversations rather than an end in itself.

I decided to hold any survey instrument in reserve. I believed that it was necessary for me to speak with HIV-positive gay men in order to determine categories by which these men understand their condition and identify any general pattern of survival strategies which might emerge. In this way my research became a pilot study pending any broader survey method.

Another change in my original intent was more fundamental than a question of any particular method. After conversations with several HIV-positive gay men and with Ki Namaste, a doctoral student at the University of Quebec at Montreal who is undertaking AIDS-related research, I was convinced that there are few gay men who would have entirely rejected the medical model. I was unconcerned about the size of my sample as I had in mind a fairly qualitative anthropological approach. I was, nevertheless, concerned that I not overlook the strategies of resistance undertaken by HIV-positive gay men who do accept, in whole or in part, the medical apparatus.

³¹ Please see Appendix A for a definition of this term.

It was my suspicion that I would encounter few people who uncritically accepted medical authority and that many of the men who did accept this model in some part would have developed strategies for living with this authority. It was a further concern of mine that this project be of use to HIV-positive gay men who would encounter the medical apparatus. If I was to speak strictly with gay men who denied any validity to the medical model I would be failing to facilitate an exploration which could be of use to what I believed to be the majority of HIV-positive gay men who would choose to have some kind of relationship with the medical system.

I felt that this approach would have another possible benefit. While I was profoundly suspicious of mainstream medicine I was not ruling out the possibility that this research could be used in a constructive manner by the medical system to better serve HIV-positive gay men.

I decided to employ a "participatory research strategy." The concept of participatory research was introduced to me by Karen Miller who graduated from Carleton University's program in anthropology and women's studies. The underlying premise of this form of research is that the product of any research is ultimately for the use of those studied. I am not, however, trying to write myself out of this project for to do so would only camouflage my involvement and fail to do credit to my own needs in this

undertaking.

I feel that anthropology can fulfil a useful niche by becoming involved in research that benefits the people who are in one sense the subjects of research. Such an approach is interpretive in that it privileges the expression of the informants in research (Maguire, 1987: 14). It is a form of critical inquiry in that my goal was to offer an analysis which might be useful to people in their interactions with the medical establishment (Maguire, 1987: 14). An obvious example of advocacy anthropology would be John Cove's work in acting as an expert witness for the Gitksan in land claims proceedings. I have not wanted to politicize my research on the grounds that a given point of view was morally just. I have instead wanted to advocate a form of anthropological research which is better science in that I am as direct as possible about my personal perspectives. These perspectives cannot help but influence the questions I ask and the analysis I offer.

Participatory Research Method

A participatory research method involved making a contribution to the community of people living with HIV or AIDS even before a final document was to be produced. This contribution was to take the form of creating a place where gay men's concerns may be addressed. It can take and has taken the form of other concrete contributions.

My work with the AIDS Committee of Ottawa has been facilitated through the help of members of staff. I have worked most closely with Glenn Rockett, an educator and outreach worker, who I had met years before in an undergraduate course. The local gay community is small enough that over the years it is possible to know many people at least as acquaintances. This informal network allowed me to be something of a "known quantity" rather than an anonymous researcher. In one of our first conversations in the spring of 1992 Rockett emphasized the importance of taking the time to become known to the community of people living with HIV/AIDS and the people working in AIDS service organizations. Rockett has generously facilitated this aim by allowing me to work with him through several facets of his work programme at the AIDS Committee. This advice was consistent with the ethnographic practice of establishing rapport with a community (Kottak, 1987: 224-225). It was also an articulation of the need for reciprocity in research.

For the past year I have participated with a focus group of the AIDS Committee which has produced a series of safer-sex education material in a postcard format. This forum was interesting to me as I was the "token academic" in a group of men from government, gay community organizations, AIDS service organizations and the business community. I found this group personally educational and a place for me

to get to know a group of local gay "elders". The most recent work of this focus group has turned my relationship with Rockett on its head. After seeking his advice for a year Rockett has now asked me, as a member of the focus group, to help propose elements of his work programme for the coming year. This is a concrete example of a reciprocal research arrangement. It is also an example of the generosity and wisdom of the people with whom I have had the good fortune to work.

Alongside the formal work of the focus group I worked with other volunteers in tasks as mundane as stuffing envelopes and as interesting as distributing flyers and acting as a resource for the launching of the information package produced by the focus group. This involved spending an evening at Tactics, a local gay bar, in my role as volunteer for the AIDS Committee.

Another example of the overlapping of my various roles was my participation in a Treatment Information Forum. These are monthly events run by the AIDS Committee which generally address issues ranging from discussions of alternative therapies to up-to-date drug trials information. The March 1993 Forum was a departure from strictly medical issues and was intended to address AIDS and culture. I was invited to participate as a student of anthropology with a different perspective than the ones usually available to the community of people living with HIV and AIDS. In this role

I was performing a voluntary act for the AIDS Committee and offered a chance to advertise my role as researcher to the community. I was invited to participate, however, not as a volunteer but as an external cultural expert. By this time I was getting used to "changing hats" if it would serve the interests of research. I looked upon the occasion as an opportunity to do a favour for the AIDS Committee, advertise my research and to elaborate on some of the theoretical basis of my research to those men with whom I had already spoken.

I believe these relationships to have been useful in a direct way for HIV-positive gay men and in this sense are congruent with the main purpose of my research. These actions also, however, serve to ally me with people who are in an elite position with regards to HIV-positive gay men. This is, in a sense, already inevitable in that my own position as a graduate student places me in an elite group. It is nevertheless a concern both theoretically and methodologically.

I am hoping to present my project as a forum for expressing otherwise unvoiced opinions and myself as a resource for the AIDS Committee. In this strategy I have associated myself with an official AIDS organization and in this sense may be regarded as having been legitimated by that organization. There are several methodological concerns inherent to this approach. My first concern has to

do with the aura of legitimacy which an association with an AIDS Committee has conferred upon me. I have been careful to express to my informants my precise relationship to the Committee and my related academic purposes in conducting research (Appendix B).

This concern is of particular importance for another strategy I am currently undertaking through the AIDS Committee of Ottawa. This strategy seeks to address my hope to have a reciprocal relationship to my informants and reconcile the sense of surreality I had in conducting research. This strategy healed the division between my "self" at Carleton University and my "self" at the AIDS Committee of Ottawa by assigning a separate, but closely related, project to each. One of my primary concerns has been one of making my research useful to a group of HIV-positive gay men who would like to speak with me. I have decided upon a way to make my project known to HIV-positive gay men in Ottawa and across Ontario. This is to take the form of a resource guide as a parallel text to the thesis.

I shall describe, in precise terms, the research which I undertook with the AIDS Committee:

I have listened to the stories of HIV-positive gay and bisexual men at different stages in their understandings of themselves having tested HIV-positive. A central focus of these conversations has been the experiences of these men with the medical system:

"How did it feel two weeks after having found out you were HIV-positive? After two months? Two years?"

"What did you do about it? How did you get through?"

It was my intention to listen carefully and illuminate patterns or structures in the stories I was told. I hoped to suggest means of surviving mainstream medical practice. I have since discovered this stance to have been somewhat arrogant in that the community of men with whom I spoke have already given enormous thought to precisely this problem. The main interest of these men in participating in this project has been my facilitation of a forum in which to make these ideas broadly available.

I hope that these stories of dealing with HIV shall be useful to gay and bisexual men who have just tested HIV-positive in a number of ways. The first benefit may be the simple fact that a gay man who has just tested positive can realize that he is not alone or the only person to have felt a certain way about being positive. These stories may also offer an idea of what it may feel like after some time of living with HIV. This may prove particularly important to rural gay and bisexual men who do not have the social or institutional supports available in urban centres.

I hope that these stories shall prove useful to men who have tested positive and are now seeking out routes of health care. These men may be able to seek out helpful situations and avoid pitfalls in medical treatment with the

advice of people who have learned through experience. My initial focus was on the experience of allopathic medical practice and alternatives to this practice. I have since found my focus directed in a different direction by the men with whom I spoke. A great deal of care was taken by these men to emphasize to me the meaning of wellness and of healing. As a result of this I have heard specific strategies for living with HIV but have also been exposed to a deeper critique of what it means to be sick or labelled as such. I shall elaborate on this critique in the following chapter.

I began these conversations in the spring of 1992 with the aim of completing the project by April 1993. This time frame allowed me to interview two dozen (24) gay and bisexual men living with HIV or AIDS in the course of formal interviews and approximately that number again in informal contexts. My informants contacted me through flyers distributed through support groups of the AIDS Committee of Ottawa (Appendix C), the Living Room - a local drop in centre, the Association of Lesbians and Gays of Ottawa and through word of mouth. Informants who were interviewed outside of Ottawa were, nevertheless, contacted as a result of my advertising through the AIDS Committee of Ottawa.

Three quarters of my formal interviews were conducted in the Ottawa area with the remainder carried out in Toronto and a final conversation in Montreal. Formal interviews

were conducted in the first three months of 1993. The stories I heard were remarkably uniform. I found no significant differences between men from different cities, linguistic backgrounds or sexual identification as bisexual as opposed to gay. There was also little difference in the content or narrative structure of stories told by men who heard about my research through different sources. These differences were primarily interpersonal disagreements about the merit of a particular doctor or the participation of a particular individual at a given AIDS service organization.

This lack of differentiation is in itself an argument for the use of a survey instrument to test this smaller case against a statistically significant sample. It is important to remember that my formal interviews were of a particular sample of men who had come to terms with HIV and AIDS to the point that they were eager to share their experiences with other HIV-positive individuals. This bias alone is an argument for a study which could examine the perspectives of HIV-positive men who have not come to terms with their condition.

In addition to formal interviews I had many informal serendipitous conversations at parties or in bar settings both in my role as volunteer for the AIDS Committee and as an individual. These informal conversations took place in the summer and fall of 1992. They were useful to me in producing an interview schedule.

I have raised a number of topics of discussion with HIV-positive gay and bisexual men. I used a series of "open-ended" questions following suggestions from my graduate committee and Michael Patton (Patton, 1990: 295-313). I should point out that these questions were always meant to be tentative in so far as they were considered important by the people whose stories I heard. These questions were only as relevant as HIV-positive men considered them to be:

- "How did you hear about this project?"
- "Are you HIV+?"
- "How long have you known you were HIV+?"
- "How did you find out you were HIV+?"
- "How does it feel to be HIV+?"
- "How did you feel when you first discovered you were HIV+?"
- "(How) has your (outlook on) life changed since you learned known you were HIV+?"
- "Has your experience of being HIV+ changed with time? In what ways?"
- "Do you think your experience of HIV has been unique? In what way?"
- "Do you think there are experiences you share with other people who are HIV+?"
- "Do you belong to a support group or some other organization of other people who are HIV+?"
- "Are you familiar with current medical debates around HIV/AIDS? Current political/social debates? Writing or other artistic productions of people living with HIV/AIDS?"
- "Are you undergoing treatment for HIV? Formal medical treatment? Alternative/holistic therapies? Counselling? Meditation? Some? All? Which of these have been the most/least beneficial? Are there any which, in hindsight, you might have avoided/sought out sooner?"
- "What advice would you offer to someone who has just tested HIV+? Someone has tested positive two months ago/a year ago/etc.?"
- "Is there any advice you would offer a gay/bisexual man who had tested HIV+?"
- "What advice would you offer concerning a resource guide for HIV+ gay/bisexual men? What other community

based projects might be useful?"

This interview schedule was useful to me for structuring my thoughts but was only useful in interview settings in a way I had not anticipated. I never managed to ask every question I had written down in an interview. I found that it was more constructive to listen to the stories my informants decided to relate to me. I found that, with some encouragement, these stories answered every question I could ask but in ways structured by the informant. The interview schedule mainly served an iconic purpose in so far as I could pick it up when conversation wandered and in so doing lend formality to what often became very informal and personal conversations. I found I rarely needed the schedule even for this purpose as it was this very informality which allowed for an open exchange of views.

I was often asked in the course of interviews whether or not the stories I was being told were answering the questions I wanted to ask. I almost never had the chance to respond before another story was forthcoming. I believe this to be a result of the impoverishment these men experience in finding places to relate their experiences. I was told by one informant that it seemed as though he was the one conducting the interview. This was yet another of the transpositions in roles which have characterized my experience of this research.

Role and Narrative

The resource guide, and its concomitant facilitation of a forum in which my informants could tell their stories, allowed me to reconcile my academic concerns with ones of applicability to the "real world." I shall elaborate on what I mean by the "real world" in a moment. It has also served to make sense of contradictions between my self-perception as researcher in the field and the way I was perceived in the course of my research. It was only after a year of work with the AIDS Committee that I was even to become aware of this disjunction.

I spent the summer of 1992 conducting informal interviews and preparing for the confidentiality process necessary to run formal interviews through the AIDS Committee. This process continued through the fall of 1992. I first knew that I had been accepted at the AIDS Committee in the winter of 1993 after the first of my formal interviews was a success. Although I had been in and out of the AIDS Committee offices for a year I suspected that many people did not know who I was or what I was doing. Rockett once pointed out to me that I was perceived to be one of his friends or volunteers. This observation brought back my sensation of surreality. Here I had been thinking of myself in somewhat grandiose terms as the first independent researcher to ever work with the AIDS Committee while all along being perceived, as it seemed to me, an

ordinary volunteer on Rockett's programme. This was apparently the case despite the fact of my project passing through the confidentiality process of the AIDS Committee and the fact that I been granted a mail-box and the privilege of using the AIDS Committee office to receive telephone messages. It was interesting to me that my sense of self-importance should have become bound up in my self-perception as a person conducting graduate research relevant in the "real world." This blow to my ego was alleviated after my first formal interview. I telephoned the AIDS Committee and spoke with the office administrator. We had always had a cordial relationship but on this occasion he was very pleased to speak with me and asked me how my "programme" was coming along. I was now understood as having a programme of my own.³²

This incident serves as an example of the importance of narrative to perception. The story I told to myself about who I was in the context of the AIDS Committee was very different from the perception other people had of my work. It is this relationship of dramatic self-perception to the "real world" which underlies the epistemological frame of my

³² I was struck by the similarity of this experience to those related to me by Karen Richter in the course of her fieldwork. Richter made the transition from anthropology student to be introduced by police officers as their "partner." The situations were different and the language specific to those situations. They both, however, served to re-understand the student researcher as having an official capacity as expressed in ascribing an institutional role to the researcher.

research.

David Carr refers to what he terms the "standard view" of narrative (Carr, 1991: 161) which:

"simply put... is the view that real events do not have the character of those we find in stories, and if we treat them as if they did have such a character, we are not being true to them." (Carr, 1991: 160)

This view is held by people espousing a variety ideological positions which are normally in disagreement about the way the world works. Everyone from Marxists to feminists, from Foucauldians to sociobiologists, seem to agree that the stories that social scientists and their informants tell about the world are in fact only models or representations of the world and not the world itself.

This "standard view" asserts that the "real" world is inaccessible through stories which lend meaning to that world. This assertion is not neutral of meaning but is itself grounded in a story about the "real" world as a place governed by chance and devoid of meaning or purpose or a mechanistic place where every circumstance is predetermined (Carr, 1991: 163). I must point out that nihilism is itself a way of ascribing meaning to events. Carr makes an eloquent observation:

"This may be true, but it is of course irrelevant, since it is not primarily physical reality but human reality, including the very activity of projecting our concerns, which is portrayed in stories and against which narrative must be measured if we are to judge the validity of the standard view." (Carr, 1991: 163)

This "human reality" is rich in meaning and purpose.

It is a place where our actions are grounded in stories which guide us to do the right thing and to know when we are doing the wrong thing. This reality is one rich in the stories we tell about ourselves and which lend coherence to representation of ourselves to ourself and to others.

This human reality is understood to be distinct from the physical reality accessible to medical science. The story of disease told by the Walter Reed dialectic is held up to be a more real story about AIDS than the stories people living with AIDS tell about themselves. I have argued that this medical myth of AIDS is itself dependent upon very old stories of illness. I may be right, but this is of course irrelevant. This medical story of AIDS is only part of the experience of living with AIDS whether it is representative of the "real" physical world or not. The remainder of the experience is in part a reaction to the validity of the medical story but is also in part independent of that story.

I have told a story of preparing for and conducting fieldwork which would be ethically tenable and methodologically consistent. It is the story of a person thinking of himself as a graduate student and occasionally finding this story surreal. It is the story of a person understanding himself to be perceived as one thing and finding himself to be perceived as another. In the following chapter I shall try to retell the stories I have

been told of what it is like to live with HIV and AIDS. I shall attempt to retell these stories in light of much older stories of what it means to be sick and what it means to be well.

Chapter Four: Stories

I call this chapter "Stories" because it drawn from the experiences of gay and bisexual men living with HIV and AIDS. With such an understanding this title is appropriate. This title is also, however, a misnomer. I have not reproduced entire transcripts of my conversations with these men³³. These stories would take on new meaning from the context in which they were told even if I were to do so. This new meaning would result from my reproducing them in the context of a thesis.

My selection from these conversations represents more than an editing process but is rather a process of re-telling the stories I have been told in order to present them in a new light. I draw patterns from the stories I have been told. I shall also point out suggestive use of metaphor used in the telling of these stories. These patterns support the model put forward in the second chapter concerning "Theory."

It is useful to recall John Cove's assertion that this form of representation "presents a lie." (Cove, 1987: 1) I have not simply put forward a theoretical model and gone out into the field to find that it is supported by research. I went into the field and listened to the stories I was told. From these stories I have developed an abstract model which

³³ Would Clifford Geertz call this "Thick transcription?"

I put forward in the theory chapter. It is useful for the purposes of a thesis to tell these stories in light of this abstraction. It must be kept in mind, however, that it is the abstraction which is derivative of the stories and not the other way round.

I have settled upon "Stories" as the title of this chapter in light of these ideas. I am not telling the stories I have been told in quite the way they were told to me. My re-telling these stories, however, is not simply the telling of "my story." The "stories" told here are of the experiences of men living with HIV and AIDS. I attempt to illuminate themes in these stories by contrasting the experiences of different men with the experiences of one man, Mark. In this way I intend to preserve the narrative integrity of at least one story as it was told to me.³⁴ These "stories" are also my story as it re-tells these experiences in the context of an academic paper and through the lens of my own interests and experiences.

Identity and Change of State

I am not the first social science researcher to have given special attention to the stories HIV-positive gay and bisexual men tell concerning their experiences of HIV and AIDS. Linda Viney and Lynne Bousfield propose narrative

³⁴ In this I am using the same approach to theme-oriented life-historical data I used in The Love that Dares to Speak Its Names. (Packwood, 1991)

analysis as a "better method" of research which can represent the experiences of "AIDS-affected" people (Viney and Bousfield, 1991: 757). Viney and Bousfield cite an informant to explain the need for their approach:

"When I have read data... lists of numbers and stuff... I have always said: "That's not me; that's not representative of me?" (cited in Viney and Bousfield, 1991: 757)

I found similar responses to the aims of my research. My informants expressed interest and support for a forum in which to express their views.³⁵ They expressed happiness, and even gratitude, that someone would record the experiences of "us old-timers." People Living with HIV and AIDS are often defined by others who do not share their perspective. I attempted to introduce the issue of self-definition in the first question I asked in formal interview settings:

Are you HIV+?

Mark: Ta-daah! According to medical science... yes.

Mark has been categorized by an institutional authority. His response to my first question indicated a critical engagement with this label:

Now you see that's exactly why I asked that question. Mark: Well medically yes I can say yes I am... it's just that in some ways nothing is different after you are diagnosed. You are the same person before and after diagnosis. You are just armed with a new piece of information. It changes your focus in a new direction.

³⁵ My research was generally assumed to be "psychosocial" in orientation. There are strong similarities between my work and that of psychosocial researchers such as Viney and Bousfield.

Mark has a "philosophical" attitude towards his experience of testing HIV-positive. His observation that "in some ways nothing is different" is an accurate reflection upon his inability to perceive a difference in the condition of his body. The change which has occurred is one of re-classification through diagnosis.³⁶ This change of state can be brutal:

Luke: Yeah it can be very negative. I was very lucky. My physician just looked at me and he said "Your HTLV-3 positive." And I looked at him and I said "So?" I didn't recognize... I'd never thought about AIDS back then - in '85.

Matthew: '85. Yeah.³⁷

Luke: Give me a break. When I asked him (the physician) what it was he told me "That's the AIDS virus." Even when he told me I didn't react. I just sat there. I didn't know what it was. I didn't know what it did. No I just sat there and just "O.K."

Matthew: I started laughing! <laughs>

Luke: Really. Then it sort of hit me "Oh shit. This is major domo."

Major domo?

Luke: Yeah. Major domo. I got really pissed. I drank two bottles of Canadian wine. Puked my heart out all night.

You started laughing?

Matthew: Yeah. It was shock.

One of my informants turned to cocaine and alcohol after finding he had tested HIV-positive. Patrick felt he had been "given a death sentence." Luke explained this attitude in saying "We figger: what have we got to lose?"

³⁶ Diagnosis may be written "DiaGnosis": the ritual process by which a new category of being comes to be "known" through the judgement of a physician.

³⁷ This conversation with Luke took place at the Living Room. Several other men joined in the conversation over the course of the afternoon.

This response has been very common and is not accidental. Anonymous HIV-testing with an emphasis on pre- and post-test counselling has only been instituted across Ontario since the beginning of 1992. This form of testing is still only available to those willing and able to travel to large urban centres. The experiences of my informants all too often reflected Matthew's:

Matthew: When my doctor told me he said that if I was putting off a vacation or things - things I wanted to do - then to do it now. "Six months to a year."

Luke: Your doctor said this?

Matthew: Oh yeah.

Matthew was told by an authoritative figure that he had only months to live. He has outlasted this prediction by many years. When Patrick discovered, to his surprise, that neither HIV nor years of "shooting coke" had killed him he reached the conclusion that he had not been meant to die. It is not only medical authorities who expect my "terminally ill" informants to die:

Luke: Yeah. I keep running in to people who say "Jeez your still alive?" Like fuck off! I not going to die just to make you happy. <laughs> I surprised the shit out of a lot of people.

In the transition from the negative to the positive an individual is placed in a new social context. This context is consistent with a story of AIDS which begins with the diagnosis of seropositivity and ends in death. This new context can either be met with denial - in the form of an escape into alcohol, drugs or sex - or into a re-evaluation of place in the world:

How is your focus changed?

Mark: Well... uh... I started to look and to find out informational things about... around HIV because I was off in a new direction. I wasn't just hearing about HIV as it affected somebody else. Now it affected me personally and how I interacted with people and with other people who have it. What is it I'm saying... now I belonged to a community ... Now I could identify with these people in a way I might not of before. I can identify with people whether they have HIV or not but it's sort of like now I belong to a group of people and we have something to talk about well "How do you feel?" "How do you live with that?" "How do you handle that?" "How do you get by in your situation?"³⁸

I wanted Mark to elaborate on this sense of "community." In this context AIDS becomes more than a disease affecting an individual but a condition signalling belonging in a group. I wondered if this rebuttal of a disease-model might be comparable to the rejection of the medical understanding of "homosexuality" as distinct from a socio-political identification as "gay" (Packwood, 1991):

When I was tested last year it was for the first time in years... and it was negative. Now I had no idea what my status was and... it became bound up in my understanding of myself as "gay" because I had, I had only stopped drinking a short time before... It was as though I had to prove that I was gay.

Mark: I think it has to do with the stigma we pick up from our culture and our society about being gay and being HIV-positive. I am a person with many aspects. But being gay is just part of it. It's part of a larger process. Uhh... Are you a person or are you a behaviour? The more I really look at it the more I realize we are not just something biologically... or something in our bodies.

This exchange mirrors the false-start I had in framing

³⁸ I was very pleased to see Mark's questions mirroring those in my interview schedule.

a question for this thesis. I intended to pose a political question and found myself faced with a mystical and existential answer. Mark engaged in a critique not only of his medical diagnosis as HIV-positive but of the nature of being in the world:

Was that the same before you tested positive? Or has it changed since you've tested positive?

Mark: It became more apparent after I tested positive. It's still a struggle... there are periods where I'll say yeah and that's it and I'll accept it. I'll get pulled into this Judeo-Christian belief. It's very very heavy for me. Part of the change came for me... It was an examination in the light. Here are the areas that could be better in your life. I feel like creating on my own...

Existential Questions

Not all the men I spoke with had quite the same engagement with experience characterized by Mark. John sarcastically dismissed this sort of thinking as "having insights." John, however, was the only man I spoke with who dismissed this posing of fundamental questions. I do not believe it is accidental that John was the only man with whom I spoke who claimed to be HIV-positive but had not been diagnosed as such because of his refusal to be tested for HIV.

Everyone else I spoke with found that being HIV-positive has changed their life:

Has it shifted your perspective?

Mark: I think what I took from that was... um... there's the experience itself and the experience as you look back at what happened. You have to be very specific about the communication, whatever you want to

call it, there's that type of answer that goes on... there's that type of dynamic.

Many of the men I spoke with used terms like "dynamic" which describe their experience using imagery suggestive of a particular kind of motion. I shall elaborate upon this dialectical imagery below. Mark continued:

Mark: On a larger scope or a larger picture for me it... caused for me I don't know... you want to talk about cause and effect? All of a sudden my awareness instead of being on the world, on all the issues that you have to deal with on a day to day basis - and sometimes on all the little concepts we have the petty concepts that we have - all of a sudden... perceptions or concepts are no longer just about normal to the world. It's all of a sudden taken out of that dynamic and put into: How do I normally relate to mankind? How do I relate as a human being? How do these human beings reach into the causes happening in our world? It's really that big. Instead of little concepts like "What's going to happen tomorrow at work?" all of a sudden you see inside, in this realm, of the essence... (my emphasis) of the pure source if you want to call it that.

Mark describes a fundamental change in perception. Where he had focused on the mundane he found himself asking "big" questions. He characterizes these as questions concerning "essence", that is to say, as existential. It was only upon transcribing interviews that I noticed that no less than half of my informants used the term "essence" in describing their engagement with HIV and AIDS. This ranged from Luke describing what "in essence" it is like to be HIV-positive to Paul posing questions which he felt were "essential to understanding" his experience.

Mark describes this "essential" change in his engagement with the world:

Mark: Well all of a sudden it's not just "What's Mark going to do for lunch tomorrow?" or "Mark is having problems with so and so..." It's all of a sudden well that's a moral attitude that's a belief and that's how they function. Going from that perspective into the big scheme of things. It's so big it's really impossible for the mind to handle it can't handle it... We're really limited in our... in our third dimension whatever you want to call it...

My informants raised all of the twelve "core narratives" outlined by Viney and Bousfield (listed in Appendix D). I was initially surprised to find that I was encountering stories which linked issues of mortality with those of community and, more fundamentally, with issues of meaning and reality.

I believe this difference in findings to be a result of an anthropological approach as distinct from one grounded in psychology. The term "homosexual" is both medical and psychological in origin. It assumes an predilection, if not an outright pathology, which is specific to an individual. This assumption is based upon a practice of reason which is diagnostic and specific to an individual. To label a person "homosexual" is to tell a story about a person which can reveal more of the perspective of the labeller than of the person subject to the label. An anthropological approach does not limit itself to an analysis of behaviours but attempts to engage with identity and community (Packwood, 1991 and 1993). It is one thing to be labelled a "homosexual" and another to declare a "gay" identity. This identity implies participation in a community and in a

history which is self-affirming and empowering.

At first I wondered how Viney and Bousfield could have failed to ask themselves by what logic the twelve core narratives they assert might be understood. I believe they fail to pose this question because it falls beyond the scope of the discipline in which their work is based. It is one thing to be diagnosed as having a mortal condition and be doomed to become an "AIDS victim." It is quite another to take the opportunity HIV and AIDS provides to pose fundamental questions about wellness and community as a "Person Living With HIV or AIDS."

Wellness and Community

I was surprised by an attitude HIV-positive gay and bisexual men conveyed to me in their stories. I found them to be expressive of an ethic of self-care and of caring. I had expected some men to have become embittered by their experience. If anything, I found the opposite:

Mark: The issue for a lot of people with HIV is taking it from a personal issue really to a global issue here. It's hard to walk in wellness. This issue of wellness... and again HIV is an issue of wellness and it is our planet that is really diseased. Not just HIV but a broader atmosphere of man's mind, of consciousness, and the struggle of the world today is between consciousness and unconsciousness. So HIV becomes something which teaches people consciousness?

Mark: It may ask that... for some people it will never be that... for some people HIV is always only going to be a personal issue and a personal struggle. Uhh... Well some people are going to walk around with the attitude that "I'm infected and I'm going to survive or I'm not." and I'd say to them "Well true. But there is

a much bigger picture." It's the thinking. It's the attitude that's diseased.

There are two ways of experiencing HIV. The first reaction of many people is to understand HIV and AIDS as a personal calamity. For many this manifests itself in the form of denial through what might be understood as a flight into the material or the sensual. I have mentioned that several of my informants first turned to alcohol or drug use as a means of ignoring a diagnosis as HIV-positive. Many others respond to their diagnosis through resorting to conventional medical care. It was very common for my informants to have initially been prescribed AZT, an anti-viral drug, only to decide to discontinue using it after the period of a year or two.

After rejecting these responses my informants found another way of experiencing HIV and AIDS. These response constitutes a re-telling of their story as members of a community of People With HIV or AIDS rather than as individuals with a "terminal" illness. For many it also implied a new understanding of experience:

Mark: You could look at any disease we have on the face of the earth, any terminal disease - cancer... leprosy...³⁹ - and then we put AIDS up there as well... and the stigma that people attach to them is the stigma of fear and ignorance. You know our concept of fear feeding itself. And how quickly that cycle can

³⁹ Mark compares AIDS to other terminal illnesses. The best reference I have discovered for this AIDS and Its Metaphors by Susan Sontag. Sontag's work grows from her earlier work concerning illness and her recovery from cancer thus "confounding my doctors' pessimism." (Sontag, 1989: 15)

be perpetuated. And people can be extremely ignorant... because you believe something well... that doesn't mean necessarily that it's true... but then again it's true in our thoughts... because I choose to believe that this light is my source... um... Because I believe that it doesn't make it true... it's true because I experience it...

Mark uses the metaphor of a cycle to describe a way of experience contradicted by his experience of AIDS. He contrasts a state of ignorance and fear with another state which one can have access to "in his thoughts." He describes his experience as one of acceptance:

Mark: What I guess it comes down to for each person with HIV is... with each person is how comfortable are they? They have a disease. They have to either come to terms with it or they don't come to terms with it. This is really what it comes down to.

Here is an either/or statement positing two states which stand in opposition to one another. Mark contrasts an attitude characterized by anger with one characterized by healing:

Mark: Now this didn't eliminate my frustrations or my anger but it also gave me an insight as to well "You've got this thing you've got to deal with. You've got more complications than someone else." I can choose to be angry about it all the time, and I have days when I am absolutely furious <laughs>, or I can try to let go of that. And say "What can you do that's more healthy or more productive?" Or even more healing. That kind of light... that kind of essence that you walk in is always more constructive for me. There is my healing. It's more caring, even if it's not for someone else, if it's just for yourself. It's more... how shall I put this... whole? Walking in love. It's certainly not just the HIV. It's the attitude. Emotionally. The spiritual attitude. And the physical make-up because all the other elements, if you talk about disease, are in trouble... life is that much more difficult.

Mark's story has important implications for

understanding his experience. Where I might have thought I would find a person crippled by a mortal disease I found someone expressing insights into spirit and meaning. James Miller describes "Acquired Immanent Divinity Syndrome" as the rhetorical transformation of "victims" of disease into saint-like personages. He is critical of this construction as he believes it places an unrealistic burden on people already coping with AIDS. The part of me that is a cynical academic was unprepared to be confronted with this form of transformation in the men I interviewed. I believed that this literary representation was a fanciful, and arguably damaging, misrepresentation of living with a terminal illness. I was mistaken. Mark radiates a genuine serenity. He really does seem to have become aware of something which I have not. Mark is typical of the men I spoke with.

I found myself having to decide whether I was being fooled by hegemonic societal forces which I should dismiss or whether I should trust my senses. I chose to trust my senses. I found myself speaking with men who had an almost frightening calm in the face of sickness and death:

Luke: We're the ones who're supposed to be sick.

Matthew: We're not sick. It's the world that's sick.

Luke: Yeah.

AIDS as Lesson

The experience of HIV and AIDS has the capacity to teach lessons in what it is to be alive and be mortal.

These issues are fundamental to being human. The stories I have been told managed to cut through my political and academic analyses and, in each case, forced me to address a unique human being. Alain-Emmanuel Dreuilhe criticizes the kind of cynical distancing analysis with which I began my research. Dreuilhe is a sociologist and thus familiar with the approach social science sometimes takes towards understanding people. What is more, Dreuilhe is a sociologist who is Living With AIDS. He observes of journalists, researchers, business-men and bureaucrats concerned with AIDS that:

"Les anthropologues de nos tristes tropiques ont rapporté un baggagge considérable d'informations et de conclusions sur nos moeurs et nos gènes, notre modes de socialisation et nos mythes, mais, ce faissant, ils ont perdu de vue notre humanité." (Dreuilhe, 1987: 12)

The anthropologists of our "tristes tropiques" (unhappy tropics/tropical unhappiness) bring back a considerable baggagge of information and conclusions concerning our customs and our people, our mode of socialization and our myths, but, in doing so, they have lost sight of our humanity. (My translation.)

Here "tristes tropiques" stands for Dreuilhe's "unhappy" condition. He is awakened by night-sweats in a temperate country. AIDS is commonly represented as a plague emerging from equatorial Africa. It is held to be a plague with miasmic⁴⁰ associations to a space characterized by "darkness."

More fundamentally "tristes tropiques" is a play on the

⁴⁰ Please see Appendix A for a definition of this term.

title of a work of the same name. Claude-Levi Strauss' (1955) autobiographical ethnography is a discussion of the imaginary space of "the field" in anthropology. Dreuilhe's story, his story, is an autobiographical auto-ethnography. Dreuilhe's fieldwork was carried out in the context of his own body. He had one key informant, himself. He finds himself to be constantly harried by "anthropologists" of various sorts. All of these researchers insist upon telling stories about his experience in which his humanity is lost.

My informants also insist upon a recognition of their humanity in the face of AIDS. Luke described his experience of going to see the AIDS Quilt. The Quilt is a travelling memorial to people who have died of AIDS. It is a massive accumulation of individual collages of material which are each dedicated to a person who has died. These patches are generally made by the friends and family of the person who has died. When the Quilt came to Ottawa I could not bring myself to go. Luke went out of loyalty to a friend:

Luke: It's like that AIDS Quilt. Seeing it ripped me apart. The only thing that came out of my mouth was "When's it going to end?" And most of the people that I've known who have died from this fucking disease have been beautiful people. Wonderful warm caring human beings. And that's why I talk about AIDS at the schools and that sort of thing because I want people to understand the human aspect of the disease. The human loss. And what kind of people it is that they are losing. And not just the disease itself. It's there... it's not the disease I care about it's the people. And the families... the families that have to support themselves after they lose someone.

Luke makes an important distinction between AIDS-as-

disease and AIDS as it is experienced. This distinction is based upon the affects of AIDS upon a common "humanity." This is the same distinction which David Carr makes concerning narratives as representation of a "physical reality" and narratives as stories which bring meaning to a "human reality." (Carr, 1991: 163) The clinical and dispassionate understanding posited by a medical story of AIDS is rejected in the face of Luke's emotions which "ripped him apart."

The lesson of AIDS is one of compassion for a common humanity. This mystical engagement with terminal illness lies far afield from standard medical understandings of AIDS. This lesson is also passed over in the twelve core narratives outlined in the psychological analysis of Viney and Bousfield. The story I was being told concerned an experience of a "human reality" not readily quantifiable or verifiable. It seemed to run counter to "everyday" perceptions of the world:

I have a lot of friends who have a more materialist outlook. They might have trouble seeing this... Mark: <laughs> It (AIDS-as-disease) may be destructive on the physical plane but if the person is aware of it even though it's destructive as a disease... it's teaching them something. It's taught me... it's taught me to be more productive with people. It's taught me a lot about interaction with people. Umm... it's shown me in some areas how to lay down barriers. And communication in relationship i.e. with the loved one. It's shown me and it shows other people how to overcome ignorance. How to overcome fear in a certain area. Those are real specific examples.

This was not the first time Mark has tried to explain

his experience to someone who had a hard time understanding how he could have such a "productive" outlook on so "destructive" as disease. It was for this reason that he took care to explain his abstract or spiritual sounding understandings in terms of "real specific" and everyday examples. These examples take the form of lessons he feels AIDS has taught him concerning his interaction with a community and a common humanity.

From this point Mark makes a still more fundamental assertion:

Mark: It's not necessarily in Christian terms but it's going to come across that way because that's where my background is... it was for me... it caused me to open, and not just me but other people I don't know if you want to call it Christian or not, but it opened me to a position of loving care for other people that I might not normally have got. The second commandment that Christ gives us is that we love others as we love ourselves. And for a lot of people that's really hard to do. For some of us, for someone with disease, that has such devastating effects... and I'm not negating the effects that this has on people - it destroys lives - and just... it really rips down people... and I think that when people get past that... and I think maybe this is what I want you to understand... when we get past that, when we get past the destructive element, the destructive nature, of all that is going on and the hurt and the pain that it causes there are some very marvellous lessons to be learned. How people globally... how people interact. How people are coming together. One of the big issues is how the gay community came together. And with open arms came to people who were sick and needy and needed help. And the networking that has gone on. Between the gay community. Without this would not be where we are.

Mark describes the effects of AIDS-as-disease in the same terms as Luke. Here AIDS is something which "rips down people." In this understanding AIDS is a "destructive

element" of "hurt" and "pain." At the same time, however, AIDS is understood through another story. In this alternative AIDS is a "global" teacher for a world which Matthew has said "is sick." In this story AIDS has brought the gay community together and is held up as a force which has the potential to teach lessons of acceptance and compassion to the world.

Mark takes care to say that it is this dichotomous telling of the story of AIDS which he wants me to understand. As AIDS had taught Mark so Mark attempted to teach me:

Mark: It's about each of us and how we begin to relate with other people... how we interact with other people. What happens is that when you have a disease or something which is catastrophic, or very hard to deal with, people... some people handle it quite differently. We all reach certain stages of acceptance and lead from there... well eventually lead to death and for a lot of people that's where it leads to because that's all they can think about. That's all they can understand. I don't know if I'm putting this good or not.

No. No. A lot of people have been saying this to me. You are putting it succinctly.

Here Mark reiterates the either/or capacity of people to either understand AIDS as a personal "catastrophe" or achieve a form of radical acceptance. It is this latter state that characterized the men with whom I spoke. Patrick even characterized HIV as a "goddess" who had taught him the meaning of life.

No matter how many times I heard HIV-positive men express similar sentiments I remained surprised that a

disease which terrifies me could be the source of a joyous engagement with life:

Mark: Yes it's hard and it's here to teach you some very hard and difficult lessons... but for me, difficult as it is, HIV is an extremely personal issue but it is also an extremely global issue. And it's here to teach our society and our world how to live with people. How to interact with people. How to love people. I don't know everything about the source or the energy... for me it is sufficient that energy is there. That's what wellness is about. I don't know if I've gone a little off topic though...

HIV and AIDS provide meaning in an everyday world with little meaning. HIV and AIDS provide purpose in an everyday world with little purpose. This is the source of "wellness" in a world which is sick. Here AIDS is understood not as an illness but as a teacher which guides a suffering gay community, and a suffering humanity, into healing.

Mark: I guess what I'm saying is everybody's got different exercises or different lessons to learn? Umm... I've learned some very hard lessons. They've taught me a lot. About who it is I am and where it is I am going and where it is I want to be. And when all of that is done and for me there is something more than this physical life...

HIV and AIDS have provided lessons which have Mark "where it is that he is going." Mark, and the other men I spoke with, insisted that these lessons are not specific to individuals but are lessons for the world. The experience of a "mortal illness" such as HIV and AIDS can show the world "where it is going."

Descending Dialectic

I came across the concept of a "descending dialectical"

logic when I realized that the story of AIDS-as-disease is structured in a series of sequential pairs. Each discrete position in the medical narrative of AIDS has its double in the form of its imminent progression to the next step towards the end. This imminence of death proves to find its own contradictory narrative in the form of the immanence of the divine.

I am not the first to discuss the story of AIDS in dialectical terms. Tim Edwards distinguishes "AIDS as a medical condition from AIDS as a social phenomenon." (Edwards, 1992: 158) Edwards introduces the inter-relationship of AIDS and awareness, AIDS and identity, and AIDS and death. He calls these relationships "dialectical" and observes that "On intending to study the impact of AIDS upon the gay community, the unintended and unexpected impact was the impact of the gay community upon AIDS." (Edwards, 1992: 158)

While Edwards has made the central observation that AIDS, gay cultural awareness and sense of identity, and death are closely bound together in a complex interdependent relationship he fails to elaborate on how this relationship is "dialectical." The model I elaborated in Chapter Two constitutes an attempt to get at the structure of the story of AIDS-as-disease and the structural transformation of this story into a myth of healing. The dialectical form of AIDS-as-disease may be termed "descending" in its

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description of a movement in a specific social-space of Judeo-Christian time and eschaton. In this history stories have beginnings and endings. People are born and live and eventually die. Even time and history has a beginning and an end. This notion of beginnings and endings is allied with a cosmos oriented with an "up" and a "down." The Tower of Babel intended to ascend to the heavens. Jacob's ladder is also a means of ascent to this heavenly space. In Hebrew Qa'balah an ascent is made from the earthy condition of "Malkuth" to the divine sphere of "Kether." Conversely, the "Sheol" was an underworld and space of the dead. This concept found a later manifestation in Christian spatialization of Hell as a place down below such as "Davy Jones' Locker."

In general terms "up" is characterized as divine and good while "down" is understood as earthly and transitory. This structure is reflected in the concepts of "transcendence" and "immanence." Experience which is transcendent is meta-physical and beyond the ground of time and history. The story of transcendent experience may be told in an ascending dialectical form. Jacob's ladder is a sequence of steps which form a digital progression away from earth. Mohammed's "night flight" ascent from the rock of Abraham progressed through seven-heavens before encountering the sphere of the divine.

Experience which is immanent⁴¹ reveals the ground of true reality - divine reality - in the earthly and unrealized ground of history. The story of experience which is immanent may be told in a descending dialectical form. Each step towards the divine is, in this story, not towards the heavens but downwards into the physical death.

Plotinus expresses his frustration at his soul's "descent into body":

"Many times it has happened: lifted out of the body into myself; becoming external to all things and self-centred; beholding a marvellous beauty; then, more-than ever, assured of community with the loftiest order; enacting the noblest life, acquiring identity with the divine... yet, there comes the moment of descent... I ask myself how it happens that I can now be descending, and how did the Soul ever enter into my body, the Soul which, even within the body, is the high thing it has shown itself to be." (Plotinus, 1991: 334)

This frustration at the transience of the physical in the face of knowledge of the divine holds within it a knowledge of wonder. As the body is temporary and insubstantial the divine is outside of history and is fully real. The experience of descent implies knowledge of a contrasting divine reality which assuages the pains and sufferings of an unreal and impermanent body. This story of immanence takes the logic of a descending dialectical movement. It is a story of healing which is thousands of years old.

While I was confident of the logic I perceived in the

⁴¹ Please see Appendix A for a definition of this term.

Walter Reed Classification system I never expected to find my informants engaged in the same kind of "deconstructive" analysis. This analysis does not take the form of an academic abstraction but is evident in the metaphors and analogies deployed by my informants to describe aspects of their experience:

Mark: If you focus on one thing, if you focus on the HIV, and on a specific aspect - on the disease - and I can't think anything past that I get locked into that mind-set of "Well I have this disease and I'm not going to function. I'm not going to be this. I'm not going to live. I'm not going to survive." Then people cease to exist. Or they cease to live. They cease to function. And they cease to carry on and they just exist. And gradually they're going downhill and downhill and downhill until finally they have physical death in the body. It's game over. (My emphasis)

Mark outlines an understanding of AIDS as a disease with effects upon the "physical body." He characterizes this understanding as one possible "mind-set" or perception of AIDS. A person with HIV or AIDS who has this understanding stops Living With HIV or AIDS and just "exists" with HIV or AIDS. This existence is characterized by a progression "downhill and downhill and downhill" through every step towards "death in the body." This progression is made clear through analogies suggestive of a movement. Luke refers to the experience of AIDS lived out by one death after another as "a real bitch - It's a vicious cycle." Patrick describes his experience by saying that "Sometimes it's this elevator ride... down into the basement."

Mark generally speaks in terms of attitudes and experiences. It is when he tells the story of AIDS in this fashion that he resorts to the system of classification deployed by doctors, the T-cell count outlined in the Walter Reed table:

Mark: Umm... whereas they're are people walking around with zero T-counts. Their body has no way of fighting off disease. I know somebody specifically walking around with a count of four - I think I mentioned this before - who is extremely well. And part of it, a lot of it, the majority of it <laughs> is in the thinking. In the attitude. Perhaps tomorrow it will be over but in the meantime what do you do with that time and that energy? How do you think? How do you function? That's what's important. If you don't believe you're going to be well you're not going to be well. And well somebody could say "That's very simplistic." Yeah it's simplistic but it's very hard. Acceptance is very hard.

In telling this story Mark offers an alternative in the form of a new attitude of "acceptance" of the condition of the physical body. Paul makes a similar link between his experience of HIV in terms of movement and the necessity of acceptance: "You have to let the ride take you where it's gonna take you."

Even more striking were poetic images used by Luke and Mark to describe the experience of AIDS-as-disease:

Luke: You've got to visualize it. It's like a roller-coaster. Some days you're up and some days you're down. Except... except right at the end then it's... it's like a heart monitor you know? You've got this line going up and down until there is just this flat line at the end and that's it.

Here Luke has succinctly told the story of AIDS in its descending dialectical mode. The story is characterized by

a progressive sequential movement until the inevitable end of this movement in physical death.

Mark's imagery is still more vivid:

Mark: But what I'm saying is... is that source or that energy or that essence, or if you want to call it that, that light that loving source... whatever you want to call it... for me it's a central strength. It's not a well, if you want to call it that, where I have water. It is the motion or the force that when I get caught in the garbage or the negative or the downward spiral... or beating myself up or not functioning well or any of the negative or destructive elements that I, or someone else, has projected or... even more than that, get pulled into umm... there's sort of like a light or guidance that says "There's something much greater here. Walk in the light." or "Be wary. This is what's going on."

Once again the dialectical progression of experience is characterized by movement. It has "motion" or "force." The mundane and everyday world of the physical is called "the garbage." Most tellingly, the experience is described as "the negative or downward spiral." In another interview Mark described this sensation as "the downward negative spiral of destruction" or "the cyclone swamp."

The HIV-positive individual is left with two choices: "They have a disease. They have to either come to terms with it or they don't come to terms with it. This is really what it comes down to." For Patrick, "it's like the song says: there are two paths you can go by, but, in the long run you can still change the road you're on." It is either the downward spiral towards death promised by the story of AIDS-as-disease or a radical alternative.

Unconditional Love

James Miller identifies an association with "Love Triumphant" as characteristic of the martyrus in corpore imbued with "Acquired Immanent Divinity Syndrome." (Miller, 1991: 60) He makes this observation as part of a dismissive critique of Randy Shilt's And the Band Played On... in its fictional account of the association of this "love" with People With HIV or AIDS. I was sympathetic to this analysis until I was surprised by the men I met in conducting my research.

It may be that stereotyping of HIV-positive gay or bisexual men as martyrs places an unnecessary burden upon someone dealing with terminal illness. This does not change the fact that most of the men I spoke with did indeed seem to have a mystical engagement with reality. This "real" reality cut through the sense of surreality I experienced through the course of my fieldwork. This "true" reality was the knowledge of "unconditional love." This category of experience - unconditional love - would be raised again and again in the course of my interviews. It is difficult to relate the meaning of this term. It may be that this category of experience may only be understood directly and not through words.

It is worthwhile to comment on James Miller's understanding of a mystical experience of "love" in that it misapprehends the experience of my informants in making the

same assumptions I had before conducting fieldwork. Miller himself interprets Plotinus in describing a Neoplatonic engagement with "love":

"instead of exalting mundane misfortunes as the ultimately joyful movements in a cosmic play, he could reduce the woofullest realities of human life - unheroic wars, fatal illnesses (My emphasis), crimes of passion - to minor episodes in an inconsequential drama at which the soul wiled away its time before returning to its permanent home outside the starry theatre."
(Miller, 1986: 197)

Miller's apparent dismissal of Plotinus' experience makes sense of his cynicism in the face of Shilts' representation of a contemporary "fatal illness." This thesis, however, is not directly concerned with any political engagement with Randy Shilt's work or any other work of fiction. Over the course of my fieldwork I have gradually abandoned any rhetoric which I would consider to be directly "political." The honesty and straightforwardness of the men I spoke with cut through an engagement which examines people or the world through that form of abstraction. The men I spoke with were not attempting to live out a stereotype but were trying to articulate an experience. The "reality" of HIV and AIDS is one which demands a harsh choice of deciding whether or not to live with "terminal illness."

Mark discusses this choice:

Mark: I guess on one level the disease is very destructive... on the personal level there is no question about it... but it's also here to teach people. And I guess what I am saying... all of this conversation is the focus, the awareness of each

individual, their understanding if they are infected or even if they are not infected is awareness... is awareness of what's going on in themselves.

Once again AIDS is described as a teacher which has the capacity to bring about self-understanding or self-awareness. Mark points out that this experience is not limited to the experience of HIV or AIDS. He broadens the implications for this kind of experience far beyond the specificity of his own experience:

Mark: Umm... and it doesn't have to be AIDS that does that. I think that anyone who has had to deal with terminal illness or someone who is terminally ill faces a crisis. You come to a position of feeling or understanding. I think on a global level this is what HIV is doing. Of course on a global level HIV is also responsible for great devastation and destruction but it is also causing people to come together in a loving caring nurturing fashion. For a very long time this has been absent. It's not just the gay community where we are seeing this but with people because this disease crosses all cultural boundaries all economic boundaries whatever... All of a sudden you've got people associating and interacting and having to have relationship.

In this story AIDS is a destructive force but is also a teacher bringing healing to "a world which is sick." The message which AIDS brings is of the reality of what Miller terms "Love Triumphant." My informants had named this experience "unconditional love":

Luke: I am a firm believer in unconditional love. When you love somebody you love them unconditionally. You do not put conditions upon love for somebody. And no matter what it is that happens in a relationship... it's done me a lot of good.

"Unconditional love" implies a capacity for seeing beyond relationships which are everyday and keeping in mind

our interactions with other people as human beings.

Unconditional love calls for a compassionate engagement with other people and with the world. Mark takes the notion so far as to correct himself when referring to unconditional love. He prefers to speak about the possibility of "love under all conditions:"

Mark: It's like we talked about major emotions and things which feed like fear feeds itself or anger does that? And if you stay in those types of issues or in those types of emotions long enough... then you will continually perpetuate the anger or the fear or the emotion or whatever it is. You feed it. You make it grow. And I guess what I'm saying is that when you become aware of that and you also tap into or become aware of the source it was for me a purpose... this is the energy or this is the light or this is the area... that you need to focus on. Not only all the garbage and all the stuff that is going on.

Mark was not the first or the last of my informants to attempt to describe to me this experience which could assuage his fear of mortal illness. While I could understand his words I found myself struggling to understand his meaning:

To know it intellectually is one thing but to come to it on an emotional level is another thing...
Mark: I am connected intellectually, emotionally and spiritually. We as human beings walk around disconnected. We are connected when we are born and at the very end. This is when people find out they are who they are. The essence of who we are is our connectedness with that source... with that love... with that healing.

Allopathic medicine attempts to address disease as a condition which is testable and quantifiable. In this understanding disease is a manifestation which is knowable in physical terms. For Mark, and my other informants,

disease was a form of "disconnection" with the self, a community, or a shared humanity. Jim stressed the importance of "making connections" with other men Living With AIDS. Matthew and Luke both emphasized the importance of community to "our guys" in living and coping with HIV.

Mark spoke in existential terms. He referred to the importance of connection with "the source" or love towards the goal of healing:

Mark: When we reconnect with that... and for me after being chronically diseased there is a lot to contend with on the physical plane or on the physical level. That's not all going to heal overnight. No one is going to wave a magic wand and it's going to be gone. But for me the understanding or the essence is in that light and that love. I use the word love because when I try to walk in that energy when I try to be in that source when I try to be that way... then it's easier. Easier to heal. Easier to heal on the spiritual side. Easier to heal on the emotional side. On the psychological side.

Healing is not a operation which begins and ends in physical terms. This observation is made in the context of a syndrome of diseases for which there presently is no physical remedy. Healing is presented as a holistic process addressing parts of human experience not generally addressed in mainstream medicinal practice. Here the conventional medicinal approach has failed to maintain the integrity of the physical and must cede the debate to one with which everyone is ultimately faced.

In Christian eschatology the world "that will reappear after the catastrophe will be the same... that God created at the beginning of Time, but purified, regenerated,

restored to original glory." (Eliade, 1963: 64) The history of the macrocosm is played out in the microcosm which constitutes our lives in a specific world and history. We are given the promise that we too shall live on after the end of our transient physical existence. When faced with our mortality our myths direct us through an ancient logic which precedes the story of fatal illness told by the science of medicine.

As Carr has pointed out the stories we inhabit are not just told through an engagement with the physical reality known by science. We live in myths which make up our fundamental "true history." These are "a sacred story... because it always deals with realities." (Eliade, 1963: 6) My informants have experienced an engagement with and awareness of this fundamental story of healing:

Mark: When you are able to heal those or have some clarity on the inside then the physical becomes less a burden. I've said this to a number of people in my condition, to a number of doctors, and I said look "Where's your heart in here? You are treating a symptom. The disease..." And I can just hear people saying "Ah ha ha there goes Mark..." <laughs> But to me the disease really is an outcome, is a symptom, at the very end. Because what's happened... the problem is that the attitudes need adjusting in terms of the emotional and the psychological. The spiritual. And not each person is aware of that. Some people take a whole lifetime to understand that I'm sick because of my thinking process. You know... you know I'm not saying there are no problems physically but people do make themselves ill.

Mark speaks of an "adjustment" that needs to take place for real healing to occur. This adjustment is made with a knowledge of unconditional love. The story of AIDS-as-

disease takes the form of a series of changes in state. The adjustment which Mark suggests calls for a change in attitude.

"Think Positive"

Plotinus asks:

"What is Love? A God, a Celestial Spirit, a state of mind? Or is it, perhaps, sometimes to be thought of as a God or Spirit and sometimes merely an experience? And what is it essentially in each of these respects?" (Plotinus, 1991: 174)

In asking this question Plotinus has anticipated the questions I have encountered by eighteen-hundred years. The stories I have been told of unconditional love have it to be a reality beyond disease and death. It is a form of truth revealed through harsh experience. Most fundamentally it is a practice of compassion. Plotinus terms this a "state of mind." My informants call this state of mind a "positive attitude."

Mark explains this attitude in contrast with one fostered by the story of AIDS-as-disease:

Mark: Some people use this disease to terrorize people and to control people. To create literally a Hell. Some people with a specific interpretation of the Bible use fear tactics instead of doing what the Bible tells them to do. The second commandment is to love thy neighbour as you would love thyself. And we have talked about this... that love should be unconditional... that love should be love under all conditions. What we should be able to do - what we should try to do - and I think this is what the message is. People who walk in that light... they love people. They love them under any condition. Because of who they are. That is the essence.

Mark presents us with the same either/or choice he has asserted before. A person with HIV or AIDS can either choose to live or die with HIV or AIDS. This choice is understood to be taking a "positive outlook" on life. My informants did not consider this to be a kind of placebo or attempt to divert their attention from the exigencies of their condition. This change in outlook is thought to have effects not just in the reality of the emotional or the spiritual but also in the physical:

Matthew: Some people keep well with the power of the mind.

Luke: Well I know. That's our biggest asset. That's what keeps a lot of us going. Our power in our mind and our positive thinking. Positive attitudes. It's like people with cancer... going into remission.

The story of AIDS-as-disease and its rebuttal in the form of a myth of healing are told in terms readily accessible by structural analysis. I have outlined the sequence of pairs which make up the descent into the physical death. I have further outlined the inversion of meaning assumed by this descent when understood as proof of the immanence of the divine. In this inversion the Person Living With HIV or AIDS, that is to say, living with an illness with terminal effects on the physical body, is able to say that it is not People With AIDS who are sick but the world which is sick.

I have pointed out an interesting inversion of connotation brought about in the ritual process by which a person changes state from the "negative" to the "positive."

Generally speaking the "positive" is held to be the good or the construction while the "negative" is the bad or the destruction. The person being tested for the presence of antibodies to HIV remaining "negative" becomes the hoped for "positive" outcome of the test.

This inversion undergoes another transformation in the stories I have been told by men living with HIV and AIDS. In order to live and cope with being HIV-positive it is necessary to have a "positive outlook" and to "think positive." Luke emphasized this point to me in giving me advice for writing this paper:

Luke: Make sure it's not depressing. Make sure you are dealing with individuals with a positive attitude. As I see it if you've got anything negative around you get rid of it. What people who are positive is a positive internal concept. They need people who think positive... have those good vibes... who are full of life... who are optimistic. You need people like that. If you are going to be around people who are constantly depressed or bummed out and everything else it's going to wear off on you eventually. So I try to avoid stuff like that. Like I say when I lose too many people around here I cut myself off from it. I go and heal myself before I come back and take more. You need that positive aspect. If you don't have that strength you'll do negative things.

My conversation with Luke and Matthew was at "The Living Room," a drop in centre for people Living With HIV and AIDS:

This seems like a positive environment.
Matthew: This is a living room not a dying room.
Luke: Exactly.

This sort of play on words and concepts is typical of the men I spoke with. Their optimism and faith in the world

challenged me when I was tired or dragged down in everyday struggles with my work or my personal life. I have been amazed at what seems to be "grace" under pressure. Jake once told me that he had bought a new battery for his car; "It has a sixty month warrantee. Like I'm going to outlive the battery!" This humour and calm extended to encompass the experience of otherwise grim situations:

Luke: I asked my doctor what I could expect now that I'm not taking anything. He said to expect a steady drop in my T-count from year to year. A reasonable quality of life between illnesses. He said to expect three years. But... he also said that they could come up with something in those three years. It also depends on me. It depends on my attitude. On my environment. I have a feeling I'm going to be one of the ones still around after everything is done. I'm going to be around to tell the stories.

Telling stories seems to be part of keeping a positive attitude. This is a way of interpreting experience and sharing it in a community and with the world. Storytelling is a practice of a positive attitude.

In a sense the men I spoke with told me stories of living and coping with HIV and AIDS. In essence the men I spoke with told me stories of living and coping with life. We live a life with two choices. In a world with no meaning beyond a slow descent and decay of our physical bodies we can choose to exist and then finally die. We have another choice where we may take meaning from love and a compassionate engagement with ourselves, our communities and our world.

The choice is that simple.

Mark: To create a Hell is really unnecessary. To focus on the negative and the destructive side. You can learn to focus on the positive side... on the loving and the caring. A lot of people might disagree with what I am saying. But it's the concentrating on living in the loving and the happiness that creates the wellness. And if people wanted to that is the lesson they could learn from HIV.

Chapter Five: Conclusion

In conclusion, I need to reflect upon this paper as an attempt to tell stories. I have attempted to re-tell the stories I have heard while telling something of my own story. This attempt has implications for the business of ethnography and for the living of my life.

What I Set Out to Do and What I Did

First, I must discuss the thesis as a research project. My research began as an exercise in the academic and the political and turned out as an exploration of reality and of faith. I have had to carry out this research in the context of ethical, theoretical, methodological and personal dilemmas. I believe this is a problem in all ethnographic writing. The practice of anthropology is distinct from both the sciences and the humanities in that it attempts to impart models of reality which are necessarily part fact and part fiction. It is not easy to quantify human experience. It is particularly difficult to abbreviate mystical experience into a series of numbers or precise words.

It is also not acceptable for an anthropologist to simply give up hope for a rigorous investigation and recitation of human experience. Ethnography cannot be a practice of navel gazing but must be one of careful listening. I have attempted to listen carefully to the

stories I have been told and have tried to re-tell them in this context so that their truths might still be evident. The only measure of my success or failure is another experience which I cannot quantify. This measure is to be found in your reaction as a reader of my story in its re-telling of the stories I have heard.

Ultimately, this is a story of what may be learned from the experience of a "terminal illness" such as AIDS. This is a story of what may be learned from responses to this illness based in unconditional love and in a way of life consistent with the knowledge of this love.

Heroic Storytelling and Literary Storytelling

I must also discuss the thesis as an academic paper and as an attempt to tell a story. I have discussed a number of ways that storytelling makes up our experiences and addressed some of the ways that I have been telling my own story through the re-telling of the stories I have heard. There is a final kind of storytelling which I have not directly addressed. It is this form of storytelling which has implications for the way anthropologists go about the business of anthropology.

This thesis is itself a highly structured story. I have tried to leave traces of myself throughout the paper in an attempt to remind the reader that these words are from a person living a real life and attempting to make sense of

his own stories. I have tried to avoid being an "author" erased from my stories through a rhetorical style which attempts to situate my feelings and experiences at an objectifying distance from these words. It is easier to attempt this than to achieve it. Even as I write these final words I feel a sense of distance from the research I have conducted over the past year. Soon this paper will serve as a form of memory and must stand on its own as a speech-act distinct from my opinions as they are shaped by experiences which await me.

One of the first things I say to students learning how to write papers in a university context is to remember that the truth of their essays is hardly to be found in any argument for or against a given position. This truth is hardly different in essays written in different faculties let alone different disciplines or in different courses. This is the result of a specific kind of truth embedded in the structure of the stories academics are supposed to tell. I call this structure an "academic poetic." This structure is a venerable practice of reason which demands a hypothesis, some form of experiment or elucidation of facts and ideas, to be completed by a conclusion. This conclusion is supported as much by its placement in the structure of an argument as it is by anything specific to a given argument.

I have tried to make this restriction upon the telling of this story apparent by the titles I have assigned my

chapters and in following a regular organization within chapters. I have tried to tell my story in a manner which reveals ideas or observations only when I have already elaborated upon ideas which serve as support. Here again I am participating in "the lie" which John Cove asserts underlies ethnographic writing which presents itself as seamless and coherent.

There are other forms of logic by which a story may be told. In Classical Greece the telling of important stories, of myths, was reserved for professional storytellers. Moses Finley calls these professionals "bards." Finley distinguishes between two kinds of poetics. The first of these - heroic poetry - is the field of bards:

"The heroic poem, a genre of which the Illiad and the Odyssey are the greatest examples, must be distinguished from the literary epic like the Aeneid or Paradise Lost. Heroic poetry is oral poetry; it is composed orally, often by bards who are illiterate, and it is recited in a chant to a listening audience... it is at once distinguishable by the constant repetition of phrases, lines, and whole groups of lines." (Finley, 1979: 29)

Finley contrasts heroic poetry with literary poetry. If anthropologists seek to be the tellers of myths for our society, our "bards," then we are a profession of bards with a literary rather than a heroic emphasis. The structure of this paper is dependent upon literary imperatives which constrain the stories I wish to tell. This is a problem in itself. This is a greater problem if I claim to accurately impart the truth of the stories I have been told.

The stories I have been told by HIV-positive men are far more heroic than they are literary. They draw upon similar experiences and are structured by the same underlying stories of disease and myths of healing. They are shared orally and communally. They are not intended to be data for the business of ethnography but as myths of healing for the business of life. This is not to say that the figure of the anthropologist as it is currently constituted is not a valuable one. The men I spoke with were glad to speak with me in part because I come from a discipline whose practice is to listen and then to preserve in a literary form. I am left to hope that I have managed to impart, not only the words, but some of the spirit of what I have been told. I hope for an ethnography which is a shade more heroic while retaining the important tasks of the literary.

Amazing Grace/Under Pressure

Finally, I must address the thesis as a part of my life. I began this paper with a puzzle: how is it that I should turn to the same classical work as Michel Foucault when faced with the possibility that I could be HIV-positive? Why the Meditations of Marcus Aurelius? This answer to this question is still a mystery to me. I can say, however, that I found the same aura of serenity in the dispositions of the men I spoke with as I did in the pages

of Marcus Aurelius' ancient words. I found the same sense of dignity and integrity of self in the face of what remain the unanswered and unanswerable questions of life and meaning.

I look back on my research and realize that the fundamental lessons I have learned were bracketed by two songs. I heard the first of these at the time I was just starting to see Jake. I heard the second of these the night I tested HIV-negative.

The first of these songs was a rendition of an old duet by Freddie Mercury and David Bowie called "Under Pressure." It is hard for me to describe how I have always been moved by this song or how much I dreaded hearing it after Freddie Mercury died. Mercury and Bowie were both androgynous and bisexual men who were role-models to me when I did not know anybody else who was like me. "Under Pressure," in particular, sums up an attitude of optimism in the face of bad times which has helped me in times when I did not have the easy life I now enjoy.

I was not the only person to miss Freddie Mercury. Some months following his death the remainder of his band - Queen - and a large number of prominent musicians and singers held a AIDS awareness and fund-raising event in his honour: the Concert for Life. I dreaded hearing a rendition of "Under Pressure" without Freddie Mercury. I could not face the tragedy of the song and the tragedy of his death.

It turned out to be very beautiful. David Bowie sang his lines with Annie Lennox as harlequin taking the place of Freddie Mercury. It worked. At the end of the song Bowie made one of the only unaffected gestures I have ever known him to make by dropping to his knee and saying a prayer. This gesture of faith was profoundly moving. I was terribly upset but had a sense of resolve that what I was attempting to do was necessary.

The evening of the day I tested HIV-negative was to surprise me even more. I was shaken and had not had time to think through my experience. I was relieved but still scared. I had been given a reprieve but no guarantee that I would be able to take care of myself such that I would not end up back in the state of uncertainty I had endured. Furthermore, I was left with a sense of loss for the end of my relationship with Jake and a feeling of bitterness that he should have abandoned me to wait out the summer on my own. Almost no one knew what I had been going through for those months. I arrived at a small party and found myself unable to communicate. It seemed that I needed to think more than I was able to speak. I remember a short conversation with my friend Sarah. She seemed to be the only person who noticed that I was withdrawn. It turned out this conversation was only a prelude for something she managed to communicate to me.

Sarah is a folk singer. The parties I have attended

which are hosted by lesbians usually find one room hosting a group of people with acoustic guitars and a knowledge of contemporary women's folk music. I found myself in the singing room largely because I could just sit and listen without anyone expecting me to make conversation. I am very glad I did. Sarah and some others performed some old standards and songs that they had written themselves. People generally request songs they know or these original songs as it is a treat to sing along and to hear the songs they only infrequently get to hear.

Then someone requested "Amazing Grace." William James characterizes mystical experience by the inability to impart such an experience in words. I cannot describe Sarah's voice or the feelings I had when I finally understood this song. It seemed that I had indeed been saved by grace. In those moments I understood life as the most precious gift conceivable. The only possible response to this understanding, it seems to me, is one of loving compassion for the world and everything in it. In those moments I found my faith.

The questions posed by this paper and by the lives of gay and bisexual men living and coping with HIV and AIDS seem to be unanswerable to an understanding of the world which is physical and ephemeral. Even when the day comes that medical science resolves the physical dilemma posed by AIDS we humans are still faced with an end to this life.

The questions posed by this paper are not, however, meant to be answered in strictly physical terms. We do not live in a physical universe but in a human universe made up of the stories we tell ourselves and share with others. Some of these stories are very old and are meant to address questions which have puzzled people for a very long time. HIV and AIDS can remind us to tell stories of love and to share them compassionately in our communities and in our world. That, in essence, is the story I have tried to tell.

References

- Ben-Sasson, H.H. Ed.
 (1976) A History of the Jewish People. Cambridge, MA: Harvard University Press.
- Bottomore, Tom. Ed.
 (1983) A Dictionary of Marxist Thought. Cambridge, MA: Harvard University Press.
- Burroughs, William S.
 (1959) Naked Lunch. New York: Grove Weidenfeld.
- Carr, David and Charles Taylor and Paul Ricoeur
 (1991) "Discussion: Ricoeur on Narrative." In On Paul Ricoeur: Narrative and Interpretation. Ed. David Wood. London: Routledge.
- Clifford, James and George E. Marcus.
 (1986) Writing Culture: The Poetics and Politics of Ethnography. Berkeley: University of California Press.
- Cove, John.
 (1987) Shattered Images: Dialogues and Meditations on Tsimshian Narratives. Ottawa: Carleton University Press.
- Crimp, Douglas.
 (1989) "AIDS: Cultural Analysis/Cultural Criticism." In AIDS: Cultural Analysis/Cultural Criticism. Ed. Douglas Crimp. Cambridge, MA: MIT Press.
- Doran, Robert M.
 (1990) Theology and the Dialectics of History. Toronto: University of Toronto Press.
- Dreuilhe, Alain-Emmanuel.
 (1987) Corps A Corps: Journal de SIDA. France: Editions Gallimard/Lacombe.
- Edwards, Tim.
 (1992) "The AIDS Dialectics: Awareness, Identity, Death and Sexual Politics." In Modern Homosexualities: Fragments of Lesbian and Gay Experience. Ed. Ken Plummer. London: Routledge.
- Eliade, Mircea.
 (1963) Myth and Reality. New York: Harper & Row.
- Finley, M.I.
 (1979) The World of Odysseus. London: Penguin Books.

Foucault, Michel.

(1980) "The Confession of the Flesh." In Power/Knowledge: Selected Interviews & Other Writings 1972-1977. Ed. Colin Gordon. New York: Pantheon Books.

(1989) The Archaeology of Knowledge. New York: Routledge.

(1990) The History of Sexuality: An Introduction. Volume One. New York: Vintage Books.

Gadamer, Hans-Georg.

(1976) Hegel's Dialectic: Five Hermeneutical Studies. New Haven, CT: Yale University Press.

Gennep, Arnold van.

(1960) The Rites of Passage. London: Routledge & Kegan Paul.

Guibert, Herve.

(1991) To The Friend Who Did Not Save My Life. Linda Coverdale, trans. Great Britain: Quartet Books.

Haraway, Donna.

(1990) "A Manifesto for Cyborgs: Science, Technology, and Socialist Feminism in the 1980s." In Feminism/Postmodernism. Ed. Linda J. Nicholson. New York: Routledge, Chapman and Hall, Inc.

Harding, Sandra.

(1987) Feminism and Methodology. Bloomington: Indiana University Press.

Harvey, David.

(1989) The Condition of Postmodernity. Oxford: Basil Blackwell.

Hegel, Georg W. F.

(1951) The Science of Logic: Volume Two, The Doctrine of Essence. London: George Allen & Unwin.

Ironstone, Penelope.

(1991) "When It Is Safe to Speak of the Silence: Toward a Poetics of Lesbian Literature." In Carleton Arts Review. Fall, No. 3 Eds. Doug Ivison and Mirjana Risek. Ottawa: Mission Control Productions.

Jakobson, Roman.

(1989) "The Metaphoric and Metonymic Poles." In Contemporary Critical Theory. Ed. Don Latimer. Toronto: Harcourt Brace Jovanovich.

- Kierkegaard, Soren.
(1954) Fear and Trembling: The Sickness Unto Death.
United States: Princeton University Press.
- Kirby, Sandra and Kate McKenna.
(1989) Experience, Research, Social Change: Methods from the Margins. Toronto: Garamond Press.
- Kottak, Conrad Phillip.
(1987) Anthropology: The Exploration of Human Diversity. Fourth Edition. New York: Random House.
- Laughlin, Charles D.
(1989) "Transpersonal Anthropology: What is it, and what are the problems in doing it?" In A Different Drummer. Eds. Bruce Cox, Jacques Chevalier, and Valda Blundell. Ottawa: The Anthropology Caucus.
- Levi-Strauss, Claude.
(1955) Tristes Tropiques. Paris: Librairie Plon.
(1963) Structural Anthropology. New York: Basic Books, Inc.
- Little, W. Kenneth.
(1991) "A Mutual Parody of Meaning in Circus Clown and Ethnographic Discourse." In Culture. Vol. XI No. 1-2 Canadian Anthropology Society
- Lukacs, Georg.
(1968) History and Class Consciousness. Cambridge, MA: MIT Press.
- Lytard, Jean-Francois.
(1991) Heidegger and "the jews." Minneapolis: University of Minnesota Press.
- Maguire, Patricia.
(1987) Doing Participatory Research: A Feminist Approach. Amherst: The Center for International Education.
- Miller, James.
(1986) Measures of Wisdom: The Cosmic Dance in Classical and Christian Antiquity. Toronto: The University of Toronto Press.
(1991) "Acquired Immanent Divinity Syndrome." In Perspectives on AIDS: Ethical and Social Issues. Eds. Christine Overall and William P. Zion. Toronto: Oxford University Press.

- Mishima, Yukio.
(1958) Confessions of a Mask. New York: New Directions.
- Packwood, Alan Nicholas.
(1993) "Browsing the Apparatus: Homosexuality, Classification, Power/Knowledge." in Border/Lines. Toronto.
(1991) The Love that Dares to Speak Its Names. Carleton University: Unpublished Honours practicum.
- Patton, Michael Quinn.
(1990) Qualitative Evaluation and Research Methods. Second Edition. New York: Sage Publications.
- Pinkard, Terry.
(1988) Hegel's Dialectic: The Explanation of Possibility. Philadelphia: Temple University Press.
- Plotinus.
(1991) The Enneads. Stephen MacKenna, trans. London: Penguin Books.
- Redfield, Robert R. and Donald S. Burke
(1989) "HIV Infection: The Clinical Picture." In The Science of AIDS. United States: Scientific American, Inc.
- Richter, Karen.
(1992) Words of Authority, Words of Control: Speaking as a Police Officer. Carleton University: Unpublished M.A. thesis.
- Rothenberg, Mikel A. and Charles F. Chapman.
(1989) Dictionary of Medical Terms. Second Edition. Toronto: Barron's Educational Series, Inc.
- Rose, Margaret A.
(1991) The post-modern & the post-industrial: a critical analysis. Cambridge: Cambridge University Press.
- Shilts, Randy
(1987) And the Band Played On: Politics, People, and the AIDS Epidemic. New York: St. Martin's Press.
- Sontag, Susan.
(1989) AIDS and Its Metaphors. New York: Farrar, Straus and Giroux.

Treichler, Paula.

(1989) "AIDS, Homophobia, and Biomedical Discourse." In AIDS: Cultural Analysis/Cultural Activism. Ed. Douglas Crimp. Cambridge, MA: MIT Press.

Turner, Victor.

(1986) The Anthropology of Performance. New York: PAJ Publications.

Viney, Linda L. and Lynne Bousfield.

(1991) "Narrative Analysis: A Method of Psychosocial Research for AIDS-Affected People." In Social Science and Medicine. Vol. 32, No. 7 Great Britain: Pergamon Press.

Watney, Simon.

(1989) "The Spectacle of AIDS." In AIDS: Cultural Criticism/Cultural Activism. Ed. Douglas Crimp. Cambridge, MA: MIT Press.

Williamson, Judith.

(1989) "Every Virus Tells a Story: the Meaning of HIV and AIDS." In Taking Liberties: AIDS and Cultural Politics. Eds. Erica Carter and Simon Watney. London: Serpent's Tail.

Appendices

Appendix A: Glossary

AIDS

Acquired Immune Deficiency Syndrome. AIDS is an acronym whose contested definition is the subject of this thesis.

AZT

Azidothymidine. An antiviral drug proscribed to slow the replication of HIV in the body.

Allopathy

"n. system of medicine that aims to produce (e.g., through drugs, compresses) a condition of opposite to or antagonistic to that affecting the ill person (e.g., applying cold for a fever)" (Rothenberg, 1989: 19)

Apparatus

"What I am trying to pick out with this term is, firstly, a thoroughly heterogeneous ensemble consisting of discourses, institutions, architectural forms, regulatory decisions, laws, administrative measures, scientific statements, philosophical, moral and philanthropic propositions -- in short, the said as much as the unsaid. Such are the elements of the apparatus." (Foucault, 1980: 194)

ddC

Zalcitabine. An antiviral drug.

ddI

Didanosine. An antiviral drug.

Diagnosis

"n. identification of a disease or other condition by evaluating the patient's appearance, symptoms, and history; by physical examination; and, if needed, by analyzing the results of laboratory tests."
(Rothenberg, 1989: 125)

DiaGnosis

The ritual process by which a new category of being comes to be "known" through the judgment of a physician.

Discourse

How a narrative is recounted. This thesis illuminates a medical discourse in light of discourses of experience.

"When in the operation of a discursive formation, a group of statements is articulated, claims to validate (even unsuccessfully) norms of verification and coherence, and when it exercises a dominant function (as a model, a critique, or a verification) over knowledge, we say that the discursive formation crosses over a threshold of epistemologization." (Foucault, 1989: 186-187)

"a discourse, by which I mean not just linguistic acts, but also a corpus of interlinked signs, verbal and nonverbal, bound by rules and characterized by regularities that construct and are patterned by social and personal reality." (Little, 1991: 80)

Gay

"the term held up specifically as an alternative and a challenge to the term "homosexual" was the term "gay." In this new identification the "homosexual" who previously could only exist as a pariah might declare instead a slogan of liberation: "We are your worst fear; we are your best fantasy."" (Packwood, 2: 1991)

Gender

A performative category with normative associations to sexual morphology. Contemporary Western society is generally understood to have two gender categories: women and men.

HIV

Human Immunodeficiency Virus. HIV is the virus widely believed to lead to the breakdown of the immune system.

Homosexual

"The reality of the category of homosexuality is illusory. It is sustained only in a specific social constitution of parallel, oppositional and contiguous categories of gender, sex and sexuality. Outside of a specific historical and social moment there is no homosexuality but simple actions and desires which within a given apparatus are understood to be homosexual." (Packwood, 1993)

Immanence

The indwelling of the divine in the physical or manifest world.

Intertextuality

I use this term following Roland Barthes. In this instance an "intertextual" relationship is one between a given text - such as "AIDS-as-disease" - and broader social narratives which inform that text - such as an ascriptive "homosexual body."

Male

I use this term as an adjective or noun characterizing sexual morphology.

Masculine

I use this term as an adjective characterizing gender.

Metaphor

A figure of speech where one term is substituted for another on the basis of presumed similarity. (Jakobson, 1989: 21-27)

Metonym

A figure of speech where one term is substituted for another on the basis of presumed contiguity. (Jakobson, 1989: 21-27)

Miasma

"But even after the germ theory of contagion, miasmatic theory lived on, shorn of its first order causative status, as a kind of vague co-factor in the explanation of many illnesses. The conviction that living in dark, dirty cities causes (or at least produces a susceptibility to) tuberculosis is a version of the miasma theory, and continued to be given credence until well into this century, long after the actual cause of tuberculosis had been discovered. It seems that something like what is supplied by miasma, the generalizing of infection into an atmosphere, is required to moralize a disease." (Sontag, 1989: 42)

Myth

A myth is a narrative which articulates meaning and acts as a meaningful guide to action. I use the term exclusively to refer to a specific ancient story of healing which is elementally related to a Christian eschaton.

Narrative

A recounting of events. A narrative is composed of a story represented in a form of discourse. This thesis contrasts a medical narrative of AIDS with a narrative arising from an experience of living with AIDS. One narrative deploys a medical and scientific discourse and is contrasted with another which has a mythic discursive form. These opposing discourses tell a different story of what are ostensibly the same physical events.

Out

This is an abbreviation of the expression to be "out of the closet", or, to open about a non-normative sexual identity.

PLWA

Person Living With AIDS

PLWH

Person Living With HIV

Postmodern

"the term post-modern is a word which has so far been used by a variety of thinkers on the basis of several different understandings of both the concept of the modern and the meaning of the prefix post (as, for instance, a "break with" or a "continuation of" the modern)... many of the more specifically defined concepts of post-modernism will be seen to have been built up on the basis of an antagonism to, or reform of, a modernism..." (Rose, 1991: 1-2)

I used the term "postmodern" in contrast with a mechanistic model of modern systems of government and medicine. The postmodern represents a transformation of this system into one which may be understood to be fragmented, less monolithic and productive of new modes of power.

Resistance

"Resistances do not derive from a few heterogeneous principles; but neither are they a lure or a promise that is of necessity betrayed. They are the odd term in relations of power; they are inscribed in the latter as an irreducible opposite." (Foucault, 1990: 96)

Sex

Morphological characteristics which distinguish females and males.

Sexuality

A category of behaviours and associations arising in nineteenth century Western medicine and law.

Story

The story is the content of a narrative in which events are causally related. In this sense a story is very similar to a myth in that a causal relationship is one which may imply a meaningful relationship.

Appendix B: Project Outline

RESOURCE GUIDE PROJECT FOR HIV+ GAY AND BISEXUAL MEN

What is the resource guide? How do you participate?

The guide is intended to be a resource for gay and bisexual men living with HIV and AIDS based on the experiences of HIV+ gay and bisexual men. How do you feel and how do you get by? Through sharing stories and strategies for living with HIV other gay and bisexual men can benefit from your experience without having to "reinvent the wheel." This guide should be particularly valuable for men who have just learned they are HIV+. I would like to include the experiences of as many people as possible. If you can spare an afternoon or evening to talk over coffee please leave a message at the number below. These conversations are anonymous and confidential.

Who am I?

I am a gay graduate student in the Department of Sociology and Anthropology at Carleton University. The guide is part of research I am conducting concerning AIDS, personal sovereignty and identity. The project has a formal aspect in the form of an M.A. thesis. While I hope the thesis may help affect public policy I feel that it is important to also produce information in the form of a resource guide which can be immediately useful in the lives of men living with HIV and AIDS.

How to get in touch:

If you would like to participate in this project please phone the AIDS Committee of Ottawa and leave a message for Nicholas Packwood. Please feel free to use an assumed name. I will checking my messages every few days. When I get your message we can arrange a time to meet at the AIDS Committee offices at 267 Dalhousie Street. I am not fluently bilingual but I would appreciate and encourage the participation of French speaking men.

Appendix C: Flyer**HIV+ GAY AND BI MEN**

Do you want to tell your story? I'd love to hear it.

I am a gay student at Carleton and I'd love to hear your story of how you are living and coping with HIV and AIDS.

Please give me a call at the AIDS Committee of Ottawa.

Nicholas Packwood

**238-5014
AIDS Committee of Ottawa
267 Dalhousie Street**

Appendix D: Twelve Core Narratives

"Table 2. The twelve core narratives categorized as personal, interpersonal or community.

A. Personal narratives

1. Coming to terms with AIDS has been difficult for me.
2. AIDS has given me such painful feelings to deal with, anxiety, depression and anger as well as loss.
3. I'm HIV antibody positive so I need to look after my physical well-being, now and in the future.
4. I am constantly faced with dilemmas raised by my own mortality.

B. Interpersonal narratives

1. Being antibody positive has upset all of my relationships with lovers.
2. Having AIDS has badly affected my relationships with so many people.
3. Telling my family about being HIV antibody positive was very difficult; it raised many problems with them.
4. I felt isolated by being antibody positive; and I've been hurt by others reactions to me now.
5. I felt betrayed and robbed of my privacy when my antibody status became known.

C. Community narratives

1. The medical profession is failing me: it treats me as a second class person and sometimes even avoids treating me at all.
2. The media have over dramatized the negative effects of AIDS.
3. I think the more we can be open about AIDS, demand our rights as human beings and take control of our lives, the easier it will be for other people to live with AIDS and be unafraid." (Viney and Bousfield, 1991: 762)

END

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