

AIDS, THE "OTHER PLAGUE": A HISTORY OF AIDS PREVENTION
EDUCATION IN VANCOUVER, 1983-1994

by

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ABSTRACT

This study describes how AIDS prevention education programs were constructed, delivered, and implemented in Vancouver between 1983 and 1994. Biodeterministic models of disease are examined through a historical analysis of documents that include newsletters, minutes of board meetings, policy reviews, annual reports, and personal journals. This study assumes that AIDS is as much a socio-cultural phenomenon as it is biological.

The findings suggest that present educational guidelines for AIDS prevention are unable to identify what messages should be communicated and fail to identify to whom they should be conveyed. This study does not recommend the use of biodeterministic models of AIDS prevention education which reflect plague metaphors. Instead, culturally relevant strategies need to be developed throughout all aspects of AIDS prevention curricula.

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CHAPTER ONE: INTRODUCTION AND OVERVIEW

Introduction to the Problem:

In spite of ten years of community-based and provincial educational attempts to prevent the spread of AIDS, HIV rates in British Columbia are increasing. The rate of increase has decreased when compared to the rates of increase of the 1980s. (Rekart & Roy, 1993). The term "HIV rates" refers to the number of people that test positive to the virus that causes AIDS. British Columbia (and Vancouver by implication) also has had and continues to have the highest per capita incidence rate of HIV in the country. Recent monitoring indicates that over ninety percent of the new diagnoses of HIV infection are between the ages of eighteen and twenty-five years old (Rekart & Roy, 1993; Brown, 1995). Women also have been increasingly diagnosed with HIV in the province.

These trends indicate a problem, namely that rational educational approaches to AIDS education are not followed. The educational guidelines are unable to suggest what kinds of messages should be used and fail to identify to whom they should be directed. Perhaps, the lack of guidance should remind us that what and whose messages have been heard and read are neither useful nor sufficient any more. Many studies have examined the AIDS epidemic, but they constitute an ahistorical account of the epidemic, lacking serious attention to the historical dimensions of the problem. In particular, the recent history of AIDS prevention education

is absent from the account of history of epidemiology (Fee & Fox, 1988; Mann, 1992a).

Conceived as a discourse analysis in a historical context, this study explores and analyzes one example of AIDS prevention education. Specifically, the study looks at AIDS prevention education programs in Vancouver between 1983 and 1994 to attempt to explain how educators have constructed, delivered, and implemented the programs. Vancouver is a useful research site because the first Canadian AIDS community group was formed here by a small group of doctors. AIDS Vancouver offered a number of crucial services in counselling and public education at a time when no one else was equipped to deal with AIDS. The organization's AIDS pedagogy was based on the premise that people should avoid engaging in behaviours that spread HIV. This message was conveyed through a variety of programs which included safe sex parties, the Man-to-Man program, condom and literature distributions, and a metropolitan hotline. In addition, the provincial government distributed a pamphlet to all British Columbian households in the fall of 1987, and established a toll-free AIDS information. The Ministry of Education developed an optional Family Life program that addressed AIDS for grades 7 through 11.

AIDS: The Other Plague?

Human Immunodeficiency Virus (HIV) was formerly known as human T-cell lymphotropic virus-III or HTLV-III, lymphadenopathy associated virus or LAV, AIDS associated

virus (ARV), immunodeficiency-associated virus or IDAV, severe combined immunodeficiency or SCID, and also, gay related immune deficiency virus or GRID. In March 1987, to eliminate the multiplicity of names in use, the American Center for Disease Control (CDC) in Atlanta, Georgia developed a definition to describe the epidemic of immunosuppression first seen in the US in the early 1980s among gay and bisexual men and intravenous drug users. The definition became AIDS (Acquired Immune Deficiency Syndrome).

Although it is believed that HIV is the necessary agent for the compromise of the immune system which results in AIDS, many manifestations are associated with AIDS (Gould, 1990; Fauci, 1991). Persons with AIDS (PWAs) have one or more severe opportunistic infections or malignancies such as pneumocystis carinii pneumonia (PCP) and Kaposi's Sarcoma (KS), and, although changing due to therapeutic advances, the vast majority of people with AIDS die within two years of diagnosis (Fauci, 1991; Brown, 1995).

As much as HIV is part of the complex problem of AIDS, so is its transmission. The spread of HIV infection and AIDS is the result of human behaviour enacted in social and private contexts; it is as much a socio-cultural phenomenon as it is biological (Sontag, 1988; Fee, 1992).

AIDS prevention education programs have relied on simplistic biodeterministic models of disease transmission and progression (Gould, 1990; Mann, 1992a, 1992b; Fee, 1992).

As well, many researchers, using survey methods, have found there is a ghostly yet deafening silence about AIDS in the discourses of young adults today (Humm & Kunreuther, 1992; Prieur, 1990). Young people who do have accurate information about AIDS, find it awkward and daunting as do many adults to bring up subjects such as AIDS and safer sex with their sexual or drug-using partners. Most have decided to take their chances rather than raise such uncomfortable and unromantic topics as past sexual experiences and personal potential for having contracted HIV (O'Malley, 1989; Kurdek & Siesky, 1990). The image of AIDS as a gay disease has also allowed young adults to feel erroneously invulnerable to HIV. Young men who engage in unprotected sex with other males do not see themselves at risk because they do not consciously or publicly identify as gay. Gay men's bodies have also been used as markers for death across the media which has contributed to denial among high risk groups and led to disassociation from the disease (Navarre, 1988; Wateny, 1987, 1988; Crimp, 1992).

Altman (1988) has stated that the "distinction between behaviour and identity, which often seems academic, is in fact vital to an understanding of AIDS" (p.301). Because the media and the public generally do not make these distinctions, gay and AIDS have become conflated, so that public perception of homosexuality becomes largely indistinguishable from its perceptions of AIDS. In addition, Crimp (1992) notes that:

the privacy of people portrayed is both brutally invaded and brutally maintained. Invaded, in the obvious sense that these people's difficult personal circumstances, most private thoughts, and emotions have been exploited for public spectacle. But at the same time, maintained. The portrayal of these people's personal circumstances never includes an articulation of the public dimension of the crisis, the social conditions that made AIDS a crisis and continue to perpetuate it as a crisis. (p.120)

People with AIDS are kept safely within the boundaries of their private tragedies.

The most powerful reason for this study is not just to provide a framework to examine how AIDS prevention education has been constructed, delivered, and implemented, but to determine the status of public discourses about AIDS prevention education in Vancouver. The study reveals that, despite governmental, public and private media and educational attempts to inform the public, the larger public still misunderstands AIDS, as a disease or an illness. This has not changed since AIDS emerged as a publicly recognized disease in the early 1980s by the CDC. In an unwitting consensus, officials from government, medical, the media, and volunteer organizations alike have contributed to the early public misunderstanding, resulting in the equation of specific marginal groups with AIDS; for example, gays, lesbians, and intravenous drug-users (Gould, 1990). See Appendix I. Despite the fact that marginal groups previously associated with the disease are no longer classified as the only groups at risk for getting and transmitting the

disease, they are nonetheless still stigmatized by the lingering and entrenched effects of the prior misunderstanding, namely the equation of these marginal groups with AIDS and death. In other words, for the most part, this equation has translated into AIDS = Gays, Lesbians, IV-drug users, as well as AIDS = Death.

Methodological Basis of the Study

A text or a discourse, in poststructuralist terms, is not an object or a thing, but an occasion for the interplay of multiple codes and perspectives (Foucault, 1977). One must seek to extract and examine the operations or means by which meaning is conveyed. Thus, a poststructuralist mode of discourse analysis aims to describe the surface linkage between power, knowledge, institutions, intellectuals, the control of populations, and the modern state as they regulate the objects/subjects of knowledge and thought. (Foucault, 1977).

Through this approach, I aim not to trace causal influences among AIDS prevention education programs in Vancouver between 1983-1994. Nor do I adhere to strict historical principles. However, the findings of the study may change existing interpretations of the history of AIDS. I show in this study how events led to the construction, delivery, and implementation of AIDS prevention education programs in Vancouver between 1983 and 1994.

Such historical records as AIDS Vancouver's policy documents and newsletters were utilized in this study.

These discourses represent important sites of public discourse around AIDS prevention education. The study also has data from personal journals of those that have been involved in the development of AIDS prevention education. These documents represent a discourse for the development, implementation, and evaluation of curriculum and instruction in the community around AIDS prevention education.

Overview

In the next chapter, I explore various discourses about the social construction of disease. I also discuss several studies about the history of disease and AIDS in cultural, social, economic, and political contexts. I conclude the chapter by outlining the development of AIDS policy in Canada.

In Chapter Three, I define "discourse" and outline various approaches to historical inquiry and discourse analysis. The approaches are based on poststructural critiques of research made by various social scientists. I offer a methodology based upon the foregoing approaches and concerns. As well, I discuss the data sources.

In Chapter Four, I outline the AIDS Vancouver's prevention education between 1983 and 1994. I explain the major assumptions underlying the construction, delivery, and implementation of the AIDS prevention education programs. I also contextualize the data vis a vis AIDS policy in British Columbia and AIDS awareness programs in the province.

In the fifth chapter, I discuss the findings of the study. The discussion is informed by the ideas presented earlier in this study. Finally in Chapter Six, I offer some conclusions based on the findings of this study. I also discuss its implications and the need for further research into AIDS prevention education. I conclude the chapter by making recommendations with regards to policy development and implementation.

CHAPTER TWO: REVIEW OF THE LITERATURE

In this chapter, I examine the social and biological constructs of disease. Several studies concerning the history of disease and AIDS in cultural, social, economic, and political contexts are reviewed. I conclude the chapter by outlining the development of AIDS policy in Canada. By doing so, I identify several implications for AIDS prevention education as well as provide context for the subsequent analysis.

Constructs of Disease

The aspects of disease that we call "social and biological" are parts of a single social reality in which disease is produced, experienced, and reproduced, and in which the cultural meanings of the experience are defined, acted upon, and struggled over (Sontag, 1988). Disputes over the meaning of AIDS have demonstrated that, in the late twentieth century, people still find it difficult to separate scientific knowledge of disease transmission from moral judgments about behaviour. This fits with the dominant ideology of the day, which tends to individualize most disease states as a consequence of personal behaviour (Fee, 1992).

Sexual behaviour is one of the most sharply contested political issues in the realm of values, morality, and what was once known as private life (Altman, 1988). Sexually transmitted diseases make private behaviour strikingly public and therefore a legitimate subject for official discourse (Fee, 1992). Different forms of discourse try to occupy the ground of public authority: theological

statements were dominant throughout most of the nineteenth century, while biomedical and scientific statements have strongly contested theological authority in the twentieth century (Fee, 1993). All such forms of discourse have included statements and assumptions about socially desirable sexual practices. For example, marriage implies monogamy.

The process of defining and redefining our understanding of disease usually involves a struggle between different groups who have a stake in the cultural construction of reality, and through it, the creation of public policy (Sontag, 1988; Patton, 1990; Fee, 1992). Given a plurality of possible ways to construct the discourse of a particular disease, many groups may be vying for the authority to define a specific reality. Implicit in the subsequent discussion is the notion of AIDS as plague.

The Changing Conceptions of Plague and AIDS as the Other Plague

An early construction of disease is the notion of plague. Sontag (1988) states, "plague is the principal metaphor by which the AIDS epidemic is understood" (p. 44). The word plague derives from the Latin "plaga" (stroke, wound, blow) and has been the predominant metaphor for collective calamity, evil, and pestilence. If a disease reached the proportion of an epidemic and if its name was infused with "plague," it became a general name for many frightening diseases that were not "plague," but plague-like. Analogous metaphors for plague as a synonym for

epidemic "can also be found in the literature of cholera, yellow fever, leprosy, and syphilis, and now AIDS" (p. 47).

The more "disgusting, disempowering, disgracing" (Sontag, 1988) the disease and the more connected to unacceptable and sinful behaviours of the victim, the more likely the disease perceived was to be a "plague." Plague holds both explicit and implicit notions about illness and well-being, good and evil.

History of Plagues

The concept of plague has not changed much since ancient and Biblical times (Lilienfeld & Lilienfeld, 1980, Rosenberg, 1988; Risse, 1988; Gould, 1990). Before the nineteenth century, epidemic diseases did not have individual identities, and record keeping was minimal at best. The words "epidemic" and "plague" were often used synonymously (Rosenberg, 1988; Gould, 1990). An "epidemic," a word derived from the Greeks to mean "among the people," is basically defined as an infectious disease which spreads rapidly and whose cause is not necessarily known. The term "epidemic" is more often a medical term, while "plague" is not (Lilienfeld & Lilienfeld, 1980). Plague, although medically defined as more than bubonic (*Yersinia pestis*), can be literally used to describe any calamity, as well as epidemic diseases. Likewise, it can be said to share sociological and religious significance. A plague, rather than an incidence of the plague, is an epidemic, but an epidemic is not necessarily a plague. As Sontag states: "it is usually epidemics that are thought of as plagues and

these mass incidences of illness are understood as inflicted, not just endured" (Sontag, 1988, p. 45).

Illness as punishment is the oldest idea of what causes illness. Although Hippocrates wrote that the "wrath of God" could not be held as the cause of plagues, illnesses have been interpreted by some people as punishments or retributions for having transgressed sacred beliefs (Lilienfeld & Lilienfeld, 1980). Just as individuals, responsible for their "bad" actions, suffer for their actions by being punished with injury, disability or death; so could masses of people suffer huge calamities. Thus, the idea of AIDS may be more meaningful to the degree that it indicates "shame" as well as blame.

History of AIDS

In general, historical studies show that AIDS has gone through three distinct phases. According to Jonathan Mann (1992), the history of AIDS is divisible into three discursive periods: silence, initial discovery, and mobilization. The period of silence started during the mid-1970s, when HIV first appeared and began to spread. As the events of HIV infection and transmission are silent, and the clinical manifestations of infections did not become apparent for months or years later, many individuals remained ignorant of the new epidemic. From the mid-1970s until 1981, when the disease AIDS was first recognized, HIV spread silently and unnoticed to five continents; at least 100,000 people became infected.

The recognition of AIDS in the United States in 1981 ended the period of ghostly silence and inaugurated the period of initial discovery, 1981-1985. During this time, the causative virus, HIV, was discovered, its modes of transmission were identified, and tests were developed to detect HIV infection. Studies using this information and technology produced three vital facts about the epidemic (Mann, 1992a). During the period, 1981 to 1985, many more people were HIV infected than had AIDS (i.e. AIDS is the tip of the iceberg of HIV infection). Second, the time between HIV infection and development of the disease is measured in months, usually in years and perhaps in decades. Third, studies during the mid-1980s showed that HIV infection was truly epidemic, affecting, although not uniformly, all regions of the world.

However, this period involved much more than biomedical discovery; substantial research was also directed at the individual and social dimensions of HIV-related risk and behaviour. In the social sciences HIV/AIDS-related questions and concerns focused attention on the limits of our knowledge about human behaviour. Around the world, those seeking to learn about HIV/AIDS-related behaviours by building upon knowledge of sexuality and self-injecting drug behaviour found that little reliable or useful information was available on these subjects (Mann, 1992a). In addition, the social dimensions of HIV/AIDS became a major challenge, as social scientists witnessed the emergence of discrimination, stigmatization, and other forms of HIV-

related prejudice, hysteria, and individual or collective forms of witch-hunting (Mann, 1992a).

The third phase in the history of AIDS started in the mid-1980s when many communities and nations developed local and national AIDS prevention programs. In general, the programs have the following key elements: information content, message and materials development, perceptions of HIV/AIDS, audiences, attitudes towards sexuality, institutional networks, linkage with health and social services, political and social leadership, assessment capacity, institutional base, strategic capability (Mann, 1992a). Problems are present in some of these elements.

AIDS Metaphors

Although AIDS may be plague-like, to say that AIDS is a plague is a statement of limited medical similarities. A plague is a disease with a very high and rapid incidence of mortality and/or morbidity after exposure. It can disseminate rapidly through a population and is most often contagious and spread by casual contact (Lilienfeld & Lilienfeld, 1980). During the Bubonic plague, people did not know that fleas on rats were spreading the infectious agent. The medical knowledge of AIDS, today, reveals none of these characteristics. However, it is an acute, infectious, progressive, chronic, and absolutely lethal virus. The plague metaphor of AIDS invites the idea that AIDS is contagious. Combining with the fear of death and the unknown and other metaphors such as "sin" and "enemy," AIDS may be understood, as Sontag suggests, as "premodern" (p. 46).

AIDS "revives the archaic idea of a tainted community that illness has judged" (p. 46).

The most significant impact of the AIDS/death/plague metaphor is its connection to fear, especially homophobia and its relationship to the disease. Jeffrey Weeks (1986), a philosopher, writes:

The mechanisms of a moral panic are well known: the definition of a threat in a particular event; the stereotyping of the main characters in the mass media as particular species of monsters (the prostitute as 'fallen woman,' the paedophile as 'child molester'); a spiralling escalation of the perceived threat, leading to the taking up of absolutist positions and the manning of the moral barricades; the emergence of an imaginary solution - in tougher laws, moral isolation, a symbolic court action; followed by the subsidence of the anxiety, with its victims left to endure the new proscriptions, social climate or legal penalties. In sexual matters, the effects of such a flurry can be devastating, especially when it touches, as it does in the case of homosexuality, on public fears. (p. 45)

These are some of the responses to AIDS as well as other diseases.

Other Responses to Plague

Guenter B. Risse (1988), a medical historian, used an ecological model, based on the notion of miasmas, to explore the dynamic relationship between the biosocial environment and the human experience of epidemic diseases. He examined the social context of epidemic diseases and the ways in which political and health organizations have historically responded to crises. Risse selected three case studies for analysis: the bubonic plague in Rome in 1656, the cholera

epidemic of 1832, and the 1916 poliomyelitis epidemic in New York City.

Risse's account shows how socially marginal groups, ethnic minorities, and the poor have often been held responsible for epidemic diseases: the Jews were blamed for the Black Death in Europe, the Irish were blamed for cholera in New York City, and Italians were accused of introducing polio into Brooklyn. He discusses the frequent infringement of civil liberties in the name of public welfare, from the hanging of violators of public health regulations in seventeenth-century Rome to the travel restrictions and quarantines of children introduced during the twentieth-century polio epidemic. Risse notes the draconian measures of isolation and quarantine generated considerable public panic and distress, while they generally failed to stem the progress of epidemic disease. From the fourteenth century to the present, despite enormous changes in the practice of medicine and social position of physicians, there has been remarkable continuity in how the profession has responded to the threat of contagion - isolate "the diseased."

Changing Meanings in Disease

Charles E. Rosenberg (1988), a historian, has provided a panoramic view of the historical changes in the definition of disease, from sickness conceived in largely individual terms as an imbalance between an organism and its environment, to the idea of each disease as a specific entity, with a specific cause to be discovered by laboratory research. He finds that the AIDS epidemic illustrates both a

continuing dependence on medicine and a reflection of culture in which it occurs. He argues that since there is powerful tradition by some people of seeing epidemics as the result of social collapse, decay and God's wrath, it may be difficult to extricate the concept of AIDS-meaning from historic plague metaphors. The extrication controversy is bound together by several themes. Rosenberg (1988) states that "One is the way that relationships between the medical profession and society are structured around interactions legitimated by the presumed existence of disease. Another theme is the negotiated aspect of the disease as a social phenomenon" (p. 12). According to Rosenberg (1988), "the perception of disease may have any one of many relationships to a possible biological substrate. In this context, AIDS arrived as a novel and frightening stranger, posing in stark form the questions about the cultural and biological meanings of disease" (p. 30).

Models of Disease Control

David Rayside and Evert Linguist (1992), two Canadian community activists, maintain it is possible to discern a fundamental struggle between two opposing groups in the unfolding of AIDS prevention education in Canada. One, drawing on elements of contain-and-control models, was based on a well-entrenched traditional approach of the medical establishment and most public health bureaucracies. For most the 1980s, "the actions of many public officials followed routines developed to deal with other diseases: focusing on protecting those not yet infected, treating the sick as

irresponsible and in need of policing, leaving drug testing initiatives to pharmaceutical companies, and retaining hypercautious methods for approving drugs" (p. 50). This perspective did not enlist the participation of community groups and politicians: the critical tasks were undertaken by medical doctors, researchers, and epidemiologists.

Clashing with this contain-and-control discourse has been a more inclusionary discourse. Community activists, reformist public health officials, and some doctors with large HIV/AIDS practices attached more significance to patients' rights. They called for comprehensive and frank education programs aimed at the entire population, generous funding of community groups to work with those most affected by the disease, extensive distribution of condoms and needles for intravenous users, recognition of the significance of discrimination associated with AIDS and HIV infection, greater funding for and coordination of medical facilities specifically for AIDS, a larger and more geographically dispersed network of doctors trained to deal with HIV and AIDS, more funds for research, and greater involvement in the policy process on the part of community groups and people with AIDS.

What gave this view special prominence in AIDS policy was that its proponents, working within community groups or in their own medical practices, had borne much of the burden of providing services to people living with AIDS and had generated safer-sex educational materials for the populations most seriously affected by the epidemic. (Rayside & Linguist, 1992, p. 51)

Governmental avoidance of AIDS in the first few years left public officials without the expertise to address the broad

range of educational and social issues posed by the disease, and established the community groups and their allies in critical program delivery and agenda setting roles. The development of community-based AIDS programs challenges the notion that a "plague" could only be contained by scientists.

Peoples' Lives in the Age of AIDS

Dennis Altman (1988), a political scientist and historian, has posed the paradox of AIDS in relation to the gay movement in the United States, Australia, and the United Kingdom. He provides a useful historical analysis of national differences in dealings with the AIDS epidemic. He notes tension between two kinds of approaches, one focusing on testing and screening efforts, the other on large-scale education and service programs. The emphasis in each country reflects differences in political cultures and ideologies in addition to the strength and degree of political organization of the gay community in each nation. Altman argues that in areas where gays have already carved out a place for themselves in the political process, gay organizations have made their strongest contributions to health policy. However, Altman's analysis is weakened by his failure to discuss the two conceptions about the educational strategies used to confront AIDS which emerged during early policy formation (Fineberg, 1992; Sepulveda, 1992). The first assumes that because of the ways AIDS is transmitted it will affect some groups rather than others, and therefore society as a whole will be best protected by taking measures

against those affected groups or individuals. The second considers AIDS/HIV to be an enemy of all people and thus deems it necessary to protect all of society's members against infection with HIV.

New Practices in Gay Communities

The decline of new HIV incidence among cohorts of gay men in the North America and Europe has often been cited as one of the most rapid and extensive changes in human behaviour ever observed (Mann, 1992b). Ample evidence indicates that prevention efforts slowed the spread of HIV in gay communities and that many men adopted safer sex practices to avoid HIV infection (Fauci, 1991; Mann, 1992a, Mann, 1992b).

To date, most data on the incidence of HIV among gay men involves well-established urban gay communities in North America, Western and Northern Europe, and to a lesser extent in Mexico and Brazil (Mann, 1992a, 1992b). Important cohort studies of gay men over the past ten years provide various historical views of the epidemic. In many urban gay communities, there has been a dramatic decline in HIV incidence (Fauci, 1991; Brown, 1995). Less information exists about new HIV sero-prevalence among bisexual men. However, a number of studies among STD clinic patients show lower HIV prevalence among bisexual than self-identified homosexual men (Mann, 1992a; Mann, 1992b).

Large-scale behaviour change was observed first in 1981 in San Francisco and New York City, and by 1984 it had reached Western Europe and Canada (Mann, 1992a, 1992b,

Rayside & Linguist, 1992, 1994). The different patterns of HIV incidence rise and decline suggest different levels of adopting and maintaining safer sex. For example, countries such as the Netherlands and France had an early decline in incidence and then a plateau, suggesting both a continued level of unprotected anal intercourse, and, probably, a relatively open sexual network (Fauci, 1991). In many cities, studies confirm that safer sex is far from universal, with a large variation among groups in the same country, across geographic boundaries and in different cultural settings (Mann, Tarantola, & Netter, 1992).

AIDS Prevention Education Programs

All AIDS prevention education programs develop messages which are carried through specific materials. The process of message/material development in programs involves extensive and repeated consultation with target audiences and includes field testing. However, message content has been ambiguous. For example, the warning against exchanging "bodily fluids" may have avoided offence, but it was interpreted incorrectly as including sweat, saliva, and tears, for which there is no evidence to suggest a possible role in HIV transmission (Siegel, Grodsky, & Herman, 1986; Fauci, 1991; Brown, 1995).

AIDS prevention education programs usually promote public awareness, but the programs also focus on targeted audiences such as intravenous drug-users or gays. (Mann, 1992a; Brown, 1995). In addition, more advanced programs try to access not only easy-to-reach target groups such as school children and health workers, but also the hard-to-

reach, such as prostitutes and their clients, self-injecting drug users, and out-of-school youth. Some communities fear stigmatization and discrimination, which inhibits targeted prevention (Brunet, 1991; Cohen, 1991; Rayside & Linquist, 1992, 1994).

AIDS prevention education programs utilized several channels. Major channel choices include mass media, "little media" (posters, brochures, flyers), and face-to-face approaches. While an advanced program will generally mix all three, it usually emphasizes approaches in which discussion and dialogue are possible (Mann, 1992a, Osburn, 1992). There is consensus that mass media channels create awareness and set the agenda, but interpersonal channels influence behaviour (Stoller & Rotherford, 1989; Edgar, Hammond, Lee, & Vicki, 1990; Hornik, 1991).

Programs vary widely regarding the explicitness of sexual content and the extent to which moral judgements accompany this information. An important issue is the attitude towards condoms and the extent to which they are promoted. More advanced programs adjust the level of explicitness in consultation with target audiences and avoid a prejudicial moral dimension. In such programs, the implicit and explicit attitude towards condoms is positive and, while targeted, the condom promotion effort also reaches the general public. Many studies show that attitudes towards condoms are strongly related to use (Barling & Moore, 1990; Ross, 1992). Condom use is also linked to the efficacy of condoms as a barrier to HIV infection (Robert &

Rosser, 1990; Strader & Baemen, 1991). Those who misunderstand the causal relationship between HIV infection and AIDS, and who have had experiences with condoms of poor quality, are more likely to believe that condoms are an ineffectual barrier to HIV infection.

While HIV/AIDS is first a health issue, its social, cultural, economic, legal, ethical, and political dimensions and impacts are now widely appreciated (Brown, 1995). National HIV/AIDS prevention education programs often form a link with and generate institutional networks including community-based and non-governmental organizations. Yet, many of these organizations are ill-equipped to do a job which requires official oversight and resources (Silverman, 1992).

There are two vital dimensions to the linkage between HIV/AIDS prevention education programs and community-based and non-governmental organizations. First, information about HIV/AIDS transmission is provided to clients along with information about condom availability, confidential AIDS test sites, access to needle-exchange programs. More advanced HIV/AIDS prevention education programs are carefully tailored to establish linkages with already available services and/or with services developed specifically in association with the health promotion program (Mann, 1992a). The second dimension of linkage involves integration of HIV/AIDS prevention education within existing health and social services. Advanced programs usually will establish close ties with such programs,

particularly in maternal and child health, family planning, and sexually transmitted disease control. The challenge is to find educational strategies which maintain optimum level of effectiveness among those programs that operate alongside and within existing networks (Sepulveda, Fineberg, & Mann, 1992).

While AIDS prevention education programs all require some level of social and political acceptance, the extent and manner of involvement of political and social leaders varies widely. More advanced programs have explicit and highly visible linkages with selected political and/or social leaders; however, leaders have left AIDS prevention programs for two reasons (Sepulveda, 1992). First, since AIDS became a health problem, emerging leaders have received intense political pressure and media attention, often to the irritation of supervisors and educators who are reluctant to share the limelight (Rayside & Linguist, 1992; Brown, 1995). Second, the lack of quick and tangible results from AIDS prevention education activities have caused frustration and fatigue among program workers and volunteers (Rayside & Linguist, 1992, 1994; Brown, 1995).

The institutional relationships between HIV/AIDS prevention education programs and national AIDS committees have involved issues of staff, budget, policy, and strategy formation. More advanced programs have adequate staff of sufficient grade and professionalism, a budget, and close linkage with overall national AIDS program and policy process. In addition, advanced programs are decentralized

from headquarters and capital cities to district and community levels. Decentralization has involved the delegation of both responsibility and authority (including financial resources) to local sites of influence. AIDS is a very costly disease and financing the care of people with AIDS and prevention programs remains one of the biggest challenges facing AIDS educators and others (Mann, 1992; Sepulveda, 1992).

Typology of AIDS Prevention Education Programs

In general, AIDS prevention education programs can be divided into three groups (Perrow & Guillen, 1990; Robert & Rosser, 1990; Mann, 1992a, 1992b; Osburn, 1992). Information type programs are focused on information. Empowering types are moderately more complex and include efforts to enhance self-empowerment as well as provide information. Finally, community advocacy type programs not only deliver information and address self-empowerment, they also strengthen community advocacy.

Broadly considered, these three program types correspond to different levels in conceptualizing health promotion itself. The one limited viewpoint (information type) defines its task as provision of information. Such programs often disseminate this information from a single source, using mass media channels and time-limited campaigns in an effort to reach many people (Osburn, 1992). The information provided is often imbued with consensus attitudes regarding risk behaviours. As HIV/AIDS is considered a health problem, information emanates from

health institution sources. Little attention may be given to health and social service linkages (Perrow & Guillen, 1990; Robert & Rosser, 1990). Information type programs have been observed during the first year or so of national AIDS program activity, with subsequent evolution to the second and third types (Mann, 1992a; Osburn, 1992). However, information type programs may persist beyond the initial period if a national AIDS program operates in an ambivalent and frankly hostile social and political environment (Mann, 1992; Rayside & Linguist, 1992; Fee, 1992).

The second stage in thinking about health promotion reflects awareness of the need to examine closely the motivating factors and constraints operating on the individuals whose past, present, and future behaviours are at issue. The individual locus of control perspective leads to concern that information be well-targeted (Osburn, 1992). Information is therefore designed with input from target audiences and includes explicit attention to health and social services needed to support, immediately and over time, specific behaviours and behaviour change. In empowering type programs, HIV/AIDS is generally described as a global problem which concerns everyone; awareness of the social dimension is reinforced by clear messages about non-discrimination.

Empowering type programs use a broader mix of media, with increasing emphasis on person to person approaches (Mann, 1992a, 1992b). The attitude toward sexuality is neutral or positive and can be quite explicit depending upon

the target audience; the approach to condom promotion is also targeted. Recognizing that people are influenced and reached by many channels and institutions, the program seeks integration in the national health system and forms alliances with other sectors of government and with other agencies and groups. Realizing that people are best reached in and through their communities, a national HIV/AIDS health promotion program seeks decentralization (Mann, 1992a). Overall, the empowering type program is integrated within, and supported by, a national AIDS program, the health sector, and the broader community (Mann, 1992a; Rayside & Linquist, 1992; Osburn, 1992). In sum, the emphasis of the empowering type program is on motivation and support for informed individual behaviour change.

The third stage of health promotion recognizes the broad policy and social dimensions of health promotion. Information provided by community advocacy type programs, developed with target audiences, emphasizes solidarity and the need to protect the rights and dignity of HIV-infected persons. The community advocacy type program is decentralized, so that information is provided from within many different institutions and organizations (Mann, 1992a; Rayside & Linquist, 1992).

The community advocacy type program distinguishes itself, particularly in the areas of linkage with health and social services and its relationship with social and political leadership and its strategic capability. Community advocacy type programs include elements of Types I and II,

but go beyond these to consider the cultural, economic, and political impediments to promotion of health. For community advocacy type programs, information about HIV/AIDS is only useful when it takes both individual and social realities into account. Therefore, such issues as women's capability in a given social system to refuse intercourse without a condom, or the availability of truly confidential diagnostic or support services, or the realities of condom distribution, availability and cost, are seen as central concerns (Mann, 1992a, 1992b; Rayside & Linquist, 1992).

AIDS Policy in Canada

AIDS policy in Canada has moved through three distinct stages (Rayside & Lindquist, 1992, 1994). These stages do not follow Mann's history of AIDS. The first began in the early 1980s, as many politicians and officials ignored the epidemic or responded very cautiously. The second stage began in mid-1985, as media greatly intensified public interest and concern in Canada and when the development of HIV blood tests raised new issues for debate. In this period, the Canadian governments began to make significant, but usually ad hoc, commitments to AIDS programs. As the number of AIDS cases increased, community groups grew in size and proliferated, with new militant voices broadening the range and intensity of criticism directed at governmental inactivity. The third period began in the spring of 1988. Protests by various community groups and activists at the National AIDS Conference put pressure on

all levels of government to develop coherent AIDS strategies.

In the confrontation between government policymakers and AIDS activists, the impact of two factors must be kept in mind (Rayside & Lindquist, 1992, 1994; Brown, 1995). The first is the presence of public health insurance throughout Canada. There is uneven access to medical personnel with an interest and expertise in AIDS, particularly outside major cities. There are also serious financial burdens on people with HIV and AIDS who wish to use drugs that are not "approved" by provincial authorities, but few of these problems are as severe as in the more privatized American health care system.

The second important factor to keep in mind is the effect of U. S. developments on Canadian public policy and community activism (Rayside & Linquist, 1992, 1994). Unlimited access to the American media meant that Canadians were made aware of the disease at about the same time as Americans, before substantial numbers of Canadians became sick. Such lead time may well have encouraged a calmer public reaction; there were fewer cases of panic about casual contact in Canada than there were in the United States, and more readiness on the part of most media outlets to avoid sensationalization. The view that AIDS was justifiable retribution for an immoral lifestyle has never had as strong a public voice as in the United States, Britain, or Australia (Rayside & Linquist, 1992, 1994; Brown, 1995).

Although all Canadians are covered by publicly-funded medical insurance, health care is primarily a provincial responsibility. The provinces organize the delivery of services, chartering and negotiating with various professional bodies to determine fee schedules, funding hospitals for capital and operating expenditures as well as to establish regional and local public health networks. The federal government plays an important role through its spending power. Legislation has also increased, especially with regards to the Canada Health Act. On several occasions in the past, the federal government agreed to match provincial contribution to hospital and medical insurance as long as their health delivery systems met a set of minimum criteria (Rayside & Linquist, 1992). The influence of federal spending is also evident in the fact that most medical research grants in Canada come from federally-funded agencies. In a more general way, the federal government has influenced the provinces by coordinating the flow of information and organizing federal-provincial meetings of politicians and officials in the health field (Rayside & Linquist, 1992, 1994; Brown, 1995).

Summary

This chapter began with a discussion about the plurality of the social constructions of disease and representations of AIDS as the "other" plague. It is difficult to separate the scientific, moral, political, and social dimensions from disease constructions. The concept of plague as understood by society has changed since

antiquity and holds both explicit and implicit notions about illness and well-being. Combining with the fear of death and the unknown, the concept of plague provides the basis for society's insistence that socially marginalized groups are responsible for epidemics and affects how the medical profession has responded to the threat of contagion, through the ideology of "isolate the diseased" (Rosenberg, 1988; Risse, 1988). Despite changes in the medical definition of disease during the last century, society's prevailing fear of AIDS as a plague and attendant social stigmas has not been eliminated. Thus AIDS revives the idea of a tainted community and contributes to homophobia. It is no surprise, then, that the first approach to AIDS prevention education was based on "contain-and-control" models of disease protection. Fortunately, community activists, reformist public health officials, and some doctors attached more significance to patients' rights and ended the call for isolation of PWAs.

AIDS prevention education has been hampered because of two antagonistic conceptions about AIDS transmission. The first assumes that educators must target their strategies towards particular groups that have high incident rates of HIV infection. The second considers it necessary to protect all of society's members against HIV infection. Evidence suggests that HIV rates are declining in the gay communities of North America and Europe. To date, this decline has been often cited as one of the most rapid and extensive changes in human behaviour ever observed. However, studies confirm

that safer sex is far from universal. This has been a problem in the history of AIDS since the period of initial discovery (1981-1985). Social scientists noted that there was little reliable or useful information on knowledge of sexuality and self-injecting drug behaviour. Other problems in institutional networks, political and social leadership, linkage with health and social services, and funding have limited the effectiveness of AIDS prevention education strategies. Three types of strategies exist and correspond to different levels in conceptualizing health promotion itself.

AIDS policy in Canada has moved through three phases. It was not until 1988 that pressure on all levels of government led to the proposal for the development of a coherent AIDS strategy. In addition the history of AIDS policy in Canada has often been different from other existing histories of AIDS.

CHAPTER THREE: A RATIONALE FOR DISCOURSE ANALYSIS

In this chapter, I define what discourse is and then I outline various approaches to historical inquiry and discourse analysis. The approaches are based upon poststructuralist critiques of qualitative research made by various social scientists. Since so much of AIDS and AIDS education involves perceptual and linguistic metaphors and constructs, I chose a combination of methods to analyze the functions of discourse about and on AIDS in policy documents. My approach is informed by poststructural notions of discourse and the formation of subjectivity.

Definition of Discourse

First, what is discourse? Discourse is the ways in which a language as a material practice constructs and represents social subjects. Discourse also means the silences in texts, in language, and the unspoken conventions of signification. Discourse, sometimes spoken of as text, is one of the most powerful ways in modern and postmodern societies for the forming and shaping of humans as subjects.

Discourses and their related disciplines and institutions are functions of power: they distribute the functions of power. They are power's relays throughout the modern social system. Foucault (1983) maintains that:

in effect, what defines a relationship of power is that it is a mode of action which does not act directly and immediately upon an action, on existing actions or on those which may arise in the present or the future. A power relationship can only be articulated on the basis of two

elements which are each indispensable if it is really to be a power relationship. (p. 220)

Power must not be thought of merely as negative, as repression, domination, or inhibition. On the contrary, it must always be seen as "a making possible," as an opening up of fields in which certain kinds of action and production are brought about. As power disperses itself, it opens up specific fields of possibility; it constitutes entire domains of action, knowledge, and social being by shaping the institutions and disciplines in which, for the most part, we largely make ourselves (Foucault, 1983). In these domains, human beings become the individuals, the subjects, that the domains make us. This phrasing, of course, makes things sound more deterministic than they are in fact, for there is no subject to be determined in advance, the subject comes to be whatever or whoever he or she is only within this set of discursive and nondiscursive fields (Hall, 1992). What Foucault means when he says that power acts upon actions is precisely that it regulates the formation of our subjectivities. "Individuation," then is, argues Foucault, the space in which we are most regulated by the ruling disciplines of language, sexuality, economics, culture, and psychology.

The study of discourse, then, leads inevitably to understanding how material "realities" act upon the actions of others, that is, of all of us, no matter where and how differently placed we are in the grid of identity and privilege these realities constitute. Foucault (1983) argues

that power is deeply rooted in social relations, but that this fact should not be taken fatalistically:

For to say that there cannot be a society without power relations is not to say either that those which are established are necessary, or, in any case, that power constitutes a fatality at the heart of societies, such that it can not be undermined. Instead I would say that the analysis, elaboration, and bringing into question of power relations and the antagonism between power relations and intransitivity of freedom are permanent political tasks inherent in all social relations. (p. 223)

Discursive analysis aims to show how events and their simultaneity within ostensibly different fields can transform entire domains of knowledge production. For example, the last decade has witnessed the production and proliferation of a number of competing AIDS discourses. According to Dickinson (1995):

many of [the AIDS discourses] are characteristically apocalyptic in tone, from the dire predictions of biomedicine to the sensational headlines in the media; from the calls for mandatory testing and quarantine of the part of Jesse Helms and other right-wing politicians to the holocaust imagery and graphics employed by Larry Kramer and like-minded gay activists; from the meta-critical interventions of intellectuals like Susan Sontag to the arresting visions created by artists like Tony Kushner. (p. 227)

In addition to these "official" discourses that the AIDS crisis has produced, the AIDS crisis has also produced a number of "unofficial" counter-discourses. By using discourse analysis, I identify how documents or discourses have mobilized certain notions and meanings of AIDS and AIDS prevention education. I also examine how certain notions of AIDS have been suppressed over time.

Historical Methods

A history seeks to reproduce and interpret concrete events as they actually occurred in time. There is no single standard by which we can identify true historical knowledge (Shafer, 1974; Scott, 1989). Rather, there are contests, more or less conflictual, more or less explicit, about the substance, uses, and meanings of the knowledge that we call history. My aim in this study is to show conflicts in the meanings as evidenced in the documents. This process is about the establishment and challenge and protection and contestation of hegemonic definitions of history (Scott, 1989).

Historians create nuanced descriptions for several purposes. Some seek to create the past as contemporaries would have experienced it. Others try to discern patterns in events over time, and thus interpret primary sources in ways that would have astonished contemporaries. Many historians want both to discover historical patterns and accurately reflect the lived experience of the past (Shafer, 1974). In addition, historians are usually conscious of the culturally specific, and hence are wary of positing universal principles. Historians often disagree about major issues of theory and practice; however, historians share a number of historiographic principles (Shafer, 1974; Scott, 1989). The three most important of these principles in the context of disease are cautious adherence to social constructionism,

profound skepticism about historicism, and wariness about presentism (Fee & Fox, 1988).

Social constructionists hold that historical reality is created by people; that is, it does not exist as a truth waiting to be discovered. Some social constructionists include the data of the biological and physical sciences in their analysis, arguing that the institutions and procedures of these disciplines are the result of complex social interactions. Historians, though sympathetic to social constructionist interpretations of the history of disease and medical practice, reject the radical relativism that denies that knowledge in the biological sciences can be independent of its social context (Fee & Fox, 1988). Still others remain uncertain about the proper scope of the theory of social construction. Consequently, this study considers that the concept of AIDS is implicated in the social construction of the phenomena it appears to describe, assembling a miscellaneous collection of instances, apparently lacking coherence other than it supplies (Christian-Smith, 1990; Smith, 1990).

The second principle, skepticism of historicism, is less controversial. Few historians now insist, as most of our predecessors did until a few decades ago, that societies or nations evolve or unfold toward goals that may be discerned with historical research: from, for example, authoritarianism toward democracy, from inequality to counter-hegemony, and from primitive to mature, even from

capitalism to a classless society. Although most scholars argue that in some areas, medical knowledge, for instance, beneficial advance has occurred in recent centuries, hardly anyone still insists that the human condition in general has been progressing as a result of inexorable historical change (Fee & Fox, 1988; Rosenberg, 1988). This study assumes that historical meanings are always embedded in our conceptions of disease; that is, the history of epidemiology must be concerned with the relationship between scientific and cultural assumptions. Historians must explore the social contexts in which "diseases" such as AIDS are produced, reproduced, defined, analyzed, and acted upon.

The third principle, wariness about presentism, is probably the most widely shared among those who use historical methods. Presentism means distorting the past by seeing it only from the point of view of our own time, rather than using primary sources to understand how other people organized and interpreted their lives. The AIDS epidemic can tempt historians to venture facile analogies with events in the past even though we know better (Gould, 1990; Fee, 1992). This study notes that the AIDS epidemic may mark the first time a population suffering from a disease has played such a large role both in the making public policy through lobbying and political activities, and through the provision of direct patient care, supportive services, and health education. Nevertheless the researcher's role is to struggle with the problems of

presentism. Thus, in the representation of AIDS as epidemic, who is speaking and who is listening? Or perhaps more importantly, to whom are we speaking and to whom are we listening?

Narrative Analysis

Many contemporary historians see the interpretative issues implicit in data collection to the construction of a historical narrative (Tuchman, 1994). However, narratives are usually loosely formulated, are almost intuitive, and use terms defined by the analyst. Narrative analysis typically takes the perspective of the teller, rather than that of the society. If one defines narrative as a story with a beginning, middle, and end that reveals someone's experiences, narratives take many forms, are told in many settings, before many audiences, and have various degrees of connection to actual events or persons (Manning & Cullum-Swan, 1994). Thus themes, principal metaphors, definitions of narrative, defining structures of stories, and conclusions are often defined poetically and artistically, and are quite context bound (Atkinson, 1990). Hence, representation becomes a concern for the historian and other social scientists. Therefore, it is necessary to caution readers that AIDS is being redefined as a disease of black, Latino, and minority communities, women, and children (Morales & Bok, 1992; Dickinson, 1995). Now that the rate of new infection is declining among the gay community, the specific association of AIDS/homosexuality is fading, and

new associations are being made. The historical process of the definition and redefinition of disease thus continues as ideologically contested and shifting terrain, requiring a method of analysis that allows for a discursive reading to be combined with a historical one.

Poststructuralism

Structuralism has been called dehumanizing in its drift and implications (Smith, 1990; Roman, 1995). As a humanist, I object to structuralism because it evicts human agency from human history; that is, people become the passive bearers of linguistic codes and deterministic approaches to ideology. People are little more than vectors of structural determinations. Structures exist as the organizing centers of social action; persons are in every sense not only the creations of such structures, but manifestations of elements and rules created by social structures (Manning & Cullum-Swan, 1994).

Poststructuralism contains modifications of structuralist themes. One must accept the difficulty of reading intentions from speech acts or texts and eschew final answers through poststructural analysis. Poststructuralists urge careful reconsideration of written texts and theory formulation, constitution, and conventional interpretation. To some extent, because the conventional canons of interpretation reflect dominant values (and writers), they obscure the virtues of writers, ideas, perspectives, and values deemed marginal or oppositional

(Manning & Cullum-Swan, 1994). In this sense, poststructuralism turns attention to the margins and reverses the usual adherence to dominant cultural values.

Texts, in poststructuralist terms, are not objects or things. The poststructuralist mode of discourse analysis implies that the social, cultural, economic, and political contexts determine to a large degree the interpretations of AIDS which are selected as socially relevant, that will represent the future social reality of the disease.

Data and Data Analysis

The following texts are utilized in this analysis: personal journals, newsletters, policy documents, minutes from board meetings, and annual reports. Access to the personal journals was secured by a number of informal meetings that took place during the fall of 1994. An educator who was a volunteer at AIDS Vancouver introduced me to writers of the personal journals. After numerous meetings, I was given permission to utilize the journals in my study because they felt my analysis would be critical for any further development of AIDS prevention education and policy in Vancouver. Both of the writers have been and are active in the development of AIDS prevention education and have been given pseudonyms in this study. Their journals are not only rich in description, but also in reflections. One of the writers is still active in Vancouver AIDS community. The other writer is now working nationally and internationally on various AIDS projects. My analysis has

been made available to them for possible misunderstandings and feedback. We had several meetings over the last year and no misunderstandings occurred.

AIDS Vancouver has kept records since its inception in the spring of 1983. I utilized several newsletters including AIDS Vancouver: The Volunteer Voice Newsletter, B. C. Persons With AIDS Newsletter, and Contact. Policy reviews were done sporadically over the last decade and board meetings were held monthly since 1983. These discourses were utilized in the study and are made available to the public by the library and archives of AIDS Vancouver. I also consulted the Annual Report of the Medical Health Officer of the City of Vancouver, 1983-1991. The city stopped publishing the "annual report" after 1991. I also consulted the Annual Report of the Ministry of Health of the Province of British Columbia for the years 1983 to 1994. The documents are distinctive contemporary forms of social organization which intersect with the largely hierarchical structures of state, business, and other administered formal organizations (Smith, 1990). They include scientific discourse as well as the public textual discourses of AIDS. I elucidate the social relations around the discourse of AIDS by comparing the "unofficial" documents to the "official" documents. By doing so, I reveal conflicts, similarities, and phases in the texts.

The investigation of textual practices makes visible many phases of the organizational and discursive processes that are otherwise inaccessible. In particular, the formal,

design, planned, and organized character of any organization depends heavily on practices, which coordinate, order, provide continuity, monitor, and organize relations between different segments and phases of organizational course of action (Smith, 1990).

Discourse analysis provides a standpoint from which the researcher's own conduct or the conduct of others can be examined (Scott, 1989; Smith, 1990). It is not only an internal reflection, but a shared practice of reflection on other discursive standpoints. Gays and heterosexuals and various groups may not share the same discourse or common standpoints. Only by comparing discourses of specific groups is it possible to discover what they share and what they do not. According to Dorothy Smith, a feminist sociologist, discourses are social relations which

are more than simply an expansion of communication beyond the local. They reorganize relationships among local everyday worlds within them and by relating them to others through common participation in the textually mediated discourse. People scattered and unknown to one another are coordinated in an orientation to the same texts. Public textual discourse creates new forms of social relations. (Smith, 1990, p. 168)

The foregoing discussion implies an approach to documents or texts which says that they are situated in social relations. It thereby avoids treating as given the very practices of detachment characteristic of the textual mode. It insists also on the materiality of the text as constitutive of the social courses of action in which the text becomes active. Hermeneutic practices - concepts,

categories, codes, methods of interpretation, schemata, and the like - must be understood as active constituents of social relations and social courses of actions rather than merely as constituents or indices of AIDS. Interpretative practices which activate the text are viewed as properties of social relations. Recognizing the documents or text as constitutive of social relations also means being interested in the social organization of the text production as a prior phase in the social relation rather than simply the work of a particular author (Christian-Smith, 1990; Smith, 1990; Roman, 1995). Thus, I contextualized the documents as to their location in a social relation.

It is necessary to emphasize the non-linearity and temporality of the concept of social relation. I analyze the contexts of the texts or acts not as limited by a time bound frame such as a setting or an occasion, but as constituents of a sequential social course of action through which various subjectivities are related. A given locally historic instance is explored as a constituent of a larger social process. It is an analysis which seeks to disclose the non-local determinations of locally historic or lived orderliness (Smith, 1990). Such possibilities as multiple simultaneous occurrences of a text, or its repeated uses on a number of occasions on which text is treated as the same, are to be seen as organizing extra-local relations among the different settings. The replicable or recurrent character, the patterning of the social relations of the ruling, depend

upon this movement between the textual and the locally historic.

The other central focus of the investigation into textual relations and forms of actions must be the reader-text relation. The text does not appear from nowhere (Foucault, 1977, 1983; Bove, 1994). The text should be understood as having been produced to intend interpretative practices and usages of the succeeding phases of the relation. The text-reader moment is contained as a potentiality in the text itself (Bove, 1994; Roman, 1995).

The predominant sources for this study are those sources which have been developed as the literature on AIDS prevention education in Vancouver. Although much of the literature on AIDS has been included, three areas (originally researched) have been omitted - the literature of AIDS in Africa, AIDS and women, and the impact of the gay press and popular society. This act of omission does not demean the significance of these issues in understanding AIDS; they are part of the phenomenon of AIDS and AIDS prevention education. Rather, these texts do not directly reveal how AIDS prevention education programs have been constructed, delivered, and implemented with gay men by gay men. Obviously, the omissions may deal with AIDS prevention education, but they deserve fuller treatment than my study alone can give.

The analytical ability to investigate the text depends upon the competence of the practitioner of those relations.

Thus the analyst does not have to pretend to withdraw as a member of society in performing analytic work (Smith, 1990; Roman, 1996). On the contrary, such analysis depends precisely upon such membership; if the analyst does not already command the interpretive method of the relational process being investigated, it has to be learned (Smith, 1990; Roman, 1995). As a person who has been a "buddy" to numerous PWAs, I am aware of the issues surrounding representation of identity and difference, safer sex, and persons with AIDS and HIV. This could raise ethical concerns for some. My location as an Eurocanadian male historian and researcher will hopefully address subjectivity concerns because I am aware that discourse itself is an event that involves not only the text, but its position within a given social space, including the speaker, location, and hearers of discourse. My analysis is mediated by the following questions. What is being said? To whom and for whom is it being said? How is it being said? These will determine how the text is constructed and read. Furthermore, my interpretation is compared to other analyzes for validity and reliability.

Insisting on the materiality of the text and on the actual socially organized activities, including writing and reading, articulating texts with social relations, as fundamental to a materialist investigation of knowledge and culture (Smith, 1990; Roman, 1996). The study of AIDS prevention education or textually mediated social relations,

undertaken here, is not a distinct field. Nor does it develop its own theories and methods of research. Rather, this study explores the actual ways in which social relations about AIDS prevention education are organized and how they operate.

Summary

The purpose of this chapter was to develop a methodology for the subsequent analysis of AIDS prevention education programs in Vancouver between 1983 and 1994. Discourse or text is a powerful way in today's society to form and shape us as subjects. Discourses and their related disciplines are also functions of power which must not be seen as negative, repressive, or dominating, though they can be. Rather, power influences various domains and institutions which, in turn, make us into the individuals we are today. Bringing into question power relations is a central feature of discourse analysis which aims to show how adjacency of events in various fields can transform entire domains of knowledge production. A history seeks to reproduce and interpret concrete events as they actually occurred in time. Historians create description of the past to establish and challenge as well as protect and contest hegemonic definitions of history.

Historians adhere to three basic principles. The first principle holds that social constructionists' interpretations of the history of disease and medical practice deny that

knowledge in the biological sciences can be independent of its social context. Second, historians are skeptical of historicism. The third principle is wariness about presentism which distorts the past from our own contemporary viewpoint.

Historians are faced with several methodological problems. Often histories tend to be narratives that are loosely formulated and intuitive. The themes, definitions of narrative, and the defining structures of the stories and conclusions are defined poetically and are quite context bound. Representation is also as problematic as narrative. The analysis often takes the perspective of the teller.

Poststructuralism holds that structuralist interpretations are deterministic, foreclosing the multiple possibilities for meaning that differently located historical subjects may make. Thus, poststructural modes of discourse analysis aims to both describe and explain not only the institutions, but the power linkages among people and those institutions. The texts utilized in this study must be understood as active constituents of social relations and social courses of actions rather as indices of AIDS. By insisting on the materiality of the texts, the study reveals how the actual ways in which social relations about AIDS prevention education are organized and how they operate. By doing so, the study also reveals how AIDS prevention education is constructed, delivered, and implemented.

CHAPTER FOUR: A HISTORY OF AIDS PREVENTION EDUCATION IN
VANCOUVER, 1983-1994

In this chapter, AIDS Vancouver's prevention education programs between 1983 and 1994 are discussed. Materials used in this chapter include personal journals, AIDS Vancouver's newsletters, minutes from meetings, annual reports, and policy documents. I contextualized AIDS prevention education in Vancouver vis a vis AIDS policy in British Columbia and AIDS awareness programs in the province. Adhering to concepts in the previous chapter, I reveal that gay men have, for the most part, constructed, delivered, and implemented the AIDS prevention education programs in Vancouver between 1983 and 1994. Furthermore, the history of AIDS in Vancouver does not coincide with existing histories of AIDS as suggested elsewhere by Mann (1992a) and Rayside and Linguist (1992).

The years from 1983 to 1986 were a time when AIDS was seen as a new and potentially epidemic disease, when AIDS prevention education was an open policy area. This period saw the outbreak of the disease in the gay community, the development of public alarm and social stigmatization, and the lack of scientific certainty about the disease. On the policy side, there was relatively little official action by various levels of government, but behind the scenes considerable openness to new policy actors and the establishment of new policy community around AIDS. This was a period of development from below. It was succeeded in 1987 by a stage of emergency in which provincial and civic servants and politicians intervened. A high-level political

response emerged. From 1992 on, these two phases have been followed by a third, the current period of slow normalization of the disease, in which the rate of growth of the epidemic has slowed and public interest and panic markedly decreased. Official institutions have been established and formal procedures adopted and reviewed; paid professionals have replaced the earlier volunteers. The high level political response has gone; the problem now is to maintain the salience of AIDS on the policy agenda.

The First Era: New Beginnings, 1983-1987

British Columbia was governed by the conservative Social Credit party from the mid-1980s to 1992. The government was led by men who were determined to distance themselves as much as possible from initiatives that could be construed as supporting a gay life-style or sex education (Rayside & Linqvist, 1992). Before public officials and health departments realized there was a "problem," a group of gay men in Vancouver recognized that friends and lovers were dying and if something was going to be done to change the situation, it would have to be led by "gay activists." Mass media in Vancouver had reported that gay men in San Francisco, Los Angeles, and New York were dying from a strange illness (Rayside & Linqvist, 1992). Many people in Vancouver's gay community were beginning to panic because the new disease was perceived and talked about as a plague. In the spring of 1983, some gay men with the support of some medical practitioners created the country's first

community-based AIDS service and education organization, AIDS Vancouver¹.

The agency's education department was started in the same year. A couple of people were responsible for organizing and training the volunteers needed to staff a hot line which provided gay men with information about the new medical crisis. At the time, AIDS Vancouver's hot line was the only local source of up-to date information about AIDS. Most of the information found in the hotline volunteers' manual, All Sexually Active Men Should Know These Facts! which was adapted from the New York Native, concerned symptoms associated with the disease such as swollen glands, pink to purple flat or raised blotches or bumps, weight loss, fever, night sweats, cough, and diarrhea (AIDS Vancouver, 1983). The hotline operated out of the Gay and Lesbian Centre on Bute Street in the heart of the West End, a neighbourhood with a higher concentration of gays and lesbians than other locales in the Lower Mainland. The location also enabled the volunteers to conduct information sessions with people who were dropping in to the Centre.

It is important to emphasize that at the time of the establishment of the hotline, these men were working with little "scientific" information about the disease. In fact, they did not know precisely how the virus was transmitted, nor did they have a clear sense of how to define which sexual activities were safer and which were not. Personal

1. In addition to AIDS prevention education, AIDS Vancouver is involved in advocacy issues. The organization offers support services for PWAs and solicits funding for research and operational expenses.

journals reveal that there was speculation about the disease within the gay community (PT, 1983; JM, 1983). "Peter," a gay man and an AIDS educator in Vancouver, stated in his journal:

I am concerned that some people in the gay community are unnecessarily stereotyping leathermen. Even though it is true that the leather community is disproportionately falling ill, there is no evidence suggesting that leather activities are contributing to AIDS. (PT, 1983)

John, also a gay educator in AIDS Vancouver wrote in his journal:

I am frustrated today, just so many "theories" about why and who gets this disease. Especially comments about so and so's tricking habits. The bottom line no one person knows. If I hear another judgmental statement about a person's sexual behaviour, I think I am going to scream. (JM, 1983)

Some men believed that complete sexual abstinence was the only way to avoid infection; others debated relative risk of various sexual behaviours. Many people in the gay community were making educated guesses on the basis of little data about the course of the epidemic. This suggests that plague-making and denial were simultaneously occurring within the community. The first newsletter, titled, AIDS Vancouver: Fighting Fear and Confusion, reveals that the educators at AIDS Vancouver were profoundly concerned that the lack of knowledge about the disease would further endanger an already panicked community:

Therefore: until we know better, it makes sense that the fewer different people you come in sexual contact with the less chance this possibly contagious bug has to travel around. Have as much sex as you want, but with fewer people and with healthy people, If don't know whether your partner is healthy - ask him directly to be honest

with you about his health. (AIDS Vancouver, Spring, 1983)

This statement is problematic because of intimacy issues surrounding sexual behaviour and the notion of contagion embedded in the word "bug." The media was reinforcing the notion of gay plague (Rayside & Linguist, 1992). The personal journals also attest to this concern. Equally problematic were the developments in the United States, namely the call for quarantine legislation and the refusal by some physicians to treat dying gay men. These developments were given attention here in British Columbia. Given the concerns facing Vancouver's gay community, AIDS Vancouver in its first newsletter announced it would be holding its first public forum in March of 1983 which was sponsored by the Zodiacs, a gay leather fraternity (AIDS Vancouver, 1983).

In the fall of 1983, AIDS Vancouver published its second newsletter, titled Who We Are and What This Is. This newsletter was distributed in various gay bars and other businesses. A major challenge facing the organization is revealed in the following newsletter excerpt:

As a group of volunteers in a non-profit society, we in AIDS Vancouver are not practising medicine or politics. We are not victims of any conspiracy, and the medical establishment and media are hardly ignoring us. Everything that can be done is, on the whole, being done. It is up to us however, to inform ourselves and to defend our sexual freedoms. What you choose to do about this problem is your decision. We can help each other, especially those of us who may be ill or may become ill. (AIDS Vancouver, Fall, 1983)

There is no mention of AIDS in the annual reports of the Ministry of Health for the province of British Columbia and

the city of Vancouver during 1983. This reveals that AIDS was not yet perceived by the governments as a health issue facing the general population. However, the public was informed of AIDS by the media.

During 1984, AIDS Vancouver published a newsletter titled When a Friend Has AIDS which was funded by the City of Vancouver and the Health Promotion Directorate, Western Region, Health and Welfare Canada. The newsletter was based on materials available from the Gay Men's Health Crisis which was and still is New York City's AIDS organization. Some of the statements in the newsletter address the alienation which PWAs were experiencing: "touch him, A simple squeeze of the hand or a hug can let him know that you still care. You can not contract AIDS by simply touching" and "Don't allow him to become isolated" (AIDS Vancouver, 1984). More importantly, it is stated in the document that "AIDS is everyone's challenge" (AIDS Vancouver, 1984).

In 1984, AIDS Vancouver renamed and revised its hotline manual. The manual became known as What are the Symptoms of Immune Deficiency. The information became much more detailed as well as clinical:

There are no certain treatments at the present time....Among the experimental agents and techniques, interferon, immunomodulators such as interleukin-2, and plasmapheresis have attracted the most attention. Interferon, which exists in many forms, is known to have antiviral properties and has shown promise in the treatment of some forms of cancer. (AIDS Vancouver, 1984)

Diagnostic testing was also addressed in the manual:

At the present time, there are several routine, inexpensive laboratory tests that may either strengthen or help to rule out a diagnosis of immune deficiency. These include white blood cell and lymphocyte counts, both of which are often low in victims of immune deficiency and skin testing with recall antigens....when immune deficiency is strongly suspected, the diagnosis may be confirmed by several lab tests that are not routinely available. (AIDS Vancouver, 1984)

A type-written document, titled A Risk Reduction Guide For AIDS, reveals that as soon as it was reasonably clear that HIV was transmitted sexually, AIDS Vancouver's education staff and volunteers borrowed safer sex guidelines and instructional forums developed in the United States in order to get the word out to gay men in Vancouver (AIDS Vancouver, Spring, 1985). The guidelines centered around high risk, moderate risk, and low risk activities.

The document, A Risk Reduction Guide for AIDS also defined what health is:

Health means much more than the absence and avoidance of disease. It is the human condition in which the physical, mental and spiritual needs of a person are in balance. Healthful sexual behaviour is an expression of one's natural sex drives in satisfying, disease-free ways. Guarding your health and respecting the health of your sexual partners means, for one thing, being aware of your body and the messages it may be giving to you. (AIDS Vancouver, Spring, 1985)

Members of a cultural community may discuss sex and health issues with each other or may rely on people outside the group for information. It is a rule of thumb in health education, for example, that women tend to get health information from one another, while heterosexual men tend to get information from the women in their lives (Fauci, 1991; Mann, 1992b). Identifying the key sources of information, whether they are community groups, magazines, and

newspapers, or members of the same cultural group is essential so that the educational effort can meet people in the places where they expect information exchange to take place. AIDS Vancouver was trying to use "heterosexual" norms to educate the gay community.

From 1984 to 1987, hundreds of men in Vancouver attended risk-reduction programs in bars, lectures halls, clubs, libraries, and community centres. They learned about the programs from friends and neighbours, from fliers handed out in gay bars, bathhouses, and other clubs, from gay newsletters and advertisements in local newspapers. Dedicated volunteers prepared the advertising, facilitated the workshops, and shared every piece of information they could glean from medical journals and the community grapevine. Funding was supplied by donations from friends and volunteers, from benefit parties, and from donation cans that sat next to cash registers in bars, restaurants, and other businesses.

Even though the efforts of AIDS Vancouver were being supported by the gay community, great concern was expressed that some people in the gay community did not support the efforts of AIDS Vancouver. One board member during a board meeting stated that "we need to help lobby for support for AIDS services within the community as well as the City Council for assistance" (AIDS Vancouver, January, 1985). Many men in the gay community were denying the possibility that they might be infected with the virus and wanted to dissociate themselves from both the organization and the

disease. Moreover, many men in the gay community perceived AIDS Vancouver as a site of radical gay politics and wanted no association with such an organization. They perceived themselves as members of society and not the "gay" community.

In 1985, as the number of AIDS cases rose dramatically, St. Paul's Hospital, a hospital located close to the city's West End which has a large gay population, decided to make the institution a "Center for Excellence" in the treatment of AIDS. The hospital formed an interdisciplinary team of about thirty general practitioners, nurses, specialists, and social workers. The inpatient services of the hospital and a provincially-funded outpatient clinic eventually found itself treating 90 percent of the province's AIDS cases, offering more integrated and coherent hospital care than was available anywhere in Canada (Rayside & Linguist, 1992; Brown, 1995).

During the same year, British Columbia became the first province to offer free testing and counselling throughout the province, and although doctors or clinic nurses were to keep track of the names of patients being tested for HIV, there was no requirement for further registering of names. A special AIDS testing and counselling clinic was established by the health ministry in Vancouver. There patients could easily supply pseudonyms to doctors or clinics, and so could have de facto anonymous tests (Rayside & Lindquist, 1992). Minutes from a board meeting reveals that this system was installed after AIDS Vancouver

representatives convinced public health officials that no one would show up for testing at a clinic where names would be on file (AIDS Vancouver, March 1985). Implicit in the discussions between the government and AIDS Vancouver was the distrust of the government. Many gay men perceived that by undergoing testing, they would voluntarily be placing themselves on a "quarantine" list.

The first group in Canada to organize people living with AIDS was Vancouver's Persons With AIDS Coalition, formed in early 1986 as a breakaway from AIDS Vancouver. The PWA Coalition broke away from AIDS Vancouver because its members felt AIDS Vancouver was not securing funding for new drugs and human rights protection for PWAs. The new organization grew quickly and developed a critical political profile. It forced the federal Health and Welfare Department to release AZT, an AIDS drug, by threatening to smuggle supplies of the drug from the United States (Rayside & Linguist, 1992).

In June of 1986, AIDS Vancouver relocated to a new site, west of Burrard Street on Davie Street. In the same month, the organization announced in a newsletter, the AIDS Vancouver Health Promotion Project titled An Introduction to AIDS Vancouver:

The "AIDS/ARC: Public Awareness and Support" project is funded by the federal and city governments for two years from July 1985 to July 1987. The \$250,000 grant provides for three staff members, an office, and specific projects in the areas of information and education, support services, and networking. Two other staff members have been hired under federal employment assistance programs. (AIDS Vancouver, June 1986)

The Annual Report of the Medical Health Officer of the city of Vancouver (1986) makes no mention of the funding for AIDS Vancouver. It is possible that the governments had hoped AIDS could be contained by the gay community. The same report addressed AIDS:

In 1986, the world woke up to fact that AIDS was not just a gay disease, but could also infect the heterosexual community. Despite numerous media stories on AIDS, no coordinated AIDS education program was undertaken by the various levels of Canadian Governments. (p.1)

The report continued:

As anticipated, AIDS continued its rapid rise with 102 cases diagnosed during the year (Up from 8 cases in 1983 and double from 1985). With the absence of effective or therapeutic measures, education remains the sole activity available to control the spread of this viral infection. There is a need for major education efforts to be directed towards persons at potential risk such as teenagers, prostitutes and drug addicts. (p. 14)

The City of Vancouver made plans for the creation of a small project group to develop AIDS education packages, nursing assessment tools and treatment guidelines, and education material for caregivers to AIDS victims. The city also received funding from the Ministry of Health to offset the cost of providing Home Care services primarily to AIDS patients in the West End. Approximately 30 patients were clients of the Home Care Program. Health officials also encouraged the Vancouver School Board to develop AIDS programs for grade 12 students (p.5). The government still had not developed a curriculum for students in the province.

In this early phase (1983-1986), the novelty and shock of a life-threatening infectious disease of potentially

epidemic proportions in the late 20th century rapidly led to a search for explanatory models with some degree of predictive power. There were no established departmental, local, or health authority mechanisms in which AIDS policy could be encompassed. There were no established expert advisory mechanisms that could deal with AIDS; in fact, there were no experts. There was no preexisting policy community around AIDS. This period illustrates clearly how a community developed around the disease, how gay activists, clinicians, and scientists coalesced and consorted, and how formal links between the various government health departments and AIDS Vancouver were noticeably absent.

The Second Era: Local Initiatives, 1987-1992

Most current interpretations of policy reactions to the epidemic have focused on AIDS policymaking as a top-down process, whereby government reacted in traditionally consensual ways, sending signals about appropriate reactions into the public domain. But, in the earlier period of reaction, policy was formed in a rather different way, in a bottom-up rather than a top-down way, with a volunteer rather than an official ethos.

Between 1987-1992, gay men continued to be part of the emergent public policy lobby around AIDS. Another part of that policy lobby was also forming about the same time. Clinical and scientific expertise on AIDS was also in the process of being established and institutionalized. The question of potential and actual heterosexual spread of the disease or threat to the population at large was the issue

that united the AIDS policy community. As well as external links, the Ministry of Health and the Health Department of the city of Vancouver developed its own internal policy machinery on AIDS. The policy lines that most clearly united the community were a stress on the need for urgent action and the need for public education to stress the heterosexual nature of the disease rather than the "gay plague" angle of the popular press.

An external policy review was commissioned by AIDS Vancouver to help identify what kinds of services and educational programs were needed because of the significant increase in the number of PWAs. The review titled Evaluation of Support Services (1987) by Judy Krueckl, a U.B.C. professor of social work, suggests that "common sense and a commitment to community empowerment led AIDS Vancouver to adopt a health education strategy that was at once practical, closely focused, and rooted in community values, organization, and politics" (p.13). As educational programs were being assessed and developed:

Gay men shared their perceptions of what they felt is needed for themselves and other gay men in Vancouver - responses grounded in their experience of the community as it copes with a major health crisis over time. (Krueckl, 1987, p. 13)

The same policy review document revealed that AIDS Vancouver's clients were satisfied with the organization's educational programs which disseminated information about AIDS through the hotline, speakers bureau, a library, forums, and information pamphlets. However, the document also revealed that:

no significant gaps in services were identified. The reason for this could well be that the target population receiving the services may be afraid to criticize the only existing comprehensive program for persons with AIDS in Vancouver. (Krueckl, 1987, p. 16)

The document does not reveal that many PWAs were living below the poverty line and most were relying on the social support of friends. PWAs were also being rejected by their own families.

The personal journals suggest that some members of the gay community insisted upon "safer sex" rather than celibacy (PT, 1987; JM, 1987). Peter, an AIDS educator, stated in his journal:

There appears to be a small group of seronegatives who continue to practice very high risk activities. Most of the fellows when I'm talking to them, and still talk about meeting somebody, they're all talking safe sex, they're talking condoms. (PT, 1987)

Nevertheless, the 1987 external review by Judy Krueckl stated that:

the high risk group in question is not as informed as they ought to be. It could be that several members of this population are using a form of denial which prevents them from altering their present lifestyle. (p. 16)

Risk behaviour had changed little from 1987 to 1989.

According to Rick Marchand, a gay man and an educator from OISE:

People acknowledge that unsafe sex is going on - they see it, they hear about it, they participate in it, although they may not like to talk much about it. But the overwhelming sense of the gay community is that change has been taking place - gay men are adopting responsible sexual behaviours and as a result community life is different from a decade ago. But personal change, even within a community that strives for social change is a difficult process. (Marchand, 1989, p.54)

Marchand's 1989 evaluation, Fighting AIDS With Education: Report of the Gay Community Needs Assessment which was commissioned by AIDS Vancouver to assess the education needs of the gay community, also identified that gay men wanted more sophisticated and positive messages to help them deal with the complex issues around sustaining changes in sexual behaviours. The two most significant recommendations of his report were:

Continue basic information on HIV transmission and prevention to the gay community, a range of materials to go out in various ways. The challenge is to be innovative and responsive to the community. The shelf life of messages is short but vigilance must be continuous. Specifically, this means: distributing condoms, safer sex cards, pamphlets to the community; running poster campaigns, and promoting resource centres and libraries of AIDS information to the gay population. (Marchand, 1989, p. 7)

and

Outreach programs must be developed to several groups within the gay community. AIDS educators need to ensure the entire community is receiving appropriate educational materials. A long term strategy for education of gay men must include campaigns that can address a spectrum of needs around HIV issues and have a clear positive message. (Marchand, 1989, p. 8)

These recommendations were accepted by the board of directors. Staff members then interviewed facilitators on the kinds of questions asked during information programs. The content of hot line calls were recorded and analyzed regularly. Staff and volunteers observed programs in order to discern more fully the group dynamics and patterns of interaction. These responses, observations, and analyses

became the raw materials from which new education programs were constructed. Marchand's 1989 report stated:

data was [sic] collected in a number ways. A community-wide survey was run. Confidential interviews with selected members of the gay and bisexual male population, as well as with selected and experienced professionals such as physicians, therapists, social workers and researchers working with gay and bisexual men. Meetings and discussions were held with AIDS educational organizations. Observations were made of evidence of AIDS education in Vancouver. Observations were made about how gay and bisexual men talked about AIDS and safer sex in everyday life. Literature on needs assessment, behavioural change and AIDS educational programs was reviewed. (p. 16)

Minutes from a board meeting also reveal that AIDS Vancouver decided to use both clinical language and sexually explicit visual material to get the widest possible message across (AIDS Vancouver, July 1989). There was no discussion, however, if some board members or educators were offended by the use of sexually explicit visual material. Much of the sexually explicit materials would not have been displayed in "public" places, especially where children would be.

According to Marchand (1989), no multicultural education existed in Vancouver and there was room for involvement by an organization like AIDS Vancouver to assist community organizations in putting together more comprehensive programs for racial and ethnic groups (p. 87). He stated:

AIDS educators in community-based organizations and government health programs must work more closely within the gay culture in developing education services....Educators must be responsive to the gay populations needs and keep themselves informed through ongoing community research and involvement. (AIDS Vancouver, 1989, p. 95)

Nevertheless "culture" as a construct lacks homogeneity in labels such as Latino, Asian, First Nations, or other reified categories of race or ethnicity in Canada.

Culture is not viewed as a monolithic term. Rather there are many variations on the underlying theme of culture. An individual might be a working-class Asian male living in a multicultural neighbourhood. It is extremely difficult to identify the separate influence of each of these cultural elements. The term culture, for AIDS Vancouver, then, collapses what others see as demographic variables, such as age, race, religion, ethnic heritage, socioeconomic status, and gender into one constellation, that for each individual would be somewhat idiosyncratic. This suggests that the prevention education strategies do not begin to acknowledge that people at risk for HIV infection do not come in the discrete packages suggested by the original epidemiological formulation of risk groups or the target audience.

AIDS Vancouver redesigned its educational programs over the next year. In addition to premising the educational strategy on culture, AIDS Vancouver's educational staff tried to answer several questions. AIDS Vancouver attempted to get a picture of the informal rules around sexual behaviour and drug use, the rules that communicate the values and beliefs held by members of the community. Some of the questions that they asked are found in the Fall 1989

B.C. Persons with AIDS newsletter:

Is risk behaviour hidden or open? Is risk behaviour valued? Does the group consider itself a group? Who are leaders and role models within the culture? Where does the group get information

about sex and health? What kind of sex talk takes place within the group? What are the positive identities available to the group? What does the group know now? (p.8)

Moreover, the organization recognized the risk of AIDS in young people. The Spring 1990 B. C. Persons with AIDS Newsletter addresses this concern:

How serious a risk is AIDS for young people. We know that HIV can infect anyone young or old as behaviour exposes them to the virus. Adolescence can be a period of profound physical and psychological change and behavioural experimentation....Young people need to be aware of the possible consequences of unprotected sexual intercourse and experimentation with drugs. They may suffer without this awareness. (p.3)

The article warned the problem may be significant:

Cultural tradition, fears or other barriers may prevent young people from learning about sexual transmission and other modes of transmission or from acting on what they have. Parents and community leaders may not support communication about sexual matters because they may not wish to acknowledge that many young people are already sexually active. In areas where there are no cultural barriers to frank discussion, health promotion programs which address sexuality many not exist because of the lack of resources or because risk is not perceived. (p.3)

In the fall of 1990, AIDS Vancouver launched a new initiative for gay men entitled the "Man-to-Man" program. It had several key components. The "Rubberware Home Parties" were described as casual, fun, and interactive evening sessions on HIV prevention and education. They took place in living rooms around the Lower Mainland. "Operation Latex Shield" was the newest area of the "Man-to-Man" program. It involved outreach in public sex environments. Volunteers offered condoms, free of charge, and on the spot counselling. The director of the "Man-to-Man" program, Christopher Koth, noted that "not everyone

seemed open to the experience" (AIDS Vancouver, Contact Fall 1990, p.6). He stated that:

This is O.K. in our minds, this workshop is guaranteed to provoke all sorts of reactions and perspectives, all of which are valid. One individual raised an interesting point when he insisted that to use the term negotiation was inappropriate. There should be no room for negotiating where life and death are concerned. Another individual would like us to have focussed more upon the emotional and not the physical issues involved with transmission. (Koth, 1990, p.6)

As a result of this observation, AIDS Vancouver developed a program to train more volunteers to back up emotional support systems. However, the forms of male sexuality related to AIDS transmission are certainly not restricted to gay men; they are forms of male sexuality that have long been celebrated and promoted. In other words, they are culturally created and reproduced in ideas of hegemonic masculinity, child-rearing patterns, and the constant selling of sex as a commodity. Society is also only beginning to come to terms with the hidden world of bisexual men in heterosexual marriages who are invisible to most AIDS programs, yet are crucially important for disease transmission precisely because of the levels of secrecy involved. It was also important to consider the needs of those men who have sex with other men, but do not view themselves as part of the gay ("Eurocanadian") community.

AIDS Vancouver was concerned about news coverage of AIDS. In the Fall 1990 issue of Contact, Cindy Letts, a volunteer, wrote:

Recently, AIDS has been regulated to second-string status in favour of environmental issues. Partly because they are easier to cover, no longer do the information lords have to grapple with such burning issues as, "Can we say sperm on TV?" Environmentalism is safe: the language is inoffensive and the issues cosy and politically comfortable. No fear here of anyone being offended if the topic of the day is recycling, rather than teaching your youngster about AIDS prevention guidelines. I don't discredit the environmental movement as unworthy of interest; what concerns me is that the media have become disinterested in AIDS. (p.70)

In the Spring 1991 issue of Contact, Rick Marchand stated that "homophobia continues to be the greatest obstacle to delivering comprehensive AIDS prevention education in Canada" (p. 13). He went further by saying:

Homophobia is the fear of hatred of homosexuals and homosexuals feelings. Probably a more accurate word to help us describe the oppression that is experienced by gay and lesbian people is heterosexism. Our sexual and cultural mores ensure that heterosexuality is valued and preferred, while other sexualities are excluded, silenced, and hidden. (p. 13)

Minutes of a board meeting in May 1991 revealed that a board member maintained "many still believe that AIDS is a gay disease. At the same time, as a society we still haven't acknowledged the devastating effect AIDS has had on gay men." This is still an issue in the gay community today; how many deaths does it take to legitimize a culture within society?

During 1991, AIDS Vancouver established Info Centres in 20 locations throughout the gay community, allowing their print material to be more readily available (Williams, Contact, Spring 1991, p. 5). Education Services and other departments at AIDS Vancouver participated in a number of

public awareness events (p. 5). These included World AIDS Days, the Gay Pride Festival, and the "newly established AIDS Awareness Week" (p. 5). As well, "AIDS Vancouver also organized and participated in community forums, and set up information booths at locations ranging from west side shopping malls to West End night clubs" (p. 5). The Helpline continued to be a major source of information and support. With a pool of 80 volunteers, the Helpline operated 63 hours a week. On average the Helpline handled 1,000 calls a month (p. 5).

In AIDS Vancouver's 1992 Annual Report, Rick Marchand says:

AIDS Vancouver has special challenges in this region of the country. Vancouver has the highest per capita rate of AIDS in Canada. Years of Social Credit government have helped to maintain the wall of denial that exists in the corporate world and in B. C.'s workplaces, central arenas in the development of supportive environments for persons living with HIV. (p. 1)

Despite financial challenges the organization launched a new educational campaign. A March 1992 newsletter titled "AIDS Vancouver's Man-to-Man Program Launches New Education Campaign," read "Gay, Bisexual, Or Straight - It doesn't Matter Who We Are. We all have Choices, Safer Choices - Safer Choices for Life." Christopher Koth, a gay man and the new director of the new program, maintained it was chosen to emphasize personal responsibility in sexual behaviour. Koth believed that the program was precedent-setting because "this is the first time, that I'm aware of, when an AIDS education campaign in the city has spoken so directly to the Gay and Bisexual community." Koth also was quoted saying

that "No apology is made to those who might think this is unnecessary or not broad enough in its approach. Gay and Bisexual men, as with all people, deserve to receive direct information which gives them options and ultimately, save lives." Koth indicated that there were still no complementary educational strategies within the province.

The fall 1992 issue of Contact revealed that "the education staff [at AIDS Vancouver] is now comprised [sic] of professionals with the skills to employ both qualitative and more formal quantitative methods of assessment" (p. 3). AIDS Vancouver was still employing structured observations of the audience.

According to a volunteer in the fall 1992 newsletter, The Volunteer Voice, women would frequently take first a brochure with a title directed to gay men because it was more colourful than the brochure with "women" in its title. Moreover, recipients of information were observed to skim through brochures in no particular order rather than reading from beginning to end. As a result of this information, the most critical introductory brochure, which was designed to acquaint a more broad audience with HIV and risk reduction, was redesigned to be more colourful than the other publications competing for the audience's attention. It was also rewritten into a modular style, with particularly important information highlighted, so that the recipient could get a meaningful amount of information from skimming the text and small units of type could be read in any order and still make a coherent educational message.

Educators at AIDS Vancouver have often struggled with designs that they were convinced should work but just did not. Minutes from a board meeting in August 1992 reveal that the educational staff have regarded evaluators as people who split hairs in order to make their jobs more difficult rather than as teammates who were working toward the same ends. In short, being open to changes is easier said than done. Knowing from the outset that revision is both necessary and inevitable helps make the process easier. In AIDS Vancouver's experience, however, the best remedy for this brand of territoriality has been the active involvement in program design and execution by members of the target community (Personal journals, PT, 1992; JM, 1992). According to minutes from a December 1992 board meeting, this involvement has helped program staff and volunteers recognize that a successful program ultimately must belong to the community it serves, rather than to its inventors and facilitators.

The personal journals attest to the fact that AIDS Vancouver understands itself to be accountable to the people it serves (JM, 1989; PT, 1992). However, accountability within the organization was an issue. In the August 1992 The Volunteer Voice newsletter, David Ross, a volunteer and a professor of history at S.F.U. said:

While nothing can now be done about the way in which the hiring committee has chosen its method of procedure, it is necessary to restore and inspire confidence in the working of the system....what is needed is a revision of appointments guidelines and an undertaking of due procedure. (p.10)

Another letter addressed to Mark Mees who was at the time the director of AIDS Vancouver is more revealing with regards to accountability within the organization and its accountability to society. Nancy Illman, a volunteer, lamented in the August 1992 The Volunteer Voice:

Unfortunately, I believe that there is far too much high-school girls' washroom behaviour being indulged by the gay community specifically, and that it is this unfortunate behaviour which has created most of the tension surrounding personnel changes. Some people have chosen to live their lives by pickings sides and lining up to take cheap shots at the other side. (AIDS Vancouver, p. 11)

As a result of the criticisms, AIDS Vancouver in the fall of 1992 published a policy statement, titled Organizational Policies. Furthermore, an "Ethics Committee" was established to "assist us in serving as a practical guide for professional behaviour and the maintenance of a reasonable standard of practice within a given cultural context" (AIDS Vancouver, The Volunteer Voice, Fall 1992). Implicit in the criticisms and the establishment of the committee was the concern over the practice of patronage. AIDS Vancouver was not hiring professionals outside the gay community.

As Dr. John Blatherwick, in his Annual Report of Medical Health Officer of the City of Vancouver (1987), stated:

In 1987, the public health arena was dominated by AIDS...The disease in the City of Vancouver continued to be reported predominantly in the gay population. In this group, there were indicators that the spread of the AIDS virus had been greatly reduced. In 1987, there were 120 clinical cases of AIDS in British Columbia, an increase of 16 cases from 1986. AIDS cases did not reach 200 cases in 1987, a number predicted by many. Whether new cases of AIDS will continue to plateau in unknown,

but it is encouraging to those people working with the disease. (p.5)

According to Blatherwick's 1987 report, AIDS surveillance and AIDS educational activities increased significantly and "liaison with other involved agencies also required greater time commitment from the Communicable Disease Control Section" (p.19). Health officials encouraged the Vancouver School Board to develop AIDS programs for grade 12 students. The city insisted that the provincial government was still not adequately addressing the emergent health crisis. Furthermore, the city recognized the potential of disease spreading into the general population.

During 1988, City Council approved policy "Guidelines for Managing HIV Infections in the Workplace" (Blatherwick, 1988, p. 7). A matter of increasing concern during 1988 was HIV infection in the intravenous drug-using population. While lacking information as to the extent of the problem, the "Health Department secured approval to initiate a needle exchange program in this group commencing" in 1989 (Blatherwick, 1988, p. 7).

Dr. Blatherwick, in his Annual Report of the Medical Health Officer of the city of Vancouver (1989) stated that:

The AIDS epidemic continued to be a problem for the entire community. The Department formulated a major initiative (to curb the growth of HIV infection in the intravenous drug-using population) was the introduction of Needle Exchange Programs, administered in conjunction with the Downtown Eastside Youth Activities Society. Enrollment in the Program soared beyond initial expectations (in 1989 an estimated 2,700 individuals made use of the service). Plans for a detailed evaluation of the impact of this program are underway for 1990. (pp. 2-3)

Of the 189 cases of AIDS reported in B. C. during 1989, a 21% increase over 1988, there were significant changes in characteristics over previous years. "All but 2 of the cases occurred in men with 3/4 of them being between the ages of 30 and 49. Two newborns were either infected during pregnancy or delivered from previously-infected mothers. Sexual transmission accounted for over 95% of the cases" (Blatherwick, 1989, p. 17).

John Blatherwick in his Annual Report of the Medical Health Officer of the City of Vancouver (1991) wrote about the "New Plague - the Scourge of AIDS" (p. 2). He also stated the "federal government announced its National AIDS Strategy in 1990 and the work of the Vancouver Health Department is an important foundation on which the National AIDS Strategy depends" (p.3). For the first time, the number of new cases dropped from 212 in 1989 to 189 in 1990 in Vancouver. However, the distribution of cumulative AIDS cases and positive HIV test results gave cause for concern:

5.6% of the positive tests (where sex has been identified) are in women, while only 1.8% of AIDS cases are in women; 1% of AIDS cases have been noted in persons whose only risk factor is injectable drug use, where 3.5 of positive test in B. C. (6.1% in Vancouver) are in this group; persons with no identified risk factors represent less than 1 % of the AIDS cases but are noted in 2.3% of positive HIV test in Vancouver - these infections may well arise from casual sexual contacts; heterosexual risk factors account for 2 % of AIDS cases but more than 4 % of positive tests. (Blatherwick, 1991, p.12)

Furthermore, these comparisons suggest "the spread of HIV infections to other than homosexual men in greater number each years. While the spread is unlikely to be explosive,

it will continue unless more resources are devoted to education" (Batherwick, 1991, p. 12). Since 1989 the city of Vancouver's Needle Exchange Program had distributed more than a million needles and this indicates a shift in the city AIDS priorities.

The government of British Columbia started formulating its AIDS policy around the same time as the City of Vancouver. In the Annual Report (1986/87) of the British Columbia Ministry of Health, AIDS was mentioned for the first time. The document states that the ministry was engaged in the "development of a comprehensive AIDS public awareness and information program for the public, health care workers, and physicians" (p.20). The same report stated that the number of patient visits to the provincial Centre for Disease Control increased from 820 in 1985/86 to 2107 in 1986/87 (p. 27). In the same year, the provincial government proposed an amendment to the Health Act giving medical health officers powers of sanctions, including quarantine, to restrict those who expose others to HIV or AIDS. This was the change that some public health officials wanted and it intensified concern among British Columbia activists about the government's conservative agenda. Nevertheless, protection against discrimination for people with AIDS and HIV was secured by a 1988 decision of the British Columbia Council of Human Rights which applied provisions of the 1984 Human Rights Act on physical disability.

However, one program did illustrate the capacity of the province's AIDS administrators to use established programs in innovative ways. The street nurse programs, which were directed towards homeless people, had been developed in 1947 and had launched a "nurses in blue jeans" program for drug users in the 1960s. Without the need for legislative approval, the program grew from one nurse to seven, operating out of three storefront offices. The nurses had already been distributing condoms prior to AIDS, and simply continued doing so, along with offering counselling and anonymous testing to prevent infections from HIV.

In the B. C. Ministry of Health Annual Report (1987/88) the government announced that "the major health problems today are chronic disease of middle and later-age, heart disease, stroke and cancer, and lifestyle choices of the individual" (p.20). Nevertheless the 1987/88 provincial Annual Report continued:

The distribution to secondary schools, public libraries, and over 500 video stores of AIDS: the New Epidemic. The mailing of AIDS pamphlets to 1.2 million households. The production of "AIDS in the Workplace"; an information package for management and employees. Development, with the Ministry of Education, of a comprehensive family life education program, which was introduced into Grades 7 through 12 in September of 1987. (p. 21)

The government's grade 7 to 12 curriculum emphasized abstinence from non-marital sex. The abstinence message reinforced the notion that AIDS and other STDs are retribution for immoral behaviour. In many cultural groups, sex without condoms is often interpreted as an act of

intimacy and trust, and so unprotected sex is highly protected within the culture because of its association with those values. For many women, for example, unprotected sex draws its value from its relationship with childbearing and motherhood, which is for some women, the only socially rewarded role open to them. From a cultural standpoint, then, risk reduction represents a significant threat to closely held beliefs and values.

In 1989, no mention of AIDS was made in the B. C. Ministry of Health Annual Report. Once again, AIDS was not a problem concerning the general public. In 1990, British Columbia was the only province that refused to provide AZT free to all AIDS patients. It was made available, free of charge, to those eligible for welfare. As a result, some members of PWA Coalition broke away and formed a new group, ACT UP. Like its American counterparts, ACT UP used aggressive, dramatic techniques to criticize the provincial government for its failure to subsidize costs for AZT for all PWAs regardless of their socioeconomic status. After a series of public protests, the government announced it would provide AZT to all AIDS patients. More importantly, the British Columbia AIDS Network was formed to bring together representatives of community groups, along with health and social agencies across the province. This indicated that AIDS policy was divergent and a comprehensive plan was needed.

According the B. C. Ministry of Health Annual Report (1991/92), the Sexually Transmitted Disease Control Division

"expanded its program for intravenous drug users to reduce transmission of diseases such as AIDS and Hepatitis B in Kelowna, Quensnel, Williams Lake, and Prince George" (p.17). This suggests that the provincial government was still not concerned about AIDS in the gay community.

The B. C. Ministry of Health also expanded its AIDS prevention education programs. In the 1992/93 Annual Report, the government announced:

This year the Sexually Transmitted Disease Control branch provided \$2.5 million in funds to 52 community-based AIDS education projects. Through the Sentinel Physician System and health unit electronic monitoring, staff continued to keep a close watch on the distribution of STDs and AIDS. They also continued with the following targeted prevention programs: Chlamydia and Venereal Warts Control; British Columbia Native Awareness; support for prisoner AIDS education, education for the gay community. (p. 28)

Finally the government was beginning to diversify its educational strategies.

During this second era, the years from 1987 to 1992, AIDS Vancouver's prevention education programs were constructed by the gay community because gay men had been the overwhelming participants in the programs. Information gathered by observation and interviewing as well as surveys were utilized to design AIDS Vancouver's prevention education programs.

Financial difficulties and the lack of government assistance hampered AIDS prevention education. The organization was also hindered by its own internal problems such as volunteer discontent over hiring practices of professional staff. The provincial and city government

began to target the intravenous drug using population. This high level political intervention occurred only when the threat to the heterosexual population became clear because the government did not care so long as merely gay men were affected. Conflict between the gay community and "professionals" emerged over behaviour changes in the gay community. The former maintained funding was needed to change behaviour in the gay community, whereas the latter maintained some gay men were engaging in high risk activities. Paid professionals also replaced earlier volunteers.

The Third Era, 1992-1994: Towards More Comprehensive Programs

During this phase, post-1992, official institutions have been established and formal procedures have been adopted and reviewed. AIDS has made structural changes to health care. Interventions on the community, civic, and provincial levels respond to the nuances of cultural particularity and detail. They are based on an understanding of sexual experience and intravenous drug using as rooted in cultural meanings and systems.

According to The Volunteer Voice (Fall 1993), the education department now consists of ten or more educators and more than two couple hundred volunteers (p.8). It offers an extraordinarily broad array of programs. According to the newsletter, "the programs are designed to address an increasingly comprehensive range of needs, from interventions that are tailored for people of limited literacy to programs that press toward untangling deeper

psychological barriers to consistent long-term safer sex behaviour" (AIDS Vancouver, 1993, p.8). Three basic kinds of programs are provided.

First, AIDS Vancouver offers a variety of risk reduction programs for people, including targeted interventions for gay men, relapse prevention programs and workshops designed to assist people in making informed decisions about HIV antibody testing. Many are offered in workshops that encourage interaction among participants. These workshops ordinarily last from three to eight hours. Theatrical presentation and intercept peer counselling models are also employed for some audiences. Virtually all of these program services are provided by trained volunteers, most of whom are members of the target audiences from which the programs are designed.

Second, information forums give HIV-infected people the facts they need in order to improve the quality of their lives and their medical care. These forums cover such issues as current therapies for HIV disease and opportunistic infections, nutrition, legal issues, and available financial support.

Third, AIDS Vancouver offers programs through a variety of community groups such as churches, schools, employers, and social and professional organizations is basic AIDS and safer sex instruction. Most of this work is given by trained volunteers. The hot line continues to provide information and referral services. The education department distributes educational literature and free condoms to those in need of

risk reduction information. Professional mental health counsellors are also trained in the ways to make risk reduction information available to the people they deal with from day to day.

In the Fall 1994 The Volunteer Voice, Marchand states that "constant testing of AIDS Vancouver's prevention education revealed unexpected layers of emotion as the community interacted with the information about HIV which they encounter in the educational intervention" (p. 2). For example, when AIDS Vancouver began the implementation of "Man to Man" Program in 1992 and 1993, the workshop focused on maintaining safer sex behavior over time. The facilitators were surprised by how much anger was generated within the group during the program. By debriefing facilitators, reviewing responses generated during exercises, and asking participants about their experiences, educators began to get at the root of the issue. The workshop focused on all the reasons it is difficult to maintain safer sex behavior and so brought forward all of the anger at having to make AIDS a permanent part of the sexual landscape in the gay community. "Why us?" was the root emotion many men seemed to express; many were simply emotionally exhausted from dealing with AIDS for so long, especially without larger community support. This resulted in considerable alteration of some of the exercises within the workshop, so that the participants had adequate time to process their feelings. It also made the program designers recognize that different facilitation skills would be needed

in the volunteer group leaders than had originally been anticipated. As a result, more experienced volunteers and volunteers with mental health experience were recruited for the program. These changes were accomplished gradually through the initial implementation of the program and the facilitators are encouraged to take an ad hoc approach to education in any given setting.

According to AIDS Vancouver's 1993 Annual Report, the education department maintains production units for publication and audiovisual materials, an educational research team responsible for assisting with program development and conducting evaluations, and corps of comprehensively trained volunteers of every demographic description (pp 1-8). The budget of AIDS Vancouver comes from public and private sources. However, lack of adequate unrestricted funding has made program expansion exceedingly difficult (AIDS Vancouver, Annual Report, 1993, p. 8).

According the B. C. Ministry of Health Annual Report (1994), evidence suggests that the impact of AIDS is occurring more among socially and economically disadvantaged populations. "For example, a Vancouver study of men with HIV infection showed that men with lower socio-economic status had significantly shorter survival than high income men" (p. 17). The same report states "there is an alarming increase in the number of HIV infections among injection drug users in British Columbia. Most cases have been reported from Vancouver's Downtown Eastside, although the problem is not confined to that area" (p. 18). Most significantly, the

Annual Report reveals that "the rate of growth in the HIV among intravenous drug users is similar to that in gay men in the early to mid-1980s. If the trend continues, IDUs may soon overtake gay men as the risk group with high number of positive tests" (p. 18). For the first time, the Annual Report (1994) made mention of women:

Five of every 10,000 pregnant women in B. C. are HIV positive. Many of these women are unaware that they have been at risk for HIV or are infected. Babies born to HIV-positive mothers have a 25% chance of being HIV positive. Two-thirds of these cases of mother-to-child transmission can be prevented, if HIV positive women take the AIDS drug AZT during pregnancy and during the birthing process. (p.18)

Based on these findings, the provincial health officer recommended that all pregnant women should be screened for HIV infection after adequate counselling and informed consent.

The problems of AIDS among women have only recently received much attention, with the lag attributable, in part, to the predominance of narrow constructions of AIDS. To date, women with AIDS have tended to be ignored and left out of programs because they did not fit easily into gay male groups, because their symptoms and constellation of infections did not fit Centers for Disease Control (CDC) guidelines, or simply because the AIDS prevention education programs were specifically designed for men. The third era is very much in progress in terms of its implications, it is therefore difficult too draw any hard and fast conclusions.

Summary

AIDS Vancouver has developed into a Type Three organization as suggest by Mann (1992a). According to Mann (1992a), AIDS organizations evolve from a Type One information organization to a Type Three community advocacy organization with linkages to various health and professional services. AIDS Vancouver was a Type One organization during the period from 1983 to 1986. By 1992, AIDS Vancouver had evolved into a Type Three organization. However, the history of AIDS in Vancouver does not coincide with Mann's history of AIDS. Mann (1992a) suggested that there were three periods in the history of AIDS. First, the period of silence which ended in 1981. Second, the period of discovery which ended in 1985. Third, the period of mobilization which began in 1985. Community activists and the civic and provincial government did not mobilize until 1987. It is equally important to note that in effect a period of silence continues because there is very little discussion of AIDS in women and in various ethnic groups. The history of AIDS in Vancouver also does not coincide with Rayside & Linquist's (1992) history of AIDS. According to Rayside & Linquist, the history of AIDS has moved through three distinct periods. The first began in the early 1980s when AIDS was ignored. The second period began in 1985 when all levels of government made commitments to AIDS programs. The third period began in 1988 when Canada developed a coherent AIDS strategies. The history of AIDS in Vancouver revealed that the civic and provincial

government did not commit to AIDS programs until 1987. Furthermore, there is still no coherent AIDS strategy in the Province of British Columbia. In the next chapter, I move the discussion to those issues surrounding AIDS prevention education that were found in the documents.

CHAPTER FIVE: DISCUSSION

This study has yielded information in response to the following guiding research questions:

- 1) What is being said about AIDS?
- 2) To whom and for whom is it being said?
- 3) How is it being said?

Lurking behind these questions is the following question, Whom has had the power to define AIDS discourse? The discussion responds to the research question and reviews findings in relation to the literature. The subsequent analysis centers around how AIDS discourses have been affected by socio-cultural and biodeterministic factors and attempts to express the hidden meanings in the discourse.

AIDS in Context

AIDS seemed to appear out of historical context. It properly belonged to a distant and less comfortable past, before economic and scientific progress had combined to banish the "ancient" plagues. People in the advanced industrial world have become familiar with a "modern" pattern of chronic diseases such as cancer and heart disease and have included a long list of disagreeable, but non-fatal illnesses. Mass infectious diseases had ceased to command the attention of health policy analysis in the advanced industrial world (Gould, 1990; Fauci, 1991). The Province of British Columbia and the City of Vancouver did not pay much attention to AIDS until the mid-1980s. The documents do not reveal whether the ministry and civic health department were doing research in the community and if any funds were made

available for such investigations. This study suggests that gay men in Vancouver and in the advanced industrial in general world perceived AIDS as being infectious. Gay men had defined health policy and rejected the "lifestyle" hypothesis developed in the United States between 1981 and 1983. However, prevention education programs emphasized "lifestyle" or behavioural changes to prevent disease and to reduce or eliminate symptoms associated with AIDS.

AIDS also challenges the assumption that the late 20th century division of diseases into infectious and chronic disorders naturally fitted economic and geographic distribution, with the chronic diseases appearing in highly industrialized nations and serious infectious diseases in less developed countries (Gorund, 1993). An epidemiologist's understanding of the transmission of infectious disease is much different from a layperson's, and is characterized by the classification of disease agents into specific categories such as fecal, oral, respiratory, vector borne, and sexually transmitted. For many laypersons, disease is classified in a much more undifferentiated way, that is, contagious, very contagious, and not contagious. Thus, once AIDS becomes glossed as "contagious" it may be spread in all sorts of ways, even if it is understood to be "not very contagious." The connection of the term "virus" to AIDS may also impute a certain association with "contagiousness." When experts say that AIDS is not transmitted by casual contact, what do they mean? Is it transmitted like other viruses?" The term "virus," which signifies a specific type

of disease agent to an epidemiologist, means something entirely different to the lay public and some in the medical profession, who use the term to describe febrile illnesses that seem to "go around" (Fauci, 1991; Gorund, 1993).

AIDS is strictly a disease of humans, and it is one of the most important diseases that afflicts humanity. Its manifestations are so varied that AIDS is an epitome of pathology, and its study is one of the interests of every branch of medicine (Mann, 1992b). It is surely the most difficult of diseases from the point of view of sociology, for it is inextricably involved with sexuality (Herdt & Lindenbaum, 1992). For example, AIDS Vancouver has attempted to reach persons that have sex with other men, but do not identify as gay. This raises an important issue surrounding research. The social practices described must be grounded in the specific details of people's everyday lives, and yet they must include attention to the complex and broader constraints affecting the behaviour that places people at risk for HIV infection.

Complex legal, medical, and ethical issues have been raised in debates about the appropriate public health and legislative responses to AIDS. Various controversial measures have been proposed by the Ministry of Health, including mandatory testing and quarantine. This development was consistent with the United States and Australian experiences (Altman, 1988; Rayside & Linquist, 1992). Opponents of such measures pointed out that their measures would drive persons at risk of infection away from sources

of medical care and counselling and argue that coercion is ineffective in controlling sexual behavior and IV drug use.

AIDS as Discourse

Non-neutral discourse has surrounded "the AIDS question" since the earliest days of this health crisis. Among the factors contributing to the emergence of non-neutral discourses were, the sudden appearance of AIDS on the international health scene, its rapid spread across national and social boundaries, the diversity and complexity of its external symptoms, the absence of effective treatment strategies, and the close association between occurrence of AIDS and segments of the national population already considered to be, in some sense, "non-neutral" themselves.

But also contributing to its non-neutrality, of course, was the fact that this "new disease" did not have a name. As a result, "there arose a dizzying array of acronyms, being bandied about as possible monikers for (the) epidemic, each contributing its own subtle commentary on the medical and social conditions at hand" (Shilts, 1987, p. 137).

Doctors were not the only persons in British Columbia who identified this disease in terms of "who it hit." From several points of view there were advantages to be gained from "naming the unnamed" in terms of such references. For one thing, terms like GRID, Gay Plague, and the like established ownership of this health condition as being persons who were not a part of the speakers' immediate experience; they made it, in other words, "somebody else's health problem," not their own. That, in turn, allowed

speakers to advance a satisfying, even if somewhat self-serving explanation, for the existence of AIDS: "suspicious people get suspicious diseases."

Learning that this "gay disease" was also showing up among IV drug users and prostitutes in the province by 1987, did not alter the logic of this argument. These were also "suspicious" populations, from the point of view of the society at large, and that made it easy to consider them as members of the same "suspect class." Reasons why persons with hemophilia were also among those at risk were obscured under this analysis unless one simply assumed, as many did, that all persons with AIDS were homosexual persons.

The ready-made appeal of these "whom it hit" labels and the "comforting" point of view that they brought to any discussion of the emerging health crisis made it all the more significant that, first within the scientific community and then, though less rapidly, throughout the society as a whole, the term AIDS became the label of choice for this disease in 1987 (Mann, 1992b). This term implies that members of any particular group are inherently "at risk" and a speaker's use of this term reinforces value-laden assumptions about the existence of the disease or the social status of those who come in contact with it.

It would be wrong, however, to conclude that the term AIDS gives speakers of English a means for overcoming the conditions of "non-neutral discourse" captured so forcefully by other, more subjective, labels. Initial appearances to the contrary, AIDS carries with it a point of view similar

to the one just described - an emphasis on the distance separating the speaker from conditions at risk, and on the irregular nature of the "at risk" condition itself (Dickinson, 1995).

The expression, "AIDS," expresses this point of view in several ways, including the combination of meanings presented by the words acquired, immune, deficiency, and syndrome. Used by itself, deficiency identifies an absence of features otherwise expected to be present in a given situation. Deficiency also implies that the situation being described has been weakened or disadvantaged, in some way, by this absence. Absent in this case is the ability to successfully resist certain types of diseases to which, under other circumstances, human beings are typically immune. Immunodeficiency is especially serious, given that it is not an inherent condition but has been introduced through contact with some external source; that is, the immunodeficiency is acquired. The wording of this label does not make clear why acquisition has occurred. However, it is clear that the acquisition of immune deficiency is not an isolated event, but is something which occurs in any number of contexts the condition is described as a syndrome. Syndrome is not a word commonly used during English language conversations in nontechnical contexts. And usually, when it does occur, the condition that it identifies has already been assigned less-than-desirable characteristics. Syndrome is an appropriate element within this term in both of these senses.

"Ordinary" English, the language spoken outside of scientific, clinical, or academic domains, contains few expressions made up of "sequences" of three or more words (Feldman, 1994). When expressions of that length do occur, the meanings of those expressions always draw attention to things distinct from the everyday experiences of speakers and listeners, to things which need to be respected (or feared) because of the special qualities associated with them. English speakers describe details of everyday experience in terms that are much less complex in structure or composition (Smith, 1990). So whatever else is implied by the meaning of the three-word phrase, reference to an acquired immunodeficiency syndrome cannot be a reference to an ordinary occurrence, measured in terms of this criterion.

We know that "length of construction" is an issue for speakers of English in this case (Feldman, 1994). Almost from the moment that acquired immunodeficiency syndrome became the term of choice in English, speakers began to rework it into the now, familiar abbreviation: AIDS. Use of the abbreviation certainly made the reference process considerably less cumbersome (Feldman, 1994; Herdt & Lindenbaum, 1992). At the same time, reference by abbreviation establishes, through the fact of shared linguistic structure, parallels between the meaning of AIDS and the meanings of other references specified by abbreviations in English (Feldman, 1994). Those references include things that people hold in high personal regard, for example, Ph.D. (particularly if it specifies one's own

achievement). In those cases, the parallels do not properly apply, and use of an abbreviation highlights this contrast. These parallels are much more appropriate in instances like LSD, TB, STD, where abbreviations specify references to things which the Canadian public does not value highly, things with which most Canadians prefer to have as little association as possible. Reference to AIDS via abbreviation underscores similarities with the social meanings common to items in the latter category, just as it contrasts with the social meanings in the former one. The exchange of information during discussions of AIDS cannot help but be affected by both of these messages. In 1984, AIDS Vancouver did encourage gay men to be explicit about their health and HIV/AIDS status. However, the statement, "I am HIV positive," has been and often remains too personally scary and potentially stigmatizing to reveal.

An abbreviation, for example, may be much easier for a speaker to remember, compared to its unabbreviated counterpart; and that, in turn, may make the abbreviation easier to learn. But it becomes possible, under such circumstances, for a speaker of English to master the abbreviated form of the "correct" expression, and to use it in conversations, without being consciously aware of the full detail of the unabbreviated phrase or the precise meaning that the abbreviation has subsumed (Feldman, 1994). In fact, in more than a few instances, for example, PCB (the pollutants found in electrical transformers), PCP (the hallucinogen commonly called "angel dust"), and HIV (the

viral agent which causes AIDS), most speakers (and listeners) of English would probably be hard-pressed to make such identifications accurately, were they asked to do so. Unfamiliarity with such detail does not prevent people from using those abbreviations when the topics under discussion require it. And by doing that, speakers are using terms they may not completely understand to talk about topics which are, in the sense just noted, unusual and irregular in their own right. Such a usage strategy makes its own contribution to the meaning expressed and exchanged in such discussions; that strategy becomes particularly relevant when the discussion involves a topic as disquieting as AIDS. AIDS prevention education programs in British Columbia have been clinical. No measurement studies or ethnographies have revealed the extent of both the misunderstanding and disassociation of AIDS in the public.

Whether the speaker uses highly subjective and emotion laden expressions like Gay Plague or GRID, or words and phrases that appear to be more objective signification of meaning, the non-neutral nature of the discourse surrounding AIDS is paralleled by the non-neutral point of view which underlies the terminology of that discourse. In other words, regardless of the message that the speaker intends to be communicating, any discussion of AIDS ultimately becomes an encounter, through language, with the "irregular status" of this health condition as well as an encounter with the uncertainty which accompanies it (Gorund, 1993). It is quite clear that some speakers of English have no problem working

in terms of such encounters and the meanings, explicit and implicit, that they contain. And in some instances, speakers actively attempt to maximize the occurrence of such language-based AIDS encounters, and to make fullest use out of the effects those encounters have on the given conversation. In other cases, and, I suspect, in the majority of instances within "ordinary English" conversation, speakers of English adopt exactly the opposite stance. Instead of maximizing language based encounters with AIDS, they turn to one or more of the following strategies to find ways to minimize the occurrence of such encounters, refocusing in the process the meaning of the discussion into other, "safer" domains.

As the study progressed, it became more apparent to the author that the outcome of events occurring in the present have been set in motion long ago in an individual's life history. The patterns of behavior established during an individual's formative years, especially his/her learned responses to a crisis situation, condition to a considerable extent his/her future response to a life-threatening illness such as AIDS.

AIDS has considerable influence in producing changes in an individual's network of social relationships. As AIDS has been bandied about with the labels "gay plague" or "gay cancer," its diagnosis can awaken dormant, or exacerbate active, feelings and attitudes of homophobia as well as discrimination within the gay community - as evidenced in Vancouver as early as 1983. Guilt is everywhere an initial

emotional response. The important point, however, is that sociology and psychology reveal that different individuals have learned different ways of processing the guilt (Herdt & Lindenbaum, 1992). But in each case the response appears to conform to the traditional, patterned way of handling stigma for that particular individual.

These techniques for managing stigma do not merely represent a set of responses stemming from AIDS as a disease phenomenon (which could be singled out and labeled as disease-phobia or AIDS-phobia). As I will explain below, "blaming the victim" and "sham," two system-maintaining ideologies, frame social relationships in the face of AIDS (Grover, 1992; Gorund, 1993). The former is an example of the social construction of traditional approaches; the latter is more closely associated with behaviour and identity.

Each system-maintaining ideology provides us with a partial blueprint for networking social ties employed by gay men. These ideologies, simultaneously considered, permit reflections upon the varied responses by gay men to AIDS as a cultural phenomenon. Homophobia, as it masks itself in these ideologies, can be accounted for from recent and current interaction as well as from a much earlier period in an individual's life history.

Homophobia

I begin with a discussion of homophobia generally, and then move on to a consideration of the system-maintaining ideologies. The goal is to pinpoint more precisely the

contribution each makes to the presentation of social relationships in the face of AIDS. Homophobia refers to the fear by heterosexuals of being in close quarters with homosexuals; among gays themselves, it refers to self-loathing. Homophobia also is a general cultural phenomenon that has been used to explain two different pathologies. On the one hand, it has been used by psychologists to explain a cultural pathology among "straights" (i.e., heterosexuals), and, on the other, it has been used by psychological observers, analysts, and clinicians as an explanation for a particular pathology which affects the lives of gay men such as the expression of homophobic attitudes by others (Grover, 1992). Although as a psychological concept it refers to the fear of same sex, in the present context, the author further identifies it as a process of internalization.

Every male, gay or straight, after all, has been raised in a household with a parent/s or guardian who usually participates in a heterosexual relationship; in his socialization, he has been liberally exposed, I may assume, to their biases and values. Among these are those associated with sexual orientation. The dominant society's values and attitudes toward homosexuals and homosexuality, along with other attitudes transmitted during socialization, then, are internalized or introjected. The system maintaining ideologies mentioned earlier channel those biases associated with the socialization of homophobic attitudes in particular ways that link them to certain repressive economic and

political behaviors that in the popular media have come to be associated with AIDS. When the source for attitudes of homophobia is external, at the group level, the system maintaining ideology that malfunctions from the point of view of gay males is "blaming the victim." The operation of this ideology allows for the inequity of sexual gender and orientation as a pervasive characteristic for major portions of society to remain unchecked.

When the origin for the attitudes of homophobia is internally derived, at the individual level, the system maintaining ideology is "sham," the preference for the production of a counterfeit society over one that recognizes the diversity in needs and behaviors of all its citizens. Only gradually does each gay male in his growing-up years become aware, with respect to his sexual orientation, of his being different, of his separateness, from members of his own family and other social groupings. "Sham" permits this individual to play out a charade of conformity as a process of managing his stigma. The gay male child or adolescent is allowed to save face by pretending to be that which he is not, a heterosexual. In those instances where he does not exhibit the appropriate behavior, a sense of personal sham can be imposed by members from these groups in an effort to bring his outward behavior more into alignment with the expected internal norm.

Homophobia and System Maintaining Ideologies

In this section, I wish to pinpoint the ways in which these system maintaining ideologies articulate homophobic

attitudes, both among heterosexuals and among gays.

Homophobia thus prepares the way in which AIDS as a cultural phenomenon becomes embedded. According to Smith (1990), the creation of ideologies that often perpetuate the status quo represents malfunctions in a culture's social and economic structure. The need for these ideologies, she continues, is greater in those societies that are stratified into haves and have-nots and whose resulting tension represents a challenge to the established order. In applying this view of social inequality and inequity to the gay community, an important contrast with other stigmatized minorities is brought into sharp focus. The discrimination against gays is not always primarily or directly economic. As a consequence of their chameleonlike status, many men can shed or take on a public gay identity at will depending on the appropriateness of the particular context. The phenomenon of "passing," a process more in tune with white expectations for black behavior of two generations ago, is an ability gays possess that is extraordinarily pervasive.

It can be argued that discrimination against gays in Vancouver is primarily political and reflects the growing recognition, or at least the perception, of their greater political influence as a result of increased internal unity. The forces bringing about extensive internal political solidarity are the same forces that are responsible for the transformation of gay men from the label of sexual "perverts" or "deviants" to their inclusion into a minority

group, a subculture. The media attention surrounding AIDS has added immeasurably to this political visibility.

In their quest to sensationalize AIDS phenomena, the media has expanded its forum for both pro-gay and anti-gay forces to bring their respective points of view to the public. The agenda for this forum extends beyond AIDS and includes the political presence of gays in the Vancouver area.

Blaming the Victim(s)

"Blaming the victim" depends on a process of identification whereby the marginalized and stigmatized group member is identified as strange and different, or in other words as outsiders and "aliens." Successful identification on the parts of the risk groups with notions of internalized self-blame require that society create them as consenting to their social disinheritance. Aspiring "victim" blamers are compelled to stress that PWAs think in different forms and act in different patterns, cling to different "truths." Both PWAs and at risk groups are so different from an implied "rest of us" in society that their stigmatization can become normalized and rationalized. This masks the deeper processes through which homophobia and fear of the disease reinforce ineffectual AIDS education. An opposition to homophobia results in a pyrrhic victory, i.e. unsafe sex practices.

As Smith (1990) declares in her discussion of ideology and sexual discrimination in the contemporary society, "blaming the victim" helps to cover up the liability of the

conditions of inequality and discrimination under which that group lives. With respect to the situation involving gay males in Vancouver and elsewhere, misrepresentation of facts was widely used as demagoguery in the campaign for a gay quarantine. It is important to recognize that "blaming the victim" consists, wherever and whenever it occurs, of a set of non-facts.

Victim blaming as an ideology and a discourse discounts the agency of those blamed. In the next section, attention will be drawn to the ways in which AIDS Vancouver documents revealed a two way interaction in the gay community in which response to victim-blaming took the form of oppositional practices of unsafe sex. As I will show, such practices are referred to as "shamming" and raise difficult issues and implications for the mainstream as well as the gay community.

Shamming the Victim(s) and "Victims" Shamming Back

Some discussion within AIDS Vancouver indicated that some members were aware that an ideology of victim blaming was inadequate to explain how and why unsafe practices were taking place despite AIDS prevention education efforts. For example, Christopher Koth in Contact (1990) wrote that "there is a need for on-going education and support for gay men because the fundamentals of sexual safety are being ignored" (p. 7). Furthermore, "a large proportion of individuals became infected during their adolescence which can indicate that are in denial about their sexuality" (p.3). Minutes from an April 1991 board meeting reveal that

some board members expressed concern that many people were concealing their HIV status and their gayness.

"Sham" is a combination of concealment and pretense. It may be aimed at refusing the stigma of homophobia and conservative moralism, but ultimately it may also ironically result in unsafe and sexual practices. Social life and good manners compel deception for even the most truly innocent and well-intentioned among us. What was stated in the document of AIDS Vancouver was also echoed by gay activist researchers. According to Feldman (1992), "engineered by fear, sham is a bridge between the undesirable and the necessary, making the undesirable useful and the necessary bearable" (p. 99). He continues, "the real problem is not whether to be a sham, but to understand when to drop the mask and when to put it on" (p. 99).

While stigma management is a general feature of society and a process that occurs wherever there are identity norms to be established. I see shamming as a form of stigma management, specific to the gay community. For example, gay youths spend their childhoods among "straights" learning compulsory heterosexual social skills enabling them to hide their gay identities. Many such youth experience the culture's rituals of courtship, dating, and even mating with clammy hands, feigned excitement, counterfeit enthusiasm, and concealed anxiety. They play out the sham of heterosexual behavior, thereby hoping to allay any suspicions about their true desires. And true to the structure of "gay sham," while they conceal the most

important truths about themselves from those most closely related to them, they engage in activities of the most intimate kind with the males they met only moments before and many times will never see again. These individuals, then, have learned a successfully "sham," often at untold personal expense. Some eventually come to compartmentalize their lives into public and personal, and to disallow them from being intertwined. Concealment becomes a self-protective and injurious strategy. Their internalization of homophobia enables their consent to deny their homosexuality in public in order to interact or get by in the straight world.

With the ascendance of conservative public rhetoric on nuclear familialism is hardly disappearing, homophobia in society appears to be a common phenomenon. It lends itself most significantly to the creation of the ghetto-like status of gay neighborhoods in the advanced industrial world. And in this respect, it has a direct role in setting the stage for AIDS. Gays as a subcultural grouping are marked off and sometimes geographically cordoned off from the larger society by virtue of their sexual orientation. As a consequence, sexually oriented businesses catering to gay social activities, gay baths, bookstores, leather boutiques, and pornographic theaters are concentrated predominantly in these areas of the city offering gay men easy access to frequent, anonymous, and impersonal sex, often times next door or down the street. This can be a barrier to successful AIDS prevention education campaigns.

Summary:

A study of sexually transmitted disease reveals the complex interplay between cultural and political factors in society's response to diseases. AIDS is becoming increasingly politicized, and fear of the disease can be manipulated to justify various political and social agendas. The advocates of individual responsibility seem uninterested in the complexities of individual motivation or the role of cultural conditioning in the shaping of behaviour. They seem to assume an uniformly high degree of autonomous individual control over one's life circumstances, denying the relevance of gender, social class, or race, and sexual orientation in determining the parameters of individual choice. If this ideological trend continues to gain credence, AIDS prevention educators will not have the power to end the AIDS epidemic.

CHAPTER SIX: CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

Conclusions

The study utilized a poststructuralist mode of discourse analysis and aimed not to trace causal influences among AIDS prevention education programs in Vancouver between 1983-1994, nor did it adhere to strict historical principles. Rather it attempted to reveal who has had the power to construct, deliver, and implement AIDS prevention education. In order to do this, AIDS Vancouver's policy documents and newsletters were utilized. These discourses represented important sites of public discourse around AIDS prevention education. The study also included data from personal journals of those that have been involved in the development of AIDS prevention education. These documents represented the discourse for the development, implementation, and evaluation of curriculum and instruction in the community around AIDS prevention education. The documents were useful in many ways. It was possible to demonstrate historical changes over time, but they are weak in one sense, they do not reveal how the organization dealt with homophobia, sexism, and racism. To address these issues, I maintain that it would be necessary to interview individuals in order to understand these issues in the context of AIDS. In addition, failure to incorporate culture as a basic underlying epistemological principle can only yield short-sighted findings. Explicating relevant cultural factors, issues, and

experiences is a time consuming process. However, without considering culture, the research will be reduced in its overall effectiveness.

Based on the evidence presented here, history has played two quite distinct roles in the AIDS story. Initially, AIDS was a "new" policy area where established interests and policy lines had not yet ossified. In an open situation, history could play a practical rather than a symbolic role. How far that role was justified is a different matter. For what lay behind this form of historical intervention was a conservative assumption that there was indeed a "lesson of history" that could be learned, that the past could be used to provide a very specific blueprint for a present-day policy reaction. It implied too that history was incontrovertible "fact" rather than a mass of differing interpretations themselves historically constructed. The belief that historical evidence was some higher form of truth was certainly useful in establishing particular policy positions in relation to AIDS and, in the 1960s (but not in the 1980s), for drugs. But the form of historical relevance adopted was more equivocal in its benefits from the viewpoint of the discipline. It implicitly downplayed some of its subtler strengths in favor of a focus on historical fact and messages that many historians would find problematic. Were historians (along with other social scientists) relapsing into positivism via AIDS?

This does not mean that history has no role to play in the future analysis of AIDS prevention education. AIDS in its later stages has, as this study has argued, opened up the possibility of other forms of historical input, which also have relevance to the development of the role of history more generally in the study of health policy. History as background is important. Historians can produce the necessary historical perspective. But historical skills can also be applied to provide a critical analysis of almost current developments. Can this type of work bear a relation to policy? History here too can be "policy relevant," although less directly than in the earlier "lesson of history" approach. History can provide some of the key tools for an overall analysis of a particular situation and can demonstrate how interests and strategies, alliances and power struggles, within policymaking can shift over time. The point here is not the "lesson of history" derived from cholera, plague, or the Black Death but a subtler analysis of the nature and determinants of AIDS policymaking. This function for the history of health policy is, it should be noted, more problematic in Canada than in the United States; policymakers in the former remain to be convinced.

What are the particular tools that history can provide? These are threefold: its use of a chronological approach; a sense of continuity as well as of change; and, within an overall chronology, the ability to interweave different theoretical perspectives and levels of interpretation. AIDS,

a "stunning metaphor" in social and welfare terms for other policy areas, has also crystallized some of the debates within the historical profession over the past decade. Historical relevance is one; so too are the debates around chronology. Chronology may not be everything, and historians have now shown that much fundamental work in history cannot be done with a purely chronological approach. Nonetheless, history, more than any other social science, knows how to study the passage of time. Another potential strength (and weakness too) lies in the historian's interest in change and continuity, in an implicit cynicism about proclaimed radical new departures in policy. A historical strength lies in locating policy change in past practice, in seeking out antecedents and preexisting tendencies that feed into policy development. At its worst, this can be an obsessive desire to deny any possibility of real change or the relevance of individual and collective effort; but, at its best, it provides a powerful means of setting policy development in its proper context. In the AIDS area, for example, "new" policies on research, or illegal drugs, can only be assessed in the light of previous tendencies and policy objectives. One basic historical question is how far AIDS brought about policy change and how far such change was dependent on preexisting interests and tensions.

The final strength of the historical approach lies in an area in which, to observers from other disciplines, it is often considered weak. This is the presumed atheoreticity of

the subject. Some historical work is indeed atheoretical and totally empirical in approach; but social historians are mostly theoretically eclectic rather than devoid of broader intellectual context. The borrowing from sociological theory in the 1960s and 1970s is one example, as are also the interest and cross-fertilization with sociological concerns. Herein lies a strength (and weakness) of history. The historical approach is unique in its generalizing ability to deal with a range of primary source material bearing on the interplay of policy interests and the development of cultural constructs and to interweave that complex story with levels of theoretical explanation all within a framework that takes account of the passage of time. The analysis of the social and policy impact of AIDS and of other issues of health and disease remains an essentially cross-disciplinary question in which history has a vital role to play; for the value of such collaboration lies not in a blurring of disciplinary distinctions, namely "postdisciplinary stage," but in a sharpening of perceptions and a greater awareness of the nature of the boundaries.

Implications of the Research

Most AIDS prevention education programs focus too much on individual behaviour and too little on the social and political factors that shape behaviour. To reduce the incidence of HIV, AIDS education programs need to help people change their sexual and drug habits. But sexuality and drug use are complicated behaviours, deeply rooted in

cultural, social, economic, and political ground. To attempt to change the behaviour without changing the social environment in which that behaviour occurs ignores much of what we know about health education. It also reinforces a tendency all too common in public health programs to blame the victims of disease rather than the perpetrators of the social conditions that create illness.

AIDS programs lack a comprehensive approach to prevention and treatment. Few AIDS services integrate prevention and treatment. In reality the two are inseparably intertwined. Support groups for HIV-positive people help them to initiate and maintain the behaviour changes that will prevent them from infecting others. But too often prevention and treatment compete for limited resources.

Equally important are methodological considerations that emerge from this analysis of AIDS prevention education. The theoretical models used for AIDS prevention education need to incorporate culture and communication more explicitly. Work must be done to define which components of the models are culturally influenced. The cultural connection must be more visible in conceptual discussions and the reports of studies that emanate from the models. Many extant studies do not include discussions of research that might have informed decisions made in the developing strategies for use with various targeted populations. It is not clear whether supplementary

descriptive research was done, or even if such research was perceived as necessary. Although such formative research may not be particularly expedient, it is nonetheless valuable. This suggests a need for a sharper focus on culture to increase the power of the conceptual models.

Such a focus requires an altered mindset, particularly on the part of researchers. We no longer have the luxury of designing studies that fail to account for the cultural diversity that characterizes today's society. It has been argued in this study that culture is a system of meanings and practices that affect the individual's attitudes and behaviours. This implies a shift from the simple pursuit of variables to more encompassing process of research.

Until recently, the gay bars and other establishments offering entertainment glorified the "fast-lane" fantasies so often considered by many outsiders to be synonymous with the gay life-style. Youth, sex, drugs, parties, leather, and to a lesser extent, sado-masochistic practices were held up by the gay male as valued and worthy of being sought after. Publications, posters, and signs paid ample testimony to the superior status of this fast-lane, multiple-partnered, anonymous sexual life-style as the normal way of living gay, a way touted for its atypically non-Western, unabashed devotion to please. Gay are self righteously accalimed for having broken the shackles of the puritanical, heterosexual lifestyle where sexual desire is met with "measured denial" (Weeks, 1986). The point is that the prevalence of this

attitude derives from the nearly universal presence of homophobia in this culture. Some gay accepts this self-indulgent presentation of life; others do not. Those who do represent the former group are most seriously at-risk for contracting AIDS.

Doing AIDS research is crisis-driven. All those involved in this endeavor are reacting with a sense of urgency to an immediate need. With taboo issues that often surround perceptions of AIDS, the emotional and moral stakes might be higher. This makes the research different from research on other health-related issues because of the impact on an entire community.

Recommendations:

AIDS prevention education should be seen as a cultural communication process. It is appropriate to suggest directions that recognize cultural diversity in future research. I hope to identify the lines of research and the methodological shifts necessary to incorporate a cultural perspective. From the perspective of a researcher, I have selected topics that I feel researchers could best address. My intention here is to identify options for research and to prioritize their relative importance. Identifying some should help communities and allies to set the terms of debate and the fight for resources, etc. in the future.

Numerous avenues are available for further exploration of the ways in which culture is embedded in the HIV educational process. Culture can be included in the

consideration of the destination, source, message, channel, and receiver variables in the creation of health promotion messages.

Choosing the destination implies asking whether a message should be designed to impact knowledge, attitudes, or action; whether a message should be processed immediately or in the future, and whether it should be designed to cause change or cause resistance to change. Although the same factual information can be found in various forms, the two basic AIDS prevention messages are: avoid sharing needles, and do not have unprotected sex. The target audience must be well understood to know which messages will be appropriate in which settings.

AIDS prevention messages and programs typically focus on skills and/or attitudes. Both foci can be enriched by attention to culture. Although communication skills are often presumed to be generalizable across different groups, one research avenue to pursue is whether some skills are more crucial or more appropriate for different cultural groups. Research might also investigate what counts as the necessary social support, strategies to regulate one's behaviour, and motivations to continue new behaviours for people in various cultural contexts.

Health promotion advocates realize that knowledge and skills alone will not change behaviours; corresponding attitudinal changes must also occur. Attitudes toward behaviours that may be pleasurable, but involve high levels

of risk, must be altered, as must perceived norms among referent groups and fear from myths and misconceptions about AIDS. Correcting misinformation is particularly important for the broadly conceived general public.

Centered on the bodily experiences of illness and death, the social meaning of the history of AIDS prevention education intimately touches upon our ideas about sexuality and societal divisions, social responsibility and individual privacy, order and instability, and above all, health and the prospect of happiness. Understanding how we respond to AIDS as an epidemic is consequently important not only for what it reveals about the ways in which health policy is created, but also for what it implies about our ability to meet the challenge of future emerging diseases and longstanding public health problems.

Not only is disease prevention translated into the realm of individual effort, but the only actions typically considered are those that can be implemented by solo individuals. Little attention is accorded to possible disease prevention strategies to be used between persons with unequal power, such as consumers versus food producers over pricing policies or workers versus employers over occupational hazards. This orientation reflects the dominant view of individuals as isolated atoms, rather than as persons who necessarily are carriers of the social relations of class, race, and gender that permeate the society of which they are a part. Intended or not,

attitudes toward the causation and prevention of diseases now affect our thinking about AIDS and, if not addressed, threaten to vitiate our still inadequate response to the HIV epidemic.

The overwhelmingly individualistic biomedical orientation of the infectious and chronic disease models and their typical disregard for the particular health status of racial/ethnic minorities in the Canada also has distorted our understanding of the full epidemiology and reality of AIDS. Much of the early writing about AIDS, for example, ignored its prevalence and unique characteristics among people of color. Patterns of homosexuality and heterosexuality are not, however, cultural givens; they have different social constructions within white and minority ethnic communities, and these differences need to be understood and appropriately addressed. Given the multiple social and economic difficulties that many of these communities face, the specific problems of AIDS need to be approached within an understanding of the issues of employment, education, housing, economic development, and the struggles against the drugs that are flooding inner city communities. Needle exchange programs, for example, should be allied with drug treatment programs and other alternative initiatives that offer some hope for an alternative to long-term drug dependence. Most of the issues that are critical for people with AIDS, such as

housing and health care, are widespread problems throughout these communities.

The epidemiological categories of "risk groups" that are firmly embedded in biodeterministic models also tend to mask the class basis of many health issues. Therefore, it is necessary to problematize "at risk." AIDS and HIV-related diseases are no exception. Official AIDS statistics, for example, report cases classified by age, gender, race/ethnicity, and mode of transmission and do not provide any information on poverty or social class. The invisibility of class in the official data mirrors the invisibility of class in public understanding and public policy. As educators move away from thinking solely in emergency terms and in terms of static, individualistic "risk groups," with the health experts in charge of strategic planning for AIDS, it should be possible to develop more coalition-based planning and policy making by involving unions, community-based, minority, and gay organizations. Other important research areas that need to be explored are women and AIDS and AIDS in popular society and media. The former is particularly important because there was very little attention given to women and AIDS in the history of AIDS in Vancouver. Secondly, there are very few clinical studies researching disease etiology of AIDS in women.

In this second decade of AIDS, educators have the opportunity to learn from the first decade, from the unique

history of AIDS itself, and no longer need to rely upon prior and not necessarily appropriate models. In seeking a more unified conception of AIDS, educators need to retain the strengths of both earlier models and use each to counterbalance the weakness of the other. If educators can begin this process with AIDS, it may also open new possibilities for dealing with other conditions that may have been too narrowly boxed into either the infectious or chronic disease model.

In conclusion, the findings of this study suggest that present education guidelines are unable to identify what message should be communicated and fail to identify to whom they should be conveyed. This study does not recommend the use of biodeterministic models of disease prevention which reflect plague metaphors. Furthermore, commonsense medical prescriptions are so familiar that we do not look for the deeper "meanings" underlying them.

There is an urgent need to consider sexual issues related to HIV prevention because of the stunning level of ignorance regarding sexuality in most if not all societies. For example, how well do existing models of sexual behaviour take account of changing environmental or situational factors? The details of seduction, sexual approach, and negotiation about sexual acts remain unobserved and unobservable through the use of existing concepts and measurement techniques about sexuality.

References

Primary Sources

Annual Reports:

AIDS Vancouver Annual Report, 1991-1994.

Annual Report of the Medical Health of the City of Vancouver, 1983-1991.

B. C. Ministry of Health: Annual Report, 1982/83-1994.
Victoria: Queens Printer.

External Reviews:

AIDS Vancouver Department of Education. (1994). Taking care of ourselves.

AIDS Vancouver Department of Education. (1991). A survey of AIDS-related knowledge, attitudes, and behaviours among gay and bisexual men in greater Vancouver.

Krueckl, J. (1987). Evaluation of support services.

Marchand, R. (1989). Fighting AIDS with education: Report of the gay community needs assessment.

Manuals:

All sexually active men should know these facts! (1983).

A Risk Reduction Guide for AIDS. (1985).

What are the symptoms of Immune Deficiency. (1984).

Newsletters:

AIDS Update. 1987-1994.

AIDS Vancouver: Fighting fear and confusion. (1983).

The AIDS Vancouver Volunteer Voice Newsletter. 1992-1994.

British Columbia Persons with AIDS Society Newsletter. 1983-1994.

Contact. 1990-1992.

An introduction to AIDS Vancouver. (June, 1986).

What is AIDS? (1985).

When a friend has AIDS. (1984).

Who we are and what this is. (1983).

Miscellaneous:

Funding proposal to the health promotion directorate: Health services and promotion branch, Health and Welfare Canada. (April 3, 1985).

Persky, S. (1988). Report of the constitution committee.

Organizational policies. (1992).

Minutes from Board Meetings:

Minutes from all board meetings which were held monthly. (1983-1994).

Secondary Sources

Aggleton, P. & Homans, H. (Eds.). (1988). Social aspects of AIDS. New York: Falmer.

Aggleton, P., Hart, G., & Davies, P. (Eds.). (1989). AIDS: Social representations, social practices. New York: Falmer.

Alcoff, L. (1991). The problem of speaking for others. Cultural Critique, 20, 5-32.

Altman, D. (1988). Legitimation through disaster: AIDS and the gay movement. In E. Fee & D. M. Fox (Eds.), AIDS: The burdens of history (pp. 301-315). Berkeley: University of California.

Atkinson, P. (1990). The ethnographic imagination: Textual constructions of reality. London: Routledge, 1990.

Atkinson, P. (1990). The Ethnographic Imagination: textual constructions of reality. London, New York: Routledge.

Barling, N. R. & Moore, S. M. (1990). Adolescents' attitudes towards AIDS, precautions, and intention to use condoms. Psychological Reports, 883-90.

Barthes, R. (1975). The Pleasure of the Text. Tr. Miller, R. Note on the text by Richard Howard. New York: Hill and Wang.

Barthes, R. (1975). The pleasure of the text. Trans. R. Miller. New York: Hill & Wang.

Bayer, R. (1989). Private acts, social consequences: AIDS and the politics of public health. New York: Free.

Bayer, R. & Kirp, D. L. (Eds.). (1992). AIDS in the industrial democracies: Passions, politics, and policies. New Jersey: Rutgers UP.

Beauchamp, D. E. (1991). Morality and the health of the body politic. In N. Mackenzie (Ed.), The AIDS reader: Social, political and cultural issues (pp. 408-421). New York: Meridian.

Boffin, T. & Gupta, S. (Eds.). (1990). Ecstatic antibodies: Resisting the AIDS mythology. London: Rivers Oram.

Bok, M. & Morales, J. (1992). Multicultural human services for AIDS treatment and prevention: Policy, perspectives, and planning. New York: Haworth.

Bove, P. (1990). Discourse. In F. Lentricchia & T. McLaughlin (Eds.), Critical Terms for Literary Study (pp. 51-76). Chicago: University of Chicago Press.

Brandt, A. (1988). AIDS as metaphor: Toward the social meaning of epidemic disease. Social Research, 55(3), 413-32.

Brandt, A. M. (1988). AIDS: From social history to social policy. In E. Fee & D. M. Fox (Eds.), AIDS: The burdens of history (pp. 147-171). California: University of California Press.

Brown, M. (1995, forthcoming). Ironies of distance: An ongoing critique of the geographies of AIDS. Society and Space, 13.

Brunet, J. B. (1991). Director, Centre Européen pour la Surveillance Epidémiologique de SIDA, personal communication.

Carter, E. & Watney, S. (Eds.). (1989). Taking liberties: AIDS and cultural politics. London: Serpent's Tail.

Christian-Smith, L. K. (1990). Becoming a woman through romance. New York: Routledge.

Cohen, M. E. (June, 1991). Using theoretical frameworks to evaluate HIV prevention programs. Presented at the VII International Conference on AIDS. Florence, Italy.

Cohen, M. E. (June 1991). Using theoretical frameworks to evaluate HIV prevention programs. Presented at the VII International Conference on AIDS, Florence, Italy.

Crimp, D. (Ed.). (1989). AIDS: Cultural analysis, cultural activism. (2nd. ed.). Cambridge, Massachusetts: MIT.

Crimp, D. (Ed.). (1987). AIDS: Cultural analysis, cultural Activism. London, England: MIT.

Crimp, D. (1992). Portraits of people with AIDS. Cultural studies (pp. 117-133). New York: Routledge.

Crimp, D. (1988). How to have promiscuity in an epidemic. AIDS: Cultural analysis/cultural criticism (pp. 237-271). Cambridge: MIT.

Crimp, D. & Rolston, A. (1990). AIDS demographics. Seattle: Bay.

Crimp, D. (1992). AIDS demographics. In A. Klusacek & K. Morny (Eds.), A leap in the dark: AIDS, art and contemporary culture (pp. 47-57). Montreal: Vehicule.

Culler, J. (1975). Structuralist poetics. Ithaca, NY: Cornell University Press.

Dickinson, P. (1995, forthcoming). "Go-go dancing on the brink of the apocalypse": Representing AIDS - An essay in seven epigraphs. Apocalypse: Theory & cultural practice (pp. 227-247).

Dub , G. & Smailes, A. (Eds.). (1992). AIDS and human rights: Sharing the challenge. (A project of the Vancouver World AIDS Group). Vancouver, B. C.

Dworkin, D.L. & Roman, L.G. (Eds.). (1993). Views beyond the border country : Raymond Williams and cultural politics. New York: Routledge.

Edgar, T., & Fitzpatrick, M. A., & Freimuth, V. S. (Eds.). (1992). AIDS: A communication perspective. Hillsdale, NJ: Hove & London.

Edgar, T., Hammond, S., Lee, F., & Vicki, S. (1990). The role of the mass media and interpersonal communication in promoting AIDS-related behavioral change. AIDS Public Policy Journal, 4, 3-9.

Edwards, T. (1992). The AIDS dialectics: awareness, identity, death and sexual politics. In K. Plummer (Ed.), Modern Homosexualities: Fragments of Lesbian and Gay Experience (pp. 275-289). New York: Routledge.

Elsworth, E. (1989). Why doesn't this feel empowering? Working through the repressive myths of critical pedagogy. Harvard Educational Review. 59(3), 297-324.

Epstein, S. (1991). Democratic Science? AIDS activism and the contested construction of knowledge. Socialist Review, 21, 35-64.

Fauci, A. (1991). The human immunodeficiency virus: infectivity and mechanisms of pathogenesis. In N. MacKenzie

(Ed.), The AIDS Reader: Social, Political, Ethical Issues (pp. 25-41). New York: Meridian.

Fee, E. & Fox, D.M. (Eds.). (1992). AIDS: the making of a chronic disease. Berkeley: University of California Press.

Fee, E. (1988). Sin versus science: Venereal disease in twentieth-century Baltimore. In E. Fee & D. M. Fox (Eds.), AIDS: The burdens of history (pp. 121-146). California: University of California Press.

Fee, E. & Fox, D. M. (1988). AIDS, public policy, and historical inquiry. In E. Fee & D. M. Fox (Eds.), AIDS: The burdens of history (pp. 1-11). California: University of California Press.

Feldman, D.A. (1994). Culture and AIDS, 2nd ed. New York: Praeger.

Fernandez, E. (1991). A city responds. In N. MacKenzie (Ed.), The AIDS Reader: Social, Political, Ethical Issues (pp. 577-585). New York: Meridian.

Fineberg, H. (1992). Preface: Strategies for communication and the media. In J. Sepulveda, H. Fineberg, & J. Mann (Eds.), AIDS prevention through education: A world view. New York: Oxford University Press.

Foucault, M. (1980). The history of sexuality. Hurley, R. (Trans.). New York: Vintage Books.

Foucault, M., Dreyfus, H. L., & Rabinow, P. (Eds.). (1983). Michael Foucault, beyond structuralism and hermeneutics. Chicago: University of Chicago Press.

Foucault, M. (1977). Language, counter-memory, practice : selected essays and interviews. Tr. Bouchard, D.F. & Simon, S., ed. Bouchard, D.F. Ithaca, NY: Cornell University Press.

Fox, D. M. (1988). The politics of physicians' responsibility in Epidemics: A note on history. In E. Fee & D. M. Fox (Eds.), AIDS: The burdens of history (pp. 86-96). California: University of California Press.

Fox, D. M. & Karp, D. R. (1988). Images of plague: Infections disease in the visual arts. In E. Fee & D. M. Fox (Eds.), AIDS: The burdens of history (pp. 172-189). California: University of California Press.

Fuss, D. (Ed.). (1991). Inside/out: Lesbian theories, gay theories. Routledge, New York.

Gamson, J. (1991). Silence, Death, and the Invisible Enemy: AIDS Activism and Social Movement 'Newness'. In M. Burawoy

(Ed.), Ethnography Unbound: Power and Resistance in the Modern Metropolis. Berkeley: University of California.

Gorund, V. (1993). The Slow Plague. Oxford: Basil Blackwell.

Gould, C. A. (1990). Beyond disease: A conceptual analysis of the language and origins of the meaning of AIDS in a socio-historic and medical context. Unpublished doctoral dissertation, University of Pennsylvania, Philadelphia.

Gould, P. (1991). Modelling the geographic spread of AIDS for educational intervention. In R. Ulack & W. F. Skinner (Eds.), AIDS and the Social Sciences (pp. 30-44). Lexington: University of Kentucky.

Greene, W. C. (1993). AIDS and the immune system. Scientific American, 3(269), pp. 98-105.

Grover, J. Z. (1988). AIDS: Keywords. In D. Crimp (Ed.), AIDS: Cultural Analysis/Cultural Activism (2nd ed.), (pp. 17-30). Cambridge: MIT.

Grover, J. Z. (1992). AIDS, keywords, and cultural work. In L. Grossberg, C. Nelson, and P. Treichler (Eds.), Cultural Studies (pp. 227-239). New York: Routledge.

Hall, S. (1988). The hard road to renewal: Thatcherism and the crisis of the left. London, New York: Verso.

Hanson, E. (1992). The promise of monsters: a regenerative politics for inappropriated others. In L. Grossberg, C. Nelson, P. Treichler (Eds.), Cultural Studies (pp. 295-337). New York: Routledge.

Hanson, E. (1991). Undead. In D. Fuss (Ed.), Inside/Out: Lesbian Theories, Gay Theories (324-340). New York: Routledge.

Health and Welfare Canada. (1990). AIDS Surveillance Report. Ottawa: Supply and Services Canada.

Herd, G. & Lindenbaum, S. (1992). The time of AIDS: Social analysis, theory, and method. Newbury Park: Sage Publications.

Hornik, R. C. (1991). Channel effectiveness in development communication programs. Philadelphia: Annenberg School of Communications.

Horton, M. (1989). Bugs, drugs, and placebos: The opulence of truth, or how to make a treatment decision in an epidemic. In E. Carter & S. Watney (Eds.), Taking Liberties: AIDS and Cultural Politics (pp. 161-182). London: Serpents Tail.

Humm, A., & Kunreuther, F. (1992). Educating teenagers about AIDS can help stop its spread. In M. D. Biskup, & K. L. Swisher (Eds.), AIDS: Opposing viewpoints (pp. 141-148). Greenhaven Press, Inc.

Karsten, P., & Modell, J. (Eds.) (1992). Theory, method, and practice in social and cultural history. New York: New York University Press.

Kayal, P. M. (1993). Bearing witness: Gay men's health crisis and the politics of AIDS. Boulder: Westview.

Knopp, L. (1992). Sexuality and the spatial dynamics of capitalism. Environment and Planning D: Society and Space, 10, 651-669.

Kotarba, J. A. (1990). Ethnography and AIDS: returning to the streets. Special issue on ethnography and AIDS in Journal of Contemporary Ethnography, 3(10), 259-270.

Kramer, L. (1989). Reports from the Holocaust: the Makings of an AIDS Activist. New York: St. Martin's.

Krieger, N., & Margo, G. (Eds.). (1994). AIDS: The politics of survival. Amityville, NY: Baywood.

Kuklin, S. (1989). Fighting Back: What Some People Are Doing About AIDS. New York: G. P. Putnam's Sons.

Kurdek, L. A. & Siesky, G. (1990). The nature and correlates of psychological adjustment in gay men with AIDS-related conditions. Journal of Applied Social Psychology, 20, 846-60.

Kurdek, L. A., & Siesky, G. The nature and correlates of psychological adjustment in gay men with AIDS-related conditions. Journal of Applied Social Psychology, 20, 846-60.

Lauria, M. & Knopp, L. (1985). Toward an analysis of the role of gay communities in the urban renaissance. Urban Geography, 6, 152-169.

Lerner, E. A. (1987). Understanding AIDS. Minneapolis: Lerner.

Lilienfeld, A.M. & Lilienfeld, D.E. (1980). Foundations of Epidemiology. New York: Oxford University Press.

Malinowsky, R. & Perry, G. J. (1991). AIDS information sourcebook. Phoenix: Oryx.

Mann, J. M. (1992a). Health promotion against AIDS: A typology. In J. Sepulveda, H. Fineberg, & J. Mann (Eds.), AIDS prevention through education: A world view (pp. 21-34). New York: Oxford University Press.

Mann, J. M., Tarantola, D. J. M., & Netter, T. W. (1992b). Prevention through education. AIDS in the world. Cambridge: Harvard University Press.

Manning, P. K., & Cullum-Swan, B. (1994). Narrative, content, and semiotic analysis. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of Qualitative Research (pp. 463-478). Thousand Oaks, CA: Sage Publications.

Marcus, G. (1992). "Commentary: More (critically) reflexive than thou": the current identity politics of representation. Environment and Planning D: Society and Space, 10, 489-493.

Meyers, T., Godin, G., Calzavara, L., Lambert, J., & Locker, D. (1993). The Canadian Survey of Gay and Bisexual Men and HIV Infection: Men's Survey. Ottawa: Canadian AIDS Society.

Musto, D. F. (1988). Quarantine and the problem of AIDS. In E. Fee & D. M. Fox (Eds.), AIDS: The burdens of history (pp. 67-85). California: University of California Press.

National Advisory Committee on AIDS (NAC-AIDS). (1992). HIV and Human Rights in Canada (A report submitted by the National Advisory Committee on AIDS (NAC-AIDS) to the Minister of National Health and Welfare). Ottawa: National AIDS Clearing House.

Navarre, M. (1988). Fighting the victim label: PWA Coalition portfolio. In D. Crimp (Ed.), AIDS: Cultural Analysis/Cultural Activism (pp. 147-166).

Netter, T. W. (1992). The media and AIDS: A global perspective. In J. Sepulveda, H. Fineberg, & J. Mann (Eds.), AIDS prevention through education: A world view (pp. 241-250). New York: Oxford University Press.

O'Malley, P. (1989). The AIDS epidemic: Private rights and the public interest. New Haven, CT: Greenhaven Press.

Oppenheimer, G. M. (1988). In the eye of the storm: The epidemiological construction of AIDS. In E. Fee & D. M. Fox (Eds.), AIDS: The burdens of history (pp. 267-300). California: University of California Press.

Osborn, June. (1992). U. S. response to the AIDS epidemic: Education prospects in a multicultural society. In J. Sepulveda, H. Fineberg, & J. Mann (Eds.), AIDS prevention through education: A world view (pp. 343-348). New York: Oxford University Press.

Palmer, S. (1989). AIDS as metaphor. Society. 44-50.

Patton, C. (1990). Inventing AIDS. New York: Routledge.

Patton, C. (1985). Sex and Germs: The Politics of AIDS. Boston: South End.

Perrow, C. & Guillen, M. F. (1990). The AIDS Disaster: The Failure of Organizations in New York and the Nation. New Haven: Yale.

Pharr, S. (1988). Homophobia: A weapon of sexism. Inverness, California: Chardon.

Porter, D. & Porter, R. (1988). The enforcement of health: The British debate. In E. Fee & D. M. Fox (Eds.), AIDS: The burdens of history. California: University of California Press.

Prieur, A. (1990). Norwegian gay men: Reasons for continued practice of unsafe sex. AIDS Education and Prevention, 2 109-15.

Quackenbush, M. & Sargent, P. (1988). Teaching AIDS. California: Network.

Rappoport, J. (1988). AIDS Inc. : Scandal of the Century. San Bruno, CA: Human Energy Press.

Rayside, D. M., & Lindquist, E. A. (1994). AIDS activism and the state in Canada. Studies of political economy, 39, 37-77.

Rayside, D. M., & Lindquist, E. A. (1992). Canada: Community activism, federalism, and the new politics of disease. In R. Bayer & D. L. Kirp (Eds.), AIDS in the industrial democracies: Passions, politics, and policies (pp. 49-98). New Jersey: Rutgers UP.

Rekart, M. L. & Roy, J. L. (1993). AIDS Update, Quarterly Report: Third Quarter 1993. Vancouver: British Columbia Centre for Disease Control.

Roman, L. G. (1996). Spectacle in the dark: Youth as transgression, display, and repression. Educational theory, 46(1).

Risse, G. B. (1988). Epidemics and history: Ecological perspectives and social responses. In E. Fee & D. M. Fox (Eds.), AIDS: The burdens of history. California: University of California Press.

Robert, B., & Rosser, S. (1990). Evaluation of the efficacy of AIDS education interventions for homosexually active men. Health Education Research, 5, 299-308.

Roman, L. G. (1995). Spectacle in the dark: Youth as transgression, display, and repression. Educational theory, Winter/Spring (forthcoming).

Rosenberg, C. E. (1988). Disease and social order in America: Perceptions and Expectations. In E. Fee & D. M. Fox (Eds.), AIDS: The burdens of history (pp. 12-32). California: University of California Press.

Rosenthal, D. B. (1989). Passion, compassion, and distancing in the AIDS literature. Urban Affairs Quarterly, 25, 173-180.

Ross, M. W. (1992). Attitudes towards condoms and condom use: A review. International Journal of STDs and AIDS, 3, 10-16.

Russo, V. (1990). A test of who we are as a people. In B. Wallis (Ed.), Democracy: A project by group material (pp. 299-302). Seattle: Bay Press.

Rutherford, J. (Ed.). (1990). Identity, community, culture, difference. London: Lawrence & Wishart.

Scott, J. W. (1988). History in crisis? The others' side of the story. American Historical Review, 94, 680-692.

Sears, J. T. (1993). Sexuality and the curriculum. New York: Teachers College.

Sepulveda, J. (1992). Prevention through information and education: Experience from Mexico. In J. Sepulveda, H. Fineberg, & J. Mann (Eds.), AIDS prevention through education: A world view. New York: Oxford University Press.

Sepulveda, J., Fineberg, H., & Mann, J. (1992). AIDS prevention through education: A world view (pp. 127-144). New York: Oxford University Press.

Shafer, R. J. (1974). A guide to historical method (2nd ed.). The Dorsey Press: Boston.

Shilts, R. (1987). And the band played on: Politics, people, and the AIDS epidemic. New York: Penguin.

Siegel, K., Grodsky, P., & Herman, A. (1986). AIDS risk-reduction guideline: A review and analysis. Journal of Community Health, 2, 233-43.

Siegel, K., Grodsky, P., & Herman, A. (1986). AIDS risk-education guideline: A review and analysis. Journal of Community Health, 2, 233-43.

Silin, J. (1987). The language of AIDS: Public fears, pedagogical responsibilities. Teachers College Record, 89(1), 3-19.

Silverman, M. F. (1992). AIDS education and politics. In J. Sepulveda, H. Fineberg, & J. Mann (Eds.), AIDS prevention

through education: A world view (pp. 349-360). New York: Oxford University Press.

Smith, D. E. (1990). Texts, facts, and femininity: Exploring the relations of ruling. New York: Routledge.

Sontag, S. (1988). AIDS and its metaphors. New York: Farrar, Straus, and Giroux.

Stoller, E., & Rutherford, G. (1989). Evaluation of AIDS prevention and control programs. Current Science Ltd, 3, S289-96.

Strader, M. K., & Baeman, M. L. (1991). Comparison of selected college students' and sexually transmitted disease clinic patients' knowledge about AIDS, risk behaviours and beliefs. Journal of Advanced Nursing, 16, 584-89.

Treichler, P. A. (1988). AIDS, gender, and biomedical discourse: Current contests for meaning. In E. Fee & D. M. Fox (Eds.), AIDS: The burdens of history (pp. 190-266). California: University of California Press.

Tuchman, G. (1994). Historical social science: Methodologies, method, and meanings. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of Qualitative Research (pp. 306-323). Thousand Oaks, CA: Sage Publications.

Van Vugt, J. P. (Ed.) (1994). AIDS prevention and services: Community based research. Westport, CT: Bergin & Garvey.

Wacher, R. (1990). The fragile coalition: Scientists, activists, and AIDS. New York: St. Martin's.

Wallis, M. (1989). Gramsci-the-goalie: reflections in the bath on gays, the Labour party, and socialism. In S. Shepard & M. Wallis (Eds.), Coming on strong: Gay politics and culture (pp. 287-300). London: Unwin Hyman.

Walters, D. (1989). AIDS the teacher: What have we learned in Canada? Canadian Journal of Public Health (Special supplement on AIDS), 80(1), 53-58.

Watney, S. (1987). Policing Desire: Pornography, AIDS, and the Media. Minneapolis: University of Minnesota.

Watney, S. (1988). The spectacle of AIDS. In D. Crimp (Ed.), AIDS: Cultural Analysis/Cultural Activism (pp. 71-86). Cambridge: MIT.

Watney, S. (1989). The subject of AIDS. In P. Aggleton, G. Hart, & P. Davies (Eds.), AIDS: Social representations, social practices (pp. 64-73). Falmer: New York.

Weeks, J. (1986). Sexuality. London: Tavistock.

Whitmore, G. (1988). Someone was here: Profiles in the AIDS epidemic. New York: New American Library.

Williamson, J. (1989). Every virus tells a story: the meanings of HIV and AIDS. In E. Carter & S. Watney (Eds.), Taking liberties: AIDS and cultural politics (pp. 69-80). London: Serpents Tail.

APPENDIX I

The initial discoveries heralding a new disorder of unknown origin were made by physicians treating patients in Los Angeles. The CDC was alerted in 1981 that previously healthy homosexual men were being treated for PCP and KS. By mid-1982, the CDC stressed the homosexuality of those affected and began studies analyzing the interrelation of lifestyle and AIDS. Analysts linked the epidemic the gay liberation and the attendant lifestyle of bars, discos, bathhouses, and anonymous sex. The CDC used the word GRID - Gay Related Immune Deficiency to explain the medical condition. The media and the popular presses stressed that the disease was a retribution for the sexual revolution and liberation of the 1960s. Only in the spring of 1983, after a year of suggestive data, the CDC recognized that the disease was more than a syndrome of homosexual men and promiscuity. Yet the CDC continued its promotion of the "Lifestyle Hypothesis" because of previous outbreaks of other diseases such as Legionnaires' disease. This trend continued until 1985, when the first medical article revealing epidemiological evidence for heterosexual transmission. The CDC then adopted "AIDS" and emphasized those groups "at risk."