AIDS: Social Construct and Implications for Social Work

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ABSTRACT

The social construction of AIDS (Acquired Immune Deficiency Syndrome), or the ways in which people perceive or think about it, is the focus of this thesis. Exploratory research is conducted through guided interviews with social workers involved in AIDS care. Their responses and perceptions are compared to those gathered from similar interviews with individuals diagnosed with AIDS or ARC (AIDS Related Complex) and family members and lovers of people with AIDS and ARC. The constructivist model is employed as the methodological framework in this process.

News magazines and professional literature augmented the data collection process. AIDS has been in the forum of public discussion for some time. Given this fact, news magazines were included as they contain data pertaining to the construct of AIDS distributed to the general public. Social workers confirmed the importance of such material by stating that much of their AIDS related information was gathered from newspapers, articles, and television programmes.

Foucault's analysis of sexuality contextualizes the news reporting of AIDS and the actions of those who live with AIDS. Sexuality is socially constructed and employed in the development of knowledge and the exertion of power. Sexuality exists as a form of social control. This perception clarifies the social construction of AIDS and the decisions and actions made by those living with AIDS.

The analysis of interviews and documentary materials concludes that AIDS has been constructed in three ways; medically, socially, and politically. Social workers and those who live personally with AIDS had the greatest perceptual agreement when they spoke of the social components of this syndrome. They were the furthest apart when they spoke of the
political aspects of this illness. Individuals with AIDS and ARC spoke of their explorations of alternative therapies and their attempts to gather knowledge about their illnesses. They also spoke of the conflicting situations which sometimes developed between themselves and the authorities they dealt with through institutionalized medicine. Social workers mentioned some of these issues, but appeared to operate on the institutional side of certain issues rather than acting as advocates for those who live with AIDS. A clear example of this is terms of reference. Those who live with AIDS used terms such as "People with AIDS" or "PWA." Social workers, on the other hand, defended their use of the clinical term "patient."

Interviews with social workers revealed how stereotypes and attitudes towards gay men changed as health care providers had direct experience with those living with AIDS. Interviews discovered that in caring for "patients" many professionals grew to care about people. Discrepancies in financial assistance and institutional support were also noted. Private agencies such as AIDS Vancouver and the PWA Coalition were found to supply many of the services needed in the community outside of hospitals. Social workers noted that they depended on those agencies when making referrals to the community. Governments were chastized for their responses to this health crisis.

General questions for social work in health care are posed as the result of these findings. Where does social work "fit" in the political framework of health care? As professionals where should and do social workers place their allegiance while engaging in every day work? Social workers should be aware of the importance of their attitudes towards those they work with and realize how that work can be effected by such perceptions. Such work begins with an analysis of one's own attitudes and beliefs.
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To those who have had, and are living with AIDS, for their teaching.

To Hal Goodwin and Nancy Waxler-Morrison, for their advice and patience.

To Glenn Allison, for his insights and ability to question.

To my family and Bob Frampton, for their endurance.
We are all on the inside of this epidemic; because we grieve over those who have already died; or because we are intellectually and professionally challenged in solidarity with our fellow human beings throughout the world to devise effective prevention and cure, and to care for those for whom innovative therapies will come too late. Soren Kierkegaard's repeated reminder to readers of Either/Or, his extended letter on existential questions, applies to AIDS and to us: "I am not speaking to you about someone else; but to you about yourself."

David Roy and Chris Tsoukas

Ethics and AIDS
AIDS: THE PROBLEM AND THE APPROACH

AIDS (Acquired Immune Deficiency Syndrome) is a major health concern in the late twentieth century. Much biological and medical data has been gathered since the first acknowledgement of this syndrome in North America during 1981. More biological and medical information still needs to be discovered. Psychosocial concerns have followed and not preceded the search for medical information in this and many other fields. The psychosocial literature pertaining to AIDS is growing and this thesis adds to that development.

AIDS and its social construct, or the ways in which people perceive or think about it, is a justifiable and previously unstudied area of concern. A review of the psychosocial literature focussed on AIDS, conducted later in this chapter, shows that professional concern to date has been focussed outwards, towards those people with AIDS primarily and then towards others associated with them. This work proposes to look inwards, at the attitudes and beliefs towards AIDS of one group of professionals, namely social workers, and to compare their perceptions with those of people who have AIDS and ARC (AIDS Related Complex) as well as those of family members and lovers of individuals with AIDS and ARC. Given the widespread reporting of AIDS, news magazines are also employed to analyze its social construct.

The approach employed in this study is based on a constructivist model. That is, it is based on the belief that "health and illness are social facts as well as biological facts".

Mishler describes it succinctly in the following:

reality is constructed through human action, and does not exist independently of it. This does not mean that the world only exists in our heads; rather, that the world as a
meaningful reality is constructed through human interpretative activity.\(^3\)

CONSTRUCTIVIST MODEL

Previous academic work has been conducted in the social construction of illness. Three very different studies have proven exemplary. Mercer explored how children in the public school system come to be categorized as mentally retarded or "mentally handicapped" to use present day jargon.\(^4\) The distribution of different ethnic groups within the total school system and the proportions of each group categorized as mentally retarded are shown in the following table.\(^5\)

TABLE I
Mercer's findings of ethnicity and the Mentally Retarded in the School System

<table>
<thead>
<tr>
<th></th>
<th>ANGLO</th>
<th>MEXICAN-AMERICAN</th>
<th>BLACK</th>
<th>OTHER</th>
</tr>
</thead>
<tbody>
<tr>
<td>PERCENTAGE OF TOTAL SCHOOL POPULATION</td>
<td>80</td>
<td>11</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>PERCENTAGE OF TOTAL MENTALLY RETARDED</td>
<td>32</td>
<td>45</td>
<td>22</td>
<td>1</td>
</tr>
</tbody>
</table>

Mercer examines these findings from two perspectives, a "clinical" perspective and a "social systems" perspective. A clinical or biomedical perspective would examine the "at risk" population of Mexican-Americans and Blacks. Theories which may account for the disproportionate representation of these two groups among those categorized as mentally retarded may include: genetic theories, or environmental theories implicating the effects of nutritional deficiency in these groups on
intellectual functioning, or perhaps sociological theories suggesting the negative consequences of fatherless families on intellectual development.\textsuperscript{6}

Mercer then examines the findings from another perspective. She looks at the categorization of mental handicap as a process. Her initial unit of focus was the public school. Through independent psychological testing she found that 1.1\% of the children in private school scored below 79 on IQ tests whereas only 0.8\% of the children in public school scored below 79. This statistic is interesting given the fact that:

only two children were reported to the study by private schools as mentally retarded...In brief, children who test at these levels (below 79) are at higher risk of being labelled retarded if they are enrolled in the public schools than if they are in private schools.\textsuperscript{7}

Mercer divided the process of categorizing mental handicap into four stages. There is the referral for testing, the test itself, recommendations made after testing, and post-test enrollment. She found that the ethnic distribution of those referred for testing was consistent with the ethnic distribution of the overall school population. After testing, she found that significantly more Mexican-American and Black children scored under 79 than did Anglo children. Recommendations to special classes for all those scoring under 79 found that "only 49 percent of those with Anglo backgrounds are recommended for placement, whereas 70 percent of the Mexican-American and Black children receive such a recommendation."\textsuperscript{8} A follow-up showed that only two-thirds of the Anglo children recommended to special classes actually enrolled in them, but almost all the Black and Mexican-American children recommended to special classes do in fact enrol in those classes. Mercer
concluded with the following:

Anglocentricism, institutionalized and legitimated by the diagnostic procedures used in the formal organization of the community, appears to be the most pervasive pattern in labelling the mentally retarded in the community.  

Scott's study of blind men 10 examines the social and psychological consequences which result from being labelled as "blind." At the time of Scott's study the Snellen chart was the determining test for the categorization of blindness. If an individual was found to have "central visual acuity of 20/200 or less in the better eye with correcting lenses,"11 then they were defined as "blind." The label "blind" has consequential reactions and perceptions. One simple perception, with long range consequences, is that many professionals and the general public think of "the blind" as a homogenous group. This is simply not true. Many of the "blind" in fact have varying degrees of sight, yet we continue to perceive them as a homogeneous whole. Perceiving them as a whole also leads us to generalizations as to their personal qualities and social experiences. These generalizations become stereotypes which Scott found to include, "helplessness, dependency, melancholy, docility, gravity of inner thought, aestheticism."12 It was found, not surprisingly, that agencies which served the blind also operated from these stereotypes.

The "professional" exchange between agency and client then became one where the client was socialized into changing the definition of himself or herself into an image similar to that of the agency's perception. As Scott succinctly states, "The client's views about the problems must be discredited." 13 As should be expected, some people did redefine their
experience in-line with that of the agency and some did not. Some maintained the agency image for the convenience of acquiring service, but dropped it beyond its usefulness. And others resisted all attempts to redefine their own experiences and subsequently resisted agency services.

Scott also examined a study of blinded veterans who received financial assistance and rehabilitation. They led independent lives and had few of the symptoms of anxiety and depression usually found in individuals who have chronic medical conditions. These findings lead Scott to conclude that "blind men are not born, they are made."14

Yet another example of previous academic work concentrating on the social construction of illness is Nancy Waxler's work, "Learning to be a leper."15 This work looks at perceptions towards leprosy, and those who have it, from different cultures. The study includes data from Sri Lanka, India, Nigeria, Tanzania, Hawaii, Ethiopia, and Louisiana in the United States.

Three interesting points developed from this examination. It was found that the stigma of leprosy is not universal:

In many societies beliefs about leprosy developed and stabilized long before written records were kept. In nineteenth-century Hawaii, however, we saw the economic and social threat of the Chinese immigrants become transformed into the social threat of the disease they were believed to carry ... the moral definition of leprosy may arise from particular historical/social/medical circumstances, different in each society.16
It was also found that the perception of leprosy in each place "provides a map for the leper." The experiences of American and Ethiopian lepers were compared and contrasted. Although the experiences were different, the process for each was similar in the sense that societal expectations had a large effect upon the experience of the leper.

Once definitions of disease are established, they have a life of their own. The maintenance of perceptions regarding leprosy no longer have a connection to the disease itself. In the example of leprosy it was found that:

even though effective treatment is available in the tropical countries where the disease is prevalent, and even though the Christian missionary organizations that are often the main providers of treatment certainly do not intend to stigmatize, the stigma of leprosy continues.

The works of Mercer, Scott, and Waxler have been presented as examples of work in the constructivist approach towards illness. Each study examines the "social transformation" of disease, chronic condition, or mental categorization. This study of AIDS and the social construct which precipitates from it will also operate from the constructivist approach.

NEW PERCEPTIONS OF SCIENCE

David Bohm, a physicist, is one of those discussing new perceptions towards science. He makes the following comments within the context of scientific research, yet these perceptions are equally relevant to social work practice and research:

In scientific research, a great deal of our thinking is in terms of
theories. The word 'theory' derives from the Greek word 'theoria,' which has the same root as 'theatre,' in a word meaning 'to view' or 'to make a spectacle.' Thus it might be said that a theory is primarily a form of insight, i.e. a way of looking at the world, and not a form of knowledge of how the world is.\textsuperscript{20}

The belief that our perceptions are insights rather than knowledge creates an opportunity to examine those insights, their nature, origin, and maintenance. David Suzuki, in "A Planet for the Taking," expresses this belief in another form when he says:

\begin{quote}
what we see is governed very strongly by what we expect to see. In other words by our beliefs, and inescapably by our values.\textsuperscript{21}
\end{quote}

The words "beliefs" and "values" may trigger internal alarms for many professionals, as most believe they operate from neutral and objective positions. Ideas of neutrality and objectivity are themselves beliefs adapted from one way of thinking about science. A full discussion of the concepts of neutrality and objectivity in the social sciences could constitute a thesis in its own right. Furstenberg and Olson's article on AIDS adds a relevant point to the discussion of objectivity and neutrality in social work practice:

\begin{quote}
Social workers differ, however, from the majority of others dealing with health in taking responsibility for developing and acting from self-awareness. \textsuperscript{22}
\end{quote}

Is it possible to maintain a "neutral" position while developing and acting from self-awareness? Neutrality and objectivity are socially constructed realities. An objective position for some will be perceived as biased or prejudiced by others. Is there a choice to be made between
objectivity and self-awareness? If there is, self-awareness better equips a profession involved in activities such as client advocacy. Operating from a position of self-awareness provides the opportunity for growth, development, and analysis. Self-awareness allows one to look at other ways of doing things. Rapoport, in a discussion of house form and culture, highlights the benefit of such activity:

> through seeing other ways of doing things, we are made aware that there are other ways, that our way may be peculiar rather than inevitable, and that our values are neither the only ones, nor the norm. Seeing other methods helps us to discover the distinctiveness of our own. Comparisons of this type also make us aware of the problem of constancy and change. 23

OPERATING ASSUMPTIONS

This exploratory work seeks to collect material aimed towards achieving an encompassing perspective of the psychosocial needs of people with AIDS or ARC (AIDS Related Complex) and their supportive networks, and as such, operates from a number of pre-requisites. Health care professionals are invited to look inwards at their personal perspectives and positions towards AIDS itself and those who have it, in addition to looking outwards at their professional practice with those individuals and families involved in the complex of experiences which occur when someone is subject to a life-threatening condition. Professional practice without self-awareness can be dangerous in that it may operate from positions of unanalyzed and unmet individual needs and consequently "miss the mark" when dealing with the needs of people with AIDS and their supportive networks. Professional inability to perceive client needs may be potentially harmful. The danger of "missing
the mark" should outweigh any "danger" involved in the acquisition of self-awareness. The knowledge gained may reveal new insights and require new responses, or it may endorse current practice. Bohm's belief that theories are actually insights rather than knowledge supports the exploration of insights or perceptions which will occur in this thesis. It is with this background regarding our problem and approach that we proceed to a delineation of the epidemiology and history of AIDS in North America.

AIDS: EPIDEMIOLOGY

In retrospect it seems fair to say that the rapid and recent appearance of AIDS initially found the Western biomedical world unprepared. It initially had no explanations for a phenomena where previously healthy individuals rapidly became seriously ill and a number of them died shortly afterwards.

General awareness of the physical conditions and symptomatology which eventually became labelled as AIDS (Acquired Immune Deficiency Syndrome) began in June 1981 with a report from the American Centers for Disease Control. Medical and social concerns have developed with the rapid and widespread appearance of this syndrome. One estimate of the overall number of people with AIDS in the world in 1986 is 100,000, with 300,000 to 500,000 showing symptomatology of AIDS viral contact, and 5 to 10 million people being asymptomatic carriers of the HIV virus (Human Immunodeficiency Virus). Initially, people with AIDS presented themselves in four general ways: "a) with pneumocystis carinii pneumonia (PCP) on its own (56%); b) with Karposi's sarcoma (KS) on its own (21%); c) with PCP and KS (6%); or d) with one or more other opportunistic infections (17%)".
The following table presents a list of the common diseases or infectious agents to which people with AIDS are susceptible.

TABLE II
COMMON DISEASES OR AGENTS OF INFECTIONS IN AIDS PATIENTS

<table>
<thead>
<tr>
<th>VIRUSES</th>
<th>FUNGI</th>
<th>PROTOZOA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Herpes viruses</td>
<td>Candida</td>
<td>Pneumocystis carinii</td>
</tr>
<tr>
<td>(Types I and II)</td>
<td>Cryptococcus</td>
<td>Toxoplasma gondii</td>
</tr>
<tr>
<td>Cytomegalovirus</td>
<td></td>
<td>Cryptosporidum</td>
</tr>
<tr>
<td>Varicella (chickenpox)</td>
<td></td>
<td>Giardia lamblia</td>
</tr>
<tr>
<td>Adenovirus</td>
<td></td>
<td>Entameba histolytica</td>
</tr>
<tr>
<td>Epstein-Barr</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

BACTERIA
Shigella
Salmonella
Campylobacter
Neisseria gonorrhoeae
Tuberculosis
(and atypical tuberculosis)
Syphilis

It is necessary to provide a brief description of the physical manifestations which develop from some of the above listed infections. It is only with this knowledge that we can adequately proceed to discuss societal and psychosocial issues and experiences. The following descriptions for each agent have been gathered from Gong, Hancock and Carim, and the Institute of Medicine - National Academy of Sciences.
Pneumocystis carinii is a form of pneumonia seen previously in cancer and transplant patients.

Kaposi's sarcoma is a cancer of the blood vessel walls. It shows up as blue to brown blotches or bumps on the skin.

Cytomegalovirus is a member of the herpes virus group. In people with AIDS it shows up as spots on the retina and may lead to blindness. It can also cause pneumonia, esophagitis, and colitis.

Candid albicans is a yeast like fungus which results in whiteish mouth sores which may extend to the esophagus and in a few cases to lesions in the brain.

Cryptococcus is a fungi which has a large effect on the personality of the person infected. The inability to speak, confusion and depression are consequences of this infection.

Toxoplasma gondii is a parasite which is a cause of encephalitis or inflammation of the brain.

Cryptosporidium is a parasite which attacks the intestinal tract and results in uncontrollable diarrhea. Dehydration, loss of necessary salts and malnutrition can sometimes result in the patient going into shock.

Not all the diseases or infections have been listed, but it should be clear that the physical conditions which result from having AIDS are many and serious. Given the many different physical manifestations which result from this syndrome, one has to ask if it is useful to speak generally about someone "having AIDS." It is useful to specify in detail an individual's infections and each person's particular health status. From this medical context the focus shifts in order to explore an historical context.
AIDS: HISTORY

Mishler's four stated presuppositions of modern scientific medicine will be used to outline the history of AIDS in North America: 1) the definition of disease, 2) the doctrine of specific etiology, 3) the assumption of generic diseases, and 4) the scientific neutrality of medicine. 29

THE DEFINITION OF DISEASE

"Disease" as a term or a condition may be defined specifically or very generally. In Western biomedicine, disease is narrowly construed as a "deviation from a biological norm."30 Just such a deviation was noted in the June 5, 1981 edition of the CDC's Morbidity, Mortality Weekly Report. It stated that previously healthy homosexual men presented themselves to medical practitioners with a form of pneumonia, pneumocystis carinii, that was usually only seen in organ transplant patients. Within a few weeks of this first report there were other reports of young homosexual men presenting themselves with a rare form of skin cancer, Kaposi's Sarcoma, which was most frequently seen in North America among transplant patients and elderly men.31 It was this "deviation from the norm" which was initially noticed and reported by the US Department of Health's Centers for Disease Control, or CDC.

The CDC eventually defined AIDS as the presence of PCP, pneumocystis carinii pneumonia, or KS, Kaposi's Sarcoma, or both, in a previously healthy individual.32 The acronym AIDS stands for Acquired Immune Deficiency Syndrome. AIDS is not a disease but rather a syndrome which renders individuals susceptible to opportunistic infections. We should be aware of this fact as much of the literature frequently discusses AIDS as a
disease entity. Yet a review of the opportunistic infections related to AIDS clearly shows there are a host of diseases in addition to PCP and KS to which one with AIDS is susceptible. The perception of AIDS as a single unified disease entity has implications for the process of medical diagnosis. This will be examined more deeply when we come to examine interviews of people with AIDS/ARC, their family members and lovers.

The perception of disease as a "deviation from the norm" requires some further comment. Normality is an abstraction, a socially constructed state. A definition of normality and the perception of its existence are socially constructed and not absolutes or givens. Then disease, when defined as a "deviation from the norm, is also socially constructed. Mishler observes that "Redlich poses the issue succinctly: 'normal for what?' and 'normal for whom?'" The latter question has specific relevance to the issue of Africans and Kaposi's Sarcoma. Initially we were told KS was a very rare form of skin cancer. In a public television documentary, Dr. Paul Volberding, the director of an oncology unit at a county hospital in San Francisco, said even though he had trained as an oncologist, a cancer specialist, he had not seen one case of KS in the course of his medical training. Through other sources we have been matter of factly told that Africans have been subject to an endemic wave of Kaposi's Sarcoma for a number of years. When Kaposi's Sarcoma was said to be rare, what was actually meant? KS is rare in North America! This does not appear to be the case for some medical reports.

THE DOCTRINE OF SPECIFIC ETIOLOGY

The doctrine of specific etiology refers to the process through which general physical complaints or symptoms come to be organized and clustered
through the use of medical theories and practice. The "presenting symptoms" are eventually analyzed to a point where a specific diagnosis is made. In everyday life the doctrine of specific etiology operates from the belief that a disease has a cause. The work of diagnosis is the process of gathering information regarding symptoms and tests which eventually concludes with a diagnosis or disease label. The constructivist model believes that the organization of general symptoms into clusters and ultimately into diseases is a process worthy of study and one which is subjective rather than scientific or neutral.

AIDS is now generally perceived as being caused by a retrovirus. Retroviruses have the enzyme reverse transcriptase, hence the prefix "retro-," which enables them to copy themselves and enter into the chromosomes of their host cell. The idea that a decreased T-cell count in the blood is caused by a viral agent is predominant within the medical community. This viral agent causation model is an example of the doctrine of specific etiology in action.

The development of specific etiology for AIDS has been rapid yet the way has not always been smooth. June 5, 1981 marked the beginning of an awareness in North America of what eventually became labelled AIDS. The term "AIDS" was not used by the Centers for Disease Control until September 1982. The point at which the virus was isolated came over two years after the syndrome first came to the attention of medical practitioners.

With the discovery of the virus came the construction of etiology. Prior to the discovery of the virus there were predictions that HIV was a blood borne virus. As with any new medical phenomena, there were other explanations and beliefs. These explanations included immune
overload, the inhalation of amyl nitrate, and diet.\textsuperscript{39} With the isolation of the retrovirus came a shift in the focus of concern. The new concern became mode of transmission. The retrovirus was found in blood products, but research broadened to body fluids in general. The discovery of the retrovirus in semen, saliva and tears were all dutifully reported and with that came an analysis of the various ways the virus could be transmitted.\textsuperscript{40} These discussions have included the analysis of mosquito bites as a mode of transmission.\textsuperscript{41} It appears that the previous lack of knowledge regarding AIDS is being replaced by very detailed information. The development of etiological information has taken time. The hiatus between physical manifestations of illness in 1981 and the development of medical knowledge has challenged the perceptions of some as to the efficacy of our biomedical system.

A loss of faith in the power of medicine is clearly shown in a lawsuit where representatives from school districts 27 and 29 in Queens, New York, sought to bar a seven year old with AIDS from attending school.\textsuperscript{42} City authorities had decided to allow the child to attend school; school district representatives challenged this decision. A point of debate in this trial was the credibility of experts. The city authorities, who said the child could attend school:

\begin{quote}
 maintained that its decision reflected the consensus of the scientific community... They stressed that the city had carefully considered the guidelines from the Centers for Disease Control (CDC), the latest scientific research, and the opinion of the child's physician... the city called forth expert witnesses to provide the scientific backing for a decision they viewed as a technical choice.
\end{quote}
The school board's lawyers and witnesses attacked these claims, charging that the city's experts were overstepping the limits of established knowledge to present their biased view. Emphasizing the disagreements among experts, they defined AIDS policy as a matter of political, not technical choice. As such, they claimed, decisions about controlling AIDS should be made in the political arena.43

The school district lawyer, arguing against the child attending school, took the discussion of expertise a step further:

Attorney Sullivan refused to release the name of a physician who claimed to have evidence about a health care worker who had contracted AIDS through casual contact. He feared that the physician would be punished for contradicting the conventional scientific wisdom. The judge defended Attorney Sullivan's effort to protect the physician: 'You know very well that Dr. Sencer or his department has a great deal ...I wouldn't say control...I'm not looking for this doctor to be punished because he's open and above board.'44

We could stay at the content level, debating the legitimacy of hearsay evidence, in addition to analysing the judge's response, but we shall look at these issues from a broader perspective. One way of understanding the preceding excerpt is to realize that AIDS involves perceptions and attitudes which include medicine and etiological information, but are not limited to them alone. At least two years elapsed from the first appearance of symptoms and ailments in 1981 to the isolation of the AIDS virus. The development of a specific etiology for AIDS also occurred in the same two years. Medical authority, or at least the perception of medical authority,
was shaken in the course of the time it took to develop that etiological information. The medical establishment now attempts to reclaim its power over the unknown in the sense that AIDS has now been diagnosed and a specific etiology has been developed. There are some like those from the New York school district, who, given the etiological development of AIDS, still question medical authorities. They would prefer to have AIDS defined as a political problem rather than a medical one.

AIDS has undermined the doctrine of specific etiology insomuch as it has brought to light the fact that medicine is an applied, rather than a "true", science. It has never been a "true" science, and a conversation with anyone at the forefront of medical research would confirm the fact that medicine cannot predict outcome, treatment, or prognosis with 100% accuracy. AIDS has shattered the public's perception, supported by the professions own mythologizing, that medicine is a controlling science. It is of interest to note how the public has handled this revelation. Many appear to operate from the belief that if we cannot know everything, then, given the fact we know so little, how can we trust the so called "authorities" anymore? Clearly a crisis of authority has occurred, and that crisis stems in part from the threat AIDS initially presented to the doctrine of specific etiology.

DISCOVERY AND NAMING OF THE VIRUS

AIDS has threatened the doctrine of specific etiology to the extent that there was some disagreement as to who discovered the virus and what it should be called. The questions as to who discovered the AIDS retrovirus and when depends upon sources, language and culture. What you call it also depends upon these factors. HIV (Human Immunodeficiency Virus) is the name
the International Committee in the Taxonomy of Viruses gave the retrovirus in May 1986. French researchers in 1983 named the virus LAV (Lymphadenopathy Associated Virus.)

In 1984 separate American researchers named the virus HTLV III (Human T-Cell Lymphotropic Virus), and ARV (AIDS Associated Retrovirus.) For the sake of clarity, "HIV" will be used throughout this thesis when referring to the retrovirus. It is interesting to note that some North American articles continue to use the term "HTLV III" even after the international change to "HIV" in May 1986. Because AIDS is new to the scientific community, the name referring to the virus makes it possible to discern acts of political allegiance and congress within that community.

THE ASSUMPTION OF GENERIC DISEASES

Western biomedicine operates from a belief that "each disease has specific and distinguishing features that are universal to the human species." Mishler makes the following observation regarding the connection between disease and illness:

the specification of signs and symptoms in biological terms is inadequate to the medically defined task of understanding and treating illness, because, although bodies have signs and symptoms, only people become sick.

This distinction between "disease" as signs and symptoms and "illness" as the experience, is useful when discussing AIDS. Medical practitioners may define AIDS by signs and symptoms, but the parameters of an individual's experience of AIDS as an illness are much broader than the delineation of signs and symptoms. The disease/illness distinction is relevant to the study of AIDS in two succinct areas. The first point being the development
and acceptance or rejection of the sick role, and second, the issue of alternative treatments. In June 1983 a group of individuals with AIDS, primarily gay men, adopted a statement at the US National AIDS Forum in Denver Colorado which is prefaced with the following:

We condemn attempts to label us as victims, which term implies defeat, and we are only occasionally patients, which term implies passivity, helplessness and dependence upon the care of others. We are people with AIDS. 51

In this statement it is clear that the sick role is not accepted. This should not be surprising given the fact that gay men have been the main group comprising those who have AIDS. Gays have had to assert their rights within the field of medicine for sometime. 52 It should not surprise any that gay men would continue to assert their rights in the case of AIDS.

It is of interest to note that none of the psychosocial literature reviewed on AIDS has mentioned this 1983 statement nor discussed the development and growth of the autonomous self help groups calling themselves the PWA (Persons with AIDS) Coalition.

The second issue relevant to our discussion of disease and illness is alternative "medical" therapies. Presently there is no "cure" for AIDS. The search for a vaccine is progressing, yet there are many obstacles involved, not the least of which is the fact that the retrovirus changes or mutates. In the meantime, those who have AIDS are exploring alternative therapies through which they wish to enhance and maintain their well-being. These therapies include vitamins, macrobiotics and meditation to name but a few. The decision to engage in such processes appears to be reasonable and logical given the fact Western biomedicine does not have an "answer" to AIDS. Yet such activity may be seen by some medical practitioners to
disrupt the orthodox balance of power and knowledge, impeding the processes of social exchange, which usually occurs in the doctor-patient relationship. A debate within Western medicine pertaining to alternative therapies and AIDS has not openly occurred.

THE SCIENTIFIC NEUTRALITY OF MEDICINE

Most medical practitioners operate from the belief that medicine is a science, albeit an applied science. Because it is seen as a science, they consequently believe they can and do employ the scientific values of neutrality and objectivity. This belief and trust in the scientific imperative and its neutrality is being debated within the field of social work. For the most part it appears that medical practitioners still believe in the neutrality of medicine. This belief in neutrality raises a number of points when AIDS and the medical establishment interact. Bayer's article, "AIDS and the Gay Community: Between the Specter and the Promise of Medicine," clearly outlines the areas of concern present:

Against psychiatry, which had classed homosexuality as a disease, the homophile movement of the 1960's had sought to demonstrate that a pseudoscientific ideology had masked the moral strictures that had long dominated Western attitudes toward sexual activity among those of the same sex... America's psychiatrists yielded to gay pressures in 1973 by removing homosexuality from their official classification of mental disorders. Now, a decade later, faced by the threat of disease and death, the power of medicine was being brought into intimate contact with the gay community... Not only was there a risk that medical justifications would be used to reverse the public victories won as the result of great
organizational efforts, but that every dimension of private sexual expression would become the target of medical scrutiny, diagnosis, and challenge. 54

These comments by Bayer raise a debate centered upon the medical practitioner as "an agent of social control" to borrow Parsons' term. 55 The categorization of homosexuality as a mental disorder is a clear example of the psychiatrist acting as an agent of social and moral control. The development of AIDS may provide another situation where social control can be exerted through medical authorities. Waxler's study of leprosy provides a relevant observation to this debate:

It is not simply that doctors are waiting outside the society with neutral values, waiting to step in to treat and to take into account society's peculiar transformations of disease. Instead the medical institution is part of society itself, and thus is implicated in the social and moral definition of disease. 56

Up to the present day the majority of people with AIDS have been individuals who remain marginally accepted by society, namely gay men, bisexual males and intravenous drug users. If one has AIDS and is not a hemophiliac or an intravenous drug user, then the diagnostic label is perceived to proclaim a further piece of information, namely that the individual is gay or bisexual. Rich, a gay man in the play As Is, comments on this fact when in "camp" humour he asks his brother:

what is the worst thing about getting AIDS? Trying to convince your parents that you're Haitian. 57

The diagnostic label "AIDS" may be interpreted both inside and outside medical institutions as "homosexual." This situation may complicate the tenuous balance in patient--practitioner relationships and account for the
absence of the Persons With AIDS Coalition in the professional literature. The situation is further complicated by the life threatening nature of AIDS itself and the opportunistic infections which occur in AIDS related illnesses. A recent survey of 94 professionals from the fields of medicine, law, and academia in the Seattle-Tacoma area found that physicians appear to fear sickness and ageing to a higher degree than do attorneys and professors. Such a finding, although it is only one study, causes some concern when the fear of sickness is considered as a complicating factor in what can sometimes be an already tentative relationship.

The fact that tentative relationships exist between gays and health professionals is emphasized in Dardick and Grady's 1980 study of the openness between gay persons and health professionals. It should be noted that this study was published one year before AIDS was first reported in North America. In a sample of six hundred and twenty-two respondents "27% felt that a previous health professional had been prejudiced towards homosexual persons." This is seven years after DSM III had excluded homosexuality per se as a psychiatric illness. This is not to say that the majority of health professionals are homophobic or antagonistic. There are some organizations, like the American Association of Physicians for Human Rights, which are actually composed of gay and lesbian health professionals. If this background information does anything, it supports Bayer's discussion regarding the differences in power which exist between gays and the medical profession. Tenuous relationships will be upheld as long as research such as Flynn, Popek and Maccario's, "Change from Homosexual to Heterosexual Behavior During a Seizure in a Patient with Acquired Immune Deficiency Syndrome (AIDS)," receives professional interest and acceptance. The practice of medicine is not the only locus where gays in general, and people
with AIDS in particular, have encountered misunderstanding and the exertion of social and moral control.

There are some grounds for believing that health administrators are defensive and control oriented when it comes to the issue of AIDS. A clear example of authoritarian and administrative bias can be seen in the government of B.C.'s decision not to provide funding to AIDS Vancouver in the 1986 fiscal year. The provincial Minister of Health, Peter Dueck, in defense of this decision, stated that AIDS Vancouver should "help their own kind".62

Few administrators are as outspoken as John MacKay, the Scottish Health Minister:

We are being asked to spend a lot of money on a disease which could easily be prevented if homosexuals and drug addicts changed their lifestyle... I think this is a straightforward moral issue. The Churches have a terrific opportunity to say there is not just moral merit but physical merit in the conventional view of Christian morality.63

Views such as Mr. MacKay's reveal, to some degree, the extent of his ignorance regarding the etiology of AIDS. Research presently available shows that the retrovirus can be present but dormant for a number of years. A change in sexual behaviours is advisable, yet that will only reduce the present incidence of viral transmission and future incidence of AIDS a number of years from now. It will not reduce the present number of cases simply because these individuals came in contact with the retrovirus sometime before the transmission of AIDS was known. A further point to be made here is that North American data have shown that homosexuals are in
fact changing their behaviours. It is the non-gay population which is still engaging in so called "high risk" sexual activity.64

It seems clear that Mr. MacKay's perspective towards AIDS has developed from a moral or religious view rather than focussing upon it as a health concern. Such perspectives will have consequences both for the supports provided and for those believed to be necessary and functional. This further emphasizes the importance of an analysis and discussion of the social construct employed when dealing with the phenomena of AIDS or with the individuals who have it.

AIDS: PSYCHOSOCIAL LITERATURE

Psychosocial interventions directed towards individuals diagnosed as having ARC or AIDS come from at least three major perspectives; psychiatry, psychology, and social work. The psychosocial literature discussed here has been gathered from a literature review employing the Social Sciences Citation Index and Index Medicus between the dates of January 1, 1981 and April 30, 1986. A total of fifty-nine articles were found. They have been categorized, for literature review purposes, into psychiatry, psychology, and social work.

Psychiatry, as is to be expected, primarily focuses on the individual patient. Perry and Tross found that:

cognitive dysfunction and mood impairment were pervasive clinical features in AIDS patients hospitalized during acute illness, but those complications were seldom explicitly diagnosed or treated.65

Some psychiatrists took views of the problem from broader perspectives. Wolcott, Fawzy and Pasnau detail the medical and psychosocial effects of
AIDS and propose a program for AIDS - effected individuals. They believe that:

Until an effective curative or preventative approach to AIDS is developed, AIDS will probably continue to be a highly 'psychosocially malignant' illness... Ideally an integrated multidisciplinary team providing coordinated medical and psychiatric care to patients during inpatient and outpatient phases of treatment should be developed.\textsuperscript{66}

In an early 1983 article Nichols states that psychiatric intervention aims to:

help patients accept their illness and to regain the ability to manage their lives.\textsuperscript{67}

Deuchar discusses the social context of AIDS in New York City and promotes psychotherapy as a clinical approach to the problem. He comments at length upon what he sees as an unjustified "AIDS panic"\textsuperscript{68} mentality in the general public.

Perry and Markowitz detail a series of existing interventions which can be used to treat AIDS related psychiatric disorders.\textsuperscript{69} These writers see the total group of those with AIDS and ARC as composed of sub groups which include medically hospitalized patients with AIDS, out-patients with AIDS and ARC, those with AIDS-related dementia and those who test positively for the HIV antibody.

Lippert, Jenike and Pato\textsuperscript{70} found that a total of three individuals who had medically unsubstantiated fears of having AIDS had those fears reduced through drug therapies.

Psychiatrists did not ignore the question of patient - practitioner problems and concerns. These concerns were initially presented in general
terms; over time they became more specific. In 1983 Nichols said physicians must address their "own bias toward homosexuals, addicts and disadvantaged persons." A year later, Deuchar said, "counter transference issues related to this (homophobia) must be worked through." Wolcott, Fawzy and Pasnau also drew professional attention toward the "conscious or unconscious negative attitudes about the subgroups in which AIDS usually occurs." By 1986 Perry and Markowitz had drawn up a list of issues which could involve counter transference in professionals: fear of contagion, stereotyping, failure to find an appropriate empathic distance, assuming an omnipresent expertise of AIDS and premature referrals to self-help groups.

The psychological literature broadens the perspective developed in psychiatry. Joseph and his colleagues outlined their work in developing a psychosocial inventory to study how gay men have responded to the presence of AIDS. They "emphasized that the strains created by AIDS extend well beyond the perceived risk of contracting the syndrome." The article examines their work at developing qualitative data, sampling, building community networks, and an attempt to characterize or detail the crises of AIDS.

Simkins and Eberhage surveyed attitudes towards AIDS, Herpes II and Toxic Shock Syndrome among psychology students at the University of Missouri. This 1984 study found that concerns were present but self-reported sexual behaviour had not changed.

The article by Morin, Charles and Malyon can be summarized in their own words:

We will discuss the continuum of AIDS-related conditions found in groups ranging from those diagnosed with the disease to the
'worried well.' Various treatment strategies will be suggested.78

The article by Morin and Batchelor examines the psychological aspects of AIDS by relying on personal and professional experiences. They conclude that:

Individuals are reacting to the threat of an unknown but deadly epidemic with fear when strength is needed, with denial when awareness is needed, with guilt when understanding is needed, and with withdrawal when caring is needed. We believe that it is the responsibility of the health and mental health community, as broadly defined, to respond to the psychological needs of persons with AIDS and to the needs of their lovers and families...
The psychological impact of AIDS is likely to remain for a long, long time.79

The only article from an individual with AIDS was written by Anthony Ferrara. He begins his work with the following cautionary note:

let me recount my personal experience, although cautioning against accepting it as 'normal' for all other AIDS patients.80

The articles by Morin, Charles and Malyn; Joseph and his colleagues; and Ferrara were all in a single issue of the American Psychologist devoted to AIDS. Joseph et al as well as Morin and Batchelor spoke of the problems which could and do occur between those with AIDS and the professional community.

Crisis prevention and crisis management are the primary perspectives present in these articles. None of them detail cases where individuals are coping and managing with their health status. This may simply be due to the fact that these articles were written in 1984. This was the "beginning" of
the "AIDS crisis" and as such the immediate problems of organizing the data and conceptualizing the interventions were of primary concern.

Of the fifty-nine articles dealing with the psychosocial needs of people with AIDS, there were only four which come from a social work perspective or were published in social work journals. Three out of the four articles were written by women. Two of the four were written in 1984 and two in 1986. Chronological dates are an important factor given the rapid developments in etiology and general medical information occurring in this field.

The only social work article written by males, Lopez and Getzel, was published in 1984. They promote a crisis intervention program which consists of practical assistance, material support and case advocacy. The second article published in 1984, by Furstenberg and Olson, makes the point that general social work practices can be employed when working with people with AIDS. They make the observation that:

Social workers differ, however, from the majority of others dealing with health in taking responsibility for developing and acting from self-awareness.

Having made the point, they demonstrate no self disclosure, nor do they probe this insight. If social workers develop and act from self-awareness they should openly express their positions. DeCrescenzo's study of attitudes towards homosexuals found that:

Social workers achieved the highest homophobia scores, while psychologists were found to be the least homophobic...most of the social workers responding to the questionnaire in this study indicated that they do not believe they know many, if any, lesbian or gay people.
None of the four articles reviewed here cites DeCrescenzo's work. Although the publication listing her work was published in 1985 her actual study was conducted in 1979. Wisniewski and Toomey's study of homophobia, probably conducted in or before 1985 but published in 1987, found "nearly one third of the participants (MSW line workers) earned scores falling in the homophobic classifications" of Hudson's Index of Attitudes towards homosexuals. Only 3.9% of the respondents scored within the classification of high-grade non-homophobics. The researchers recommend that findings be cautiously interpreted but state that: 
results of this study lend preliminary empirical support to the implied assumption that social workers manifest signs of homophobia.

Homophobia, an irrational fear of gay men or lesbian women, is presented in the four social work articles on AIDS as an attitude which can be changed with information or education rather than as a belief or world view. Before problems such as homophobia can be addressed we must admit, even reluctantly, that the concern is more than a lack of knowledge. Only then can corrective measures be initiated. Homophobia must be addressed in order for professional activity to occur.

The two articles written in 1986 do not advance the knowledge base much beyond those pieces written two years previously. Dunkel and Hatfield focus on countertransference issues encountered when working with people with AIDS. They point to the importance of "developing and acting from self-awareness" to repeat Furstenberg and Olson's previous insight. Christ, Wiener, and Moynihan of the Sloan-Kettering Cancer Centre of New York City operate from a stress/coping model of intervention. They comment upon the usefulness of support groups once individual counselling has stabilized
the patient. The label "patient" is used consciously as their perception of the individual is definitely that of a patient:

For a young, vigorous person, becoming a debilitated, symptom-wracked, possibly dying person -- often within a few weeks or months -- it requires a massive adjustment. The purpose of this article is to increase understanding and facilitation of this adjustment.90

Such professional perceptions may limit and control the scope of interventions possible in a given situation. It may be true that the people they see are physically weak and debilitated but it must be asked whether all people with AIDS have the same experience. Christ, Wiener and Moynihan detail a further concern which exists in this field:

Unlike cancer patients, AIDS patients with opportunistic infections have no structured treatment regimen to follow that will help them cope with the fear of the progressive effects of their disease.91

Each of the four social work articles has a perspective which adds to the dialogue surrounding the care of individuals with AIDS. Yet none of them attempts to achieve a comprehensive perspective from which to address the large number of components and their possible permutations. For the sake of argument and the maintenance of clarity it seems useful to distinguish between the five following groups in relation to AIDS:

1) Those individuals diagnosed with AIDS or ARC (AIDS Related Complex) and those who test positive for the HIV antibody.

2) The family members, friends, spouses, and lovers of those in the previous group.
3) The organizations and institutions of assistance, both volunteer systems and those mandated by various levels of government.

4) The medical establishment, which includes health care practitioners and the health care system.

5) The final group, all those not included in the first four, "the general public."

INDIVIDUALS WITH AIDS, ARC, AND SEROPOSITIVE FOR THE HIV ANTIBODY.

For the sake of discussion these three groups have been gathered together, even though the experience of each is unique. There is no medical data presently available which can categorically delineate the interconnections between AIDS, ARC, and antibody seropositivity. As time goes on, and more studies are undertaken, the connections, or lack thereof, will become evident. Given this situation, professionals should be aware of the attitudes and perceptions which we direct to these three groups.

THOSE WITH AIDS

The point at which an individual is diagnosed with AIDS deserves professional attention. Professionals may ask neutral questions surrounding diagnosis rather than assuming how people feel about the diagnosis. What do these individuals feel others are thinking, and what concerns do they have for the present and the future. Such questions and research, if being done, have not entered the literature. For now it should be sufficient to say that more questions need to be asked and less assumptions made of individuals who have been diagnosed as having AIDS.
THOSE WITH ARC (AIDS Related Complex)

The label AIDS Related Complex or ARC has been given to conditions such as lymphadenopathy, a reduced platelet count in the blood, fatigue, diarrhea, and fever, called the wasting syndrome by some people.\(^9\)

The progression of ARC to AIDS can be a major concern for those diagnosed with AIDS Related Complex. Epidemiological information is still at the developmental stages. At one point it was estimated that 5 - 20% of those diagnosed as having ARC would go on to develop AIDS. Researchers are now tentatively saying that the developmental rate may be much higher after seven or more years of exposure to the virus.\(^3\) To put it simply, not enough is yet known. The simplicity of that statement must not deny the pressure and difficulties undeniably experienced by people with ARC. Some individuals with ARC are less able to conduct activities of daily living than some people with AIDS. People with ARC can also experience the constant tension of not knowing their health prognoses. The issues and concerns for individuals with ARC are related to but separate from those of people with AIDS.

THOSE WHO ARE SEROPOSITIVE FOR THE HIV ANTIBODY.

When one "tests positive" for the antibody it means the antibody for the HIV virus has been found in your blood. For the antibody to be present it means you have to have been in contact with the virus itself at one time. Any categorical extrapolations beyond these two facts regarding the "chances" of getting ARC or AIDS cannot be clinically nor scientifically justified at this time.

Research is being done, but our chronological perspective is not long enough to begin making generalizations. It seems that a lack of information
has never prevented people from holding opinions while believing them to be facts. Such is the case with seropositivity and HIV testing generally. This is clear in a recent poll conducted for the VANCOUVER SUN which reported June 5, 1987 in a front page article that:

British Columbians favor mandatory testing and reporting of AIDS, but are still unclear as to how and where they can catch the deadly virus.  

The article goes on to discuss issues such as immigrants being "tested for AIDS" and the listing of partners of people "who test positive for AIDS." The tacit assumption in these discussions on page one is that the test tells you if you have AIDS. The same paper, eight days later, June 13, 1987, on page 11 at the bottom of the page, discusses "the AIDS Test." The first question - "Does the AIDS antibody test tell me if I have AIDS?" and the answer - "No. But it does tell you that some time in the past the virus has entered your blood stream and that your body has developed specific antibodies to it." More will be said regarding testing generally in a later section of the thesis. For now it is sufficient to say that there are also specific concerns for people who test positive for the HIV antibody.

SIGNIFICANT OTHERS OF THOSE WITH AIDS, ARC, OR SEROPOSITIVITY

The term "significant others" is meant to include family members, friends, spouses and lovers of those in the three previously discussed groups. Those who find themselves in supportive relationships with others who are experiencing life threatening conditions may seek answers to two basic questions, which may be asked as follows; What is going to happen? and what do we need to do? Such questions develop once the initial process
of confirmation and acknowledgement of the news has been achieved. This process of adaptation and acknowledgement is continuous. The process of adaptation to a life threatening condition is further complicated in those cases involving AIDS.

Potential complications may include some of the following issues. Is the individual with AIDS gay or bisexual? If so, did the family member or friend previously know of the other's sexual preference? If the person is gay/bisexual and the significant other did not know, what is his/her reaction to this information?

How did the significant other find out the other had AIDS? Was this information relayed through the individual with AIDS or was it told by a third party?

What access does the significant other have to updated medical information regarding AIDS? This can depend upon where the individual lives, his/her relationship with medical practitioners and the comfort of both the significant other and the medical practitioner in discussing AIDS.

Where does the significant other live? Does he/she live close to the individual with AIDS? If they are geographically close to the person with AIDS, it is fair to ask if they are being required or expected to provide supportive services to the individual with AIDS.

What was the nature of the relationship between the significant other and the individual with AIDS prior to the latter's diagnosis? How has that relationship changed? What physical complications are being experienced by the individual with AIDS? These are some of the general issues and potential complications present for a person who has a significant other with AIDS.
Lovers of individuals with AIDS may have further complications. The presence or absence of such complications depends upon factors such as the length of their relationship, the health status of the lover not diagnosed with AIDS, and the lover's relationship with the ill individual's family, to mention but a few issues. There may be legal complications of ownership and inheritance given the fact Canadian laws give no sanction nor recognition to same sex relationships. These are by no means all the problems which face the significant others of those who have been diagnosed with AIDS, ARC, or seropositivity. These few brushstrokes should serve as a backdrop for the research which proceeds later in this paper. Before that work develops we must briefly discuss organizations and institutions of assistance.

ORGANIZATIONS AND INSTITUTIONS OF ASSISTANCE

Organizations and institutions of assistance are major players in the process of caring for individuals with AIDS. In Vancouver these organizations include private agencies such as AIDS Vancouver and the Persons with AIDS Coalition. AIDS Vancouver provides a number of services within the community. These services include weekly groups for friends and family members, one-to-one volunteers or buddies for individuals with AIDS, emergency financial assistance, advocacy, counselling and education. McLaren House, a five bedroom house, provides low cost accommodation for individuals with AIDS who are able to physically care for themselves.

The PWA (Persons with AIDS) Coalition is an autonomous self-help group which provides support services to individuals with AIDS and ARC. They also investigate alternative treatments and attempt to provide funds for individuals to engage in alternative treatments if they so wish. The group has weekly meetings where people share their experiences and problems.
Individuals representing the Coalition have met and continue to meet with provincial and federal health officials to express their concerns regarding issues such as the release of the drug AZT and changes to the provincial Health Act. They also provide spokespeople for conferences and the media upon request. These are the primary organizations and institutions of assistance present and active in Vancouver beyond those of the medical establishment.

MEDICAL ESTABLISHMENT

Although the need for medical treatment grows with an increase in the number of cases, the number of practitioners active in AIDS care is small. For a number of reasons St. Paul's Hospital in Vancouver was the first hospital in B.C. to develop a comprehensive and coordinated treatment system for people with AIDS. The increase in the number of individuals requiring medical care meant that other hospitals gradually had to assume their share of responsibility in this field. Some hospitals, as exemplified by an incident at the University Hospital, UBC site, did not assume their burden of care willingly. Other hospitals have slowly developed programs and procedures for dealing with the medical care of individuals with AIDS.

The Infectious Disease Clinic of St. Paul's Hospital provides out-patient medical treatment, monitoring, counselling, and coordination of medical and supportive services with Health Units, homemakers, AIDS Vancouver and the PWA Coalition. The clinic's title of "Infectious Disease" is partially a misnomer as it only treats those who have AIDS or ARC. St. Paul's Hospital is located in the "West End" of Vancouver, in close proximity to where a large number of gay men reside. The development of St. Paul's as a centre for AIDS treatment is undoubtedly a consequence of this
residential fact as well as a number of other political and organizational factors.

A growth in the medical establishment's programs and procedures needs to be weighed against opinions such as those reported in November 1987, which stated alarmingly, that 27% of American doctors surveyed said it was not unethical to refuse to care for an AIDS patient.\(^97\) Statistics such as these become even more ominous when combined with the unconsciously sanctioned perogative of social control our society tacitly implements through the medical establishment.

Social control is not the exclusive perogative of medical practitioners. Nurses, social workers and physiotherapists exert considerable influence over access to non-mandatory medical services and supports. Compare for instance the experience of an individual perceived as a "good" patient to those of one who is "non-compliant" or a "malingering" to see social control in action. The research interview discussions will examine social control as experienced by those with ARC and AIDS.

The other primary players under the umbrella of the medical establishment are the provincial Ministry of Health and the federal Department of Health and Welfare. More will be said about these bodies within our discussion of the research interviews.

THE GENERAL PUBLIC

Given the current level of media attention and educational campaigns focussed on AIDS it seems difficult to believe that anyone in North America has not yet heard of AIDS. Yet there is a chasm between a generalized awareness of its existence and the acquisition of updated medical information. There is a further gap between the presence of adequate
medical information and its transformation into rational acts and a sensitive perspective towards AIDS and those who have it. A review of media materials gathered from weekly news magazines as well as anecdotes from interviews will hopefully shed some light on this previously unstudied area. This area is of vital importance for it is ultimately in the world and within society that we move, live, and have our being. This exploratory study of AIDS and social construct initiates enquiries necessary for further research. The next chapter examines the medical and social context of AIDS through an analysis of weekly published reports and news magazines.
CHAPTER 2
AIDS: CONTEXT AND DOCUMENTARY MATERIAL

AIDS exists in a medical, social, and political context. The next chapter examines the development of medical and social constructs of AIDS through an analysis of documentary material. The medical context of AIDS is gathered through a chronological analysis of the Morbidity, Mortality Weekly Report, or MMWR, from June 1981 to April 30, 1986. The etiological and epidemiological developments of AIDS began to appear in the MMWR on June 5, 1981. This report was the first in North America to follow what came to be labelled AIDS. The MMWR is published by the Centers for Disease Control, which is a branch of the United States Department of Health. It has been chosen here because it is a "front line" publication which reports epidemiological developments. The social context of AIDS will be examined through a similar process.

A social context of AIDS is analyzed through reports in the news magazines Time, Macleans, and Newsweek. This process examines information transfers between these news magazines and the MMWR. It also looks at the way in which AIDS is reported in news coverage. With the medical and social contexts of AIDS we are able to analyze the interviews of those living with AIDS which follow in chapter four.

The medical and social contexts of AIDS lead to a discussion of the syndrome's political context. This is lead by insights from Michel Foucault. Foucault, writing before the appearance of AIDS, spoke of the construction of sexuality. He analyzes the employment of developing knowledge and power as instruments of social control. This analysis leads to explanations of respondents' actions and the news coverage surrounding this issue. But our work begins with the medical context of AIDS.
THE FIRST EIGHTEEN MONTHS:

Morbidity, Mortality Weekly Report first reported what eventually came to be labelled as AIDS on June 5, 1981. The eighteen months between June 1981 and December 31, 1982 saw the establishment of a developing etiology for this previously unknown condition. The acronym "AIDS", which stands for Acquired Immune Deficiency Syndrome, was first used in the MMWR's September 24, 1982 report. Prior to this time the term employed was Kaposi's Sarcoma - Opportunistic Infection syndrome, or KSOI. By December 17, 1982 there were 788 adult cases of AIDS reported in the United States.

Kaposi's Sarcoma, or KS, and Pneumocystis Carinii Pneumonia, PCP, were the first two opportunistic infections clinically observed. KS and PCP are not common ailments and it was noted that they are "associated with host immunosuppression."¹ Within a year of its first report, the Centers for Disease Control, or CDC, suggested that:

Underlying immune deficiency appears to be the common denominator for the development of the opportunistic infections and tumors associated with the KSOI syndrome.²

Sexual transmission of an infectious agent between homosexual males was hypothesized in the CDC's June 18, 1982 report. Less than a month later, July 16, 1982, the report of PCP in three heterosexual males with Hemophilia A "suggests the possible transmission of an agent through blood products."³ IV drug users and Haitians were previously recorded as other groups reporting opportunistic infections.⁴

These developments led the CDC in its November 5, 1982 issue to surmise:

that a transmissible agent may be involved. If so, transmission of
the agent would appear most commonly to require intimate, direct contact involving mucosal surfaces, such as sexual contact among homosexual males, or through parenteral spread, such as occurs among intravenous drug abusers and possibly hemophilia patients using Factor VIII products.  

The CDC's December 10, 1982 issue reported the case of a twenty month old child with unexplained cellular immunodeficiency and opportunistic infection. The child received transfusions of platelets from a donor later found to have AIDS:

If the infant's illness described in this report is AIDS, its occurrence following receipt of blood products from a known AIDS case adds support to the infectious-agent hypothesis.  

This finding led the CDC to hypothesize that "If the platelet transfusion contained the etiologic agent for AIDS, one must assume that the agent can be present in the blood of a donor before onset of symptomatic illness and that the incubation period of such illness can be relatively long."  

On December 17, 1982 four more cases of infant immunodeficiency were reported. The CDC again cautiously states that "if the infants described in the four case reports had AIDS, exposure to the putative 'AIDS agent' must have occurred very early... Transmission of an 'AIDS agent' from mother to child, either in utero or shortly after birth, could account for the early onset of immunodeficiency in these infants."  

These etiological suggestions developed by the end of 1982 are hypotheses based solely on epidemiological information. The HIV virus has not yet been isolated and there is no clinical test available to determine the presence of AIDS or the antibody. The first report which used the acronym "AIDS" noted the existing difficulty in defining a case of AIDS:
Editorial note: CDC defines a case of AIDS as a disease, at least moderately predictive of a defect in cell-mediated immunity, occurring in a person with no known cause for diminished resistance to that disease. Such diseases include KS, PCP, and serious OOI. (Other Opportunistic Infections) Diagnoses are considered to fit the case definition only if based on sufficiently reliable methods (generally histology or culture). However, this case definition may not include the full spectrum of AIDS manifestations, which may range from absence of symptoms to non-specific symptoms to specific diseases that are insufficiently predictive of cellular immunodeficiency to be included in incidence monitoring. Conversely, some patients who are considered AIDS cases on the basis of diseases only moderately predictive of cellular immunodeficiency may not actually be immunodeficient and may not be part of the current epidemic. Absence of a reliable, inexpensive, widely available test for AIDS, however, may make the working case definition the best currently available for incidence monitoring.9

While realizing the difficulties the CDC found with incidence monitoring, the accuracy of the CDC's etiological development should be noted. By the end of 1982 they had predicted AIDS to be caused by an infectious agent spread through sexual contact, blood products and the sharing of needles. All of these predictions, based on epidemiological findings, proved to be true. This accuracy is also seen in the development of hospital and laboratory precautions.
Although the etiology of AIDS was not yet fully known, the CDC developed tentative hospital and laboratory precautions and published them on November 5, 1982. These procedures were based on hepatitis B viral precautions and were prefaced with the following tentative observation, "airborne and interpersonal spread through casual contact do not seem likely."10

Eighteen months after the first report of AIDS, the CDC had developed hospital and laboratory precautions, hypothesized the existence of an "AIDS agent" which could be transmitted sexually between homosexual males, and noted that such an agent may also be transmitted through transfusions and blood products. These observations were not conclusive, yet they directed future research developments. For the purpose of tracing the etiologic growth of AIDS, these 1982 developments provide a touch stone to which future developments can be compared and contrasted.

THE YEAR 1983

The year 1983 began with 788 cases of AIDS in the United States and ended with 3,741. A total of 318 cases were reported in other parts of the world, 51 of which were from Canada. In May of 1983 the CDC first reported Gallo's developments with the HTLV virus. The major developments in 1983 were further discussions on the transmissibility of AIDS and the CDC's defense of risk group classification in epidemiology.

In June it was noted that "the failure to identify cases (of AIDS) among friends, relatives, and co-workers of AIDS patients provides further evidence that casual contact offers little or no risk."11 Three weeks later the CDC reported that four of the total cases were "reported to be health-care
personnel not known to belong to groups at increased risk for AIDS." These findings were not taken at face value as the following analysis from the same report shows:

They denied belonging to known AIDS risk groups; however, the accuracy of data concerning sexual activity and IV drug use cannot be verified. None gave a history of caring for an AIDS patient, however, the possibility that these patients had forgotten or unknown exposure to the blood of AIDS patients cannot be entirely excluded.

These four cases provide no new information regarding occupational risk related to health-care personnel. Transmission of AIDS within hospitals has not been reported. Recommendations for prevention of AIDS in health-care personnel have been previously published, and these personnel are urged to become familiar with and adhere to these recommendations.

DEFENDING EPIDEMIOLOGY/RISK GROUP CLASSIFICATION

September 1983 saw a departure from the etiologic development of AIDS, the CDC's defense of risk group classification. It begins this defense with the statement that, "Classification is an essential part of any epidemiologic investigation... and serves such purposes as formulating prevention recommendations, providing direction for research, and identifying medical needs." In the next sentence the CDC chastizes growing social intolerance and fear directed towards those people classified as risk groups:

the classification of certain groups as being more closely associated with the disease has been misconstrued by some to mean
these groups are likely to transmit the disease through non-intimate interactions. This view is not justified by available data. Nonetheless, it has been used unfairly as a basis for social and economic discrimination... there has been no evidence that the disease was acquired through casual contact with AIDS patients or with persons in the population groups with an increased incidence of AIDS. AIDS is not known to be transmitted through food, water, air, or environmental surfaces.15

The tone and content of this report are unique when compared to all those MMWR reports preceeding it. Why is this so? Some hints may be found in publications outside of the MMWR. The year 1983 found the American federal government being pressured by political groups to do more regarding AIDS. The CDC is a branch of the U.S. Department of Health and Human Services and as such is subject to some degree of political pressure. On August 1, 1983 the Executive Director of the National Gay Task Force testified before the US House of Representatives Subcommittee on Intergovernmental Relations and Human Resources. Virginia Apuzzo, the Executive Director, spoke of six areas of government failure in AIDS related issues:

- a failure of expedite funding for research;
- a failure to provide proper funding methods;
- a failure to stem AIDS hysteria through public education;
- a failure to address the question of the safety of the blood supply;
- a failure to include affected groups in decision making;
- and a failure to recognize the rights of confidentiality and privacy of patients.16

The MMWR's report of September 9, 1983, which chastizes "social and economic discrimination," may be a response to public criticism, which includes that
of Ms. Apuzzo. The CDC's report of September 9th both justifies its procedures of data collection while also attempting to "stem AIDS hysteria through public education." That Ms. Apuzzo's criticism was made on August 1, 1983 and the CDC's report appeared on September 9, 1983 is hardly serendipitous. As the etiology of AIDS develops we will see the CDC again placed in the position of public educator. The next year, 1984, brought further developments in AIDS etiology.

MORE CASES/ISOLATING THE VIRUS

The year 1984 saw a large increase in the number of AIDS cases and the isolation of the retrovirus, which was initially named HTLV-III in the United States and LAV in France. Epidemiology also developed to the extent that heterosexual sexual transmission of the virus was noted. In December of 1983 there were 3,741 reported cases of AIDS in the United States, by November 1984 there was an increase of 3,252 cases for a total of 6,993. One month later, another 2,064 cases had been reported for a total of 9,057 by December 17, 1984. It is debatable whether widespread awareness of AIDS and the isolation of the retrovirus assisted in the increase of reported cases. Suffice it to say that the number of cases increased substantially in this year.

This disturbing increase in the number of AIDS cases was offset by reports in July that American and French researchers had isolated the virus which caused AIDS. With the isolation of the virus work could begin on a vaccine. This was the good news. More good news came in October when it was reported that heat treatment appeared to destroy the AIDS virus in experiments with Factor VIII concentrate. Factor VIII concentrate is the clotting factor required by hemophiliacs and it is collected from donated
blood. These developments were leading to procedures which could analyse and subsequently protect the safety of the blood supply.

Another epidemiologic development was noted in 1984. It was reported that female to male sexual transmission of the virus occurred in Africa. The extent to which female to male transmission was a factor in the USA was not previously known.

If asked, clinicians would probably have said that AIDS was coming under control or within the scope of Western biomedicine during 1984. The retrovirus was isolated, the risk groups known, and the modes of transmission were becoming well defined. Efforts could now be placed on public education, risk reduction and the development of a vaccine.

TRANSMISSION TO HEALTH-CARE WORKERS IN THE WORKPLACE

The possibility of disease transmission in the workplace was an early concern in the development of an AIDS etiology. In August of 1983 the CDC began a surveillance program of health care workers who had documented exposures to potentially infectious body fluids. By December 31, 1984 there were 361 health-care workers, HCW's, enrolled in the surveillance registry. In November of 1982 the CDC stated that:

It appears prudent for hospital personnel to use the same precautions when caring for patients with AIDS as those used for patients with hepatitis B virus infection, in which blood and body fluids likely to have been contaminated with blood are considered infective. Specifically, patient-care and laboratory personnel should take precautions to avoid direct contact of skin and mucous membranes with blood, blood products, excretions, secretions, and tissues of persons judged likely to have AIDS.17
Given the above recommendation it is interesting to note that two years after the recommendations were made the CDC's surveillance programme of health-care workers records that:

Postexposure care varied considerably. Forty-eight percent of exposed HCWs received either no specific treatment or local wound care only, while 35% received immune globulin alone or in combination with other treatment.\(^\text{18}\)

Approximately one-third of those exposed to potentially infectious body fluids received immune globulin, a standard treatment for those exposed to hepatitis B. Hepatitis B clinical precautions have been suggested for over two years, yet only a minority of those health-care workers exposed did in fact receive standard post-injury care corresponding to hepatitis B precautions. This situation raises questions as to the degree of precaution compliance present in health care settings. Seven months after this report the CDC noted that a large number of accidents in health care settings were potentially preventable. They stated that:

Epidemiologic studies of needlestick injuries in hospital personnel indicate that over 40% of the accidents are potentially preventable if recommended precautions are followed when handling needles or other sharp objects.\(^\text{19}\)

In November of 1985, twenty-seven months after it began, the CDC's surveillance project of health-care workers made the following statement:

Current evidence indicates that despite epidemiologic similarities of HBV (hepatitis B virus) and HTLV-III/LAV infection, the risk for HBV transmission in health-care settings far exceeds that for HTLV-III/LAV transmission. The risk of acquiring HBV infection following a needlestick from a HBV carrier ranges from 6% to 30%,
far in excess of the risk of HTLV-III/LAV infection following a needlestick involving a source patient infected with HTLV-III/LAV, which is less than 1%. 20

Figuratively speaking, the circle of etiological development and clinical precautions was completed with the November 15, 1985 statement quoted above. In November of 1982 the CDC tentatively suggested that hospital personnel use "the same precautions when caring for patients with AIDS as those used for patients with hepatitis B." 21 Three years later, the virus had been isolated and antibody tests developed. With this knowledge and these tools the circle was completed when the 1985 study concluded that hepatitis B precautions were adequate for the prevention of AIDS transmission in health-care settings. One final point of interest in this debate is the fact that those who were hospitalized with AIDS received health care from a concentrated number of hospitals. The same report which recorded the risk of infection from needlestick injuries noted that: "75% of all AIDS cases have been reported by only 280 of the more than 6,000 acute care hospitals in the United States." 22 Such statistics rebuke arguments proposing that a lack of infection prevention education in health care settings could be due to the large number of hospitals caring for individuals with AIDS.

The development of knowledge regarding AIDS, its etiology and clinical precautions, does not appear to have reached those engaged in health-care service delivery. This is the only logical conclusion possible when one measures the lack of post-injury care and the large proportion of preventable accidents against the fact that clinical precautions, which weathered etiological developments, were issued in November of 1982. The next section of this discussion looks at the prevention and transmission of AIDS outside
health-care settings. Again we will examine the CDC's guidelines as well as how they are perceived and followed.

AIDS AND CDC SCHOOL ATTENDANCE RECOMMENDATIONS

On August 30, 1985 the CDC published a four and a half page set of guidelines outlining recommendations for the care of children infected with the HIV virus. These recommendations dealt with school and foster care settings. The issues discussed included legal issues, confidentiality and risks of transmission. The report also dealt with the risks existing for those children with HIV infection. The publication noted that "such children (with HIV infection) may have a greater risk of encountering infectious agents in a school or day-care setting than at home. Foster homes with multiple children may also increase the risk."23

The report concluded with eleven recommendations. Recommendation number one adequately summarizes the thrust of the report:

Decisions regarding the type of educational and care setting for HTLV-III/LAV-infected children should be based on the behavior, neurologic development, and physical condition of the child and the expected type of interaction with others in that setting. These decisions are best made using the team approach including the child's physician, public health personnel, the child's parent or guardian, and personnel associated with the proposed care or educational setting. In each case, risks and benefits to both the infected child and to others in the setting should be weighed.24

These recommendations were developed with the assistance of six reports showing that transmission of the virus to family members outside of the
known risk groups was not known, "other than the sexual partners of HTLV-III/LAV-infected patients and infants born to infected mothers, none of the family members of the over 12,000 AIDS patients reported to CDC have been reported to have AIDS." References for the six studies supporting this conclusion were provided in the report.

The same edition of the MMWR also noted work from the National Institutes of Health where the HIV virus had been isolated from the tears of an individual with AIDS. The CDC developed three recommendations for the prevention of HIV transmission in situations involving eye examinations, the use of instruments having contact with the eye, and contact lenses used in trial fittings. These recommendations concluded with the following editorial note:

All secretions and excretions of an infected person may contain lymphocytes, host cells for HTLV-III/LAV; therefore, thorough study of these fluids might be expected to sometimes yield this virus. Despite positive cultures from a variety of body fluids of infected persons, however, spread from infected persons to household contacts who have no other identifiable risks for infection has not been documented. Furthermore, there is no evidence to date that HTLV-III/LAV has been transmitted through contact with the tears of infected individuals or through medical instruments used to examine AIDS patients.

The transfer of this information from the MMWR to the popular press with regard to children with AIDS attending school is of interest. Before that analysis begins one further point has to be made regarding AIDS and transmission through casual contact. The CDC reported that six studies of households had shown no evidence to support a claim that transmission
occurred through casual contact. One of the six studies reported was the "Lack of household transmission of HTLV-III infection, EIS Conference, Atlanta Georgia, April 1985" by researchers Friedland, Saltzman and Rogers et al. This specific work was not reported in the popular press until February 17, 1986 by this time the conference presentation had developed into a New England Journal of Medicine article. The CDC reported this research in August of 1985, it was first publicly presented in April of 1985, yet the newsmagazines did not report it until February of 1986, a delay of five and a half months between the CDC publication and the popular press. When the CDC reported a possible case of AIDS transmission from child to mother on February 7, 1986 the news was covered by Time and Newsweek ten days later. We may not get any answers, yet we should ask why such time discrepancies exist between reports of "good" and "bad" news. Reports in the popular press covering the story of children with AIDS attending school may assist with the development of potential answers regarding time discrepancies.

SCHOOL ATTENDANCE AND THE POPULAR PRESS

The opening of schools in the autumn of 1985 brought the issue of AIDS into the classrooms of North America. Ryan White, a thirteen year old with hemophilia and AIDS, was not allowed to attend school in Kokomo Indiana. This decision was made by the District School Superintendent. This decision was made even though Indiana state health officials said children with AIDS could attend school under certain circumstances. Ryan's mother responded to this decision with legal action, suing school officials for what they claimed was an act of discrimination. This background set the scene for the confrontation previously
discussed in New York City between two school boards, which sought to prevent a child with AIDS attending school, and the City's Board of Education, which stated that the child could attend school. News stories and photo opportunities were bountifully supplied by this confrontation and reported in the popular press.

The editions of Time, Macleans, and Newsweek for September 23, 1985 all carried reports of the school controversy. These reports were respectively titled, "The New Untouchables," "An epidemic of fear" and "The fear of AIDS." The stories detail individual examples of discrimination experienced by a number of persons with AIDS. The Time article had a one page sub article on AIDS etiology and epidemiology entitled "Not an Easy Disease to Come By." Newsweek ended its cover page article with a sub article entitled "Sins of Omission: Press coverage of AIDS has left some things unsaid." An essay in Time's September 23, 1985 edition cautioned against "The Start of a Plague Mentality." Not all news magazine reports of September and October were educational. The September 30, 1985 edition of Macleans ran a column by Barbara Amiel which contained the following:

AIDS anxiety is spreading. Dentists won't treat victims of AIDS. Travel companies are trying to screen them out of tours, and firemen say they do not want to give them mouth-to-mouth resucitation. This attitude is not unreasonable.

Amiel's article is entitled "AIDS and the rights of the well." Amiel's mentality crept into editor Kevin Doyle's Macleans column on November 18, 1985. His argument is outlined in the following excerpt:

The steady advance of medical science offers no defense against the blind, primeval fear that besets humanity in the face of the
epidemics that regularly confront it... many otherwise rational people express deep-rooted terror about the dangers of simply coming into casual contact with victims of the mysterious disease. At the same time, there is a growing clamor in favor of quarantining AIDS victims...

Children are often careless about their bodily functions. As well, their unsupervised behaviour can involve such seemingly harmless secret rites as exchanging blood oaths and a host of other activities that can cause disease to spread. Quarantine is a sad and difficult decision for anyone to reach. But if it can become accepted, then every effort will have to made to provide the most humane and fulfilling educational and social opportunities for the victims.38

At best, this is misinformed liberalism; at worst, it is irresponsible epidemiology. The profound consequences of such attitudes have not been thought out in either of these Macleans articles. The words of Tom Stoppard provide a relevant counter point, "life in a box is better than no life at all. I expect."39 The development of a "plague mentality" appears to have overtaken "the public" with respect to the issue of children with AIDS attending school. It seems justified to assume that this developing attitude of "self-interest-for-protection-sake" may account for the lack of "good" news pertaining to the absence of AIDS transmission in households. This rising defensive stance could be labelled a "laager mentality." "Laager" is the word the Boers used to describe the manoeuvre in which they circled their wagons in a ring for protection when they were under attack or preparing to fight. The development and or existence of a laager mentality goes a long way towards explaining the CDC's publication of November 15, 1985.
THE CDC, PUBLIC TRANSMISSION, AND SOCIETAL EXPECTATIONS

On November 15, 1985 the CDC published an eleven page summary of recommendations for preventing the transmission of the HIV virus in the workplace. The first two paragraphs of this summary contain the following:

The information and recommendations contained in this document have been developed with particular emphasis on health-care workers and others in related occupations...Because of public concern about the purported risk of transmission of HLTV-III/LAV by persons providing personal services and those preparing and serving food and beverages, this document also addresses personal service and food-service workers. Finally, it addresses "other workers" -- persons in settings, such as offices, schools, factories, and construction sites, where there is no known risk of AIDS virus transmission...

these recommendations state that food-service workers known to be infected with AIDS should not be restricted from work unless they have another infection or illness for which such restrictions would be warranted.40

In the third paragraph the CDC again states that "recommendations that would prevent transmission of hepatitis B will also prevent transmission of AIDS."41

In effect, this publication tells us nothing new nor anything previously unpublished pertaining to the transmission of the HIV virus. It seems fair to ask why the CDC wrote eleven pages, their longest AIDS related publication to date, to say nothing previously unreported. The CDC has again "crossed the line" from medical research publication to societal educator and critic. The "cross over" first occurred in September 1983 when the CDC justified its
risk group classification and criticized the social and economic
discrimination developing towards individuals with AIDS. The CDC's eleven
page publication can only be understood, given the fact it says nothing new,
when it is examined in its political and societal context. This publication
"makes sense" as a response to the rising anxiety of the "general public."
Waxler's observations regarding leprosy also assist us to understand this
publication and the public's response to AIDS:

the definition of a specific disease and associated societal
expectations often depend as much on the society and culture as on
the biological characteristics of the disease itself... society's
definition of and expectations for a particular disease are
sustained by social and organizational forces that may have little
to do with the disease itself as a biological process.\(^\text{42}\)

These social expectations and social definitions were clearly present
in the New York trial regarding a child with AIDS attending school. Social
definitions of probability and risk were one focus of debate, as Nelkin and
Hilgartner observe in the following:

Scientists are socialized to avoid definitive statements and to use
a language of probability. Thus, their testimony was peppered with
qualifications: 'extremely unlikely,' 'reasonable certainty,'
'infinitesimally small,' 'would not be expected.' The school board
and the judge interpreted such qualifications as lack of knowledge:
'They don't know the answers.' Confusion reigned between evidence
and proof, between facts and theories, between findings and
explanations, between probable judgements and unassailable
conclusions. Establishing the level of risk was one issue;
deciding about the acceptability of risk was yet another.
Thus, different interpretations of the scientific knowledge were paralleled by conflicting views of its policy implications. Interpretations of scientific knowledge and their policy implications continues our discussion into the area of AIDS and dentistry.

THE CDC and DENTAL TRANSMISSION PREVENTION

In April of 1986 the CDC issued its third in a series of transmission prevention recommendations for dental practices. This report broadened the discussion of risk transmission by making two related and important points. It appears that infection prevention measures have not been adequately followed by dental practices in the recent past; this situation causes risks for the patients as well as their practitioners. The CDC expresses this position by observing that:

While few in number, reported outbreaks of dentist-to-patient transmission of hepatitis B have resulted in serious and even fatal consequences. Herpes simplex virus has been transmitted to over 20 patients from the fingers of a DHCW. (Dental health care worker) Serologic markers for hepatitis B in dentists have increased dramatically in the United States over the past several years, which suggests current infection-control practices have been insufficient to prevent the transmission of this infectious agent in the dental operatory.

It should be noted that infection control practices and not infection control recommendations have been "insufficient" in the dental operatory. This dental recommendation closes the chronological time period under examination.
AIDS is interpreted or constructed as a biological problem in the MMWR. As epidemiological data was gathered a proposed etiology of AIDS developed. Clinical and laboratory precautions also came to be proposed. AIDS is shown not to be transmitted casually, as there is no evidence of household transmission. This is the clinical or biological interpretation of data gathered by the Centers for Disease Control.

The parents of some school age children had a very different construct of AIDS. AIDS is seen as an unknown and unpredictable deadly disease. Only the absolute certainty that AIDS could not be spread in the school setting was acceptable to these parents. Given the fact that medical people would not give promises of 100% safety, parents felt that children with AIDS should not attend school. Parents would not hear nor accept a biologically based probability model which operates from the premise that nothing can be predicted with 100% accuracy. For the parents only absolute 100% promises were sufficient. AIDS became a political issue which was constructed and argued by parents on points which did not perceive the technical or biological data as neutral information, nor accept it as "expert testimony." Parents knew what they wanted to hear and would accept nothing less than that. This social construction of AIDS operates from the perception of a threat and a demand for safety, safety as defined by the parents. When this demand was denied or disputed the resulting conflict expanded to a political level which obscured the issue of viral transmission.

With this medical context we return to 1981 and follow news magazine coverage of AIDS for the same five year period as the MMWR. Time, Macleans and Newsweek have been chosen because they are published at weekly intervals as is the MMWR and thus enables a chronological comparison of all four
publications. A chronological list of the three newsmagazines' reports is found in the Appendix. The newsmagazines Time, Macleans, and Newsweek were chosen because they are readily available and widely circulated. Macleans was specifically chosen as it is the only Canadian based publications which uses the same news magazine format of Time and Newsweek. All three publications were chosen because they include pictures as well as written news. An analysis of this material focuses on the construction or perception of AIDS in news reports. This data details the social context of AIDS and leads to a discussion of sexuality and power which ends this chapter.

AIDS AND NEWSMAGAZINES

The search period for articles in Time, Macleans, and Newsweek is the same as that used for the MMWR. This period is from June 1, 1981 to April 30, 1986 inclusive. Any articles on AIDS have been included in this search. Before this analysis begins we need to briefly discuss what has been termed "documentary reality."

DOCUMENTARY REALITY

Time, Macleans, and Newsweek are published at weekly intervals. The date published on their covers is always a Monday; yet they are on sale up to four or five days before the actual date printed on their covers. They are similar to post-dated cheques, having arrived ahead of time with a written date still in the future; yet they portray themselves as weekly news magazines which record the latest current events. This discrepancy between date of availability and the date of "publication" is part of what Dorothy Smith collectively terms "document time." All of our articles exist in document time. Document time is not restricted to an analysis of
chronological dates. Smith uses the term to refer to the final form of the account, the published material we purchase. She examines the process which precedes the publication, namely the process of development or production. She terms this process the "social organization of the production of the account." Once an article or publication has reached the point where it exists in document time Smith believes it to be:

that crucial time at which much if not every trace of what has gone into the making of that account is obliterated and what remains is only the text which aims at being read as 'what actually happened.' 49

In other words, experience comes to be annulled or represented by language. The reading or hearing of an account is a separate experience from that of its production. The reading or hearing usually "bypasses the processes which produced the account." 50 Smith maintains that "a documentary reality is fully constituted only in the completion of both phases." 51 In our previous discussion of the MMWR publications we examined them with an interest in analysing their process of production. Through the use of background material we sought to account for publications which were "out of character," namely the defense of risk group classification and the eleven page publication on transmission prevention. This discussion will attempt to analyse the newsmagazine publications centered on AIDS with the purpose of working "back" towards the production of the account. Smith spoke of the traces of production frequently being hidden in the document's final form. Our aim here may be termed a search for "trace elements of production." This search may not be simple or straightforward. Tuchman's observation and analysis of television news is an example of such a search. Tuchman sees
the "production of the account" somewhat akin to spinning a "web of facticity:"

to flesh out any one supposed fact one amasses a host of supposed facts that, when taken together, present themselves as both individually and collectively self-validating. Together they constitute a web of facticity by establishing themselves as cross-referents to one another.52

Tuchman believes that the process of making and listening to "the news" transforms the actual events which are being reported; "news imparts to occurrences their public character as it transforms mere happenings into publicly discussable events."53

This analysis will examine newsmagazine reports of AIDS as publicly discussable events. Two other publications will assist in this analysis. The Centers for Disease Control MMWR and a the Canadian gay newsmagazine The Body Politic. The MMWR is published weekly and The Body Politic was published ten times per year.

The MMWR provides the biological context of AIDS. The Body Politic provides an alternate source of news. The Body Politic was chosen as it was the only nationally distributed gay news magazine in Canada until it ceased publication in February 1987. It was chosen over its American cousin, The Advocate, in an effort to balance Canadian and American based publications. An openly gay news magazine was chosen in an effort to check or measure the social perception of AIDS found in the mainstream news magazines of Time, Macleans, and Newsweek. Given the fact AIDS initially appeared predominately in gay men, a gay news source was felt to be necessary to record their perception of AIDS. This material has been gathered with a national and North American focus in mind. This accounts for the selection...
of these publications over other materials such as the New York Times. Other publications have been employed, but they do not provide primary material.

THE FIRST REPORT

The first report of AIDS in Time and Newsweek came on December 21, 1981. Why now? AIDS first became noticed by the medical establishment in June of 1981. By December of 1981 there were almost 180 cases of PCP, KS and other infections. Does the rising incidence of these infections explain why these newsmagazine reports were published? It is sometimes difficult to surmise or search for the incident which nurtured the newsmagazine article. Yet it does not appear that these first newsmagazine articles were due to a rising number of diagnostic cases. An article in the New England Journal of Medicine may have brought these newsmagazine reports to life. The Newsweek article referred to Dr. Siegal's article directly and Time spoke of KS as "one of a variety of ailments that have been suddenly turning up in young homosexual men, according to last week's New England Journal of Medicine." It appears that AIDS became a "publicly discussable event" when a New England Journal of Medicine article was published and "picked up" by the newsmagazines. The next AIDS article to appear in any of the three publications came one year after these first two reports.

The second report in the popular press was published in Time's December 27, 1982 issue. The article of origin which developed this piece was from the CDC and published on December 17, 1982. The CDC article speaks of research into the recent appearance of immune deficiency in young children.

One and a half years after AIDS was observed in the medical community,
three news magazines had published a total of three reports. Two were
developed from the same article in the *New England Journal of Medicine* and
the third article was developed from a report in the *MMWR*. From the
previous chapter you may recall that by the end of 1982 the CDC had
predicted AIDS to be caused by an infectious agent as well as published
hospital and laboratory precautions. None of these have been reported in
the three news magazines. It should not be surprising that *The Body
Politic*, an openly gay news magazine, had much more coverage of AIDS during
the same year and a half. The first AIDS related report in *The Body
Politic*, or TBP, was published in September 1981. Its source of
origin was an article from the *New York Times* published on July 3, 1981
which reported on the work of Alvin Friedman-Kien and the recent incidence
of KS among gay men.

In TBP's November 1982 issue two major articles were published. The
first, "Living with Kaposi's" was a seven page article in which a man
who had Kaposi's for over a year was interviewed along with his lover, a
close friend, and his parents. The article then outlined and described the
response to this illness existing in the public press and the gay community.
A second article, in the same issue, is entitled, "the real gay epidemic:
panic & paranoia." This article looks at what is known and not known
about KS, PCP and other opportunistic infections. This same issue also
noted that the US House of Representatives and the Senate voted to override
a presidential veto of August 20, 1982 which had stalled the passing of a
$500,000 grant for AIDS research. The year and a half which saw three
reports in the "main stream" news magazines saw articles in TBP which
discussed etiology, epidemiology, research funding and the personal
experiences of an individual living with the illness. TBP's articles
presented a variety of information and perspectives not found in the articles of *Time*, *Macleans* and *Newsweek* for the same time period.

GAY PRIDE 1983

Gay people across North America have gay pride parades every year towards the end of June. These celebrations commemorate the riots which began on June 28, 1969 when patrons of the Stonewall Tavern in New York City resisted arrest during one of the routine police "round-ups" of openly gay people. The Stonewall riots are seen as the marker or beginning of Gay Liberation or the Gay Movement.

The articles of July 4, 1983 in *Time* and *Newsweek* seem to have developed from demonstrations regarding AIDS funding which occurred during the gay pride activities of that year. Both articles had pictures of a candlelight vigil and *Time* had a photo of people holding posters with stenciled numbers on them, each one representing a person who died from AIDS. These pictures may in fact record different stages of the same gathering. *Newsweek*’s article is entitled, "The Panic Over AIDS" and *Time*’s second article is entitled "The Real Epidemic: Fear and Despair." *Time*’s first article is called "Hunting for the Hidden Killers." Each of *Time*’s articles begins with a graphic consisting of a stylized test tube containing a black liquid and a white skull and crossbones. The *Newsweek* article’s second page had a reduced headline from the *New York Post* stating "L.I. GRANDMA DEAD OF AIDS." *Newsweek* titles this graphic with "Headline: Creating hysteria?" One could ask the same question of a picture directly above this graphic. The picture portrays three jail personnel who are "taking precautionary steps" according to the picture’s credit line. Those "precautionary steps" have resulted in the two men at each end being
equipped in riot gear which includes helmets, face shields, extra heavy clothing, and heavy gloves. Both the guards have hand guns in holsters and have positioned themselves in a "gun fighter stance." The middle man is dressed in a disposable "medical" outfit which includes a hat, face mask, gown and gloves. He is carrying a portable radio. At the time this article was published clinical precautions have been in the public domain for seven months and it was noted that the CDC in June of this year stated that "casual contact offers little or no risk." The Newsweek article ends under this picture with the sentence, "The challenge lies in persuading nongays that there is no need for hysteria." The discrepancy between picture and words, or between written report and visual semiotics, are extreme. The only thing clear is that the message is mixed, and may represent editorial ambivalence towards the topic.

COVER STORY/COVER PICTURE

If asked, Newsweek will claim to have written the first cover story on AIDS when compared to our other two news magazines. This first article opens with the following sentence, "Since it came into public view in 1981, derisively called 'The Gay Plague,' AIDS has stricken 1,300 Americans." It is interesting that the word "derisively" meaning mocking or jeering has been used when one of the two writers who created this piece also worked on the first Newsweek article on AIDS, entitled, "Diseases That Plague Gays." It appears there is a discrepancy between what is written in one article and that which headlined their first article on AIDS.

The first AIDS related cover picture appeared in the August 8, 1983 issue of Newsweek. This picture is an excellent example of reporting in
which Tuchman's "web of facticity" has been subtly spun. The cover picture shows two men facing the camera, each with an arm around the other. One of them leans his head on the other's shoulder. The cover graphic reads:

GAY AMERICA

Sex, Politics and

The Impact of AIDS

On the first inside page the subjects in the photograph are identified with the following sentence, "The deadly affliction called AIDS has spread throughout the land -- touching among the hundreds, NEWSWEEK's cover subjects Bobbi Campbell (left), who has the disease, and his friend Bobby Hilliard, who does not." Although these two men are called the "cover subjects" we never hear another single word about them in the seven pages of writing which follow. The Body Politic, in an article published at the same time as this picture, provides us with information on Bobbi Campbell:

THOUSANDS DEMAND AIDS FUNDING (title)

Thousands of lesbians and gay men took part in marches across the United States to demand more funding for research and treatment of AIDS... In San Francisco, a dozen AIDS patients carrying a banner that read, "Fighting for Our Lives" led a crowd of 10,000 from the Castro area to the city's downtown area... Bobbi Campbell, the longest surviving San Francisco resident diagnosed with the disease, told the crowd, "we are not victims, we are fighters. It is not important to worry about when we will die; rather we should be more concerned about how we live." An event which protested a lack of AIDS funding and programmes was used as a photo opportunity to weave a Newsweek story with the following title and opening sentence:
GAY AMERICA IN TRANSITION

A turning point has been reached, and AIDS may mean the party is over.

The Hothouse was legendary in gay San Francisco -- a four story, 10,000 square-foot pleasure palace filled with inviting private alcoves and the paraphernalia of kinky sex: harnesses, chains and shackles. This report's opening tone of moral censure exemplifies the process in which "actual events" have been transformed into documentary time. Our "trace elements of production," funding protests, have been obliterated. In their place a story of changing behaviours has grown.

The year 1985 was the year in which AIDS "hit the front pages" of the newsmagazines under our review. The years 1983 and 1984 saw a total of ten articles in each year from all three news magazines put together. In 1985 forty articles were published. In our search period of almost five years a total of six cover pictures were found, five of the six were published in 1985. The coverage of school attendance in September of this year has already been discussed in conjunction with MMWR publications. Our discussion here concentrates on the weeks of August 5th and August 12th 1985. All six newsmagazine issues of these two weeks published AIDS related articles. The first articles of August 5, 1985 focussed on the announcement that Rock Hudson had AIDS.

TWO WEEKS OF AIDS:
August 5 - 12, 1985

Articles in Time, Macleans, and Newsweek reporting that Rock Hudson had AIDS were published under the following respective headlines:
Word that Rock Hudson had AIDS dramatizes a growing problem.

Rock Hudson and the war against AIDS.

AIDS strikes a star.\textsuperscript{75}

The announcement that a "public figure" had AIDS brought headline attention from the news magazines. These articles were written from a perspective that AIDS is still perceived as a "gay disease." This assertion is supported by an excerpt from the second paragraph of Time's article of August 5th:

For most Americans, whose lives have not been touched by the epidemic, the announcement (Hudson's) brought home for the first time the grim reality that AIDS is spreading unabated, inevitably striking the famous and the familiar. As of July 22, the Centers for Disease Control (CDC) in Atlanta has recorded 11,871 U.S. cases including 5,917 deaths.\textsuperscript{76}

When one "stands back" from these words it is difficult to logically connect the two thoughts contained in this excerpt. In the United States there were nearly 12,000 cases of AIDS and 6,000 deaths and most Americans "have not been touched by the epidemic." Have few people been effected by AIDS before news of Rock Hudson, or is this statement based on a perception rather than factual data? I believe it is a social perception and one which is supported by two separate attitudes. The first is what could be tenuously described as a "North American phenomena," the vicarious experience acquired by following the lives of movie "stars" and screen "idols." \textit{Time} said it neatly with a pun they may or may not have intended, "Word that Rock Hudson has AIDS dramatizes a growing problem."\textsuperscript{77}

Explaining the second attitude, the general public's lack of contact with AIDS and those who have it, may be found in a \textit{Newsweek} poll of 1983. A
Gallup poll was conducted for *Newsweek* on July 20 and 21, 1983. The margin of error was reported to be plus or minus four percent. The first question was:

Do you have any friends or acquaintances who are homosexual?

<table>
<thead>
<tr>
<th>YES</th>
<th>24%</th>
</tr>
</thead>
<tbody>
<tr>
<td>NO</td>
<td>76%</td>
</tr>
</tbody>
</table>

Do you feel that homosexuality should be considered as an accepted alternative lifestyle?

<table>
<thead>
<tr>
<th>YES</th>
<th>32%</th>
</tr>
</thead>
<tbody>
<tr>
<td>NO</td>
<td>58%</td>
</tr>
<tr>
<td>DON'T KNOW</td>
<td>10%</td>
</tr>
</tbody>
</table>

If one person in ten is homosexual then many of the 76% who said no in the first question do in fact know gay men and lesbian women. Some may not actually know about their friends' sexual orientation, but others will consistently refuse to see or acknowledge that they have gays and lesbians for friends. The general public experiences a myopia of convenience with respect to issues of homosexuality and this is supported by the acceptance of an apartheid, or separate development, mentality among some gays and lesbians. There are historical and legal reasons for this system of belief among many gays and lesbians. A comprehensive analysis of this system is beyond the scope of the present work. However, one point of relevance is the discussion of Boswell's historical analysis of social tolerance which shows that hostility towards homosexuality has not been constant, but began in the West during the twelfth to fourteenth centuries.79

This symbiotic relationship between the "straight" and "gay" worlds
results in many non-homosexuals having no personal connection with AIDS. The August 12, 1985 editions of *Time*, *Macleans* and *Newsweek* promote a personal connection with AIDS that moves beyond the gay community.

All three newsmagazines had cover pictures and cover stories of AIDS in their August 12, 1985 editions. In five years these magazines published six AIDS related cover pictures. Three of those six cover pictures were published in this single week. The only development which adequately accounts for this high profile is the previous week's announcement that Rock Hudson had AIDS. *Time's* cover has the virus, magnified 135,000 times, destroying a T cell with the title "AIDS, The Growing Threat." *Macleans* has a picture of Rock Hudson with the caption, "The new terror of AIDS." *Newsweek* has an inset photograph of "AIDS victim Rock Hudson" with the words:

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AIDS

It is the nation's worst pubic health problem...
Now fears are growing that the AIDS epidemic may spread beyond gays and other high-risk groups to threaten the population at large.81
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This "new terror," "growing threat," and "fear" is one of public perception and the creation of a news "story" rather than an actual medical emergency. A web of facticity has anthropomorphized the virus to the point where it "may spread to threaten the population at large" when if fact clinical precautions have been publicly available for nearly three years, since November 1982, and a presentation in April of 1985 spoke of the "lack of household transmission of HTLV-III infection."82

These news magazines report no new medical information; by 1985 the
etiology and epidemiology of AIDS have been established for almost a year since the virus was clinically isolated in 1984. The "growing threat" is in fact a growing awareness of the disease. AIDS became a "high profile" news story when Rock Hudson, a "public figure," developed the illness. The report that Rock Hudson was gay came at the same time it was reported he had AIDS. To borrow a Hugh Maclellan title for metaphorical purposes, the announcement that Rock Hudson had AIDS struck at the "two solitudes" of AIDS. The solitudes were the two communities, homosexual and heterosexual. For many people AIDS occurred "in the gay community," a social, political and cultural body with which most people eschewed any connection or experience. It was foreign "out there," it was "their problem." AIDS in a public figure mysteriously brought the problem closer to home. Hudson was embodied as the "individual you know" who had AIDS. People now identified with someone with AIDS. AIDS now had a face. The threats and crisis reported in these news magazines stem more from the fracture of two solitudes than they do from any new medical or biological information pertaining to AIDS. Attempts to account for this crisis within the collective mentality lead to an exploration of the differences between the solitudes of the homosexual and the heterosexual, and therefore sexuality.

SEX, SEXUALITY AND AIDS

AIDS is being said by many to have brought the "sexual revolution" to an end. In the words of Newsweek, "AIDS may mean the party is over." There are some in the gay community who feel AIDS may be used or seen as a threat to the process of gay liberation. The words "revolution" and "liberation" develop from a perception that sex and sexuality were repressed and are now free, were once taboo and are now openly discussed. Some
evidence supports these views, but do they fully encapsulate the history of sex and sexuality? Are there other ways of looking at our Victorian sexual legacy and the time which preceded it? Foucault attempts to analyse the development of sexuality from another perspective. His work has something to add to our discussions of AIDS.

Foucault believes that our sexual legacy from the 19th and early 20th centuries is one where "the discourse of sex has been multiplied rather than rarefied; and that if it has carried with it taboos and prohibitions, it had also, in a more fundamental way, ensured the solidification and implantation of an entire sexual mosaic." From the 19th century onwards we have spoken more about sex than ever before. This work has resulted in what he terms the development of a scientia sexualis, science of sex or a medicine of sex as opposed to the ars erotica or erotic arts which existed and to a degree still do in some Middle Eastern and Eastern cultures. Our emphasis on a scientia sexualis perspective brought a series of consequences to the West's search for knowledge.

Developing a "medicine of sex" brought with it a search for the "truth" of sex. Foucault uses this search for the truth as his working hypothesis for the analysis of sex and sexuality:

The society that emerged in the nineteenth century...did not confront sex with a fundamental refusal of recognition. On the contrary, it put into operation an entire machinery for producing true discourses concerning it. Not only did it speak of sex and compel everyone to do so; it also set out to formulate the uniform truth of sex. As if it suspected sex of harboring a fundamental secret. As if it needed this production of truth.

This search for the truth about sex had two effects upon what Foucault
called the peripheral sexualities, one of those being homosexuality:

This new persecution of the peripheral sexualities entailed an incorporation of perversions and a new specification of individuals. As defined by the ancient civil or canonical codes, sodomy was a category of forbidden acts; their perpetrator was nothing more than the juridical subject of them...

Homosexuality appeared as one of the forms of sexuality when it was transposed from the practice of sodomy onto a kind of interior androgyny, a hermaphrodisism of the soul. The sodomite had been a temporary aberration; the homosexual was now a species.91

To play with a linguistic metaphor, what was once an adjective is now a noun. The term "homosexual" developed into a label, or in Foucault's words, "a species." It was through this label that all aspects of the "homosexual" were assessed and analyzed. The "development of homosexuality," if such a term may be applied to the process, is one example of a wider phenomena, in Foucault's words the "administration of bodies and the calculated management of life."92

Supporting this position, Foucault points out that the economic and agricultural growth of the eighteenth century, with its increased resources and production, grew quicker than the developing population. The two great threats towards life, epidemics and famine, were coming within the realm of control. Western Europe was developing to a point where:

death was ceasing to torment life so directly. But at the same time, the development of the different fields of knowledge concerned with life in general, the improvement of agricultural techniques, and the observations and measures relative to man's life and survival contributed to this relaxation: a relative
control over life averted some of the imminent risks of death. In the space for movement thus conquered, and broadening and organizing that space, methods of power and knowledge assumed responsibility for the life processes and undertook to control and modify them.93

The room to move, or gap, which had developed with the gradual control of death, came to be filled with the process of control over the body, both personal and politic:

Broadly speaking, at the juncture of the 'body' and the 'population,' sex became a crucial target of a power organized around the management of life rather than the menace of death.94

Sex as a target of power came to be transformed into what we now assume to be a given, sexuality. Foucault sees sexuality, as an idea and a process, developing within an historical context:

Sexuality must not be thought of as a kind of natural given which power tries to hold in check, or as an obscure domain which knowledge tries gradually to uncover. It is the name that can be given to an historical construct: not a furtive reality that is difficult to grasp, but a great surface network in which the stimulation of bodies, the intensification of pleasures, the incitement to discourse, the formation of special knowledges, the strengthening of controls and resistances, are linked to one another, in accordance to a few major strategies of knowledge and power.95

Sexuality is not a given, but rather a social construct. Foucault believes it is part of the management of life which operates within a system of
knowledge and power. What does all of this have to do with AIDS and news magazine reports?

The "crisis of AIDS" reported in the August 1985 news magazines may be a crisis, but a crisis of knowledge and power as opposed to medicine and disease. The "threat of AIDS" was mentally contained or controlled within the wider community while it was perceived as an illness which was isolated within the gay community. Reports that a "public figure" had AIDS and children with AIDS were seeking to attend school exposed for scrutiny the perceptual ghetto many had constructed to control AIDS and separate it from society at large. When the myth that AIDS equalled homosexual was broken, AIDS appears dressed with anthropomorphic qualities:

Central Africa was almost certainly its cradle, and monkeys its probable hosts. No one knows precisely how or why the virus moved to man, and no one is sure just where and when it embarked on its intercontinental killing spree. But it lurked in the United States for several years before anyone was aware of its presence -- silent, deadly, perversely prolific.96

These words are dramatic, possibly melodramatic, they are also the opening words of Newsweek's August 12, 1985 article. The perception or construct of AIDS changed with the announcement that a "public figure" had AIDS.

This work has contextualized the social constructions of AIDS found in news magazine reports. It is with this context in mind that we shift our focus to our research outline and the interview data which it gathered.
CHAPTER 3
THE RESEARCH PROBLEM

Gathering data regarding the perception or social construct of AIDS is the primary focus of this thesis. The data have been collected from three different groups; individuals diagnosed with AIDS or ARC, family members, and social workers. Materials drawn from news magazines and academic journals have been included as AIDS is now discussed beyond the circle of those involved in the medical aspects of AIDS. AIDS is now in the public forum.

KNOWLEDGE BUILDING FUNCTIONS

The knowledge building functions of this thesis are simple yet important. To date, the psychosocial literature regarding AIDS lacked self-reflexivity, focusing primarily on individuals with AIDS, to an extent considering the circle of significant others, and almost completely disregarding the professionals involved. This research seeks to gather and develop empirical data which may begin to assess the constructs of AIDS and its experience as lived by people with AIDS and their significant others. This assessment specifically examines the perceptions of social workers operating in AIDS related care.

PSYCHOSOCIAL LITERATURE

Medical technology has made rapid advancements in the area of AIDS etiology, yet the point where a "cure" is developed is still some time in the future. In the meantime, those who have been diagnosed with AIDS, like others experiencing any life-threatening illness, depend in some part upon supportive relationships from family members, loved ones, friends, and institutionalized systems of assistance. There is a growing body of
literature dealing with the psychosocial needs of people with AIDS within the disciplines of psychiatry, psychology and social work. In a literature review employing the Social Sciences Citation Index and Index Medicus for the period including January 1, 1981 to April 30, 1986 the following numbers of psychosocial articles written in English and focussed on AIDS were found in each respective year; 1981 - 0, 1982 - 0, 1983 - 4, 1984 - 19, 1985 - 25, and up to April 30, 1986 - 11. If an increase in the number of articles may be interpreted as an increase in interest, it can be said that interest in the psychosocial needs of individuals with AIDS is increasing. It is not sufficient to stop at such a conclusion. An analysis of the ways in which such concerns are expressed is required to complete the picture.

The development and expression of supportive relationships at the interpersonal and institutional level are dependant upon the perception or construct each of the components, individual or institutional, have of AIDS and those people who develop it. The majority of those articles addressing the psychosocial component of AIDS concentrate on the individual with AIDS and the problems which they encounter internally, within themselves, and externally, within society at large. Only seventeen of the fifty-nine articles found in this search mention the issues of professionals' perceptions and prejudices. Almost all of these comments are of an aside nature. Words such as "stereotyping", "homophobia", "anxiety", and "countertransference" are used when discussing the issue of professional perceptions of people with AIDS. These articles all state that education is needed to deal with such issues. Most authors seem to operate from the belief in a process something akin to the following; confusion/misperception/prejudice + education = new perception/truth. This belief is not surprising, as the majority of those writing these
articles operate within the linear medical process which proceeds from examination to diagnosis and concludes with treatment. This process is based in the experimental model and scientific inquiry. Such procedures may be effective when dealing with physical ailments. But human perception is not changed so easily nor effectively simply through the administration of education. Given this fact, the social constructs or perceptions of professionals are particularly important. The constructivist model employed here develops new ways of perceiving and understanding the psychosocial dynamics of AIDS.

CONSTRUCTIVIST MODEL

All the literature reviewed regarding the psychosocial care of people with AIDS is based on the biomedical model. This research will employ the constructivist model. Mishler describes this approach as consisting of the following:

Health, illness and medical care are social facts; that is they are socially constructed categories that define and give meaning to certain classes of events. Whether or not a particular behavior or experience is viewed by members of a society as a sign or symptom of illness depends on cultural values, social norms, and culturally shared rules of interpretation. This approach is in contradistinction to the biomedical model of diseases as defined by reference to universal, culture-free criteria.¹ This perspective is useful for a number of reasons. AIDS is an historically recent phenomena, that it is without history accounts to a great extent for trauma associated with it. This approach allows for the analysis of current perceptions and has potential for the development of new responses. The
constructivist approach is also of benefit to us given the fact that many of those who are presently living with AIDS come from socially marginalized groups, namely gays/homosexuals and IV drug users.

RESEARCH DESIGN

An exploratory model of research has been chosen for a number of reasons. Research and papers, in significant numbers, focussing on the psychosocial aspects of AIDS only began appearing in 1984. The literature review found that many of these articles were focussed on the identified patient rather than the caregiver and institutions of assistance. Many operated from the medical model and a "scientific" process of enquiry. Research employing the scientific imperative usually operates with a belief in objectivity. Faith in an "objective" process acquiring "objective" data rests upon ground previously surveyed by Goffman. There will always be investigative bias when the researcher's "attatchment to his conception of himself as a disinterested expert" superceeds the analysis of a problem or issue. In this work the issue of social construct in primary. An exploratory research model is best attuned to gather relevant data towards this goal.

Medical publications and news magazines have been employed in an effort to explore the context of AIDS and how those living with this syndrome act in the situations they experience. Perceptions and actions can only be understood when examined with a contextual awareness. Narrowly defined inquiries may gather useful information, but the general tendency toward specific details rather than general contexts contains difficulties. Bohm, when speaking about mathematics, makes this point with an analogy of human vision:
The details of what we see are picked up in a small central part of the retina called the fovea. If this is destroyed, then detailed vision is lost, but general vision, which comes from the periphery of the retina, remains. But if the periphery is damaged, while the fovea remains intact, even the details lose all their meaning. By analogy, we asked if science was in danger of suffering a similar 'damage' of its vision. By giving so much emphasis on mathematics, science seems to be losing sight of the wider context of its vision.\(^3\)

Attempting to understand the meanings of human activity requires a contextual perspective. Exploratory research allows for the operationalization of such a perspective.

Exploratory research employs a broad perspective from which specific investigations may follow. Given the historically recent appearance of AIDS a broad perspective is best suited to the development of generalized knowledge. Lakatos believes that progress is achieved through the examination of a series of theories rather than isolated theories.\(^4\) Using Bohm's definition of theories as insights\(^5\) again supports a broad perspective which can be achieved with an exploratory model of research.

This research proposal was reviewed and approved by the University of B.C. Behavioural Sciences Screening Committee. Potential participants with AIDS/ARC and significant others were initially approached through agencies.

A total of sixteen guided interviews were conducted. The number of respondents are as follows: people with AIDS or ARC - 5, family members or lovers of people with ARC or AIDS - 5, and social workers - 6.

People with AIDS or ARC were contacted through the Persons with AIDS Coalition. Family members and lovers were contacted through AIDS Vancouver.
Social workers were contacted through personal contacts. Respondents from the Persons with AIDS Coalition and AIDS Vancouver were initially contacted through third parties in order to agree to participation in this study.

This sample can be labelled a convenience sample as the first five people in each group agreeing to be interviewed became the respondents. Only one individual, a female with AIDS, declined to participate.

The findings of this work should be seen as directions for future work rather than generalized conclusions in and of themselves. Suggestions for further work are presented at the end of this paper. A general discussion of medical social work and social support leads us to an examination of the guided interview and its format.

SOCIAL WORK AND SOCIAL SUPPORT

Medical social work is seen as an intermediary between the unit of care, the identified "patient" and "family", and the biomedical system. The process and mechanism of social support warrents scrutiny. The perception a professional has of the needs and the situation experienced by a unit of care, being the diagnosed individual and significant others, will undoubtably effect the solutions promoted by the professional to meet those challenges. There may be a role for social workers as intermediaries between the family and the biomedical system, but social support should be of interest to social workers involved in AIDS work for a second reason. The majority of those individuals diagnosed with ARC or AIDS requiring medical treatment are in fact members of socially labelled and possibly socially marginalized groups.

Interest in social support is also justified by recent developments in psychoneuroimmunology or PNI. Work in PNI is steadily gathering scientific recognition. This is not to say PNI has been previously unknown, but rather
it has been previously unrecognized within mainstream scientific thought. PNI is developing data which supports the opinion that an individual's sense of self, outlook on life or mental state, can effect his/her body's immunology and hence his/her well-being. Such insights may not be radical to the "common sense" mind, but such insights are now slowly gaining scientific recognition. It should be noted that PNI did not develop in response to the outbreak of AIDS. Work with PNI has been conducted and discussed since 1975 by practitioners such as Ader. Much of the research conducted involving PNI has been done in the field of cancer.

RESEARCH INSTRUMENT: GUIDED INTERVIEW

The determination of social supports develops from social perceptions or social constructs present in the individual, be they "patient" or "professional." This work seeks to look at those social perceptions.

Parallel guided interviews with the three groups defined above was made with the intention of acquiring a wholistic view. At various times in any illness the ill individual may be unable to conduct his/her affairs or be unaware of the dynamics which occur around them. At such points in time family members or significant others play particularly important roles. Any gathering of data which does not review the experiences of family members and significant others would be less than a composite picture of the reality which occurs when one lives with a life threatening condition. It is acknowledged that family members and lovers will have different perceptions, both should be collected if possible.

The family members and lovers interviewed, except one, were not related to those respondents with AIDS or ARC. Data pertaining to the experiences of family members and lovers themselves was preferred over an attempt to
check on the accuracy or similarity of perceptions between those with AIDS and their own lovers and families. Interest in the role and experience of family members and lovers was the primary reason for choosing interview respondents.

In one instance a lover of someone with AIDS asked if the interviewer wished to do a joint interview which included his partner who had AIDS. The decision to conduct that joint interview was made because the two lovers of individuals with AIDS previously interviewed were seen after their lovers had died. The desire to achieve a comprehensive perspective, which included as many perspectives as possible, was the determining factor in this decision.

The term "parallel interviews" means that the questions were asked in as identical a fashion as possible for each of the three groups. This design then allows for a comparison of their responses. That comparison shall include the process of measuring a "fit" between the experiences of those living with ARC and AIDS and those working in a professional relationship with them.

INSTRUMENT CONSTRUCTION

The interviews were designed to be as parallel or similar as possible. While parallel in design, each interview has slight but natural variations. For social workers these differences included specific questions dealing with their professional practice. The first set of questions looked at the number of cases the social worker has dealt with, the degree of involvement and the type of services provided, as well as the process of referral.

The topics covered by the guided interview include the following: illness to diagnosis, family/social dynamics, construct of AIDS, terms of
reference, medical information, services and supports, the media, government and agencies, and daily perception.

ILLNESS TO DIAGNOSIS

The interview constructed for individuals already diagnosed with ARC or AIDS focussed on two separate periods of time: that which included the beginning of illness and that which occurred at and after the point of medical diagnosis. The period from illness to diagnosis is that time in which the individual did not feel 100% healthy and noticed an inability to perform tasks and functions which were previously achievable. It was felt important to focus retrospectively on this period of time as the initial medical diagnosis of AIDS lent itself to such a format. Initially any medical diagnosis of AIDS was defined as the presence of Kaposi's Sarcoma or pneumocystis carinii pneumonia or both in previously healthy individuals. When the viral antibody test was developed in 1983 a positive result to this test was added to the definition of AIDS. This is a narrow biomedical definition of disease. Given the large number of opportunistic infections to which people with AIDS are susceptible and the long incubation period of the virus, it seemed logical to assume that individuals would likely experience a period of illness or unease prior to the point of medical diagnosis. The label AIDS Related Complex or ARC was developed sometime after the initial appearance of AIDS, when clinicians saw a number of individuals who were in fact ill, but did not fit the current medical definition of AIDS. Given the fact social work as a profession is involved in social networks and social support it also made sense to examine this period of time before medical diagnosis. Interest in this period of time also develops from a belief that there is little
material to date which examines the movement from being a physically well and socially functioning individual to that of a "patient", in the sense that one is diagnosed as having a medically defined disease.

The period from illness to diagnosis could also provide an opportunity to see the developing interaction between an ill individual, the medical practitioner and the medical establishment. The experience from illness to diagnosis might effect the relationship of the post diagnosis period.

FAMILY/SOCIAL DYNAMICS

Questions regarding social supports and social connections focussed on three periods of time, those periods including, well-being, illness, and post diagnosis. Any work focussing solely on the post diagnosis period may reach erroneous conclusions as they may attribute the presence or absence of supports to the medical diagnosis when in fact such conditions may have existed prior to diagnosis.

Questions pertaining to family dynamics were asked of those with AIDS and ARC in order to gather specific information regarding family members which may or may not have been collected in the discussion up to this point in the interview.

Family members and lovers were asked about functional relationships in the sense that they were asked about regular contact between family members and the individual with ARC or AIDS prior to the point of medical diagnosis. One question also sought to examine what could be termed the "period of delay" between the individual with ARC or AIDS receiving the diagnosis and the decision and process of sharing the diagnosis with significant others.
CONSTRUCT OF AIDS

The questions developed around the construct of AIDS were specifically oriented to each of the three groups interviewed. People with ARC or AIDS were asked if they had known someone with ARC or AIDS prior to their own diagnosis. Questions asked here sought to see if there were changes in perception towards AIDS which occurred when one was diagnosed himself or herself with ARC or AIDS. Family members and lovers were asked if they had known or had contact with people with ARC or AIDS before they found that their significant other had ARC or AIDS.

Family members and social workers were asked questions regarding homosexuality given the fact that AIDS and homosexuality are connected in the minds of many people. If the family member with ARC or AIDS is in fact gay or homosexual, the respondent was asked questions regarding the awareness of this fact and its effect upon them and the family. This area was of interest because the interviewer has heard of a few instances where family members found out that their son was both gay and had AIDS at the same time. If family members were in this position another question sought to see if there was any change over time in concerns or feelings of discomfort if in fact there had been any previously.

For social workers the questions focussed on the social worker's thoughts towards homosexuality generally and their degree of comfort in providing services to gay people. They were also asked if they themselves had any openly gay friends. These questions were the result of reviewing De Crescenzo's work on social workers and their perceptions towards homosexuality.11

Under the rubric of social construct questions were asked regarding ideas of the general public's perceptions towards AIDS and the people who
have it. Questions were also asked regarding personal experiences which supported the respondent's beliefs. This was done to see if there was a "fit" between the experiences of people with ARC and AIDS and the literature of professional journals which looked at the same area.

TERMS OF REFERENCE

Questions were also asked of each group regarding preferred terms of reference for individuals with ARC or AIDS. People were asked why they chose the terms they did. This question was meant to touch upon the complex question of labelling. One question is by no means a full examination of the issue but as an exploratory work it seemed logical that such a question should be asked.

MEDICAL INFORMATION

Another single question touching a complex issue asked the respondents about their sources of medical information. AIDS as a medical entity is very recent. The etiological information focusing on AIDS is equally new and constantly changing. Given this situation, I was interested in discovering how and from whom these respondents gathered their medical data. This information would also shed light on the relationships developing between people with ARC and AIDS, family members and medical practitioners.

For social workers another specific set of questions focussed on opinions regarding the similarities and/or differences between contexts of AIDS and those of cancer. These questions were asked to see if AIDS was being approached or thought of in a different manner to that of cancer. These questions were also another way of asking questions regarding the social construct of AIDS.
SERVICES AND SUPPORTS

The next area of discussion sought to examine the area of social services and social supports required for people with ARC and AIDS. The definition of "services and supports" was left to the individual being interviewed. Questions in this area sought to explore a number of issues. Those issues include the perceived existence of any gaps in service. They also aimed at the discovery of what individuals felt should be included as supports and services. And finally, these questions were developed to explore the "fit" between concerns expressed by those with ARC and AIDS and social workers. The concerns raised could also be measured against the literature in order to expose their similarities and differences.

Questions regarding social support also sought to gather information as to the resources used to meet individual needs. For those with ARC and AIDS these questions sought to examine to what degree previous friends were called upon to meet new needs and to what extent new contacts were involved in meeting these requirements.

THE MEDIA, GOVERNMENT AND AGENCIES

One set of questions focussed on perceptions towards the media as well as group and government effectiveness. A specific question asked if the respondent knew of AIDS Vancouver and the Persons with AIDS Coalition. This was meant to both confirm or deny the respondent's knowledge of the organizations if these groups had not been previously mentioned. It also provided them with an opportunity to express opinions regarding these two organizations.
DAILY PERCEPTION

The final two questions for individuals with ARC/AIDS and family members/lovers sought to bring the experience of ARC or AIDS back to a personal level. The first question explored the area of daily perception regarding the presence or reality of AIDS. Specifically, the question asked whether ARC or AIDS is one part of their life or central to their daily thoughts and activities. The final question again explored the issue of social construct in so much as it asked if the interviewee would speak to someone who was in a position similar to their own and had just received the "news." If affirmative, what action or cause would they follow.

The final question for social workers asked whether social workers had noticed or were involved in any instances of prejudice or discrimination in the course of working with AIDS in their institution. These questions were asked in order to get an "insider's view" of some of the problems and issues surrounding the medical care of individuals with AIDS. It was also the opportunity to see if problems as expressed by individuals and significant others were being seen or picked up as problems by social workers in medical settings. All three sets of interviews ended with a final question where the interviewee could bring up any important points or issues which had not already been discussed.
CHAPTER 4

THE CONSTRUCT OF AIDS FROM THREE PERSPECTIVES

This chapter details and analyzes data gathered from the sixteen guided interviews. Analysis of this material has been guided by a constructivist approach where the three contexts of AIDS, medical, social and political, are employed to organize the findings. Together these three contexts of AIDS form the total experience of living with AIDS; separated we are able to examine details of experience and compare those to the perceptions of social workers. In this analysis the term "those living with AIDS" is used to represent both significant others and those diagnosed with AIDS and ARC.

THE MEDICAL CONSTRUCT OF AIDS

Social workers and those living with AIDS had predominately similar medical constructs of AIDS. The only marked difference was noted when the diagnosis of AIDS was discussed. The four components of the AIDS medical construct are; definition of AIDS, trajectory of illness, point of diagnosis and sources of medical information.

DEFINITION OF AIDS

Respondents began with a biomedical description of the AIDS syndrome. Almost all said AIDS was caused by a virus which was transmitted through blood and body fluids. Their responses lead from the medical into the social definition of this illness, which began with a discussion of AIDS, to use Lalonde's words, as a "disease of choice." One of the individuals with AIDS had the following to say about AIDS and stigma or blame:

I have never had anything to be ashamed about this disease. I refuse to let it stigmatize me, I've done nothing wrong. This is a no fault disease.
Social definitions of AIDS included a range of perceptions based upon personal experiences. One man said "AIDS opens the door." By this he meant that AIDS in and of itself is the initiator of the medical problem, but the opportunistic infections are the experience of this illness. The virus damages the immune system and opens the body up to opportunistic infections.

A mother, whose son went through a painful and difficult illness which included pneumonia, meningitis, hearing loss and blindness, said AIDS was a "devastating disease, dreadful." Only those who have survived experiences such as hers can fully appreciate the truth of that statement.

The lover of a man with KS had this observation of AIDS, "by calling it a terminal disease you tend to limit hope." At the time this interview was done, this man's lover had been stable for eight months after being diagnosed. Both stage of the illness and the context apparently assist in the establishment of a definition of AIDS.

An individual with KS also described AIDS in a manner consistent with his experience. He has maintained his job since being diagnosed. He had the following to say:

AIDS is a condition you have which doesn't necessarily lead from one step, to the next step, to the next step. It's something you learn to live with. In the beginning it helped to think of AIDS as something you live with, you're not dying of AIDS, you're living with it.

A lover wished to stress the issue of education regarding transmission. He said "I would want to stress how difficult it is to get it."

Echoing the above pattern, social workers also began with biomedical definitions of AIDS and then included social components of the problem. AIDS was described as a "syndrome," a "progressive illness," and a "multi-system,
One social worker made a distinction between the employment of clinical precautions in the hospital and the fear many people have of AIDS and those who have it:

There are special (infection prevention) precautions that are taken; I don't think that means you act differently towards somebody with AIDS.

Social workers also spoke about the blaming some people with AIDS receive. Victim blaming, in the minds of social workers, is due to the sexual mode of viral transmission. The social workers interviewed did not have this judgemental attitude, but reported it from their experience with others. One worker noted that attitudes towards AIDS and those who have it are very important and powerful:

When you are sick it is alot easier to be sick if you don't have to spend energy trying to deal with other people's prejudice, other people's feelings about your disease and "you deserved it" types of attitudes. Even if you don't say anything to the person, even if no words are exchanged, it can be a look, or something, and that person knows exactly what you're thinking. Even knowing how someone feels about you can use up a lot of energy.

A male social worker, who had been involved with the one-to-one "buddy" program in AIDS Vancouver, spoke of the changes he had experienced in his definition of AIDS:

AIDS is something different depending on who get it, symptoms can be quite different. That's something I noticed recently. I always focussed on the one end where somebody was really
sick because that was my experience. It wasn't until I began taking the second fellow to the clinic (St. Paul's outpatients) once a week and saw perfectly healthy people who had full-blown AIDS. It was really a revelation for me because I always worked with people at the other end of the continuum. I had no idea that somebody could be so healthy, functioned really well, looked good. It depends on each individual...The common characteristic is that it is slowly debilitating...I think most workers see it as I used to see it, which was as a total sickness with no possibility of functioning, and with some hysteria.

The perception that AIDS is "different depending on who gets it," can be supported with an analysis of the experiences reported by our respondents. The term "trajectory of illness," adapted from Glaser and Strauss, has been used to discuss these experiences.

TRAJECTORY OF ILLNESS

From the interviews conducted with family members, lovers, and individuals with ARC and AIDS themselves we may conclude that the process or trajectory of illness is unique for each individual. Figure 1, found in the appendix, "charts" or outlines the process of illness for each case. The experience of each individual varies with respect to time periods and symptoms. One individual had a three year interval between the diagnosis of ARC, or lymphadenopathy, and the diagnosis of AIDS, in this case PCP. Another individual had no "warning signs" and was diagnosed with AIDS with one small lesion of KS. This individual reports never having felt ill or not well up to the point of his diagnosis. At the time of his interview, eight
months after diagnosis, he was still working.

Major symptoms revealed in interviews included general malaise, night sweats, shortness of breath, colds and depression at the initial stage of illness. Symptoms experienced at the point of AIDS diagnosis and afterwards included KS, PCP, dementia, lymphatic cancer and meningitis. Within this wide range of variations four types or experiences of illness emerge when time is chosen as the comparative yardstick. Figure 2, found in the appendix, categorizes the experience of illness by creating a six stage process which begins with well being and ends with death. Intermediary stages include undefined illness, ARC-lymphadenopathy, assorted opportunistic infections, and AIDS. The respondent's experience or "illness story" has been charted through these categories using months as the interval of measurement. The total time periods reported in individual cases ranges from nine months to fifty months. Attempts to categorize the experiences, for the sake of analysis, has resulted in the four following "types":

TYPE 1: Development from well being to ARC/AIDS occurring over a period of two years or more, and stable six months after diagnosis.

EXAMPLES a) One month presenting symptoms, 29 months stable with ARC.
            b) Eight months presenting symptoms, 36 months with ARC, 6 months with AIDS.

TYPE 2: Development from well being to ARC/AIDS within one year and stable six months after diagnosis.

EXAMPLES a) Twelve months presenting symptoms, diagnosed with AIDS for ten months, still working.
            b) Ten months presenting symptoms, diagnosed with AIDS two months, stable.
TYPE 3: Development from well being to ARC/AIDS within six months and stable six months after diagnosis.

EXAMPLES a) Four months presenting symptoms, stable 26 months after diagnosis of AIDS.
b) Less than one month presenting symptoms, still working eight months after diagnosis of AIDS.

TYPE 4: Development from well being to ARC/AIDS within six to twelve months, and death within six months of AIDS diagnosis.

EXAMPLES a) Wellbeing to ARC in seven months, five months of opportunistic infections to diagnosis of AIDS, death six months after diagnosis of AIDS.
b) Seven months from well being to opportunistic infections. Three months of opportunistic infections to diagnosis of AIDS, death four months after diagnosis of AIDS.
c) Eleven months from well being to death.

As one respondent described it, "AIDS opens the door," but the experience of illness after the point of diagnosis is unique to each. The four "types" outlined above precipitated from specific data analysis as points of discussion. They are not intended to represent summarized descriptions of the illness experience, for the experiences evidently range enormously. They can be seen to differ from the gradual onset of symptoms and a period of stability or a plateau after diagnosis to a rapid onset of symptoms and stability; and even to a rapid onset of symptoms followed by death shortly thereafter. Six to twelve month units aply characterize the predicaments. Any sober reflection on ones personal experience of illness, usually limited to a few days or at most a few weeks will intimate the arena
of physical debility and vulnerability experienced by those under scrutiny here.

THE POINT OF DIAGNOSIS

Even though AIDS is a syndrome, there comes a point in time, an appointment or a test result, where the diagnosis is actually made by the practitioner and told to the identified patient. We must not assume to know the reactions to the communication of a diagnosis.

One mother commented that the diagnosis alleviated fear. The diagnosis:

  takes away some of the fear, because you sit there and not knowing what is wrong with you gets worrisome.

One individual said he had been diagnosed with lymphadenopathy for almost three years. He had lost jobs because the employer did not believe he could be sick so often. When he was diagnosed with PCP he said:

  It really came as a relief for me as it (AIDS) had finally caught up with me and I had to deal with it. I heard of people back east I had been with seven years ago dying of AIDS, and then five years ago, and then two years ago, so when I finally got the diagnosis it was a relief. Since I have been diagnosed I haven't been healthier, I'm dealing with those things I never did before. I've been troubled with my sexuality over the years and this is like a second coming out.

A third respondent described his point of diagnosis as "very conclusive, but very minor." He said he had a friend who was a nurse and this friend suggested he get a biopsy done on the small purple spot which
had recently appeared on his hand, at the base of his thumb. This spot was smaller than the diameter of a ten cent piece. This individual had tested positive for the HIV antibody earlier in the year. He went to a specialist and he found the the "doctor was frankly fairly insensitive about the whole thing. He took one look at it and said, you've got KS, you've got AIDS." A biopsy was done and the results did confirm the initial diagnosis. The individual with KS states that "when he gave me the results of the biopsy he was straightforward...but straightforward with a lack of compassion. I was not in the office more than ten minutes."

Social workers were generally mute on the point of an AIDS diagnosis. Most individuals seen by social workers had been diagnosed prior to social work involvement. Social worker's silence in the area may also stem from the fact that medical social work frequently begins with a list of service needs and the processing of referrals to appropriate community resources. AIDS Vancouver was cited by social workers as a primary counselling resource. The diagnosis of AIDS and its meaning may have been discussed in AIDS Vancouver or through weekly groups in the PWA Coalition.

**SOURCES OF MEDICAL INFORMATION**

Almost every respondent spoke of culling medical information from a variety of sources, both popular and specialized including newspapers, magazines, medical journals and television. One mother said she had been reading AIDS related articles since the time they first appeared in newspapers. Having a gay son and gay brother, she felt she should know about AIDS. She also felt the knowledge might assist her in warning her son of any preventative practices once they developed. In retrospect, she said, "In a way I was preparing myself" (for AIDS). Other respondents spoke of
seminars, books and medical journals as their sources of medical information. AIDS Vancouver and the PWA Coalition were also mentioned as sources of medical information. No one interviewed depended upon their medical practitioners as sole source. They were unanimous in acknowledging additional and informative sources of data. The individuals with AIDS also spoke of gleaning information pertaining to alternative therapies. This data was gathered and disseminated through the PWA Coalition. The Coalition was cited by all those with AIDS as the primary source for them of alternative therapy information.

Social workers also sought medical information through a variety of sources. Two workers spoke of social work in-service programmes where people from AIDS Vancouver contributed up-to-date epidemiological data. One worker spoke of a public symposium she had attended at John Oliver High School. Another worker spoke of workshops, the topic of which was "safe sex." While one worker indicated medical journals and doctors on the ward as sources, all social workers spoke of the information they had garnered from reading newspapers and watching television, pointing to the prevalent influence and affect of those even at a professional level.

Social workers were questioned about the similarities or differences between AIDS and cancer. One worker said that cancer usually occurred in people older than those who have developed AIDS. Another noted that cancer is not sexually transmitted and therefore those who get cancer are subject to a level of sympathy not directed towards those with AIDS. A third said the opportunistic infections developing from AIDS require care needs which differ from those of cancer. One worker commented that AIDS can include mental deterioration as an opportunistic infection and only cancers of the brain exhibit similar deterioration.
The basic perceptual agreement reported between social workers and those living with AIDS may stem from a decision to categorize other "medical" aspects of AIDS, such as HIV testing and alternative treatments, under the political construct of AIDS, which follows later. Before that discussion begins we examine the social construct of AIDS.

THE SOCIAL CONSTRUCT OF AIDS

Social workers are closely aligned to those living with AIDS when they spoke of the social construct of AIDS. The three components of the AIDS social construct are; individuals with AIDS and significant others, AIDS and the general public, and support services.

INDIVIDUALS WITH AIDS AND SIGNIFICANT OTHERS

Some interview questions exploring announcements to others of an ARC or AIDS diagnosis elicited responses regarding the nature of communication between individuals with ARC/AIDS and significant others. In three of the nine interviews there were problems regarding communication between the diagnosed individual and parents. In all three cases the parents in question also had difficulty with their sons being gay. In one case a mother from out of town made the lover promise that he would tell the other family members that his ill partner had leukemia. In the interview the lover said, "she's been homophobic all her life. She felt a homosexual was mentally ill; she still thinks so now." One mother who was interviewed said her ex-husband has had difficulty with the fact that his son has AIDS. The young man first told his sister that he had KS. Two months after diagnosis he came to visit his mother in the Lower Mainland and told her he had AIDS. The last person to be told was his father. The mother said, "as far as his Dad is concerned, he
has cancer, he doesn't have AIDS." The father was worried what his own friends and neighbours will think if they knew his son had AIDS. The mother observed that "some people have trouble accepting this (AIDS) just the same as some people have trouble accepting a person's homosexuality." This mother has had no such problems. "I've known my son was gay for at least fifteen years. I had a pretty good idea before, because I'm his mother after all." When she was asked why he waited two months to tell her she felt he may have not been sure as to her reaction to the news.

A third individual spoke of the problems he had had with his adoptive parents. He was diagnosed with a form of cancer first and AIDS second. He comments on his relationship with his parents in the following:

My parents and I really don't get along all that well. They don't really accept that I'm gay. They know it but they have trouble with it. Last fall they came out to the coast for three days and it didn't go well as they were asking all these questions. It has been easier for them to deal with the cancer because it doesn't have questions about "Did we do anything wrong?" etc.

I told them I have cancer and said you can tell other people if you want. I don't live in Ontario anymore, but they still do, so that is their concern.

In four cases when individuals were initially diagnosed with ARC/AIDS they chose to be selective as to who they told. This selectivity was a condition of reasonable expectations given the reactions they knew or expected would follow this information.

One individual said he told his mother as soon as he had been told he had ARC. He said it was some time before he told friends about his medical
condition. He said he went through his address book deciding who he should tell first. In those cases where he did not feel he wanted to tell them right away he "sounded them out" by discussing AIDS with them in general terms. He said that after finding out how they felt about the issue he told them he had ARC. He said that none of the responses were negative. This respondent said telling these friends was "like coming out again." "Coming out" is an expression used to describe the process of telling family, friends and others one is gay. It is both an internal and an external process.

In two cases parents were told that their son was gay and he had AIDS at the same time. In one case the respondent said:

My mother took it reasonably well, my father, not at all well. My mother only has my sister to talk to. She can't talk to any friends because my father won't let her.

Data was not available for the second case as to the parents' reactions. The parents did not live in the Lower Mainland and visited the individual with AIDS once over the course of the illness. The respondent in this case was the lover of the man with AIDS.

Individual reasons were given in each of the four cases where others were not initially told of the diagnosis or told not to tell anyone else. In one case a man delayed telling his lover of over thirty years that he had been diagnosed with AIDS. The man with AIDS said he had been afraid that his lover would leave him so he delayed the news. The partner without AIDS said:

It blew my mind. He read all the stories where the guys were lovers and one got AIDS and he got kicked out of the house...That was his biggest concern, that I would walk out on him.
An individual with AIDS asked his mother not to tell people he had AIDS in order to protect a former lover. The city where they lived had a small gay community. The old lover was afraid he would be shunned by everyone when they found out that his former partner had AIDS. The decision to not share the diagnosis was based on a concern for his former partner rather than a personal fear.

One individual said he felt no need to tell his family as they were not living in British Columbia and he has not been particularly close to them. At the same time he had not purposefully hidden the fact from them either. This young man said his brother, also gay, knows he has AIDS. He said his brother saw him on CBC television's The National, the ten o'clock newsbroadcast. The young man further explained his decision not to tell his family he had AIDS in these words:

I don't feel a need to contact my family and tell them I have AIDS because they will only try to rescue me and I don't need to be rescued. I accept responsibility for everything I have done and everything that has happened to me.

I feel that those people who want to be rescued make it happen in that they allow it to occur.

In our fourth case, the individual with AIDS decided he would not tell people at work. His decision not to tell people at work has been made to "preserve a sense of normalcy." He stated:

It is good that they don't know (at work) because if they knew, it would alter how they would perceive me. They wouldn't perceive me as a healthy individual, instead of being me, I would be that person with AIDS and my sole identity would be that...A person with AIDS and I feel so much more than that.
The "two solitudes" of heterosexual and homosexual experience were explored when social workers discussed experiences with gay men and their significant others. Three of the social workers interviewed spoke of new understandings they had acquired regarding the gay community in general and gay relationships in particular. One worker observed that:

The gay community rallied, organized itself, and motivated itself. Maybe this was always there, but because I am not a member of that community, I was not aware. I don't think these caring people just all of sudden turned up because AIDS happened. Maybe it got them together? The other side is that I wasn't aware of the caring and sharing in that other community.

One worker spoke of the connections she found operating in AIDS Vancouver which worked towards meeting the needs of those with AIDS when other systems of support could not or would not help:

I didn't know there was a network like that until I had some direct experience...I think there is a perception in the general public that the gay lifestyle is not long enduring relationships, carefree, selfish in a way, self-centered. If I was guilty of stereotyping, that was the stereotyping for me.

Another worker said she also had reassessed much about gay relationships through her work with those who have AIDS. Up to this point she did know gay people, but she did not know of the strengths of the bonding which existed between partnered males. This had been learnt in the hospital working with those who had AIDS and their lovers.
AIDS AND THE GENERAL PUBLIC

One man spoke of the experience his lover had when he told two female bridge partners he had AIDS. These women did not know he was gay nor did they know anything about AIDS. One of the women read the information regarding transmission and she accepted the information that she was not at risk. She visited the house more often than before. She would make food for him and she would hold his hand and give him a kiss, which she had always done before. One of the other bridge partners had a totally different reaction. My respondent tells of her reaction once she found out her bridge partner had AIDS:

One of the women, who was the sweetest women you could hope to meet. When he told her, she turned out to be the biggest bitch you could hope to find. She started telling all the neighbours "keep away from this house - you'll get AIDS" and "I've been over there, I drank tea and I've eaten there and I might have it now." It was just bloody ridiculous. I just couldn't believe it. The last person I would have expected to react that way, and she's a nurse! You'd think a nurse would have better sense.

A social worker, who did not know of this incident, made general remarks which are applicable to this situation:

I think alot of people are still nervous...alot of that is just ignorance. It's people's ignorance and fear and the fear prevents them from getting past the ignorance.

One respondent quit her last job to be with her son while he was dying. While discussing perceptions in the general public, she spoke of an incident when she was applying for work after her son had died and she had returned
to the Lower Mainland:

I had my interview and everything was great and they had virtually told me I had the job, and then they said "what did your son die of?" These were two sweet old ladies and when I said it, I just felt a coldness. They had told me they would let me know in 3 or 4 days because they had pretty well made up their minds. I waited a week and called back to see if they had made a decision and she was very short with me. She said "Oh, we have far better qualified people than you." So I am quite certain it was the word "AIDS" that did it. That was my one bad experience with it. I felt I lost the job because I told the truth, so now I don't tell the truth when I am with strangers, I say he had meningitis or something like that.

A social worker echoed this perception when she said "cancer is a legitimate disease and AIDS isn't right now...The sympathy aspect in cancer is not present in AIDS."

One mother and a lover spoke about the indifference towards AIDS expressed by friends and co-workers. One individual felt in her conversations with friends that:

Most of the people I've told are willing to listen to me but it is difficult to talk to them about this because they would rather not talk about it, they don't understand a lot of things about AIDS. In the back of their minds (they are thinking) "this is not my problem."

One of the lovers interviewed has similar reactions at his workplace. He observed that:

Most of my friends are straight, they don't know I am gay, so,
of course, I couldn't tell them. I know from talking to them, whenever it comes up, they know absolutely nothing about it (AIDS). Every chance I get, I'll make some little remark about it just to let them know I know something about it, without making it too obvious. I think they probably figure they are not at any risk, why should they even know about it, why think about it.

Not all members of the general public are indifferent to AIDS, some are fearful. Some respondents felt that fear was stemming from the fact AIDS is now a reality in the heterosexual community. One individual who volunteers answering an AIDS information line said "now it is hitting the heterosexual, or other segments of society; and it's panic time." Another respondent echoed this feeling when she observed that:

    Now it's getting to be a heterosexual disease. That's frightening some people and now it's not just a gay disease anymore. Before they used to think "you know these gays, it's their disease, as long as they've got it and don't worry us, that's OK". I think people are becoming a lot more aware.

A social worker observed a similar shift in awareness:

    This is a people problem, this is your (everyone's) problem too. I think AIDS will slowly become our problem, all of our problem.

AIDS may eventually be seen as everyone's problem, but there are many who wish to make it the problem of others. One social worker noted that in her private life:

    I have alot of friends who still say we have AIDS because we have gay people in North America. Some people are never going
to accept knowledge and are going to go from the gut.

Social workers related a number of work related experiences which support the perception that some people "go from the gut" with respect to AIDS. In the summer of 1987, an incident occurred in one of the lower mainland hospitals which supports this perception;

I had a patient on one of the wards, two semi-private beds sharing the same bathroom. One patient found that the other had AIDS or was testing for AIDS, I can't remember which. This girl went totally hysterical and refused to use the bathroom and wanted a transfer immediately. If not, a discharge from the hospital... the doctor went in, her doctor was a specialist in contagious diseases, and I happened to be there when he went to see her. He was trying to say what the studies have shown and it just didn't work. It didn't appease her. As far as she was concerned the statistics were totally irrevelant.

Another worker who had worked in child welfare, spoke of an experience in a lower mainland hospital:

I took in a woman and two kids to the hospital to have the kids medicalled. It was quite slow as usual. The woman said to me, 'I should just tell them I have AIDS ha ha ha,' meaning all hell would break loose at that point and she would get served right away.

That same worker spoke of the ignorance of etiological information among young people with respect to AIDS in particular and sexual education in general:

Most of the kids I have contact with don't know how to use a condom properly. I asked a 16 year old if he knew and he said,
'I don't have to worry because my girlfriend is on the pill.' And I told him it is effective against pregnancy but doesn't do anything for STD's and that was a bit of a suprise for him. He thought somehow that the pill was a magic protector.

SUPPORT SERVICES

Support services have for clarity, been separated into five categories; financial, peer, emotional, palliative and survivor. Each of these types of supports will be discussed with brief examples from the respondents.

FINANCIAL SUPPORT SERVICES

Almost all those interviewed with AIDS spoke of the financial constraints which precipitate as a consequence of having AIDS. "One of the biggest problems people face is financial support, people are ruined financially"... This financial constraint is compounded for those who actively engage in alternative therapies. One man said his HPIA (Handicapped Person's Income Assistance) monies were largely spent on treatment and therapy for himself and his lover. This man said his lover carried the expenses of rent and food. Not every individual with AIDS has a lover or access to a second income. One individual said he had his income assistance supplemented by monies from his mother who lived back east. One man considered himself lucky because he worked for the federal government and he used vacation and sick time up to the point of our interview. He planned to see what his union and Canada Pension could do regarding future financial assistance. One lover spoke of the help AIDS Vancouver gave him regarding procedures for acquiring HPIA for his partner.

It now appears that individuals with AIDS are getting their HPIA
applications processed quickly and efficiently; this has not always been the case. One man spoke of how it took over five months from the time of his application for HPIA benefits till the point where he got his first cheque. The application was expedited with the assistance of AIDS Vancouver and the First United Church. The respondent spoke of the home visit made by the Financial Aid Worker and the fear she emanated, which he believed was homophobic. He said she sat at the table and touched as little as possible because in his words "there was AIDS everywhere." He also humourously recalled the fact that when she had visited, his lover had just moved out of the bedroom because the man with AIDS had been having difficulty sleeping. A friend had also just arrived from eastern Canada so the one-bedroom apartment "probably looked like a brothel to her." The five month interim caused real hardship since this man had worked in the lower income service industry and, in his words had, "not put money away for my old age." The fact that HPIA applications are now efficiently processed may be due in part to the pioneering work of this man and the pressure exerted. One social workerspoke of a case where two weeks had elapsed between an HPIA application and its acceptance, but that application was processed almost two years after the former application.

Social workers also broached the financial supports required for those living with AIDS. One worker observed that most people with AIDS belong to the age group between twenty to forty years. During this period of time most people are paying off bills rather than saving money, so financial resources are not available to deal with long periods of unemployment. She noted wryly that "you don't get rich on HPIA." All workers admitted that the resources available through the provincial income security programmes were totally inadequate to meet the actual needs of those people who have AIDS. One
worker remarked that financial concerns were a stress to the men he had seen while acting as a buddy. He wondered what effect this stress had on their ability to cope with their illness.

A concrete example occurred during a postal strike. The man with AIDS was housebound and unable to pick up his monthly cheque. He had also moved since the previous month. His buddy, our respondent, went to the office to get the cheque and ensure the paper work was done. He waited thirty-five minutes to see a Financial Aid Worker and left without getting the cheque as he had to go to another appointment. During his thirty-five minute wait he noticed no one else had come to see this particular worker. The cheque was acquired on a second visit with telephone calls being made prior to the office visit. There are bureaucratic reasons for office procedures, but no thought is given to the consequences of such procedures for those experiencing physical illness or discomfort. In this case the waiting was done by a buddy, but our respondent was concerned that those with AIDS would have to wait themselves unless they had someone to do it for them.

Examples where the income assistance system has not accommodated the special needs of those with AIDS is not limited to B.C. A recent article in the Toronto Star records a similar yet more disturbing experience:

But even more difficult than adjusting to the drop in income...eating macaroni and cheese instead of steak, not visiting friends and living in a smaller apartment...has been learning to deal with the unexpected hassles and indignities of being poor.

There was the social worker who wanted to know why Reilly hadn't sold his microwave, the last appliance left from his opulent apartment; the clerk who kept insisting Reilly's lover
come in person to get a welfare cheque even though he was
dying in bed and Reilly had legal power of attorney. And then
there was the day Bowyer died, when Reilly spent three hours
waiting in a crowded welfare office for a form that guaranteed
payment for the funeral home. Without it, attendants refused
to pick up his lover's body.
"The hardest thing I had to do in connection with Kevin's
death was to sit there and control my emotions in front of all
those people."^3

Although social workers interviewed commented on the general financial
pressures of those who are living with AIDS, they seemed not to contemplate
nor explore the social and emotional repercussions of suddenly limited
incomes.

PEER SUPPORT

The term "peer support" refers to the support those with AIDS get from
their immediate friends and acquaintances. It also encompasses the support
those caring for people with AIDS derived from their own friends and
acquaintances. One man felt that his lover's two closest friends didn't call
on the ill individual very often after he had been diagnosed with AIDS.
Friends told the lover to "get away" and give himself some time alone. His
feeling was "I'll have time to deal with this later" and in the meantime he
continued to care for his lover. The caregiver felt that friends should deal
with the issue in the same way. The trajectory of debilitation or decline
varies with each individual, with some it is immediate. Clearly, tuning in
to that immediacy also varies with the individual.

One of the mothers interviewed said she knowingly set aside her own
feelings in order to deal with the needs of her son. She said he was "terrified" of coming home with her to a place where he had no supports. He stayed in the town where he went to university and where the greatest number of his adult friends lived.

One of those interviewed said she felt the gay community had "bonded together" to support each other. She spoke of the fact that her son was considering shared accommodation with another gay man because of the high cost of living. The other man did not have AIDS but he wasn't afraid of getting AIDS from her son. She was pleased with this situation. Another respondent voiced the feelings of many who were interviewed when she spoke about others not really wanting to hear anything about AIDS. She said:

I've been willing to talk to anyone about it. This is one reason why I joined the support group; it has helped me very much because there are other friends and family members (in the group). It is much easier to talk to someone in the same group...If a person is not directly in it they think, "this isn't my problem, it's not going to happen to me. None of my family is homosexual, I've got no problem."

One social worker felt that some of the peer support "fell away" after a period of time. He found that a core group continued to have contact with the man who had AIDS. His group of friends maintained contact, but did not visit as frequently as they had during the initial period of his illness.

Those with ARC and AIDS were asked if their group of friends had changed since diagnosis. They spoke of the new relationships which had evolved with others with AIDS and ARC through groups like the PWA Coalition. Changes in peer support may be due in part to changes in socialization which gradually develop once an individual has been diagnosed.
EMOTIONAL SUPPORT

Various needs and experiences of emotional support were listed by the interview respondents. A need to share the experience with others and be supported by them were discussed by two of the men with AIDS. One man said "I'm lucky to be living with someone. I think it would be really difficult if I was living alone." One of the men had once had a one-to-one buddy from AIDS Vancouver, but he did not have one currently. The man with AIDS said he like having someone to talk to:

When I get a new symptom or something changes it would be nice to have someone to talk to and I may need to go back and get another buddy at a later time.

AIDS has developed new forms of intimacy in gay culture. The support groups and buddy programs are one form of this intimacy. Many gay men previously searched for intimacy through sexual activity. The presence of AIDS has caused some to channel such energies in other directions.

The emotional supports developing from gay based organizations may not be consistently given in other institutional settings. One respondent recounted the treatment his lover had received on two different wards in the same hospital. His concerns and complaints were heard and his lover was supported by the staff on the floor where many individuals with AIDS were treated. Over time this man's lover developed dementia and he was placed on a long term care ward during another admission to the same hospital. Our respondent found the care and support on the long term care ward unsatisfactory. When he complained to the general practitioner he was told, in a manner meant to explain the caregivers' behaviour, that his partner was the first person admitted to that floor with AIDS. The lover found this explanation unacceptable.
Two lovers of men with AIDS spoke of how their emotional needs and supports had been met but they felt those of their lovers had not been fulfilled. One man spoke of the need for some sort of "automatic counselling", one-on-one, or group counselling which could meet the genuine needs of those with AIDS who did not seek counselling themselves. He felt that providing counselling only for those who specifically asked resulted with some who needed counselling not getting it.

Social workers emphasized the importance of emotional supports for those living with AIDS. One worker observed that people with AIDS "need quite a bit of hope" and she felt this was to be given through family and friends rather than institutions. Another worker echoed this perception when she spoke of her experience when physicians have referred her to someone who has been diagnosed with AIDS:

I'm not an expert in what they are feeling. It is hard for them to talk about it. Luckily in a lot of cases they have really good supports. It may not have been family support: they have had a network of friends, or their lover has stayed, or one member of the family has turned around. And for some of those people I have found it alot easier for them to start to come to grips with the idea "my life is going to change." Somehow having people around may make it somewhat easier. Those people open up and want to talk.

Another worker said her "faith in families has risen" while she has worked with those who have AIDS. She found that those who "do better" or "cope" with AIDS better are those with a social network and a positive attitude. She also felt that those investigating alternative treatments do better. She felt that social networks, emotional supports, and alternative
treatments were part of a process she labelled "getting control of one's life." She saw her role as a social worker assisting people to gain control of their own lives.

PALLIATIVE SUPPORTS

Two respondents, whose loved ones had died, spoke of the need for palliative care services. One of the respondents felt palliative care treated individuals like they were fragile and she felt this did not take place in an acute hospital setting. She said she felt there was a need for "a place to die, to die well when they reach that point." She felt such a facility was sorely needed in the lower mainland. One man had similar feelings regarding palliative care. He felt hospitals do not provide nor are they equipped for care focussed on the individual and their particular needs. He wished there was care focussed to "deal with the specific person, not just the disease, not just the ward, not just the shift." He felt this sort of focussed care was missing.

A lack of palliative care services was also identified by social workers. They felt this gap was part of the greater problem AIDS presented to the medical system. Social workers felt that many people with AIDS could live in the community for some time with adequate supports. They found that limits on homemaker hours made it difficult to arrange for people to remain at home. In many cases people returned home only because volunteers from AIDS Vancouver were available to "fill the gap" between the services provided by homemakers and those required. The Long Term Care system will not accept people with communicable diseases and will therefore not accept those who have AIDS. This decision therefore limits the number of residential possibilities available to someone with AIDS.
When palliative care is required there are few facilities or operative networks available. Palliative care is available through specialized wards in acute care hospitals. All social workers felt such care should be based in the community and supplied with adequate supports. One worker felt that McLaren House, a low cost rental home run by a non-profit society, was the beginning of a movement towards community based care. All workers felt that more services and supports were required in the area of palliative care.

SURVIVOR SUPPORTS

Supports for the "survivors," or those left after someone has died, are not limited to lovers, family and friends. One individual who has been living with AIDS for over three years spoke about "survivor guilt," a term now being used in the San Francisco area. It describes the feelings those with AIDS sometimes have when they wonder why they have lived so long after others they have known have died. "Why me? Why have I lasted so long?" One man said he had seen more of his contemporaries die than his sixty-five year old mother. He wondered why he was still alive. People deal with such questions in the PWA Coalition support meetings.

One man spoke of how he went to see a psychologist through AIDS Vancouver to deal with guilt feelings he had over not being able to care for his lover at home. His lover wanted to die at home. He also spoke of the void which was left after his lover had died. He said he had been needed for a year and a half and then all of a sudden he was not needed anymore. He decided to put his name in as a buddy in an effort to deal with the loss and try to be of assistance to others.

One mother spoke of the continuing difficulty she had since her son's death. She felt things were being taken away from her unfairly. In her
words, "half my life's work has been taken away." Half her life's work refers to the fact she had raised a son and a daughter as a single parent. One man spoke of his experience with the AIDS Vancouver support group after his lover had died. He went once but did not go again because the group was primarily composed of people going through the pre and post diagnosis of AIDS stage. He said there were very few people there who had survived a death. He felt that his views would be "hard for others to hear" and he recounted one of his early experiences with the group when someone had spoken of their experience after their loved one had died. He felt that individuals at each stage had very different experiences, but there was only one support meeting every Thursday, so he decided not to go anymore.

Grief support is an important component in AIDS work. In the past ritual mediated individual and collective grief, today communication is the strongest element in contextualizing it. This is particularly true of those in the gay community who have experienced alienation from institutionalized religions.

Social workers did not mention support services to those who remain after someone has died. All workers knew of the AIDS Vancouver family support meetings and had made referrals to that group at some time. Little direct discussion of survivor supports by social workers may be due to their primary focus upon the hospitalized and diagnosed individual. This focus is a consequence of the role social workers play in hospital organizations.

Social workers learned about the gay community and gay relationships through their clinical practices. Their perceptions of attitudes in the general public and support services were similar to those living with AIDS. Social workers do not share the same number of perceptions when the political construct of AIDS was discussed.
THE POLITICAL CONSTRUCT OF AIDS

The greatest divergence of opinion between social workers and those living with AIDS occurred in the political construct of AIDS. Those living with AIDS have adopted a political perception and construct of AIDS which social workers did not articulate. This divergence of opinion is examined through the following: terms of reference, perceptions toward medical authority, HIV antibody testing, the media, and organizations.

TERMS OF REFERENCE

The words "gay," "heterosexual" and "straight" are all terms of reference in the process of social definition through which individuals distinguish themselves from others and make sense of their place in society.

A man with AIDS in the United States observed:

In the media, everyone's a victim of fire, of cancer, of mugging, of rape, of AIDS. In the world of reportage, no one is doing well. Victims sells newspapers. Does anyone consider the impact of this cult of the victim? Does anyone realize the power of the message, "You are helpless, there is no hope for you"?

As a person with AIDS, I can attest to the sense of diminishment at seeing and hearing myself constantly referred to as an AIDS victim, and AIDS sufferer, an AIDS case - as anything but what I am, a person with AIDS. I am a person with a condition. I am not that condition. 4

One respondent expressed the same opinion in very direct terms:

I have always refused to let the disease slow me down or rule me. There's plenty of time to rest when you're dead. I am not going to play invalid because then you are type cast and you assume the
role. I refuse to assume the role of victim.

This feeling was relayed by most individuals interviewed. Four of the five individuals with AIDS said they used the term "PWA" or "Person with AIDS." Three of these men were active in the PWA Coalition. One of these individuals said he thought the term "PWA" was a political term as well. One man with AIDS said he had not thought of a term. His diagnosis was very recent so this may account for his answer. One of the lovers liked the acronym he had heard from one of the AIDS Vancouver workers where AIDS stood for "Angels in Distress". One of the mothers said her term was "victim". She said she realized that it may not be popular with some but she felt her son was a victim. Given the difficult and painful illness he endured before dying, her term can be more than understood in the light of her own experience. One lover said his lover who had died did not like the term PWA. The lover with AIDS felt this term was impersonal. He asked not to be referred to as a "PWA".

There may be a generational split for terms of reference. "Victim" may be a term older people will choose, but those in their middle thirties might not use. The term "PWA" may be "too political" for the older generation of gay men. One of the men with AIDS made a simple suggestion regarding this issue, "find out the term they feel comfortable using themselves."

All social workers but one said they used the term "patient" when referring to individuals with AIDS. Only one social worker used the term "persons with AIDS." This individual explained his use of the term by considering what he would prefer to be called if he acquired AIDS:

I wouldn't like to see myself as a victim if I got it. From the people I know who have AIDS, they would prefer to just see themselves as having AIDS, a disease, they are not victims, they
don't like to see themselves as victims. Person With AIDS is just a calm sort of fact, and that's why I would use that term.

Those who used the term "patient" had a number of justifications for the use of this term. One worker analyzed her use of this term in the following:

I use the word "patient" being in hospital that is a blanket term for anyone being admitted. From another perspective (the word) "individual" is probably a good term to use. But in the hospital there is a jargon, the hospital is deluged with all kinds of terms and terminology. Patient is what I feel comfortable with simply because (it is used) in rounds and in discussing with doctors. It's interesting, because I do make a differentiation when I talk with families. I try not to say "patient" because it sounds clinical. I say "your husband, your mother, your sister, your wife, or whatever..." I don't think patient is a negative term.

Another social worker admitted to using the term "patient" while also admitting that as a term it might be less than ideal. Her justification: "Once you come into the hospital you are no longer Mr. Joe, you are now patient." Another worker felt that the term "patient" does not stigmatize anyone. She disliked the term "victim" as it creates a mentality of dependency and powerlessness. It becomes a passive approach to an illness. This worker also felt that those who insist on being called PWA's are frequently politicized and she feels the words are "only labels." Labels they may be, but they are powerful constructs of reality. The term "patient" places diagnosed individuals in a subordinate power position within the biomedical system.
PERCEPTIONS TOWARD MEDICAL AUTHORITY

One individual made a number of comments about the medical community while relating his own experiences once he had been diagnosed with AIDS:

You begin picking and choosing who is competent and you begin to make a lot of decisions. You don't just accept that all doctors are authority figures. All of a sudden you realize they don't have all the answers, so you can begin to formulate your own reality by observing information from all these sources and make up your own mind.

In our whole society we are trained from childhood to believe in the medical profession. Put a lot of faith in doctors, that's the traditional way we are taught to regard the medical profession. Therefore, if a doctor tells you you've got a year and a half to live, you believe in the message, it becomes self-fulfilling.

Of the nine histories related in these interviews, three individuals changed medical practitioners when they were diagnosed with AIDS. In two cases the individuals did not feel the medical practitioners had been "on top" of the illness process. In both a diagnosis of AIDS was not given until the individuals were diagnosed with PCP. These men changed doctors at the point of diagnosis fearing inadequate care both retrospectively and in the future. The third individual who changed his medical practitioner, however, provided the most vivid example of communication breakdown between practitioner and client.

This individual had been participating in a health monitoring project since 1983. The project consisted of periodic physical examinations, the compilation of a sexual history, and blood sampling. The respondent spoke
of reading an article in *Maclean's* which said doctors in studies may not tell you if you were seropositive for the HIV antibody. There are two possible articles this man may have read. On February 4, 1985 *Maclean's* stated that "Surveys of male homosexuals in major Canadian cities last year have shown that as many as 30 percent of them harbour the antibodies."\(^5\) In its May 27, 1985 edition *Maclean's* reported that the Canadian Red Cross confirmed that two individuals in the Vancouver area had died of AIDS acquired from infected blood transfusions. It said that the blood donors were being traced, but Dr. John Derrick, an advisor on blood to the Red Cross said, "donors whose blood is found to contain AIDS antibodies will not be contacted immediately because of concerns about the significance of the test results."\(^6\) As a result of reading one or both of these articles the respondent asked in the spring of 1985 if he was seropositive for the HIV antibody. The response was affirmative.

That he was seropositive came as a shock. He had always been told "Your blood work is fine." He interpreted this statement as everything was "OK" and that he had not been exposed to the HIV virus. He was even more upset to find that his first blood sample taken in 1983, which had been frozen awaiting the necessary diagnostic procedures, had shown at some indeterminate date, to be positive for the antibody. This information was not relayed to the respondent until he questioned his doctor specifically as to his antibody status. With laconic understatement the respondent reported, "I was not pleased to have been kept in the dark." He blamed both himself and his physician. He succinctly observed that "in 1985 people did not know what questions to ask...how alert to be...the whole scope of the problem...I blame myself for remaining in ignorance."

Approximately three to four months after this incident our respondent
went to a hospital experiencing shortness of breath and a high fever. Three days later he returned, his condition was worse, and he was diagnosed with PCP, and therefore AIDS. As a result of his experience, our respondent now says all people should, "Question the hell out of your doctors. Question what he means when he says your blood work is fine."

Communication between medical practitioners and those they treat was discussed by one social worker. In her words, medical information has to be told "again and again." In the initial stages of illness people "don't hear two-thirds of what is said." Social workers can assist hospitalized individuals by restating the information or by asking the physician questions, already discussed between the worker and the person with AIDS, when the social worker, physician, and hospitalized individual meet. This particular social worker practiced in a clinic. The clinic practice made such three way meetings more likely than for those social workers practicing on regular hospital wards. The social worker did not address communication problems similar to the previous case. She addressed the "fine tuning" of communication as opposed to the withholding of basic information.

People were asked whether they felt AIDS was central to their lives and if that was positive or negative. Those with ARC or AIDS said that AIDS was central to their thoughts but were not uncomfortable with it. One man said, "AIDS in a way is central to my life, but not in a negative way. My thinking is about daily health and well-being." One individual with ARC said he felt ARC and AIDS were central to his life but he felt he would like to get a part-time job to do something and feel worthwhile. One individual with AIDS who was still employed said he felt work as a relief from the stress of AIDS. He felt it would be more stressful to "invent something to do every day."

One man who had lived with AIDS for over three years spoke of the
changing and developing attitude he had towards death:

The first year or so I used to fear death, that it could happen at any moment. A lot of my agitation for drug therapy and advocacy were geared towards trying to do something to save my life before it was too late. There's got to be a threshold you cross over, a point of no return without having done something. The next year I was much calmer, and right now I simply don't think death is lurking around the corner, it could be.

One mother spoke of seeing her son as healthy and living with AIDS rather than dying from AIDS:

There are so many different ways to look at an incurable illness like cancer or AIDS, or anything else. It is very much your mental attitude that has a lot to do with your recovery or your whole acceptance of the problem.

One individual saw a relation between his questioning stance towards the medical profession as representative of the relationship between the gay subculture and our predominate heterosexual society:

I think gay people in general have always questioned authority figures. We've been told a lot of things we have discovered are not true...A lot of the stuff about AIDS was found not to be true. You question the medical community, you begin to become a connoisseur of the medical community.

This issue has been examined by Bayer in *Homosexuality and American Psychiatry: The Politics of Diagnosis.*

The actions of the medical community itself have coloured the perceptions of some towards that same community. In 1987 the Canadian Medical Association resolved at a general meeting that in some cases of AIDS
it was permissable to break patient-practitioner confidentiality in the broader interest of the health and well being of others beyond the diagnosed individual. This decision was met with the following opinion from an individual with AIDS:

I am appalled with the Canadian Medical Association's changing of ethics so that confidentiality is not sacred. They have made a severe breach in the doctor-patient relationship.

One person with AIDS concluded his discussion of medical authorities with the following words:

They've come a long way. They had the feeling that I was a well meaning patient and that I would soon see the light and drop dead. I think I have quite amazed them, which is good, damn it, they need to be shook up and realize that there are people who are doing reasonably well.

Interactions with the medical system have also provided insights. One individual was diagnosed with lymphatic cancer. When he went to his appointment with the oncologist he was accompanied by a friend experienced in this area. That is, the person was both sympathetic and knowledgeable:

he helped me by asking questions I wouldn't have thought about. He helped me take away the unknown element and that has done much to help me with all of this.

Accessing and receiving service from the health care system also fell under scrutiny. One mother related:

As he got worse we were trying to get him in a palliative care hospital out of town. They had never had an AIDS patient. We had been waiting around three or four weeks and then they said they wouldn't know anything til their next meeting, which was
a month away. There had to be all kinds of things done. They had to draw up a plan of how he would be treated and all the rest of it. So I phoned Svend Robinson (an openly gay member of Parliament)... and in three days he was accepted.

Discussions surrounding the acceptance of people with AIDS also took place in palliative care wards inside B.C. One social worker assigned to a palliative care ward spoke of such a debate in her hospital:

Nurses were really worried and concerned. There was a real dilemma about whether they should mask and gown, how they would handle the situation. They decided to get somebody in from AIDS Vancouver to talk to them. After that they calmed down quite a bit and handled it quite well.

There was almost a bit of animosity or hostility between nurses. There were some saying they weren't going to go in there with a big mask and gown and everything else. They thought that was a real crummy way to treat the patient. Other people were saying they should protect themselves. At that point, even though the hospital had a statement on how to care for AIDS, nurses felt it was very vague and wanted more direction. Things went well overall, they did manage.

With the help of AIDS Vancouver, a non-medical organization, nurses in this lower mainland hospital were able to handle their first case of AIDS. The following experience tells what can happen when organizations such as AIDS Vancouver are not available.

A man with AIDS was planning to return to his family home which was outside the lower mainland of B.C. In preparation for her son's return, this man's mother went to "check out" the services and facilities available for
her son. He did not need any immediate medical attention. The "buddy" of the man with AIDS related this mother's experience:

At the hospital she explained that her son had AIDS and was coming to live at home and she wanted to find out what services were available, if required, to bring him into the hospital. The doctor wrote out the AIDS Vancouver hotline number on the back of a card, handed it to her, said "call them," turned and left. She made other calls to community health, they had no information at all; they didn't want to talk to her. Finally she waited a couple of days, took a different tactic, and instead of inquiring politely she said, "This is the way it is." She demanded to be assisted and that changed their attitude a little bit. She is also trying to set up something for people there because there are other people with AIDS in that community. It's underground. She is trying to let them know she is a safe person, she has left her name and phone number around the city. She went to her doctor and he is supportive and angry at the hospital's response. He will supervise any admittance to hospital.

Without AIDS Vancouver as an educator and advocate, this mother was on her own trying to access care from the local medical system. Advocating service and providing education came from three separate systems in each of the mentioned incidents, one being political, another a volunteer/educational organization, and the third, a physician from within the local medical community. In some instances other routes to medical services have been chosen.

One man with AIDS spoke of his experience regarding a test his doctor
had ordered for a T-cell count. He found that taking responsibility for his own care may not be appreciated by the medical practitioner:

The doctor requested a test to get the T-cell count. The doctor's office screwed up the dates as they (tests) are only done on certain days. I called a friend who works at the hospital and arranged my own blood test. The doctor saw this as a terrible threat to his authority, as if his authority had been challenged.

He gave me literally shit on the phone.

Here's a doctor who just a few days before diagnosed me as being terminally ill, told me flat out you've got a year and a half to live and you'll be dead in eighteen months...and then he's giving me shit on the phone.

He phoned back and apologized, but did not give a simple apology, but said he (the doctor) was under a lot of stress.

ALTERNATIVE THERAPIES

All five individuals with AIDS interviewed said they engaged in some form of alternative therapy. These therapies included diet, vitamin therapy and meditation. Research into the developing naturopathic treatments for AIDS was also conducted. One individual was philosophical about the lack of support he found from his physician for alternative therapies:

I've gone to other practitioners besides the allopathic (biomedical) practitioner. My allopathic practitioner cannot professionally believe in what I'm doing or else he would be labelled a quack. All he says is keep up what you are doing,
it seems to be doing O.K.

Another spoke on the issue of developing treatments for AIDS. He said he was:

learning information about medicine and therapies that they (doctors) don't know about. They are a little resistant. It's like sharing their seven years of earning an MD with someone who is a mere patient.

Only one of the four social workers employed in acute care hospitals discussed alternative therapies. Having investigated alternative therapies for a personal medical condition she lent them some degree of credence. This finding does not mean social workers did not discuss, as a matter of professional deportment, alternative therapies with hospitalized individuals. It is worth noting that social workers did not mention the possibilities of alternative therapy as part of the services they provide to those with ARC or AIDS.

Social workers can observe medical organizations with "one foot in and one foot outside" these institutions. Social workers made some general comments about AIDS with respect to this vantage point. One individual noted that the job she had been hired for required an MSW degree. There were workers with MSW degrees in the hospital but none of them applied for the position. The worker could not account for this behaviour and wondered if it was the result of attitudes towards AIDS. Another social worker observed the following in her hospital:

People with AIDS are admitted to one of two wards in the hospital, both are medical teaching wards, one is not mine. I noticed that in the other ward the (social) worker wasn't involved with people with AIDS. The head nurse carried out
talking with the patient or providing the patient with information, contacting AIDS Vancouver, or talking with the family.

The respondent tentatively accounted for this difference with the fact that the social worker on the other ward was a recent graduate. She commented further on social work in medical settings by saying, "social workers have to jump in and say what they can do and will provide." She felt that her role would be set by others unless she herself acted to shape the role.

One respondent commented upon her sense of vulnerability that was awakened after having worked with people with AIDS:

You hear about the nurse pricking herself with a needle she just used to give the patient an injection. Every once in a while that part of the reality comes back to you. "Wait a second, I'm vulnerable here," unlike dealing with some of the other people with different diseases. I have to look out because there is a risk for me, perhaps, if for instance I get pricked with a needle or what not. That reality comes in once in a while, when you hear it happened to someone else on the ward.

One respondent related her experience with a colleague where the sense of vulnerability became predominant. While in a methadone clinic, this respondent worked with another MSW line worker who became acutely concerned about the possibility of contracting AIDS from the clients attending the clinic. Expressions of this vulnerability began with the statement of concerns during afternoons when staff used the same washrooms as clients had used in the morning. Later, this worker said she would no longer shake clients' hands for fear of contracting disease. At the height of her fear,
this worker threw out pens or sprayed them with Lysol if a client had touched it. Our respondent questioned the effectiveness of a worker with this client group when operating from such intense anxiety. When our respondent changed work sites, finding employment in a lower mainland hospital, she had the following to say about the way in which she hoped her co-workers would respond to anyone with AIDS:

If they found AIDS here, they would approach it with curiosity, interest, and compassion. They work very properly within the system, none of them really buck the system. I don't think they would be great intermediaries to get things changed within the system, but if they had to work with people with AIDS they wouldn't have any problem. They would be good.

A debate on the role of social workers as intermediaries or advocates in a medical setting will take place later when these findings are summarized.

Perceptions within the medical system are not stagnant. They can change, but change may not solely to due to the practitioner's perceptions or abilities. The mother who spoke earlier of her problems with the palliative care ward also spoke of the changes which occurred on that ward:

When he did die they (palliative care nurses) said to us, we really thank you for letting us have him; because he was such a beautiful person. It has taken away any fear of AIDS. They (palliative care) hadn't had an AIDS patient and there was fear there. Somehow because he was so terrific and the family too, because my daughter and I had done a lot of his nursing in acute care, and they knew we had done everything for him. When we went in we would kiss him and this sort of thing, the nurses said that it made them feel so good to know we were so
comfortable with it. And because he was such a nice person they grew to love him and forget about the AIDS. And they said if all the young men with AIDS were like him they would gladly have them.

The changes may have been precipitated by role modelling from mother and daughter as well as a gifted and engaging patient rather than the maintenance of a professional mode of practice.

Social workers also commented on the attitudinal changes staff developed towards AIDS once they had cared for specific patients. One worker spoke of a particular man:

I think he taught them (nurses) alot. He did alot, I don't think consciously, in terms of changing people's attitudes and changing people's lives. If he has one legacy, that certainly is a legacy he left the hospital.

One worker commented generally on the staff development which grew from having cared for people with AIDS:

Staff got to know them as individuals and not 'a disease.' 'The disease' is no longer some enigma out there in space. The disease has a personality, and a name; you know it is happening to a person.

When social workers were asked about specific instances of discrimination or prejudice, a number of incidents were discussed. One worker felt discrimination can be manifested in subtle forms. In one case she felt the head nurse was using a patronizing moral tone when dealing with those who had AIDS. She makes the following observation:

(It is a) sort of motherly idea -- "you've been naughty and now you're home." The words (spoken) don't sound right; it's
how they are being said.
The social worker went on to say she felt that such behaviours had their source in one's attitudes towards AIDS; "it's where you're coming from and from what you think this disease is all about." Such discrimination is subtle and possibly benign, but discrimination none the less. In other instances discrimination is more direct.

One social worker spoke of a woman she knew who had been on a methadone program for seven to eight years. She had been dressed to go out for dinner and cut her finger to the extent that it required stitches. At the hospital this woman was asked for a drug history. She told the nurse she was on methadone. Our respondent tells what happened then:

When she said she was on methadone the conversation stopped. It was like a wall had come down. The nurse went away (from the bed) and came back with gloves (on.) From then on there was no conversation, the nurse just went to ice. The client was treated shabbily. It was a horrifying thing for this woman...There is a real attitude problem (towards addicts).

Another social worker, in a different hospital, struck a related note when she spoke of the attitudes present in her ward:

There has been one IV drug user and (in caregivers' minds) is that one notch above (a gay male) or equal?

That there should be an evaluation at all belies impediments to true care.

Not all discrimination is negative. In one instance the head nurse of a ward assigned a practical nurse specifically to one man with AIDS to see that he "looked good" for his family. Family members were coming to see him one last time before they returned to eastern Canada. The social worker believed this was done so "the parents would know he was cared for and to
make them feel he would be cared for when they are not here."

One worker spoke about the fact that she worked in a teaching hospital. She felt it was one of her duties to tell people with AIDS they had a right to say "no" if they did not want to be seen by students in rounds. At the same time she realized that rounds were one of the realities in a teaching hospital. Her goal is to balance the needs of the individual with the needs of the institution. The very achievement of this balance is threatened by tacit institutional allegiance.

THE HIV ANTIBODY TEST

A number of the interview respondents spoke of their experience with the antibody test. One example is the case discussed earlier where the results of the test were not shared with the respondent until he asked directly whether he was seropositive or not. In another case an individual with physical symptoms of ARC and AIDS was not diagnosed as having ARC/AIDS for three months by the doctor, as his blood tests were not seropositive for that period of time. This individual was sent to a psychiatrist for counselling. When his later blood tests were positive the medical practitioner said he did not have to see the psychiatrist any longer. The diagnosis of AIDS necessitated a positive antibody test. It could not be applied beforehand.

One bereaved lover told his friend who was contemplating having the test, not to have it. He stated that:

I don't think it benefited me in any way and to a certain degree it has hindered me...

A friend of mine was contemplating it and I said this is what I have gone through, you can't do anything about it once you
find out. It (the test) should not in any way, shape, or form cause you to be more safe with sex. You should be safe with sex period, regardless of whether you have that test.

Many individuals in the gay community promote the idea that one should assume, for the purpose of sexual activity, that one is seropositive. The rationale for this is that the medical benefits of such a decision may be gained without the possible detrimental mental and social consequences such medical information may bring.

Two lovers, one with AIDS and the other seropositive, spoke of the experience they had taking the HIV test as well as its meaning for them. One lover went and took the test and found he was seropositive. Before he had taken the test he said, "I figured it was medical information I could handle." When he discovered he was seropositive he found the experience upsetting. He said, "When you convert to seropositivity there is a bit of a mental adjustment. I went through two weeks where I was upset about the fact...you adjust to it." His partner also decided to take the test and his results were seropositive. They reported that their general practitioner was not concerned about their sexual practices because they had both tested positive. After some of their own research and enquiries both partners agreed that they should practice safe sex between themselves. They gave two reasons for this decision. The first consideration stemmed from the fact that both of them may not have been exposed to the identical virus. As one of the respondents said, "what I have may not be the same as what my lover has." Medical developments are indeed discovering new varieties or strains of the HIV virus, validating this concern. The second reason for assuming safe sex practices may also have biological justification. One of the lovers asked, "What is the effect on the immune system of re-introducing the
virus over and over again?"

In this conversation the lovers also discussed the meaning of the HIV test. The word "meaning" is meant to denote what the test tell us; what information does it convey? One of the lovers commented that in the medical literature, "what being seropositive means has changed, the ground keeps shifting." Both respondents said that at the time they had been tested a positive result:

meant you had a 10% chance of getting AIDS, now statistics go up to 80%. There seems to be some confusion as to what it (being seropositive) means.

The lover, who tested positive, asked a number of rhetorical questions regarding the HIV testing process:

What does the test mean? What if I tested a false positive? Is a second test worth my while? Our G.P. does not do a follow up (test). Given the consequences it should be followed up.

Shortly after the HIV test was developed, the process of getting tested twice with pre and post test counselling was suggested within the medical community. These two men got tested only once with no counselling before or after the test. None of the individuals interviewed who had been tested spoke of HIV test counselling. The technological development of the test and its administration initially lacked appropriate social and psychological supports within the medical community.

In some ways the HIV seropositive test has been seen to be of benefit to individuals and organizations beyond the individual to whom it has been administered. In August 1988 the Financial Life Assurance Company of Canada announced a mandatory "AIDS test" would be required for those seeking
policies from their company. As said before, this is a test for the HIV antibody, yet it is commonly called the "AIDS test" by those outside the medical profession. A justification for this procedure stated that, "by testing everyone, we can keep our costs lower." \(^9\)

On April 25, 1986 the Ontario Branch of the Canadian Bar Association released a publication entitled, "Report of the AIDS Committee". It had the following to say with regard to antibody tests of hospital patients:

> It has been argued that testing for HTLV-III antibody positivity should be done as a prerequisite to entry into hospital...Notwithstanding the possible benefits for research purposes, and given the very negative social impact of such testing, we are not persuaded that routine screening tests, even if they are conveniently available, would be of sufficient medical significance to require them prerequisites for hospital admission.

> We therefore recommend that, upon entry into or during a stay in hospital, the HTLV-III antibody test should be done only when clinically indicated, as a result of the history, physical examination, or other ordinary decision making parameters in such matters, and only when consented to by the patient after an appropriate explanation. \(^{10}\)

In 1988 the Hastings Center Report published a series of articles under the title, "AIDS: The Responsibilities of Health Professionals." The five articles contained in this publication were prefaced with the following:

> Health care workers in America, as well as those in other advanced societies, have for the past four decades only dimly fathomed the routine experience of those who care for the sick
in prior eras: the risk of acquiring their patients' infections and sometimes lethal diseases. Acquired Immunodeficiency Syndrome (AIDS), caused by the Human Immunodeficiency Virus (HIV), has ruptured this psychological aura of invulnerability.  

This psychological rupture has not healed for some practitioners even though the risks of transmission among health care workers have been shown to be low. The 1988 Canadian Medical Association annual meeting in Vancouver provided an opportunity for some to express their positions regarding HIV testing and informed consent. An article in the Toronto Globe and Mail reported that:

Dr. Sterling Parker, a Kamloops B.C. obstetrician and gynecologist, said he believes a doctor has the right to conduct whatever tests he feels are necessary on a patient. 'I think the patient gives implied consent when they seek medical services,' he told the meeting.

Another physician, Dr. Victor Dirnfeld of Richmond B.C., was even more forceful in his argument against informed consent for HIV testing. In a radio newscast excerpt from the Medical Association conference he made the following statement:

To require informed consent in blanket fashion under all circumstances before HIV testing can be done puts a loaded gun in a game of Russian roulette to the head or to the heads of the health care providers I've just mentioned.

A compromise resolution on this issue was adopted at the annual meeting where consent for the HIV test was to be obtained "wherever possible." Dr. Andrew Young, chair person of the committee which drafted this policy is
reported to have said "justifiable exceptions would be rare."\textsuperscript{14} Ronald Bayer's remarks, recorded in chapter one, regarding the promise and the spectre of medicine are echoed in this issue of HIV testing and the varied opinions among medical practitioners regarding their employment.

One gay couple's experience in a lower mainland hospital reveals the extent to which perceptions regarding HIV testing and safeguards can effect the quality of a hospital experience. A gay man in his thirties was hospitalized for five to six weeks in 1987. This man does not have ARC nor AIDS, nor had he been tested for the HIV antibody. He has had recurring episodes of astio melitus since he was twelve years old. In its acute phases this illness would give him difficulties with his ankle. In the first two months of 1987 he began to develop astio melitus and a staphylococcal infection in his ankle. In a routine blood test, taken shortly before this acute phase of illness, his family physician told him he had tested positive for the hepatitus B antibody. He had no clinical signs of hepatitus B infection prior to this blood test. (Many gay men in fact are positive for the hepatitus B antibody. Gay men were solicited for hepatitus B vaccine trials because of the high incidence of this illness within the gay population.)

This man's astio melitus developed to the stage where he was hospitalized in order to receive intravenous treatment every four hours. This procedure was continued for approximately five and a half weeks. At that point he was discharged home with oral antibiotics.

Hospitalization, for this man and his lover, was a difficult experience for a number of reasons. During the admittance procedure the male lover was listed as his next-of-kin. This information, as well as the fact the "patient" had tested positive for the hepatitus B antibody, may have been
what lead one of the residents to ask our respondent if he was gay. He said yes he was gay as he felt no reason not to tell them. Our respondent recalls:

This information (that he was gay and positive for the hepatitis B antibody) was volunteered when I was admitted and this set off all sorts of bells and whistles in their minds. For the balance of my stay I was tagged with the BBF (Blood and Body Fluids) sticker, with all the necessary precautions that went along with that, needle precautions and so forth. It was interesting to see how different bodies throughout the hospital staff reacted to that.

The first reaction of the staff was focussed upon the HIV test. Our respondent recalls that when he was admitted:

the resident quite earnestly entreated me to have the HIV test. I said that unless they felt it was absolutely essential, I saw no reason for it. I had been well advised not to have it... I had other members of the staff come along in the next few days. The senior came along with his gaggle of interns and residents and one of the younger ones was quite pushy about the whole thing. He said "we have to operate on you, we really want to know." I think it had nothing to do with my well-being so I passively resisted it.

Our respondent's lover was very angry when he discovered this situation had occurred. The "patient" had been admitted with a fever of 104 degrees F and this condition continued for a week until the infection was stabalized. It was during the period of fever and discomfort that he was pressured to take the HIV test. His lover felt that the ill individual was "not up to
(his) regular strength of personality and character" and as such it was unfair to pressure him to take the test. An operation was not required and he did not take the HIV antibody test. In light of the Canadian Bar Association's recommendations, almost a year old when this man was hospitalized, HIV testing in this situation did not appear warranted nor justified. In retrospect the hospitalized individual and his lover wonder to what degree their refusal to comply with this testing request effected the care they received for the next month. Our respondent was hospitalized in the acute ward and given intravenous drug therapy every four hours. He was treated under the BBF (Blood and Body Fluids) infection control protocol throughout his hospitalization. This is the same protocol used for those with Hepatitis B, those positive for the HIV antibody, and those with AIDS. Our respondent and his lover found different levels of compliance to this protocol from the various components which make up the hospital staff.

The procedures included within the BBF precautions have consequences for nursing, building maintenance, and kitchen staff. During the course of his stay, our respondent found the only measures consistently applied were those pertaining to meal preparation. In this hospital those with the BBF precautions were served their food with disposable utensils. This meant that eating utensils were plastic and all plates and bowls were disposed of in the patient's room. To accomplish this procedure, all meals were taken out of their insulated trays and placed in the room on a cardboard tray. The consequence of this procedure was consistently cold meals. Our respondent recalls that, "I don't think I had a warm meal there in months." When this procedure was questioned, it was said that each unit of the hospital is responsible for its own procedures and there was no recourse to appeal them. Our respondent found that meals were the only "treat" in the day and to have
them consistently cold made his hospitalization that much more uncomfortable.

Nursing staff did not administer the BBF precautions consistently. At the same time our respondent and his lover said the nursing staff were the most "reasonable" group to deal with in the course of the hospital stay. One of the BBF precautions is that gloves be worn when administering or discontinuing an intravenous tube. Gloves prevent contact with blood, which can occur when the IV needle is given or withdrawn. Our respondent noticed that "the older nurses" did not always wear gloves. He said that some nurses were somewhat "cavalier" in administering the BBF precautions. The lover responded to these inconsistencies by pointing them out to the nursing staff, he said:

I'd rattle the cage once in a while and then they would use them (gloves) again for a couple of shifts, and then the whole thing would start over.

The hospitalized individual added to this observation:

At that point we were clear, if this was going to be inconvenient for me, we were going to stick to the rules and makes things inconvenient for them too.

The hospitalized individual commented upon the precautions employed by one particular member of the housekeeping staff. He said she would not enter the room unless she was wearing a gown, gloves, and hat. His lover found these "precautions" to be ironical given the fact the room's cleanliness deteriorated, "the dust bunnies grew," while the housekeeping staff exerted considerable efforts to maintain their infection control procedures. The hospitalized individual had had enough of this treatment by the time it came for him to leave:
On the day I was being discharged she (the housekeeping staff) came through, and one of the nurses, one of my favourites, a very competent nurse, saw her with this outfit on and said, 'what's all this?' I didn't say anything. She (the housekeeper) came through for one last swipe, without her regalia on, before I left. I said 'aren't you taking acute chances?' At that point I was ready to get a few digs in.

An unusual reaction to this hospitalized individual came from the dermatology department. Our respondent went to the dermatology department to have a rash on his arm seen. This rash was due to the intravenous. While he was there he asked if the resident could remove some small pin head warts he had on his face which had to be removed once every few months. While he was there he thought he might as well get it done. The senior specialist on duty asked our respondent his sexual orientation prior to treatment and was told he was gay. The resident on duty said the warts could not be removed because she had no way of disposing of the needle. (They were using an electric needle which is cleaned and reused, not replaced.) When our respondent asked for a reason why it could not be done he was first told it was because of the possibility of being HIV positive and then because of his Hepatitis B status. Our respondent grew angry and said "What do you mean by that?" He felt he was being discriminated upon the supposition that he was HIV positive. The senior dermatologist on duty took over at this point, removed the warts and then said to the resident, "I'll sterilize the needle, for what it's worth."

Our respondent felt this comment was meant as a mild rebuke to the resident for her handling of the situation.

At the end of his hospitalization our respondent felt worn out by the experience and at the emotional "end of his rope," in his words. On the
last day in hospital our respondent was talking about his hospitalization to the male resident who had been on the ward throughout his stay. The response he got from this resident was not what he expected. The resident responded to his complaints regarding the inconsistent and sometimes inappropriate infection control measures with the following:

As a gay man these are some of the things you are going to have to learn to live with.

Our respondent answered him with the following:

I've been living with this (the possibility of AIDS) very well for the past few years. I think it's about time somebody else, like yourselves, learn to live with it too.

Social workers spoke little of the difficulties they had encountered as the result of experiences with HIV testing. A male social worker who had volunteered his services through AIDS Vancouver spoke of his own experience when his doctor suggested he take the HIV test:

My doctor recommended I have the HIV antibody test. The reason he wanted it was for his own information so as to establish whether to treat stuff I have with it in mind. That I was HIV positive and could be manifesting one of the opportunistic diseases, or whether I was HIV negative and he could nix all of that right there. I had a rash (on the neck) and in my case he said he would have to treat it as an S.T.D. (Sexually transmitted disease) initially.

One of the social workers employed in a hospital was concerned about the absence of pre and post-test counselling. In one case an individual took the antibody test in January and found out he was positive. The man
entered hospital with AIDS in October with no counselling during the nine month interval. This worker felt that post-test counselling could have been valuable and beneficial for this man. No social workers mentioned an incident similar to the case related above.

THE MEDIA

Generalized remarks from all respondents suggested that media reports have been sensationalistic in the past, but they are slowly improving. One individual said the reports should have "less scare messages" in them. Many respondents were involved in public education through the media. At least two of the respondents have been on national television broadcasts regarding AIDS. One person volunteered on the AIDS Vancouver telephone "hotline" dispensing general information regarding AIDS transmission and initial symptoms. All of these people were willing to share their knowledge and medical information. They saw the media as a means through which education could be transmitted. At the same time, many commented on the fact that AIDS received more media attention as it spread to the heterosexual population. Explanations for this phenomena are best summarized by the following from one of the mothers interviewed:

I think the media attention is good; it is too bad it wasn't done years ago. I think it wasn't done because of the stigma put on the homosexual community. "It is a homosexual problem" (the media thought), or most of the cases were homosexual and this is why it wasn't brought out in the media so much. And all of a sudden it started to hit the heterosexual segment of the population and all of the attention is brought out.

One of the people with AIDS was even more pointed in his remarks regarding
the past response of the media towards the coverage of AIDS:

The media is seeing this very much like an Arthur Haley novel, its got love, sex, politics, death... They have not been very helpful. The majority of articles are doom and gloom. They don't publicize that someone is doing well. They don't believe that a patient can take control of his life. The (PWA) Coalition is treated as an oddity.

This view is echoed by James St. James, another person with AIDS, in a national radio programme on the news coverage of AIDS:

The media, when it first started out, was very sensational. Back in those years when I was first diagnosed there were only eight of us in Toronto who had AIDS. And the stories were flying furiously, don't touch the patient, when you go in as a nurse cover from top to bottom in an asbestos suit with a snorkel. It was just crazy. But that did a great deal of harm. It told the people diagnosed with AIDS "there is no hope, no hope at all, that they were all going to die." And that's not true. I've lived over four years with this disease...I've lived a long time with this disease and they can too.15

Social workers also felt that media coverage had become less sensationalistic and less dramatic over time. All felt that information was being relayed to the public in some form, but they still had reservations regarding media coverage. One worker said reports were improving but "I am tired of mosquitos and toilet bowls" (being discussed as routes of viral spread.) Others felt that the media creates fear which can be unhealthy. Another worker felt that high profile media coverage was not entirely
They are oversaturating people...they will then move on to something else. There isn't any information on how to cope with it, on support groups, on what is being done. There is no follow through.

Current debate in the news media regarding AIDS is centered on the question "who educates?" Jack Layton, a Toronto City Counsellor and Chairperson of the Board of Health believes the media has an important role to play as educator. He believes the news media "should become part of a strategy to provide Canadians with the information they need to save their lives and that means a completely different kind of approach." A "medical specialist" reporter who works for a nationally broadcast television news programme does not agree that the media should be educators. She justifies this position with the following statement:

It's the difference between educate and inform. I think it's the role of governments, schools, municipalities to educate. I think it's our role to inform, but if that information is accurate then it acts as education. But it's not our role to go out there into the community to tell people how to use condoms, how to put them on, not to use drugs. We can inform people what the experts are saying, but we have to deliver the news.

I feel no special responsibility to do features or sidebars on AIDS than I do for any other story of interest. There's nothing especially important in our role in terms of educating. We musn't be co-opted, to be seen as educators.
The reporter's distinction between "educate" and "inform" is not clearly defined. A hint of the distinction may be found in the last line, "we musn't be co-opted." It appears she believes that education is biased or based on a goal or expected outcome. Information is portrayed as "neutral" and should be presented in a "neutral manner." Such thinking among newspeople is in line with the findings of Tuchman and the analysis of Smith already discussed in previous chapters. Newspeople believe they are neutral or at least strive to provide neutral "information" which people can use or ignore of their own free will. In other words they can eschew any social responsibility. Such perceptions miss or ignore the points made by the two individuals with AIDS.

What is reported becomes "the story." AIDS has become a "file." The television reporter previously mentioned clearly makes this point during the same interview:

The story is extraordinary. The story is incredible. For those reasons alone the sidebars, the features, the human interests, the civil liberties, the extraordinary complexities of the immune system are of interest to the public, therefore we respond to that need to know. Not as educators, but as people who have information who are learning things, who want to transmit that information in a way that is exciting, interesting, and accurate.18

The words "exciting and interesting", but not the word "accurate", go a long way towards explaining the news coverage already discussed in *Time*, *Macleans*, and *Newsweek*. Those with AIDS and their loved ones will probably continue to look elsewhere, as they should, for good news. The effect of news coverage upon the social construct of AIDS will continue to be a mixed set of messages as long as arguments over the media's role continue.
ORGANIZATIONS

AIDS Vancouver and the PWA Coalition were cited as the most helpful organizations when it came to support for individuals and families. Introductions or referrals to AIDS Vancouver and the Coalition were made in a number of ways. Hospital referrals from social workers was one of those ways, but personal volition impelled most toward connection with these two groups. One person with AIDS spoke of how his lover went to AIDS Vancouver and the Coalition while the man diagnosed with PCP was still hospitalized:

While I was in the hospital my lover went to AIDS Vancouver and the Coalition and said, "I want someone to go and talk to him about AIDS." My lover made the connections for me and I don't know how they could have been made without him.

These organizations were said to be the most helpful in the areas of emotional support, referrals and advocacy. One of the men spoke of attending PWA Coalition functions:

It took away a lot of fear. I was suddenly in a room full of people with AIDS. It removes fear and the isolation of being alone.

These two organizations however did not meet all the supports needed for those with AIDS and their significant others. Two lovers spoke of how they felt their lovers had not received as much support as they may have needed. One of the men with AIDS had dementia and this complicated attempts to get him counselling and support. The second man with AIDS felt his needs were being met by his lover and others around him. He decided not to get services directly from AIDS Vancouver or the PWA Coalition. The lover went to AIDS Vancouver support groups and found them helpful.

Social workers all named AIDS Vancouver as the most helpful
organization. One felt AIDS Vancouver attempted to "fill the gap" in services needed and those available through the health care system. Another said she always started with AIDS Vancouver and they had resources available to meet the particular needs of those with AIDS. Yet another said she went to AIDS Vancouver when all other possibilities had been explored. This worker also felt that AIDS Vancouver provided services which were not available anywhere else. In one case a man with AIDS and his mother, who came from eastern Canada to care for him, were given passes to Expo 86, passes which someone had donated. The worker felt such services were important and not available through any other organization.

Three social workers had one reservation regarding the organizational support available for those with AIDS. They felt that AIDS Vancouver was identified with the gay community and were concerned that such an identity might hinder some individuals from seeking assistance there. Social workers felt the services currently available were directed to gay men. They were concerned that services for women, children, and hemophiliacs were not currently available. Social workers felt that services to these people were not available; they had no clinical experiences to date to support such an opinion. Social workers felt supports for those with AIDS had been centralized in AIDS Vancouver and felt that a broader base of services would be useful. One worker said she had not "heard of groups through health units, family services, or mental health" and wondered why this was the case.

Three of the social workers had not heard of the PWA Coalition. One social worker had only recently heard about the Coalition. This finding coincides with the absence of social worker comments regarding alternative therapies.
The provincial government was named by most people as the least helpful entity. Reasons cited were its refusal to fund AIDS Vancouver, its low income assistance rates, and the general perception of AIDS found in the Social Credit government. One of the respondents who had met with provincial government representatives had this to say:

My sexuality is none of their business and has nothing to do with this medical issue, though most members of the Socred government seem to treat this entire issue like an outdated medieval morality play. We are constantly faced with homophobia in the government.

The federal government was also criticized by those with AIDS for not releasing experimental drugs on compassionate grounds. They feel that decisions regarding treatments can be made by those who have the illness. Such perceptions are in line with those already expressed regarding alternative therapies. Friction exists particularly between the individuals with AIDS and governmentally regulated institutionalized medicine.

Social workers also saw the provincial and federal governments as least helpful. They found the B.C. Ministry of Social Services and Housing and the Ministry of Health slow to address the problems presented by AIDS. Social Services and Housing was cited for the low rates of income assistance they provide. They were also indicted for the fact that they had made no effort to educate any of the children under the care of the Superintendent when some of those children are at risk of having contact with the HIV virus. The Ministry of Health was criticized for inertia, complacency, and general ambivalence towards AIDS. When speaking of the Ministry of Health one social worker rolled her eyes and said caustically, "it has a few problems."

The provincial and federal governments were generally reprimanded for
their refusal to plan for the future needs in AIDS care. Social workers felt more services would be required and felt both levels of government were not acknowledging the urgency to project future needs. One worker said, "if the Premier or the Prime Minister had a relative who had AIDS there would be a lot more money."

AIDS has been primarily constructed politically by those who live with it. Social workers discussed few of the political components and challenges of this syndrome. Our final discussion "backs away" from the material for a broader perspective of the issues and concerns.
CONCLUSIONS AND EXTRAPOLATIONS

AIDS barrages the health care system with issues and questions pertinent to social work in health care. AIDS challenges the process of diagnosis as well as the development and implementation of effective treatments. Experimentation directed towards a vaccine and the exploration of alternative therapies have opened discussions as to the roles and employment of power by practitioners and recipients in the health care system. Specific examples of client-practitioner conflict were cited in interviews when individuals with AIDS sought to participate in their own health care. Social workers did not directly comment nor analyze their roles in these conflictual situations. Social workers did not generally discuss alternative treatments. Data should be gathered regarding the social worker's perceptions towards client participation in health care decisions and the role of social work in the power dynamics of medicine.

AIDS challenges twentieth century North America's belief that medical knowledge has an upper hand on disease and suffering. AIDS has exploded that myth of control. Many reacted to AIDS with fear and anger towards "the other," the one with AIDS or thought to have it, when the fear was actually an internal feeling more than an external reality. The history of AIDS has few incidents which justify a fear of those with AIDS and no evidence to condone the discrimination and immoral behaviours of those terrified by AIDS. Everyone involved in AIDS care must grapple with the existence of hope and strength in the midst of life and suffering. Such work encompasses issues which have not been professionally examined. Those "living with AIDS" deal with them every day.

AIDS challenges the discrepancies of a medical and social system which does not provide a continuum of care for those who experience chronic
physical ailments with episodic periods of acute illness. Financial constraints were named as a primary concern by those living with ARC and AIDS. Financial issues should be seen as part of the continuum of care. Recently formed community based organizations, AIDS Vancouver, McLaren Housing Society, and the PWA Coalition have sought to cover discrepancies in care, but have not consistently had governmental nor societal support.

Social workers were concerned that existing organizations may not be able to meet the needs of all those living with AIDS or those who will have AIDS in the future. Yet medical social workers continue to refer individuals solely to these organizations. Medical social workers have not been instrumental in the formation of any new groups focused on AIDS. Social workers privately criticize the lack of governmental funding for income assistance and medical care. Social workers have not been known to speak publicly on these issues.

Not one news magazine article in the five years reviewed reported a social worker commenting on the issues surrounding AIDS. Social workers must analyze their professional activity in light of the balances many maintain between client support and advocacy and the invisible cord of institutional allegiance which limits the movements and binds the actions of many workers. Do social workers have clearly defined roles in such circumstances and situations? If they are not defined, what should they entail? Have social workers reflected upon the ethics involved in the balancing act many act out in their daily life and practice.

AIDS challenges the professionalism and empathy of health care providers. Interviews discovered that in caring for patients many professionals grew to care about people. The labels and stereotypes which surround AIDS disappeared when nurses and social workers had personal contact
with those who live with AIDS. Knowledge of gay people, their enduring relationships and social consciences, grew when workers had direct experiences with gay men, their lovers, and those in significant relationships with them. Is this knowledge and experience being reported in the wider community?

Social workers have been advocates of socially marginalized and stereotyped groups in the past. Work with the mentally handicapped and educating the larger community as to their needs and abilities is but one example of such work. Should social workers adopt a similar role in the field of AIDS care? To date there has been no such systematic public education initiated by the professional body of social workers. The Canadian Association of Schools of Social Work has initiated a project on AIDS and Social Work curriculums, but this education is internally and not externally directed.

The development of general social work strategies in AIDS work should be explored. Valuable information was gathered when individuals living with AIDS and those in significant relationships told their "stories," their experiences with the health care system. Gay men spoke of AIDS as a "second coming out." These experiences contextualized and explained many of the actions and decisions made by those interviewed. It is not known if full "histories of illness" are taken by social workers in the general course of practice. Do social workers see such histories as necessary and useful? The analysis of existing modes of practice and the development of a general practice approach could be beneficial for those who have not had extensive clinical experience with AIDS and those who live with it.

Where does social work "fit" in the political framework of health care? One worker said she defines her role or else she accepts a role assigned by
others. Social work is in the midst of a movement towards "professionalization." Within the profession this process includes licencing, registration, and the acquisition of university degrees, or their equivalents, as qualifications for practice. Outside the profession this process includes political positioning within the health care system. Where do social workers individually, and the profession as a whole, seek to place themselves within hospitals and health care systems? A continuum base on allegiance would include the following points; client oriented advocate, neutral position, and institutionally oriented worker. Such positions should be weighed against the professional activity they engender. Walking the tight rope between advocate, intermediary and social control agent must be ever conscious to those working in this field.

Labelling people with AIDS as "patients" is one example where interviewed social workers were on the institutional side of an issue. Social workers must be comfortable with and able to defend the positions they choose if they wish to act from positions of self-awareness. Professionalization, positioning vis a vis those receiving health care, and access to power are all relevant to the future of social work practice in health care generally and in AIDS care particularly. An examination of this area is required.

AIDS presents a host of implications for social work practice. The ways in which we think about AIDS effect what we see and do about AIDS as professionals. This process is largely dependant upon individual beliefs and constructs. Social workers are challenged to face those issues, debate them, and consciously operate from an ethically constructed system of practice. In order to do that we must begin, as the quotation which began this work stated, with ourselves.
FOOTNOTES - CHAPTER 1


5. Ibid., p. 112.


7. Ibid., p. 159.

8. Ibid.

9. Mercer, Labelling the Mentally Retarded, p. 120.


13. Ibid., p. 77.


16. Ibid., p. 189.

17. Ibid.

18. Ibid., pp. 189-190.
19. Ibid., p. 190.
30. Ibid., p. 4.


42. Doris Nelkin and Stephen Hilgartner, "Disputed Dimension of Risk; A Public School Controversy over AIDS," The Milbank Quarterly 64 (supplement 1 1986): 118-142.

43. Ibid., pp. 127-128.

44. Ibid., pp. 129-130.


50. Ibid., p. 12.

51. The Body Politic (Toronto), October 1983, p. 29.


60. Ibid., p. 115.


76. Ibid., p. 1302.


83. Ibid., p. 60.


86. Ibid., p. 455.

87. Ibid.


90. Ibid., p. 173.

91. Ibid., p. 174.


FOOTNOTES - CHAPTER 2


7. Ibid.


13. Ibid., pp. 359-360.


15. Ibid., pp. 466-467.


24. Ibid.

25. Ibid.


32. Time, September 9, 1985, p. 73.


34. Macleans, September 23, 1985, pp. 61,63.


41. Ibid.

42. Waxler, "Learning to be a leper," p. 169.


49. Ibid.

50. Ibid.
51. Ibid.


53. Ibid., p. 3.


76. Time, August 5, 1985, p. 38.

77. Time, August 5, 1985, p.3.


81. Newsweek, August 12, 1985, cover.


86. Ibid., p. 53.

87. Ibid., pp. 57-58.

88. Ibid., p. 54.

89. Ibid., pp. 57-58.

90. Ibid., p. 69.

91. Ibid., pp. 42-43.

92. Ibid., p. 140.

93. Ibid., p. 142.

94. Ibid., p. 147.

95. Ibid., pp. 105-106.

FOOTNOTES - CHAPTER 3


16. Ibid.

17. Ibid.

18. Ibid.
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APPENDIX 2

GUIDED INTERVIEW FOR PEOPLE WITH ARC OR AIDS

The guided interview will ask questions in relation to the process beginning with illness, then diagnosis, and subsequent adaptation. These questions will cover the following areas:

- the beginning of illness
- the interim between illness and diagnosis
- the point of diagnosis and its communication to others
- the individual's "construct" of AIDS
- discussion of social support services, requirements and realities

Thank you for volunteering to be interviewed. I would like to audio tape this interview in order to compare responses. All information is confidential and these tapes will not be kept beyond the time needed to analyse them. Are you willing to have this interview recorded? Please read and sign this consent form if you agree with its contents.

I would like to share the results of my study with you if you are interested and I am more than willing to talk about it anytime before it is finished. It is my plan to submit a copy of the final draft to both AIDS Vancouver and the Vancouver PWA Coalition.

Beginning of Illness

To begin with I would like to briefly discuss your experiences with reference to two points in time. The first point is the time at which you began feeling sick or ill, in the sense that you were finding it difficult to do what you regularly did. The second point is the time at which you were diagnosed or told you had ARC or AIDS.

Is the separation of those two points clear to you? If so, could we begin.

When did you first feel yourself getting sick and unable to do things?

How long ago was that?

What changes did you first notice regarding work, social life and daily activities?

Were there any other changes which haven't already been mentioned?
I would like to make a switch and focus on the period of time beginning with when you noticed these changes and ending with the point when you were told you had AIDS. Does that make sense to you?

When were you told you had AIDS? By "having AIDS" I mean full blown AIDS as opposed to testing positive for the antibody.

So you began feeling ill in \_\_\_\_ of 19\_\_ and you were diagnosed as having AIDS in \_\_\_\_ of 19\_\_.

What was going on during those \_\_ months?

How did you get along with the family and friends during that time?

How did you and your doctor get along during that time?

Do you still have the same doctor as your G.P.? Why? or why not?

Can you describe the general emotions you have during those \_\_ months.

**Diagnosis**

This may be difficult, but I would like to focus specifically on the day or point when you found out you had AIDS.

Could you please tell me what happened when you found out you had AIDS. Or could you tell me about the time you found out you had AIDS. Or could you describe the situation when you found out you had AIDS. (Probes to ask if not volunteered.)

- who told you?
- as best you can remember, what were you told?
- what were your feelings then?

What did you think about right after you found out? By that I mean what did you think about: on the way home, for the rest of the day, for the rest of the week?

What was the first thing you did after you were told you had AIDS?

Who was the first person you told once you knew the diagnosis?
Were there any things you thought of doing or saying but eventually did not?
Do you will have any of these thoughts?
How long did you know you had AIDS before you told someone else?
What were your reasons for doing what you did?

Family

I would like to make another switch now and focus on you and your family. To begin I would like to ask some general questions about how you and your family have gotten along prior to your diagnosis.

Do you have any family in the lower mainland?
Do you have regular contact with family members such as Mom, Dad, brothers or sisters?
What kind of contact do you have, e.g., visits, telephone calls, letters?
Are you closer to one member of the family than the rest?
Have you had any contact with your family since diagnosis?
Does any particular family member know you have been diagnosed as having AIDS?
If so, what have they said?
What do you believe they think about it?
Have any family members been out to visit?

Construct of AIDS

Did you know anyone with AIDS before you were diagnosed?
What would you call them; close friends, friends, acquaintances, etc.?
Prior to your being ill, did you try to visit them or make contact?
If so, why? If not, why not?
How would you describe AIDS to someone who had never heard about it or didn't know anything about it? What would you tell them? What would you say?
Do you think your view of AIDS is individual or widespread?
What do you think the general public knows about AIDS? Do you have any personal experiences to support this?

What do you think the general public feels about AIDS and those who have it? Do you have any personal experiences to support this?

What is your reaction to the statement that being diagnosed as having AIDS usually means the person diagnosed is gay/homosexual/bisexual?

Various words have been used in the press to describe those people who have been diagnosed as having AIDS, e.g. "victims," "PWA," "clients," and "patients." What is your preferred term? Why?

Have you gathered medical information from sources other than your doctor? If so, where?

**Social Support Requirements**

What services/supports do you feel you need now? What services/supports do you actually get? Do you feel there are supports in the future you may need? When I use the term "services and supports" I want you to define them in any way you want.

As new problems have developed who have you gone to for assistance? Do you go primarily to an individual or a group?

How important did you see relationships before you became ill? Has this feeling changed since diagnosis?

Since diagnosis has your primary group of friends changed? If so how? and if so why?

Would you categorize all the media attention focussed on AIDS as good/bad/or indifferent? Has it had any personal effect upon you? If so, what?

What group/organization/government has done the most in your opinion for AIDS and individuals with AIDS? and which the least?

Do you know about AIDS Vancouver and the PWA Coalition? Do you have any contact with them?

Do you feel AIDS is only one part of your life or do you feel it is now central to your daily thoughts and activities?
Do you feel your opinion is shared by others around you? The general public?

If someone had just been diagnosed, and they asked to talk to someone with AIDS:

(a) would you agree to see them if you were asked? Why?

(b) if so what would you say to them?

Thank-you very much for your time. When my work is completed I am willing to meet with you to share my findings at that time or any time in between if you wish it.
APPENDIX 3
QUESTIONS FOR FAMILY/FRIENDS/LOVERS

Before we begin this interview I need to know if your family member/friend/lover is living or not. That information will help me phrase my questions properly. (If he/she has died) How long ago was that?

Thank you, now I would like to begin.

Illness/Diagnosis

How long has/had your family member/lover been ill? By ‘ill’ I mean not able to do what he/she normally did?

Could you tell me how you were told they had AIDS? Who told you?

To the best of your memory, what were you told?

What was the first thing you did after finding out?

What were your feelings once you were told? How long had your family member/lover known they had AIDS before they told you?

Did he/she place any conditions on you regarding this information?

Did you maintain regular contact prior to discovering your family member/lover had AIDS?

How often was that contact?

Construct of AIDS

Did you know anyone with AIDS prior to finding out that your family member/lover has/had AIDS?

If so, how would you categorize your relationship with them; close friend, friend, acquaintance, social contact?

Did you try to visit them or make contact? If so why? If not, why not?

How would you describe AIDS to someone who had never heard about it or didn’t know anything about it? What would you tell them? What would you say?
Do you think your view of AIDS is individual or widespread?

What do you think the general public knows about AIDS?
Do you have any personal experiences to support this?

What do you think the general public feels about AIDS and those who have it?
Do you have any personal experiences to support this?

If your family member is/was gay/homosexual, did you know that before finding out he was diagnosed as having AIDS?
How comfortable are you with someone being homosexual?
If you have any concerns/problems would you tell me what they are?
Have these thoughts/feelings/concerns changed over time?

Various words have been used in the press to describe those people who have been diagnosed as having AIDS, e.g. "victims," "PWA," "clients," and "patients." What is your preferred term? Why?

Have you gathered medical information from sources other than your doctor?
If you where?

**Social Support Requirements**

What services/supports do you feel individuals with AIDS require?

What services/supports do they actually get?

Are there any future supports you feel your family member/lover may need in the future?

Do you feel there are any extra service needs for individuals with AIDS because of the range of opportunistic infections?

As new problems developed, where has/did your family member/lover gone for assistance?

Do you believe your family member’s/lover’s group of friends has changed after diagnosis? If so how? Why?

Would you categorize all the media attention focussed on AIDS as good/bad/or indifferent.
Does it have any personal effect upon you? If so, what?

Now I would like to talk about some of the organizations involved with AIDS and the care of individuals with AIDS?
What group/organization/government has done the most in your opinion for AIDS and individuals with AIDS? And which the least?
Do you know about AIDS Vancouver and the PWA Coalition? Do you have any contact with them?

Do you feel AIDS is only one part of your life or do you feel it is now central to your daily thoughts and activities?
Do you feel your opinion is shared by others around you? the general public?

If a family member/or lover of someone just diagnosed with AIDS asked to speak to someone:

(a) would you agree to lee them if you were asked? Why?

(b) if so, what would you say to them?

And finally, do you feel there are any special problems encountered by family members/lovers of those with AIDS that we have not already talked about?

Thank you very much for your time.
I hope to share my work with you once it has been completed and am willing to meet with you to share my findings at that time or any time in between if you wish it.
APPENDIX 4
QUESTIONS FOR SOCIAL WORKERS

Have you dealt with any clients who have had AIDS?
If so, could you state in general terms what services you provided?

Were there any other requests you were unable to perform but referred to other agencies or individuals?

Construct of AIDS
How would you describe AIDS to someone who had never heard about it or didn’t know anything about it?
What would you tell them?
What would you say?

Do you think your view of AIDS is individual or widespread inside the social work profession?

What do you think the general public knows about AIDS?
Do you have any personal experiences to support this?

What do you think the general public feels about AIDS and those who have it?
Do you have any personal experiences to support this?

Have your thoughts/attitudes towards homosexuality shifted with the development of AIDS as a medical problem?

How comfortable are you providing services, talking to, dealing with someone who is homosexual?
If you have any concerns/problems would you tell me what they are?
Do you have any openly gay friends?

Various words have been used in the press to describe those people who have been diagnosed as having AIDS, e.g.
"victims," "PWA," "clients," "patients,"
What is your preferred term? Why?

Have you actively sought out medical information regarding AIDS?
If so, where have you gone for this information?
If not, what has been your primary source of information?
Social Support Requirements

What services/supports do you feel individuals with AIDS require?
What services/supports do they actually get?
Are there any future supports do you feel individuals with AIDS may need in the future?

Do you feel this client group has any extra service needs different from those of people with cancer?
If so, what would those services be?
If not, what are the similarities between AIDS and cancer?

Would you categorize all the media attention focussed on AIDS as good/bad/or indifferent?
Does it have any personal effect upon you? If so, what?

Now I would like to talk about some of the organizations involved with AIDS and the care of individuals with AIDS.

What group/organization/government has done the most in your opinion for AIDS and the care of individuals with AIDS? and which the least?

Do you know about AIDS Vancouver and the PWA Coalition? If so could you tell me more about them?

This question is asked with an emphasis that all sources of information will remain confidential. I will not identify the individual nor their affiliated agency, if any, when writing up this information.

To your knowledge, has there been any incidences of "discrimination" or "prejudice", in the widest use of these terms, towards individuals with AIDS within your work setting?
If so, could you tell me more about the circumstance?

And finally, do you feel there are any special problems encountered by this group that we have not already talked about?
APPENDIX 5

Founding Statement of People with AIDS/ARC
(The Denver Principles, 1985)

We condemn attempts to label us as "victims," which implies defeat, and we are only occasionally "patients," which implies passivity, helplessness, and dependence upon the care of others. We are "people with AIDS."

We recommend that health care professionals:

1. Who are gay, come out, especially to their patients who have AIDS.

2. Always clearly identify and discuss the theory they favour as the cause of AIDS, since this bias affects the treatment and advice they give.

3. Get in touch with their feelings (fears, anxieties, hopes, etc.) about AIDS and not simply deal with AIDS intellectually.

4. Take a thorough personal inventory and identify and examine their own agendas around AIDS.

5. Treat people with AIDS as whole people and address psychosocial issues as well as biophysical ones.

6. Address the question of sexuality in people with AIDS specifically, sensitively, and with information about gay male sexuality in general and the sexuality of people with AIDS in particular.

We recommend that all people:

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us, separate us from our loved ones, our community, or our peers, since there is no evidence that AIDS can be spread by casual social contact.

2. Do not scapegoat people with AIDS, blame us for the epidemic, or generalize about our lifestyles.
We recommend that people with AIDS:

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda, and to plan their own strategies.

2. Be involved at every level of AIDS decision-making and specifically serve on the boards of directors of provider organizations.

3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.

4. Substitute low risk sexual behaviors for those that could endanger themselves or their partners, and we feel that people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.

People with AIDS have the right:

1. To as full and satisfying sexual and emotional lives as anyone else.

2. To quality medical treatment and quality social service provision, without discrimination of any form, including sexual orientation, gender, diagnosis, economic status, age, or race.

3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment, and to make informed decisions about their lives.

4. To privacy, to confidentiality of medical records, to human respect, and to choose who their significant others are.

5. To die and to live in dignity.

## APPENDIX 6

**NEWS MAGAZINE ARTICLES TIME, MACLEANS AND NEWSWEEK**

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**Six Stages of Illness: Four Types**

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<th>Well Being</th>
<th>Undefined Illness</th>
<th>ARC Lymphadenopathy</th>
<th>Opportunistic Infection</th>
<th>AIDS</th>
<th>Death</th>
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</thead>
</table>
FIGURE 2

Trajectory of Illness

0 12 24 36 48 MONTHS

Died
AIDS
Opportunistic Infection
ARC
Undefined Illness
Well Being
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