1-1-1993

HIV infection in the workplace : an exploratory study of its impact on the infected employee.

John E. Rich

University of Massachusetts Amherst

Follow this and additional works at: https://scholarworks.umass.edu/dissertations_1

HIV INFECTION IN THE WORKPLACE:
AN EXPLORATORY STUDY OF
ITS IMPACT ON THE INFECTED EMPLOYEE

A Dissertation Presented

by

JOHN E. RICH

Submitted to the Graduate School of the University of
Massachusetts in partial fulfillment of the requirements for
the degree of

DOCTOR OF EDUCATION

September 1993

School of Education

HIV INFECTION IN THE WORKPLACE:

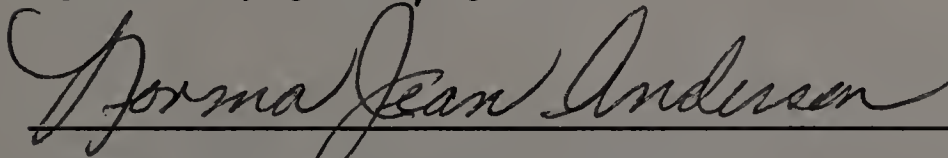AN EXPLORATORY STUDY OF

ITS IMPACT ON THE INFECTED EMPLOYEE
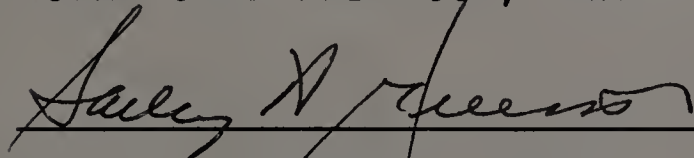
A Dissertation Presented by

JOHN E. RICH

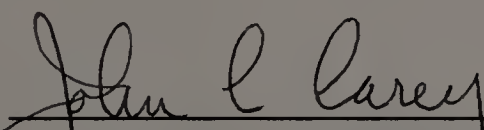Approved as to style and content by:

_____

DONALD K. CAREW, CHAIR

_____

NORMA JEAN ANDERSON, MEMBER

_____

SALLY A. FREEMAN, MEMBER

_____

BAILEY W. JACKSON, DEAN,

SCHOOL OF EDUCATION

ACKNOWLEDGEMENTS

This paper is mostly an act of love. Love is certainly intermingled with the prose.

And, as with any birth, it is laden with emotions: fun, gladness, sorrow, joy, fear, pain, celebration, anticipation, mystery and more. It reflects hours of working alone and hours of working with various people - directly or through their writings. It required hours of experiencing myself and of experiencing others. It leaves me, even now, feeling saddened by the nature of its content and by the need for its writing. But need there was and need there is for this and more and ultimately for a change in the way we think of and respond to those with HIV infection.

My first and most profound thanks go to all those who were with me as participants in the groups. I thank each one for his presence, his vulnerability, his spirit and his willingness to share his story with me. I hope I have done it justice; I feel their is so much more to be done. I wish you all the best of health, life and success.

In acknowledging people who come to mind; who helped make this completion possible, I return to a novel *Borrowed Time: An AIDS Memoir* by Paul Monette. Written in 1988, it spoke to a time when AIDS was sheathed in mystery and misunderstanding. At times, I wonder how much things have changed. But it was that novel that stirred the compassion, sadness and anger in me. When I looked around in the world

My children are also wound through and about these pages. I wonder if and how they will ever appreciate that. I hope they do and I hope to show them the way of the world as I know it and give them the way to navigate their path with wonder and excitement. Mom and Dad and Judi all added their support and encouragement along the way. Thanks much.

Last but certainly not least, there is Michael, who has pointed the way and helped open doors that make a lot more than this paper possible. Thanks much and lots of love.

And lots of love to you all.

ABSTRACT

HIV INFECTION IN THE WORKPLACE:

AN EXPLORATORY STUDY OF

ITS IMPACT ON THE INFECTED EMPLOYEE

SEPTEMBER 1993

JOHN EDWARD RICH, B.A., MANHATTAN COLLEGE

M.Ed., Ed.D., UNIVERSITY OF MASSACHUSETTS AMHERST

Directed by: Professor Donald Carew

Many of the more than one million people infected with
the HIV virus in the United States continue to work after a
positive test for the antibody to the virus that causes
AIDS. As the numbers of HIV infected people grow in this
country, more and more employers, co-workers, counselors,
friends or family, will have to deal with the compound
issues of HIV infection and work. Therefore, knowing and
understanding the issues of concern to HIV infected
individuals while they continue to work will become
increasingly important.

To gather this information, a series of Focus Groups
were conducted. From the tapes and transcriptions of the
groups, discussion items were identified and clustered for

each group. They were then analyzed for: convergence across groups; areas of common concern; and inferences into attitudes held by those who are HIV infected.

Because the disease is relatively new and because very little data exists about the impact it is having on those who are working and infected, this research project was an exploratory one. It attempted to gain insight into how people are coping with these two issues while learning more about them. Because of the lack of current information on this topic, the groups were facilitated with low structure to generate as many ideas as possible from the participants.

The purpose of the research was to supplement existing information about the impact of HIV/AIDS in the workplace. This study changed the prevailing focus of existing research/writing and brought it to those individuals who are both dealing with the disease as a personal reality and continuing to work.

In gathering this data, another goal was to provide information that will help make the work-life, and thus the overall quality of life, better for those who are HIV infected.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

THE PROBLEM

> Pilots call it "flying blind" and they fear it more than anything else. Their vision is obscured, and their instruments go dead. They have no sense of where they are or where they are headed. Without constant feedback, they can only guess how to adjust the complex controls that guide the airplane.
> Constant, quality feedback is equally important to those charged with leading an organization and managing its human resources. Feedback becomes even more critical as we experience a quickening pace of change - the move to a global economy, pressures to hold down costs and increase productivity, dramatic changes in workforce demographics that translate to a shortage of skilled workers. (Knapp and Parente, 1989, p. 3)

Introduction

Few who watched Elizabeth Glaser speak before the nation at the Democratic National Convention in July, 1992, could not have been moved by the story of a woman fighting for her life and the life of her one surviving child. Both she and her child are infected with the HIV virus as was another of Mrs. Glaser's children who lived seven years before dying.

Elizabeth Glaser is not alone in her struggle however, she is joined by over one million other Americans who are fighting this same battle to save their lives and to continue to be productive members of our society.

Part of the battle Glaser is fighting is to increase public awareness and understanding of this disease. Fears, misperceptions, blame and prejudice are a few of the

negative responses some Americans have to this disease. Discrimination, unfortunately, is often the result of these feelings. Reports of discrimination against people with HIV/AIDS have risen from 400 in 1984 to over 92,500 in 1988. (West, 1991) Of these reports, 37% were employment related. In a more current study, discrimination was cited by 36.5% of the respondents in health care and 26.1% in the job. (National Association of People with AIDS, 1992)

A response to these social realities on the part of those who are HIV positive and working is often silence. Silence, unfortunately, results in a lack of awareness on the part of all people. It is particularly evident in the lack of literature that deals with the issues people who are HIV positive and working are facing.

This lack of data represents a major deficit in labor market information, social sciences and management information. The numbers of people who are HIV positive and working are too large and growing too quickly to be ignored; there are over one million people who are HIV positive in this country. We can make assumptions about the needs of this group both on and off the job, but we have little research to substantiate or disprove any assumptions about HIV infection's impact on those working. Even if we consider this group of infected people as "only" living with a chronic illness or disability, the numbers of those infected with this disease are too large to be ignored.

If one of the primary concerns of business is to respond effectively to the needs of its workforce in order to maximize efficiency, HIV infection warrants an increased response from business. However, with this disease responses are varied and often emotionally charged, and rarely positively.

From an organizational perspective, the disease can be broken down into three general categories: the infected workers, the co-workers, and the managers. A fourth category, the consumers, is another very real area of concern, but one that is not of primary concern to this paper.

Again, it is important to note that there are growing numbers of workers who are are HIV infected. This means that employers are increasingly likely to have to respond to the legal, health, productivity and medical/insurance issues of HIV infection in the workforce. Organizations can not chose to ignore their legal requirements to make reasonable accommodation for the needs of HIV infected workers without risk of litigation. Employers have to be informed, therefore, of both their legal obligations as well as the broader needs of their HIV infected workers.

In addition to legal concerns, organizations will want to maximize the productivity of HIV infected workers as they do with other workers. So, as HIV infection increases in the workplace, organizations will need to know more about how to

respond effectively to the needs of these workers to maintain workplace productivity.

From an economic perspective, medical and insurance costs will increase. Organizations will need to review their benefits programs to both protect the legal rights of infected workers and to control costs whenever possible.

Organizations will also have to respond to the concerns of co-workers. These concerns may have to do with health and safety, productivity and/or legal issues. As co-workers learn that others within their organization are HIV infected, they will have a variety of responses. Some may be fearful, others may be compassionate. Whichever, the organization will have to respond with increased education, information on medical policies and legal information. Perhaps support may even be necessary for those distressed by the news of their own infection or that of a co-worker.

Employers will need to deal with these dual issues of confidentiality of medical records and the safety needs of co-workers.

Finally, organizations will have to train managers to be effective in responding to all of these issues in the workplace. Managers will need to know the extent of the laws protecting HIV infected workers, receive training in homophobia, and understand better the impact of disabilities on workers.

It becomes clear, therefore, that HIV infection is a major issue for organizations now and will increase as both

the numbers of infected workers and the awareness of cases increases. Organizations will have to deal with the issues of economics, human rights, legal rights, morale, and policy development in response to the disease. Because so many of these issues are based in legal requirements, organizations do not have the option to ignore the issue.

Current medications and medical information will increase both the numbers of those working with HIV infection and their ability to function, detected or not. Without more information on the needs of this population it seems unlikely that any employer will be able to respond effectively to employee needs effectively.

Employees Have Legal Rights

Employment and productivity for those who are HIV positive is at least as important as it is to other members of our society. It serves as a means to financial well-being, social interaction, a sense of productivity and responsibility, medical/health benefits, long-term purpose, growth, physical well-being and a host of other factors. Yet, many who are HIV positive would be denied the right to work, not because of physiological necessity associated with their disease, but because of the false assumptions and fears of many in our society. For these reasons, and to provide and maintain basic civil rights for those who are HIV infected, this disease is considered a medical

disability. It is listed as one of the conditions protected under law in the Americans With Disabilities Act of 1990. This act took effect in 1992 and extended protection to people with HIV/AIDS both on and off the worksite.

AIDS and HIV is not an unknown disease to employers and insurers. Both have grappled with the issue because of associated costs of responding to the disease. The average annual cost of treatment for a person with HIV infection is about $5,000 while the annual treatment cost for someone with AIDS is about $30,000. The lifetime cost of treatment for the disease averages between about $85,000 to $100,000 per person. (Woolsey, 1991,5)

The economic realities of this disease have resulted in much research, attention and literature. There is an abundance of information available to detail how organizations can respond effectively to the disease with new policies, legal responses and medical/insurance coverage. Urban areas have various associations formed to respond to questions from employers. However, with the passage of the new requirements of the ADA, awareness and response to HIV/AIDS can only be heightened. Employers will find that legal protections offered to people who are HIV positive and in the work force require them to disseminate more information than they currently do and to respond to a broader array of problems. The issue will not remain only a cost management issue for employers. They will be required

6

to also respond to the human needs of their infected
workers.

Statement of the Problem

Therefore, the problem that needs to be addressed has
several components. One is that there are many people in the
workforce who are HIV infected - known or unknown. Second is
that employers and co-workers know very little about the
disease and its social and historic roots. Three is that
very little is known about the issues that those who are HIV
infected and employed are dealing with.

Because employers will be forced to deal with the
issues of HIV infection in the workforce more often and in
more ways than they have in the past, there is an increased
need for information, research and dialogue. It remains
difficult however, to understand the disease without
understanding some of its past. And if there is to be a
truly meaningful discussion of this disease and its impact
on workers, the fear of retribution has also to be
addressed. But it has first to be acknowledged. This
research will help make the reality of issues better
understood. It can not solve all of the related problems.

AIDS as a disease has been diagnosed in the United
States since 1981. During that time, over 150,000 people
have died from complications caused by this disease. Another
230,000 are currently diagnosed as having AIDS and over one

million are diagnosed with HIV infection. (Schmalz, 1992)

Between 40,000 and 60,000 annual new cases of HIV infection

are expected every year in the United States for the near

future or until a vaccine is developed. (Eckholm, 1992)

Because the primary age range for these people is between 24

and 44, (Foreman, 1991, b) many of these people are in their

prime working years and are either already gainfully

employed or soon about to enter the employment market.

Because HIV infection is not visible or apparent and because

the ADA prohibits testing for HIV infection prior to

employment, many new people will become employed who are

already HIV positive.

Each person newly diagnosed with HIV infection can

have up to about 14 years of productive work before being

totally disabled by AIDS and the opportunistic diseases

associated with it. Even then, people may be able to return

to work after treatment. (Georgia, 1990)

This fact about the disease also means that employers

may currently have people working for them who are HIV

positive, of whom they are unaware. Many people with HIV

infection do not disclose that status in the workplace

voluntarily and others do not know themselves of their HIV

status. While there are potentially many reasons for lack of

disclosure, one is certainly a fear of discrimination,

another may be a desire for privacy. Whatever the reasons,

the lack of disclosure of HIV status represents a legal

liability to employers, particularly with current ADA

mandates. Therefore, this lack of information on the employers' part can complicate its situation because it remains responsible for maintaining both the health and safety of all workers and the legal rights of those who are HIV positive.

As employers learn more about the HIV status of those who are positive, they will benefit from knowing what that person's physical, psychological and emotional needs are in the workplace. This information will help employers make reasonable accommodations as required by law and maintain productivity.

In addition to being of value to employers, information on this topic, will be helpful for social service providers. It will help them to better understand the issues created for those working with HIV infection. As information for employers has been motivated by economic issues, information for the social service community has been motivated by medical and psychological factors. Training for these providers typically contains a segment on the medical aspects of the disease, statistics, transmission modes, and counseling issues. (Georgia, 1990; United Way of Central Maryland, 1988) It may include first hand accounts of what having the disease is like, but has not included research data on issues for HIV infected people in the workplace. Knowing this can only add to the quality of service and support. However, this information does not exist currently.

Statement of Purpose

To gather this information, a study was conducted to gather information from those who are both HIV infected and currently employed. This study focused on those who are HIV positive and not diagnosed with AIDS. That was not to minimize the needs of those with AIDS, but rather to focus on the needs of those with HIV infection, in part because the years of work they have are generally so much greater in length and their numbers so much larger.

Because work is as integral a part of the lives of HIV infected employees as anyone else and because employment is a source of critical health care benefits for many, work takes on perhaps a more important role for those who are infected. Yet from the experiences of this writer working with people who are HIV positive, there appears to be a continuous balancing act within those who are HIV infected and working. Topics being balanced included maintaining suitable employment and continuing to be responsible and productive on the one hand with aspects of managing one's health care and limiting stress on the other. The two do not appear to be highly compatible and there seems to be no major means of support for this struggle.

With this understanding of the current situation for employers, co-workers and those with HIV infection, there

were four primary goals to this research project. They included:

1., To learn more about the important concerns and needs of those who are working and HIV infected;

2., To determine the diversity of needs among various individuals;

3., To understand better how employers can meet these needs; and

4., To establish a basis for future research to support employers, social service providers and those with HIV infection as they continue to struggle with issues of work and maintaining health.

This study began to explore the issues of particular importance to those workers who are HIV infected.

As current literature for employers focuses primarily on the need to create an effective policy, to communicate that policy to the employees and to communicate an understanding of the disease and how it is spread, it misses crucial information about the reality of the work situation for those who are HIV infected. (United Way of Central Maryland, 1988; Bohl, 1988; Woolsey, 1991, 2, 3 &4; Citizens' Commission on AIDS, 1989 National Leadership Coalition on AIDS, 2, Lambert, 1988) If the overwhelming concern of most research remains the burgeoning costs of managing the AIDS epidemic in the workplace, it will lack an understanding of the full needs of those employees who are HIV infected.

Whether we examine employer response or social service provider response, it must be informed by data relating to issues of those struggling to remain productive in the workplace while dealing with HIV infection. If employment issues for this population remain tangential to the literature surrounding this disease, key components of the client's life will be missing. The very ability of HIV infected clients to access psychological, as well as medical care often hinges on their ability to maintain employment and the benefits of health coverage.

Individuals who are HIV infected also serve to benefit from an increased understanding of the issues surrounding HIV infection in the workplace. As more and more people struggle to create normalcy with this disease, the ability to understand what the issues generally faced by people who are working and HIV infected, will help more and more remain productive, employed, and mentally well. This information can also serve as a basis for increased advocacy on the part of those who are HIV infected. As understanding of the issues increases, those with HIV infection will be betterr able to ask for specific programs, support or accommodation as necessary. In addition, people who are working and HIV infected will be better able to support one another on an interpersonal basis as they obtain a clearer understanding of the problems they collectively face in the workplace and the subsequent solutions.

Overview of the Study

This exploratory research into HIV infection in the
workplace and its impact on the infected worker used
qualitative research methods. A review of the literature on
the subject revealed that there is little written on the
needs and concerns of HIV infected workers and their
expectations for employers. In addition, no survey was found
that has assessed these needs or concerns. Due to this lack
of information, focus groups were run to obtain original
data from people who are HIV infected and currently
employed. Group membership was based on a current diagnosis
of HIV infection and at least part-time current employment.
People meeting these broad guidelines were asked to
volunteer for participation in the groups. During these
focus groups (a minimum of three groups were planned - four
were held) members were asked to discuss concerns and needs
they currently experience in relation to their work. The
groups ran for about two hours and were audio-taped. Signed
releases (Appendix I) were obtained from participants and
confidentiality of identity, employer and issues were
assured. Confidentiality between members was also requested
as a condition for inclusion in the group. Membership was
obtained through various organizations and through various
random outreach means, e.g., newsletters, press releases,
etc.

As a result of these groups, items of concern to HIV infected workers were identified and isolated by listening to the audio-tapes and reading the transcriptions. Personal judgement of the researcher was used to eliminate similar items and to combine related ones.

Demographic information was gathered through the use of a questionnaire including such items as: age, gender, sexual orientation, race, years of HIV diagnosis, means of infection, weekly hours of employment, type of employer, years of employment in the field and educational level.(Appendix II)

As a result of each focus group, a summary of items of concern to the participants was made. Review of the items reflected the level of consensus and concerns, and stated or perceived significance to groups members.

Similarly, a review of items across the groups was concerned with identifying similarity of items. Discussion attempted to explore reasons items may have been discussed, attempting, if appropriate, to see if demographic factors played a part. The final desired outcome was a pool of information that related to the issues and concerns of those who are HIV positive and working.

Using qualitative research methods enabled this project to generate preliminary data on a sensitive and little-researched topic. People who are infected with HIV and are working provided the information necessary to generate a greater understanding of their concerns. They

became the experts on this subject. The process of a focus group, versus individual interviews or other qualitative methods allowed for the benefits of group interaction to enrich the development of items via group discussion. Confidentiality of group participation maximized the quality of interaction and positively effected the number and quality of items.

By conducting the focus groups, the researcher benefited from the interaction of group members with each other and himself. Conducting the groups provided a first-hand understanding of the issues confronting people, the contextual issues surrounding those issues and emotional responses.

Significance of the Research

There are several factors that contribute to the significance of this research:

The **first** is the fact that so little research has been done on this topic;

Second, is the fact that people who are HIV infected are living and working for longer periods of time;

Third, is that rates of infection are expected to increase thus putting more infected people of working age into the labor market;

Fourth, relates to costs associated with both lost productivity and medical and health care that are expected to increase because of two and three above;

Fifth, is that the implementation of new laws will provide those who are HIV infected and working with new legal protections;

Sixth, is the anticipation that advocacy and support will increase as both the number of HIV infected people and the understanding of the disease grows (although there is no predictable positive corrollation between increased numbers infected and understanding of the disease with increased support); and,

Seventh, is the tremendous human need of those who are HIV infected and working that is not being addressed.

AIDS and HIV is a billion dollar industry in the United States with $1.2 billion spent on AIDS-related life and health care in 1990 alone. (Woolsey, 1991, 2) This trend is not expected to end in the known future and life expectancies are expected to lengthen for those with HIV infection. In addition to lengthening life expectancies for HIV infected people, the quality of that time is expected to improve. This will increase the ability of someone with HIV infectión to continue working.

Because this country has included HIV/AIDS in the ADA, we are now committed to providing legal protection to HIV infected people in relation to employment. If people who are HIV infected are going to remain in the workplace, it is to

the advantage of both employers and those infected to know as much as possible about their needs and concerns.This information will have a positive impact on the cost of doing business.

Secondly, because people with HIV/AIDS have such a large social service network, it is once again to the advantage of both the service providers as well as the clients to understand the inter-relationship of work and HIV infection.

Definition of Terms

Working - gainfully employed at least part-time.

HIV infection - the medical condition of having tested positive for the antibody to the Human Immunosuppressant Virus (HIV). This means that the person has been infected with the virus and that it is active within his or her body. HIV infection can last up to 14 years before a person is diagnosed with AIDS. There are two stages of HIV infection: symptomatic and non-symptomatic.

AIDS - The condition of a person who is HIV infected and who has developed one of the opportunistic diseases that the Centers for Disease Control lists or who has a t-cell count of 200 or less. The most common disease diagnosed is pneumocystic pneumonia. A person usually lives about two years after having been diagnosed with AIDS.

Symptomatic - Having or manifesting one of more of the symptoms associated with HIV infection including night sweats, fevers, loss of weight, swollen lymph nodes, chronic diarrhea, persistent herpes infection, thrush, fatigue/weakness.

Non-symptomatic or asymptomatic - Being HIV infected but not having developed any of the symptoms associated with it. Typical range of time for an HIV infected person to remain non-symptomatic is from a few months to about 10 years after infection.

Health care benefits - insurance coverage provided to pay all or part of the costs of medical diagnosis and treatment, prescriptions, hospital visits and psychological services. Most of the references to health care benefits is in relation to employers even though they can also be provided by community and state agencies.

Focus Groups - Structured, facilitated groups of limited duration to elicit discussion on a desired topic. In this situation, the groups focused on the members needs and concerns at work.

Social Service providers - Any professional: therapists, counselor, social worker, agency personnel, nutritionist, etc. involved in the non-medical treatment, and/or support of those with HIV infection or AIDS

Limitations of the Study

This study was not an exhaustive look at the issues currently impacting people with HIV infection or AIDS. While new information was gained on the needs and concerns of people with HIV infection in relation to work, it is reasonable to recognize several limitations of this study.

The limitations of this research began with the inability of the researcher to gather data in the field of HIV infection and employment. As stated earlier, there is much written about the legal, economic and physiological aspects of the disease. There is also a lot about the general counseling needs of those with HIV infection and underlying emotional and psychological issues. There is, however, very little written about what is happening with HIV infected men and women as they continue to work.

To overcome this obstacle, it became clear that this research was exploratory and would help establish a base for future research to be more quantifiable or more extensive. A survey would require an understanding of issues to build question items from. The thought of building a questionnaire without a base of information appeared ill-founded. That process is more achievable now.

Other factors impacting on the study included the following:

First, no non-working HIV infected individuals were studied. This would include people who are not working

because of personal preference or for medical reasons. Because we did not collect information from this group of people, we can not know what influence they would have on the study, especially regarding why they may choose to stay away from employment.

Second, co-workers were not surveyed. A rich pool of information remains to be explored regarding the needs and concerns of those who work with HIV infected or people with AIDS or their perception of the situation.

Third, the survey was limited in its input to people living and working in primarily urban, northeastern cities. We were not able to generalize this information to those in rural environments or even to other parts of the country.

Fourth, we were not able to obtain a reasonable response from various segments of the population, e.g., black, Hispanic or female populations. Because the survey population was obtained through various agencies, minority and gender could not be assured appropriate representation. Also there was under-representation from those who have become infected by HIV through intravenous drug use.

Fifth, because of the diverse nature of the disease and how its symptoms manifest, we were not able to differentiate between issues of significance to someone relatively recently diagnosed and someone in advanced stages of HIV infection or even AIDS.

Finally, the methodology itself presented certain limitations. Among those was the focus on determining "what"

or "why" rather than "how many." It allowed for the establishment of the ranges of attitude without being able to assert the representativeness of the findings. (Goldman, 1979, p. 44)

One of the requirements of the research was confidentiality. Because of the emotional and social issues surrounding HIV infection, many people are protective of their status. Due to this need, gathering information in such a way as to address specific needs of men of color versus white men became difficult. The data gathered was an amalgamation of issues and concerns of all group members. Dividing it into subgroups by any variable remains impossible except for the several broad categories is impossible.

So, while the research had resulted in significant information regarding the issues of working men who are HIV infected, it is hard to generalize this information. We can not make assumptions for people of color, people who may have contracted the disease via intravenous drug use or heterosexual contact. We can not generalize to women, Asians or other ethnic sub-groups.

The data gathered speaks about gay, white men who contracted the disease via sexual contact. It talks about men who are close to or about 35 years of age and who live in east coast metropolitan areas.

As we can not generalize to other populations, we also can not identify variables within the studied population.

For example, we can not differentiate data by age, occupation or educational level. We can not differentiate items based on years of diagnosis or symptoms experienced to date.

To do any of these manipulations of the data would require a standard instrument that asks respondents to rank items and provide demographic information. These could then be coded and clustered by the various criteria of interest.

There is value and need for this type of information. There is value in being able to say that certain issues faced by those with HIV infection cross many variables. There is also value in identifying which issues are specific to those working in certain environments, with certain educational, ethnic or socio-economic backgrounds, etc.

Also of interest would be a study to determine the change in issues as people progress through the stages of the disease. To understand better how the issues change as time progresses would provide employers and care-givers with data to alter responses.

The ultimate purpose of any research may also be to better respond to this disease and to those who suffer with it. The more data we have, the better our response will be. This researcher certainly hopes that the research contained within this study can serve as a useful point of departure for further studies.

CHAPTER 2

HISTORY AND LITERATURE

Introduction

> An epidemic is any unusual outbreak of a
> disease, even one more case than should be expected.
> Because the disease never existed before, AIDS, then,
> was automatically an epidemic. (McLaughlin, 1989,
> p.19)

AIDS is a new disease. The first cases were reported

in Africa in the early 1970s.(McLaughlin, 1989) The first

reported cases appeared in the United States in 1981 (Kain,

1989) but it was not until 1985 that a significant turning

point occurred in both public and political recognition of

the disease. It was in that year that several events

occurred. The pivotal one, from a public relations

perspective, was the announcement that Rock Hudson had died

of AIDS. Other events that year included The first

international conference on AIDS (Wachter, 1991); mandates

by federal and state laws to require reporting of AIDS

cases, (Georgia, 1988); the introduction of screening for

donated blood to determine the presence of the AIDS virus;

Ryan White, a 13-year-old hemophiliac, was barred from

school in Indiana (*Positively Aware,* 1992); C. Everett Koop

researched and wrote the national report on AIDS; 5,000

people had died of the disease; and another 5,000 cases of

AIDS had been reported (Wachter, 1991)

AIDS had arrived in the consciousness of the U.S. Yet, the president of the United States had not spoken publicly about this disease, its toll on human life, the suffering it was causing or the medical responses the government was taking. It was another two years before President Regan spoke about the topic of AIDS in advance of the opening of the Third International Conference. (Wachter, 1991)

Fornstein (1989) has pointed out how differently this country's reaction to the AIDS epidemic would have or could have been if the president had responded to the disease differently or earlier.

> Imagine, for instance, if soon after the epidemic was
> under way, the president of the United States had held
> a press conference, perhaps while sitting on the bed
> of a man with AIDS, and said: "My fellow Americans, I
> want you to know that your government is fully
> committed to dedicating whatever resources we have
> toward finding a cure and a treatment for those
> afflicted, and to educating us all about the
> transmission of this virus. I furthermore implore you
> not to punish or ostracize people who are sick or who
> are drug-addicted because of your fear of AIDS."
> Hearing and watching the president model a posture
> that deplores homophobia, racism, and irrational acts
> would provide Americans with some psychological
> supports for containing their fear. (Fornstein, 1989,
> p. 167)

Yet, denial, fear, and irrational acts remained the primary response of most Americans to this disease. That same response still acts as a plague within this plague and prevents those with the illness from getting the benefit of social support and commitment for fighting this disease.

Separating this disease from its social, political, historical and medical context is difficult, if not counterproductive. In doing research on the impact of HIV infection in the workplace with a special focus on the HIV infected worker, information on these contextual areas is important to understanding the issues completely.

This chapter will look at the history of this disease from its known origins in Africa, provide an overview of the statistics surrounding the disease, outline the primary means of contagion, and differentiate between AIDS and HIV infection. This information will be foundational to a review of discrimination and social responses to the disease in this country and to legal responses to it. A final review of literature will focus on workplace issues presented by the disease and include costs, recommended responses and rationale for such.

This information will provide an overall context for understanding the issues and concerns of those who are HIV positive and working. The information gathered from those who are in that situation may then suggest a future course of action for social activists, legislators, employers and concerned individuals.

Though the days when the media shied away from AIDS are gone, at the outset of the epidemic, media coverage was scant. The 1982 announcement by the CDC of the appearance of AIDS-related illness received only a one day mention in *The New York Times* and *The Los Angeles Times*. At that same time,

the discovery of cyanide in Tylenol resulted in *The New York Times* writing a story a day for a month with 23 more pieces in the following two months. (Shilts, 1988)

Today, media coverage is constant, not just about the AIDS epidemic in this country, but in other parts of the world. A special Health Section of *The Boston Globe*, November 25, 1991, dealt with AIDS in this country and around the world. Similar coverage appeared in *The New York Times* in June of 1992. Press coverage of Magic Johnson has overshadowed the previous coverage of Rock Hudson. Magazines of all types: popular, science, entertainment, etc., have had stories of people and events surrounding AIDS. Television and cinema have now covered the epidemic with personal stories and educational programs. Together, this coverage has brought the issues surrounding AIDS and HIV infection into most people's vocabulary and minds. Yet it has been the stories of popular "heroes" such as Magic Johnson and Rock Hudson that have begun to change the response of people and to increase their awareness of the disease. Johnson's contribution to informing the public of AIDS and HIV has been more effective than C. Everett Koop, past Surgeon General of the United States could ever have hoped with his nationwide mailing in 1986.

With information about the reality of AIDS and HIV has come a variety of responses from people. Those responses include a range of emotions: compassion, fear, anger, denial, sorrow and confusion. Each person's response is

impacted by factors such as education, religion, geography, culture, finances and personal emotional resources. Understanding the disease itself is a prerequisite for further understanding of how each one of us may respond more effectively to this disease and those who are suffering with it.

People can only replace fear with rationality if they understand the disease and those suffering with it. Schoeman (1991) said

> "People infected with HIV have much to fear besides the disease. Because of the association of AIDS with promiscuity, primarily homosexual but also heterosexual, or the self-abandonment connected with intravenous (IV) drug use, any adult with AIDS is suspected of degeneracy. One in five Americans regard those with AIDS as deserving their suffering because of their immorality." (p. 134)

A Chronology of Events - U.S.A.

The first language of AIDS began in **July 4, 1981** in an issue of the Center for Disease Control's (CDC) *Morbidity and Mortality Weekly Review* (Kain, 1989).

Physicians in New York and Los Angeles reported finding rare, fatal pneumonias (pneumocystis) and cancers (Kaposi's sarcoma) in two groups of previously healthy homosexual and bisexual men. Due to the immediate reference to homosexual and bisexual men, the first name for what we now call AIDS was GRID - gay-related immune deficiency. Because of the focus on the gay aspects of the disease, public perception of the disease and its suffers was and to

27

some extent continues to reference their affectional orientation. Presidential candidate Pat Buchanan (Reuters, 1992, p. 12) campaigned for election by calling AIDS "nature's form of retribution" against homosexuals. He was supported by 30% of the voting electorate in many states when they voted for him.

Disease investigators from CDC and other agencies, began to compile a profile of AIDS cases to identify what they had in common. The pattern of disease spread indicated that blood and/or sexual contact was the link among cases.

In late **1983**, French and American researchers independently isolated the virus which causes AIDS. The French termed it "Lymphadenopathy-Associated Virus" or LAV; the Americans named it "Human T-cell Lymphotrophic Virus Type III" or HTLV-III. An international commission finally changed the name, in **1986**, to "human immunodeficiency virus" or HIV to clarify and simplify communication about the disease. (Kain, 1989)

The discovery of a specific virus allowed research to focus on better identification, treatment, cures and preventive medicines, including a vaccine. Researchers began to define how the virus attacked the body, and confirmed that blood, semen and vaginal fluids were the body fluids responsible for transmitting the virus.

News from the Front, a California AIDS-information organization, published the first nationally recognized advice pamphlet on "safer sex." This one, 40 pages long, was

published in May, **1983** and titled *How to Have Sex in an Epidemic*. (Patton,1990, p. 45)

The First International Conference on AIDS was held at the Centers for Disease Control in Atlanta in **1985**. About 10,000 cases of AIDS had been reported and about 5,000 deaths. (Wachter, 1991, p. 16)

In **1985**, Federal and state laws were changed to require that every case of AIDS be reported to health authorities. Sites providing anonymous and confidential HIV antibody testing were set up in most states. (Georgia, 1988).

After **March, 1985**, all donated blood was screened for HIV antibody assuring that transfusions would be less risky. Antibody testing was developed that year and used to indicate the presence, sero-positivity, or lack of presence, sero-negativity, of the body's antibody (virus fighter) to the AIDS virus. In response to this terminology, HIV positive came to describe those people who had been tested for the virus and were found infected because antibodies were detected within their blood.

Rock Hudson died of AIDS complications in **1985**. Ryan White, 13-year-old hemophiliac, was barred from school in Indiana. (*Positively Aware,* 1992) Then U.S. Surgeon General C. Everett Koop mailed a report on AIDS to homes across the nation in **1986**. In the mailing, Koop called for widespread AIDS education and explicit prevention efforts, including information on safer sex techniques. (Wachter, 1991, p. 19)

In **1987**, Retrovir (Zidovudine or commonly called AZT), a drug that inhibits replication of HIV, was licensed by the Food and Drug Administration (FDA). AZT, manufactured by Burroughs-Wellcome Company became an immediate rallying point for those with the disease. It represented the first step toward a notion of curability for the disease and toward an optimistic perception of a PWA's ability to survive the infection. The price of AZT also engendered national publicity as groups, primarily ACT-UP, reacted strongly to the initial high costs ($14,000 annually) of obtaining the drug. Through demonstrations and sit-ins, the price of AZT was lowered eventually (to $1,500 annually) and it became generally available to all those who wanted it. ACT-UP began as a group in **1987** and the poster/slogan "Silence = Death" was created by them. (Crimp, 1990)

Also in **1987**, President Ronald Reagan gave his first speech on the topic of AIDS at a fundraiser in Washington, D.C. On the evening before the opening of the Third International Conference on AIDS, Reagan talked primarily about the need for compulsory testing of immigrants, potential newlyweds and prison inmates. (Wachter,1991, p. 104)

In **1987** AIDS was added to the list of "dangerous and contagious diseases" resulting in exclusion of individuals either HIV positive or diagnosed with AIDS from entering the United States. (Wachter, 1991, p. 29)

By **1989,** 100,000 cases of AIDS were reported and by
the end of **1991,** 200,000 cases were reported by the CDC.
(*Positively Aware,* 1992)

In **1992,** two new drugs were added to the Federal Drug
Administrations' (FDA) list of approved drugs: DDC and
DDI.(Eckholm, 1992)

1993 saw the definition of AIDS expand to include
three new clinical conditions: pulmonary tuberculosis,
recurrent pneumonia and invasive cervical cancer as well as
a t-cell count of 200 or less. (Centers for Disease Control,
1993)

Worldwide AIDS Statistics

The earliest known reports of what we currently call
AIDS were reported in Africa. The virus is similar to one
found in green monkeys there even though that virus is not
harmful to them. By the mid-1970s, cases can be documented
in central and east Africa. Among the earliest victims was a
female Danish surgeon working in Zaire. Her symptoms began
in about 1973. (McLaughlin, 1989)

There are currently about 1 to 1.5 million people
diagnosed HIV positive in this country and about 10 million
people officially reported as diagnosed with HIV in the
world (Foreman, 1991) The highest concentration of AIDS is
reported in Africa, with 6.5 million cases. The rate of
increase is expected to be largest in Asia, with about

500,000 cases reported now, but expected by the end of this

decade to dwarf the figures now being reported in Africa

(See Figure 2.1)

A recent report released by Harvard University sets

the number of adults infected by the year 2000 at between 38

and 110 million with an additional 10 million children. It

claims that
> "about 24 million adults and children will have
> developed AIDS - up to 10 times as many as today. The
> new report also predicts a sizable shift in the
> worldwide location of AIDS cases. It says that within
> eight years, 42 percent of all AIDS infections will be
> in Asia, surpassing the 31 percent in sub-Saharan
> Africa" (Haney, 1992, p. 15)

While AIDS does not currently rank in the top ten

killers for Americans of all ages, it is the leading cause

of death for Americans between the ages of 24 and 35 (West,

1991) and ranks fourth for Americans age 25 to 44 and sixth

for people aged 15 to 24, according to Foreman (1991, b).

About 40,000 to 80,000 people are newly infected with HIV

each year in this country and 3,000 AIDS diagnoses are

reported each year. (West, 1991) In its eleven years of

diagnosis in the this country, AIDS has claimed the lives of

a little over 152,000 Americans. (See Figure 2.2) Viet Nam

claimed the lives of 54,000 Americans. (Newsday, 1992)

> "Up to 2,000 babies are born infected each year, and
> most will die before age 10." (Eckholm, 1992 p. E5)

1.2 (in millions)

ASIA--

AFRICA-

0.8

0.4

N. AMERICA

L. AMERICA

EUROPE

0

1980   '85   '90   '95   2000
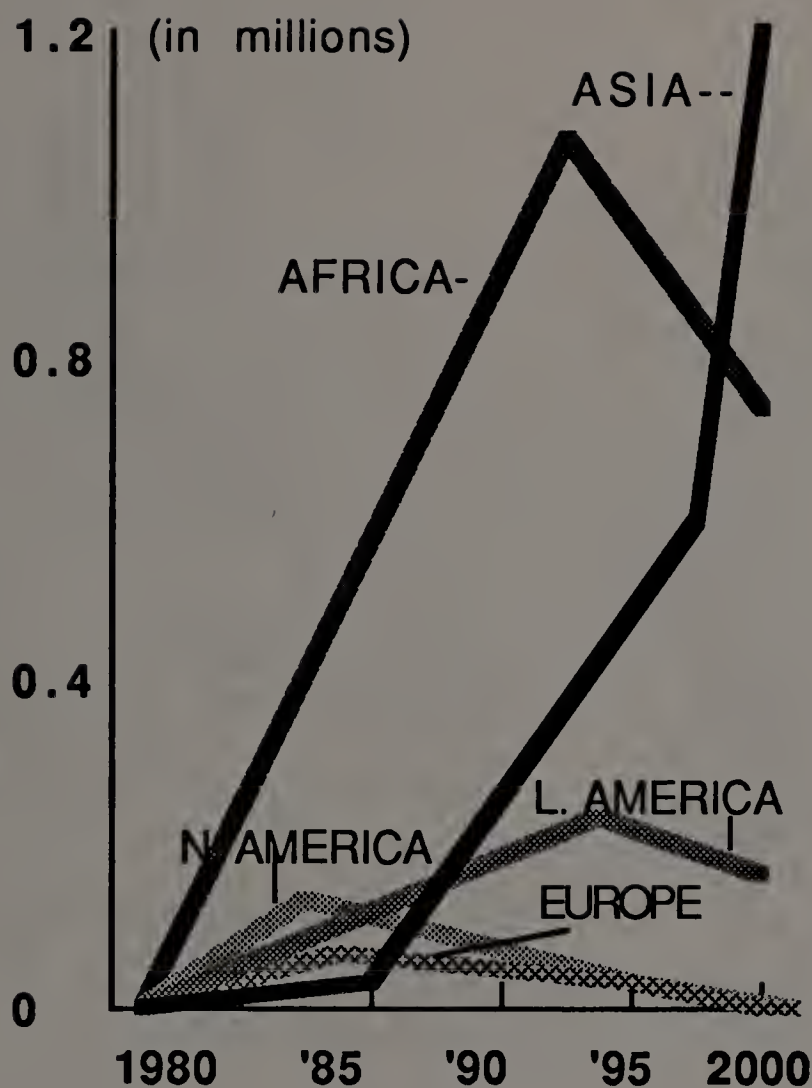
Adapted from *The Boston Globe*, Nov. 25, 1991

Figure 2.1: Projected Annual Adult Infection Rate

Sixty percent of people with AIDS are white, 25% are
black and 14% are Hispanic, reflecting a disproportionate
prevalence of the syndrome among minorities. (See Figure
2.3) Ninety-three percent of PWAs in the United States are
males. (Kelly, 1988) Magic Johnson pointed out in a recent
Boston speech that African-American numbers lead the way in
percentage growth of AIDS in the categories of children,
adults and women. He said, that

> "54% of all teenagers with AIDS are minorities, that
> 50% of all children with AIDS are minorities and that

33

in the Greater New York-New Jersey region, the leading
killer of black females between the ages of 17 and 30
is AIDS." (Ryan, 1992, p. 92)

(as of March, 1992)

AIDS Cases

218,000

152,253

AIDS Deaths

81   82   83   84   85   86   87   88   89   90   91   92

Figure 2.2: Total AIDS Cases in the U.S. this Decade

In contrast to these statistics, heart disease and

cancer claim over 434,000 people in a year.
    "Federal funding for AIDS research reached $1.6
    billion in 1990, a year after 40,000 Americans had
    died of the disease. At the same time, federal
    spending for cancer, which killed 500,000 in 1989 was
    $1.5 billion, and spending for heart disease, which
    killed 750,000, was less than $1 billion." (Wachter,
    1991, p. 82)

Costs of AIDS/HIV Growing

Economists have estimated that the total annual U.S.

costs associated with AIDS will surpass $65 billion by 1992,

1 to 1.5 million Americans are
estimated to be infected with HIV

**218,000 AMERICANS
diagnosed with AIDS**
(as of March, 1992)

54% or 117,720
WHITES

29% or 63,220
BLACKS

16% or 34,880
HISPANICS

1% or 2,180 OTHERS
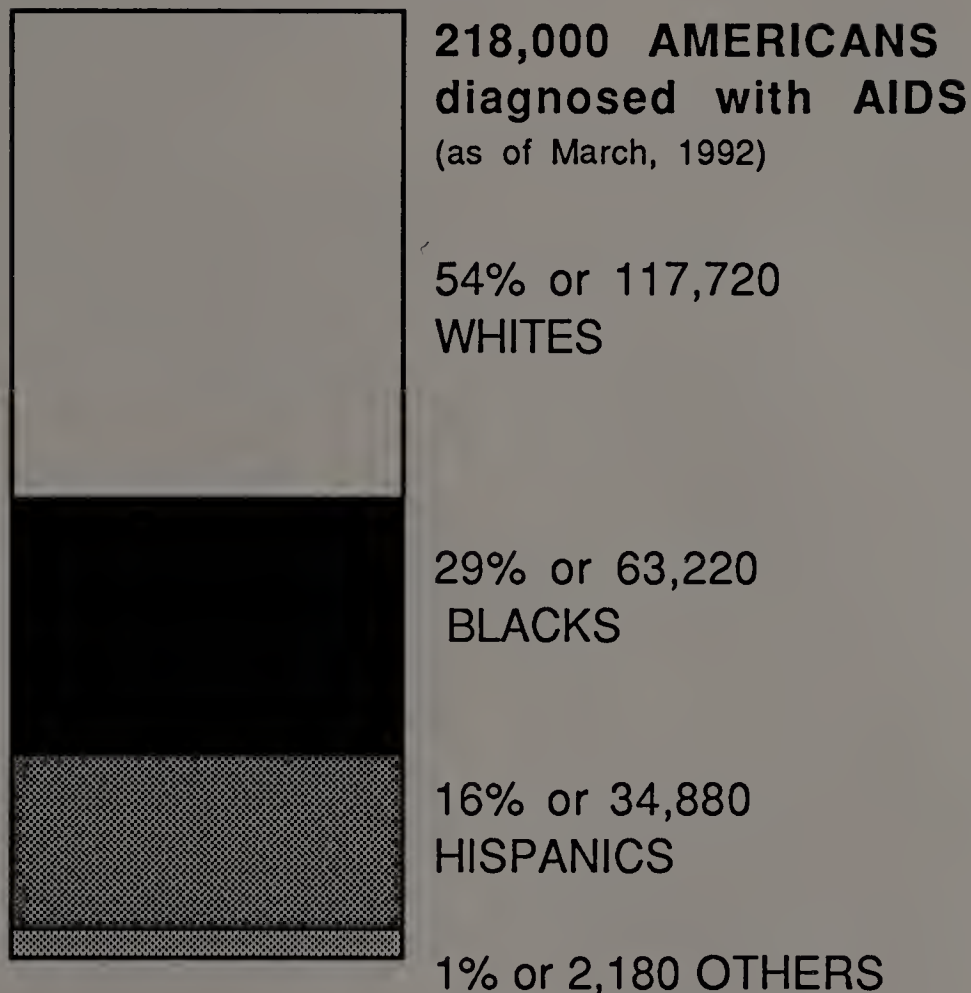
Adapted from *The Boston Globe,* Nov. 10, 1991

Figure 2.3: Racial Composition of AIDS Cases

up from $8.7 billion in 1986. (Klosinski, 1987) The cost of

treating people diagnosed with AIDS was approximately $5.8

billion in 1991. Fred Hellinger, director, Cost and

Financing, Agency for Health Care Policy and Research,

estimated that total costs for treating both those with AIDS

and those who are infected but lack symptoms will reach

$10.4 billion by 1994. (Woolsey, 1991, 2)

Most of the projected increase is due to additional AIDS cases, rather than rising medical costs. Hellinger projected 100,061 new cases will be diagnosed in 1993, compared with 68,698 in 1991. (Woolsey, 1991, 2)

Hospitalization accounts for 80-90% of the direct medical costs of treating HIV-related illness. Lifetime treatment costs for persons with AIDS range from $24,500 to $147,000 per patient. These costs vary because the presence of local support services and out-patient care reduces the overall cost of patient care. (Klosinski, 1987)

> The average "lifetime cost of treating an HIV infected person in the United States is $102,000 and means that it could cost more than $18.58 million just to provide care for the more than 178,000 American adults and children diagnosed as having AIDS." (Newsday, 1992, p. 7)

Because HIV-related illness strikes people within their prime working years, generally 20 to 45, significant productivity is lost dues to illness, disability, and premature death. In 1991, AIDS will account for 12% of all income lost due to illness; the annual costs of illness and death from AIDS will be over $55 billion in productivity. These costs do not include the costs of educational programs on either the corporate or federal level. (Klosinski, 1987)

According to a survey released in October of 1991 by the American Council of Life Insurers and the Health Insurance Association of America, U.S. life and health insurers paid an estimated $1.2 billion in AIDS-related life and health claims in 1990, compared with $1 billion in 1989. Group life claim payments rose 48% to $374.8 million in 1990

from $253 million in 1989, while group health claims

declined slightly to $439.7 million from $455 million.

Another $367.8 million involved life and health policies

purchased by individuals. (Woolsey, 1991, 2)

Costs Less Than Other Catastrophic Illness

"Early in the epidemic, experts predicted that
lifetime treatment costs for an average case would hit
$300,000. Now the consensus is that those treatment
costs average only about one-quarter of that, though
treatment costs in some cases can top $100,000."
(Woolsey, 1991, 5, p. 81)

Hellinger estimated that the average annual treatment

costs for AIDS is $30,000 with lifetime costs at $85,000.

Treating someone who is HIV positive costs about $5,000 per

year. This compares to other catastrophic illness as

follows:

Annual Treatment of Catastrophic Illness:

AIDS (annual cost)	$30,000
AIDS (total cost)	100,000
Lung Transplant	240,000
Liver Transplant	235,000
Heart Transplant	148,000
Pancreas Transplant	70,000
Kidney Transplant	51,000 (Woolsey, 1991, 5)

A Mature Epidemic

> Researchers now speak of a "mature" epidemic, or the "plateauing" of new cases and deaths, and of a pool of HIV-infected people that is in a "steady state."
>
> About 45,000 people will die of AIDS this year, Federal experts believe, and the toll will rise until it levels off at about 50,000 a year by 1994
>
> The CDC estimates, very roughly, that one million Americans are infected with HIV, the virus that causes insidious damage culminating in AIDS. And they believe that 40,000 to 80,000 are newly infected each year - about the same number who die. Hence, a "steady state." (Eckholm, 1992, P. E5)

Because it is a slow and new disease, knowing its future course is difficult. Little data exists in longitudinal studies of those infected. So the actual impact on the heterosexual community can only be guessed at from what we know about the rates and means of heterosexual transmission around the world. One thing is clear, if the rate of heterosexual transmission begins to increase in this country, the same risk-reduction behaviors will be necessary for that population as are necessary for the homosexual, bisexual and IV drug populations. The risk factors for heterosexually transmitted disease would parallel those behaviors of homosexuals: frequent sexual encounters with different partners; engaging in activities that permit semen, blood and body fluid exchange; and history of previous sexually transmitted diseases. (Kelly, 1988)

While 75% of the cases are spread through heterosexual activity in the world; 59% of the cases are spread by homosexual and bisexual activity in the United

States. Only 6% of the AIDS cases in the United States are spread by heterosexual activity, while 22% are spread through intravenous (IV) drug use. (See Figure 2.4)

Even though the disease is different in every country there are common factors between the disease and how societies respond to it. The perspective of Dr. Jonathan Mann, professor of epidemiology and international health at the Harvard School of Public Health may have meaning as we explore the epidemic in this country and relate to it on a world-wide basis. He said,

> Every country in the world has gone through the same basic phases, initially denying and minimizing the problem. Then something happens that raises awareness, a specific event or a specific person. The Rock Hudson story occurred in many countries - with some fashion people in Brazil, for instance, or the death of ex-president (Kenneth David) Kaunda's son in Zambia.
> The time from the first report of AIDS cases in a country to getting a national AIDS program under way has averaged two to four years, closer to four in most countries. You would hope, as we warned Asian countries...that this could be short-circuited.
> But what we are talking about is the transformation of scientific knowledge into public policy and social and political commitment.
> The bottom line is that it has not yet been possible to jump-start countries from doing virtually nothing to a tremendous amount of activity until certain things happen. (Foreman, 1991, p. 36)

What Factors Determine the Risk of Infection?

> AIDS has proven to be not only a lethal but an unusual disease, remaining much more highly contained within identifiable risk groups than most other viral infections owing to its narrow avenues of transmission. This is fortunate since it means that many persons are unlikely to be exposed to HIV or contract AIDS. (Kelly, 1988, p. 17)

The CDC has long recognized that AIDS can and does infect anyone in our society. Because of this, it uses the following categories to report AIDS:

Adults/Adolescents:	Children:
-homosexual/bisexual male	-Parents at risk for/has HIV/AIDS
-IV drug user	-Hemophilia
-Homosexual/bisexual IV drug user	-Transfusion
-Hemophiliac	-Undetermined
-Transfusion	-Heterosexual*

*Heterosexual cases include: men and women who have had heterosexual contact with a person with AIDS or at risk for AIDS and persons with/without other identified risks who where born in countries in which heterosexual transmission plays a major role (Georgia, 1990 p. 8)

Blood, semen, vaginal secretions and possibly breast milk are body fluids that carry significant amounts of the virus. The greatest concentration of HIV is found in blood and semen.

Direct blood-to-blood contact is the most risky form of contact between two people because virus enters the bloodstream immediately. Semen-to-blood contact is the next riskiest route, by either vaginal or anal intercourse. Women can pass the virus through infected vaginal fluids to their sexual partners, although there appears to be less risk. Oral sex may provide a route for transmission via mucous

membranes in the mouth or small cuts, such as those created by routine tooth brushing. (Georgia, 1988)

HIV is both a sexually transmitted and blood-borne virus. According to the CDC (1985), it is transmitted by the following means:

1. Sexual intercourse (vaginal, anal and possibly oral) with an infected person: male to male; male to female; female to male; female to female (possible)

2. Parenteral (direct contact with the bloodstream):

a. Sharing IV drug paraphernalia with an infected person:

Sharing an IV needle with an infected person can inject the virus directly into the user's bloodstream.

b. Transfusion of contaminated blood or blood products:

Since 1985, this method of transmission has been greatly reduced by screening of the nation's blood supply for HIV antibodies. This transmission method also applied in the past to persons with hemophilia who used blood products made from the blood of other people. All blood products are now heat treated to eliminate the risk of HIV infection.c. Occupational exposure: Less that 1/2 of 1% of health care workers who have been exposed to infected blood/body fluids on the job have become infected. Accidental needlesticks are the primary way that health care workers become infected. (Georgia, 1990)

Due to increased risk of exposure and fear of contagion within the health care workplace, the CDC conducted specific studies of the spread of HIV infection on those who work in that environment. These studies indicated a low level of risk of contagion, about .05% following high risk exposures.

While this is the only work environment with significant risk of contagion at the workplace, by knowing the means of transmission and how difficult the virus is to transmit in the workplace, workers in other environments may feel safer working with or for a person infected with HIV.

While it is not relevant to the subject of this paper to explore in depth the notion and practice of "Universal Precautions," the CDC encourages that all health care workers respond to all patients as if they are infected. The same advice is given to all individuals in relation to choosing and relating to their sexual partners.

HIV Positive Versus AIDS

HIV infection and AIDS are related to one another but indicate two distinct levels and types of illness. The recent diagnosis of Magic Johnson as HIV positive has increased public awareness of the differences between the two. That difference can be briefly defined in the following ways:

HIV positive indicates:

-The HIV screening test has shown the presence of
the body's defense to the HIV virus by the creation of
virus-killing antibodies;

The World   U.S.A.

25%		59%
All other causes		Homosexual contact
75%		22%
Heterosexual contact		IV Drug use
		7%
6%		
7%		

IV Drug use among homosexual men

Heterosexual contact

Hemophiliacs, transfusions, other
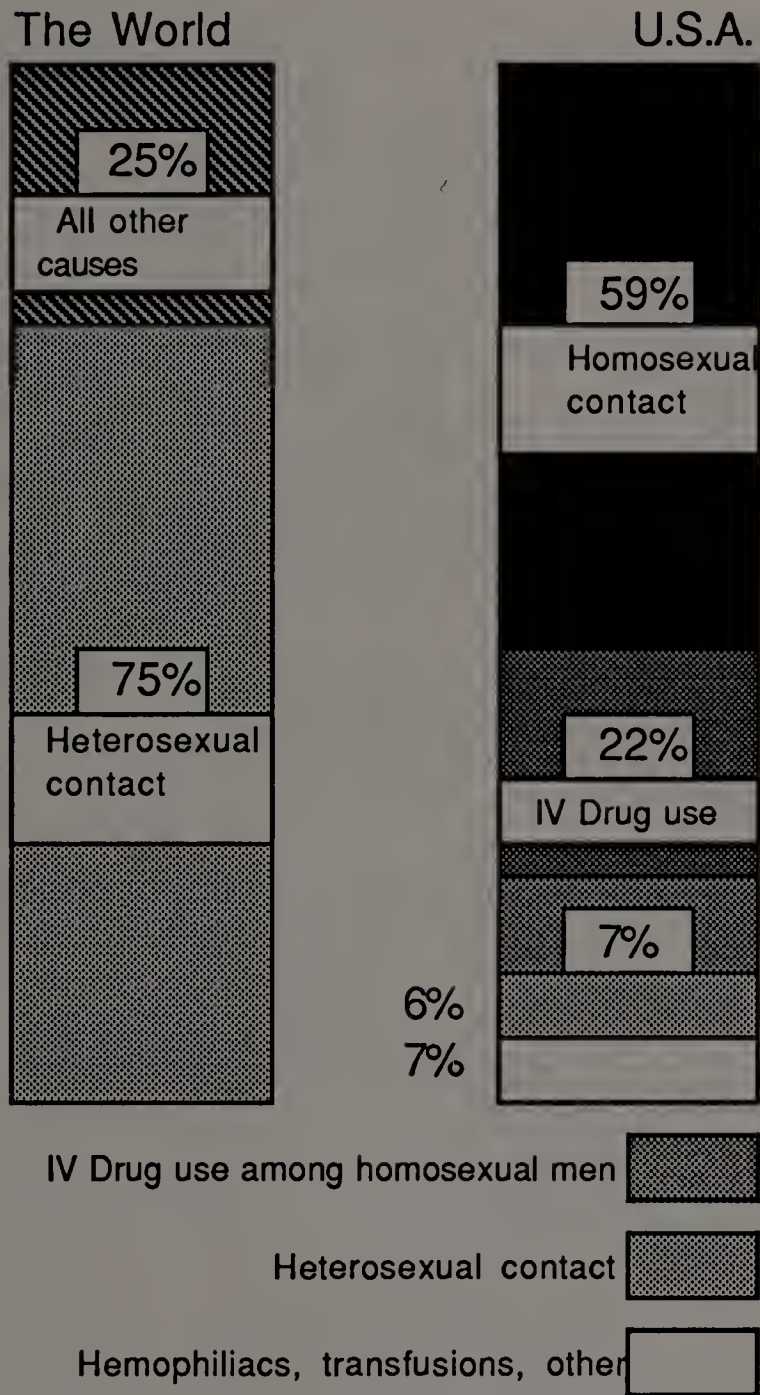
Adapted from *The Boston Globe*, November 25, 1991

Figure 2.4: Causes of HIV Spread

-A person is infected with the human
immunodeficiency virus, the virus that causes the
development of AIDS;

-An HIV positive person can pass the virus on to
another person through identified behaviors;

-Additional tests can help determine how well the
immune system is working and whether medication is
appropriate;

-A person who is HIV positive may be healthy and
productive for years, showing no signs of illness;

-A positive test result does not mean a person has
AIDS, but everyone with AIDS is HIV positive.

Having AIDS means:

-A person is infected with the HIV virus;

-The body's immune system is weakened by the
disease;

-The person is suffering from an opportunistic
disease, usually a rare cancer or pneumonia;

-50% of those who become HIV positive progress to
AIDS within 10 - 14 years;

-People with AIDS survive a median of 2 to 2 and
1/2 years;

-Rare opportunistic diseases are usually the cause
of death, not HIV itself.

Description of Symptomatic HIV Infection

Within the range of HIV infection, AIDS is "the tip of the iceberg."

The progression of the disease includes first, the seroconversion of the individual: he or she has created antibodies to the virus. This usually happens within six months of infection in most people. Then the virus goes into incubation and the status of the individual is classified as "HIV-positive but asymptomatic." This condition can last varying lengths of times in different people, up to about 14 years. (Kelly, 1988)

The next stage of the disease is a condition referred to as "HIV-related symptomatic illness" (formerly known as AIDS Related Complex - ARC). Persons with symptomatic illness also have a suppressed immune system and may have some of the same signs and symptoms as a person with AIDS. The difference between the two is that a symptomatic person has not been diagnosed with an opportunistic infection: cancer, pneumonia, wasting syndrome, tuberculosis, salmonella or dementia. (Winiarski, 1991)

Like persons with AIDS, people who are symptomatic may be able to function at different levels at difference times. The effect that HIV has on individuals varies. Persons with symptoms progress to AIDS at varying rates. (See Figure 2.5)

Description of AIDS

AIDS is a syndrome which means it includes a range of signs and symptoms of disease. There are three components to a diagnosis of AIDS. They include:

1. identification of an opportunistic disease;

2. establishment of cellular immune deficiency, either by clinical laboratory tests or by the presence of a disease associated with immonosuppression; and

3. ruling out alternative factors that might cause immune deficiency, such a lymphoma, leukemia, congenital immunodeficiency, or a history of steroid or other immunosuppresive therapies. (Kelly, 1988)

Pneumocystic pneumonia is diagnosed in about 60% of the AIDS cases reported to the CDC. Other commonly occurring diseases include: Kaposi's sarcoma (skin lesions), Cytomegalovirus (damage to eyes), Herpes, Epstein-Barr virus (fever, fatigue) Mycobacterium (wasting, fatigue, fever), and dementia. (Kelly, 1988)

Psycho-social Aspects of AIDS

Health and well being are not just matters of paying attention to our bodies. Overall wellness includes many physical, social, psychological and economic factors. Some of these include lifestyle habits, quality of family life, friends, loved ones, self-worth, work and financial

resources. These factors have an impact on people regardless of HIV status. Being responsive to these needs, may be critical to creating effective responses to HIV infection.

However, HIV infected people wanting support from friends, loved ones or co-workers often find themselves rejected and socially isolated. Adding to the pressure of the disease is the potential loss of job, medical insurance and financial resources.

And so, to effectively combat this disease, increased public awareness is critical. Whether an individual has tested positive for the virus or not, people must begin to shift behavior to practice safer sex and responsible IV drug use (clean needles) to prevent the spread of infection. Knowing more about the reality of the disease and its spread can improve relations between those with and those without the infection.

Once a person knows he or she is positive, we have to be able to respond to the psychological and emotional needs that will arise with that knowledge. The responses of persons with AIDS to their illness is similar to that of people with other life-threatening illness. People usually go through the five emotional stages of dying described by Kubler-Ross (1988):

  1. denial and isolation,

  2. anger,

  3. bargaining,

  4. depression , and

5. acceptance.

The order of the stages may vary, and sometimes overlap, but they are usually experienced.

Other emotional problems this researcher has seen people face after a diagnosis of HIV infection or AIDS have included:

-Loss of self-esteem;

-Fear of discrimination;

-Fear of dementia;

-Self-blame concerning the means of transmission;

-Loss of control over one's life plans.

-Loss of financial independence; and

-Inability to support and care for oneself.

The workplace has a unique role in responding to the psychological needs of employees with HIV/AIDS. These needs can include:
    -Referral to both psychological and medical help.
    Early intervention can be important in prolonging
    life, according to doctors. The company's ability to
    facilitate such a referral at the earliest date can
    clearly make a difference in the person's workplace
    productivity and in the quality of care provided
    -Familiarity with benefits provisions: health
    insurance coverage, life insurance, leaves of absence,
    disability. Of course, the majority of these persons
    may not develop debilitating symptoms. There is,
    however, comfort in knowing what provisions are
    available.
    -Other personal support: access to legal advice
    (wills), child care provisions, financial planning,
    and other family-related matters.
    -Educational support for co-workers: if it becomes
    known that the person is carrying the virus, or should
    rumors to that effect begin to circulate. (Bohl, 1988,
    p. 17)

"Incubation Period"		
"Window Period"		**AIDS**
Usually from six to twelve weeks after infection	Time frame varies from a few months to up to 14 years after infection	Usually occurs 10 to 14 years after infection
May include temporary flu-like symptoms upon infection	May include no symptoms of HIV infection or may include development of symptomatic HIV infection	Increasing illness and disabilities associated with AIDS
HIV Infection	Positive Antibody Test	AIDS Diagnosis Death

Source: Georgia Department of Health, 1990

Figure 2.5: Progression of HIV Illness

49

AIDS as a Disability

In addition to these response, business is also obligated by law to respond to the reality of AIDS as a disability.

In 1990, the U.S. Congress included AIDS as a disease specifically covered under the Americans with Disability Act (ADA). This act guarantees all people access to employment, public accommodations, transportation, public services and telecommunications. Signed into law on July 26, 1990 by President Bush, the new law took effect two years after being signed. (July 26, 1992)

Because of the scope of the law, it has the potential to have a large impact on the way business responds to both individuals with HIV infection or AIDS and the disease in general. The full effect of the law will become known only as court cases illuminate interpretations and applications over the next few years.

The need for legal protection for those with HIV/AIDS is very real. The American Civil Liberties Union reported that even in today's more informed environment, news of or fears in relation to AIDS prevents infected people from obtaining housing, employment, insurance coverage and medical care. This negative bias appears to be increasing as there were fewer than 400 cases of discrimination filed in 1984. This figure had risen to over 92,500 by 1988, with 37% employment related. (West, 1991)

Some of this discrimination may be based on the background or lifestyle of those within the high-risk populations for AIDS: gay men and IV drug users. Other forms of discrimination are a result of fear or lack of understanding of the disease and how it is spread. Whatever the cause, people with HIV/AIDS are being discriminated against and it is no longer legal.

Discrimination is not unprecedented in this country, nor is legal protection from it. This country's biggest example of a social/political response to discrimination is the Civil Rights Act of 1964. This law extended protection to people against discrimination because of race, sex, national origin, color or religion. Just as discrimination against people for these reasons is real and creates the need for legal protection of constitutional rights, so too is the need for protection of rights for those with disabilities, of which HIV/AIDS is included. The National Council on Disability pointed to the fact that discrimination is real for those with disabilities in areas of employment, transportation and public accommodations. They reported that existing laws were not sufficient to protect the basic rights of those with disabilities. (Thompson, February 1992) Despite prior legislation to prevent discrimination against people with disabilities, including the 1968 Architectural Barriers Act and the 1973 Rehabilitation Act, the actual number of people with disabilities who were employed has fallen from 1970 to 1985.

(See Table 2.1) The following graph depicts the decrease in
employment. (See Figure 2.6) This drop is in light of the
fact that 66% of those who are disabled report they want to
work and only one-third are working. (Keye Productivity
Center, 1991)

Discrimination Parallel for Those with HIV/AIDS

The reality of discrimination against those with
disabilities is parallel to those with AIDS/HIV. In a survey
by *Crain's New York Business* in 1988, 40% of the employers
in New York City, said they would not or were unsure if they
would allow a non-symptomatic worker with AIDS to remain on
the job. 68% of the respondents were either negative or
unsure if they would retain an employee with symptoms.
(Bayless, 1989)

Even though this survey was conducted before the ADA
extended legal protection to PWAs, New York City and State
already had laws protecting the right to employment of those
able to perform their responsibilities regardless of HIV
status.

In that same survey, only 42% of employers thought that AIDS
should be considered a medical handicap and only 6% of
employers preferred to keep those with AIDS at full pay with
benefits if she or he did not return to work. 34% reported
they would do so for someone in the last stages of cancer or
emphysema. (Bayless, 1989)

Table 2.1 Employment Discrimination Against the Disabled

	Total employment	Males	Females
1970	4,938	3,592	1,346
1980	4,505	3,055	1,540
1985	3,847	2,353	1,494

Hunter (1990) found in the first national survey of AIDS discrimination that 260 agencies responding to the survey reported 13,000 complaints between 1983 and 1988, increasing by 50% from 1987 to 1988. 30% of those reporting discrimination were those who cared for someone with HIV/AIDS or were perceived to be HIV positive. (See Figure 2.7)

The substance of the discrimination was focused by more than 30% of the respondents on insurance, housing, access to government programs or health care.

Hunter concluded that there were three primary causes of the discrimination:

1. Ignorance about how HIV is transmitted created irrational fears of contagion.

> Although no workplace transmission of the virus has ever been documented outside the health care setting, and in spite of the scientifically recognized conclusion that, as the American Public Health Association has stated, 'HIV is not transmitted through casual contact, animals, blood donation, food, inanimate objects, insects, saliva, skin, vaccines or waste,' medically unjustified firings, evictions, and denials of service remain common. (Hunter, 1990, p. 2)
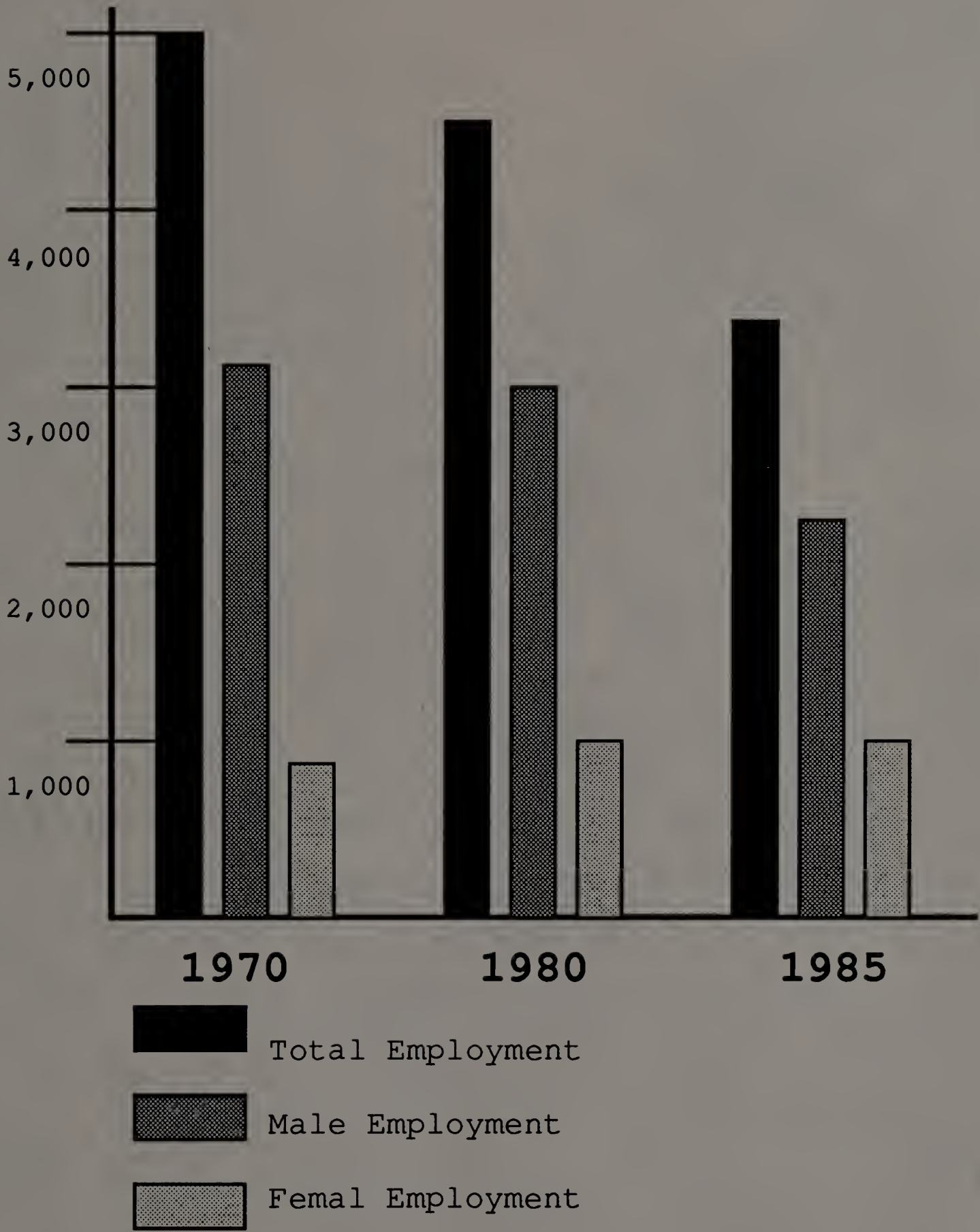
Adapted from Keye Productivity Center, Not dated

Figure 2.6: Employment of People with Disabilities

54

2. The stigma attached to any association with HIV
illness is a strong motivation. This is tied to racial and
anti-gay prejudice, Hunter pointed out.

3. Economics played a key role as well.
Insurance companies, doctors, dentists, nursing homes,
landlords and employers discriminate against those
with HIV disease based on the perception that future
payments or fees may not be met, that productivity may
diminish, or that care costs will be too high.
(Hunter, 1990, p. 2)

Employment

37%

Housing

16.4%

Public
Accommodation

15.6%

Health Care

5%

Government
Services

9.9%

Insurance

13.3%

Violence

2.9%
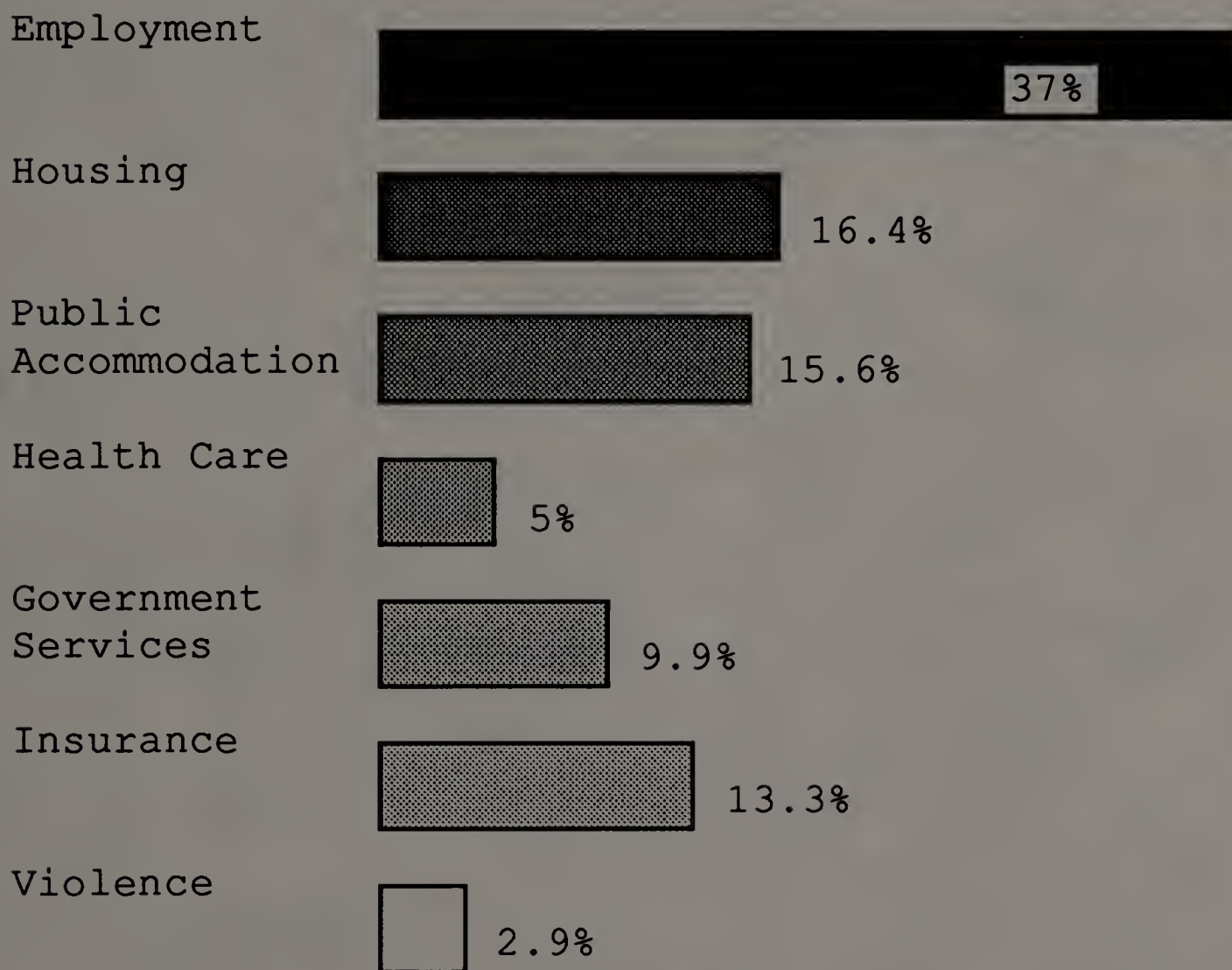
Adapted from Hunter, 1990

Figure 2.7: Discrimination Cases Filed

Hunter said that the fear of discrimination deters

people from being tested and treated and that the fear

attached to working with people with the disease prevents

cooperation and preventive programs. She pointed to the

Presidential Commission on AIDS report that said
> HIV discrimination is impairing this nation's ability
> to limit the spread of the epidemic... (Hunter, 1990,
> p. 3)

Discrimination against people with HIV/AIDS is thus

well documented. As the numbers of people with the disease

increases and as the number of blacks and Hispanics (people

less likely to process legal complaints) with AIDS/HIV

increases, tension will likely grow between those with unmet

legal rights and those who pay the concomitant costs of

responding to those needs.

Even in the area of health care, discrimination is a

real phenomenon for people who are HIV infected. A recent

survey of physicians by the American Medical Association

indicated that 50% of them would prefer not to work with HIV

infected people and 48% would prefer to refer those patients

to another practitioner. (*Men's Fitness,* 1991) 55% of health

care workers in general reported severe distress and 35%

reported moderate stress due to AIDS in their workplace.

(Schoeman, 1991)

> Money will play an increasing role in defining
> the scope and degree of future HIV/AIDS
> discrimination. As the number of HIV-infected persons
> rises to more than a million by 1992, insurers,
> employers, health care providers and others may
> increasingly attempt to cut costs through
> discrimination. Our results indicate that forms of
> discrimination are likely to become more subtle and
> preemptive as time goes on. (Hunter, 1990, p. 46)

The problem is worsened by the fact that people with

HIV/AIDS will be living longer and so subject to more

discrimination. Even though the ADA provides added

56

protection for individuals, perceptions of illness or the

likelihood of such may result in closed doors for those

seeking employment or medical treatment.

The Americans With Disabilities Act - 1990

Hailed as the most comprehensive civil rights
legislation since the Civil Rights Act of 1964, the
new law was welcomed with a party on the White House
grounds. The various speeches made on that day had
one unifying message: that barriers to disabled
people's full enjoyment of employment opportunities
and of the rich array of activities offered by our
communities must fall. (Kaplan, 1991, p. 2)

The ADA "provides a clear and comprehensive national
mandate to end discrimination against people with
disabilities. It extends civil rights protections to
more than 43 million people in areas of private and
public sector employment (Title I), public services
(Title II), public accommodations - all businesses and
service providers, new construction, and public
transportation by private entities - (Title III),
telecommunications (Title IV), and miscellaneous
(Title V)." (Williams, 1992, p. 42)

Title I of the Act focuses on employment. Employers

with more than 25 employees are covered by the Act effective

July 26, 1992. Two years later, July 26, 1994, the Act will

become law for employers with more than 15 employees.

(Williams, 1992)

An individual with a disability is defined within the

act to be any person who:

-1. Has a physical or mental impairment that
substantially limits one or more major life
activities (i.e., caring for one's self, performing
manual tasks, walking, seeing, hearing, speaking,
breathing, learning and working);
-2. Has a record of such an impairment (has a
history of, or has been misclassified as having a

mental or physical impairment that substantially
limits one or more major life activities);
   -3. Is regarded as having such an
impairment.(Warren, 1991, p. S4A-4)

   The law specifically includes those with HIV infection

who do not represent a direct threat to the health and well-

being of others.

   While much of the language of the ADA comes verbatim

from section 504 of the Rehabilitation Act, it also adds new

language. And, even though the ADA is based on existing law,

it does not supplant or supersede either federal or state

laws covering discrimination against individuals with

disabilities. The ADA specifically states that nothing in

the law can be construed to limit or reduce the coverage of

other state or federal laws, including the Rehabilitation

Act. (Thompson, 1990)

   In the new language of the act, the two areas of

"substantial limitation" and that of being "regarded as

having an impairment" are defined and specifically

protected. Other new language eliminates the need for

affirmative action programs by employers.

      The agency states that "substantially limits" means
      significantly restricted in the ability to perform a
      group of jobs as compared with the average person
      with similar training, skills, and abilities. The
      agency also notes in this definition that a person's
      inability to perform a particular job is not
      substantial limitation on the major life activity of
      working. The section on "regarded as having an
      impairment" states that a person is covered by the
      law if he or she (1) has an impairment that does not
      limit a major life activity, but is treated as
      though it does; (2) has an impairment that limits

58

working only because of the attitudes of others; or
(3) has no impairment but is treated as having one.

In response to concerns expressed by employers about
the way that the interaction of these sections might
unreasonably broaden the statue's coverage, the EEOC
has, in its appendix to the regulations, clarified
the third prong of "regarded as having a
disability." that is, if the employer cannot
articulate a non-discriminatory reason for the
employment action, an inference can be drawn that
the employer is acting on the basis of myth, fear,
or stereotype. This clarification should protect
employers who make selection decisions based on the
inability of a person to meet a physical requirement
of a job. (Warren, 1991, p. S4A-20)

In regard to affirmative action programs, the ADA

specifically stated that affirmative action programs are not

required. However, for those companies/organizations

required by the Rehabilitation Act to develop affirmative

action plans, those requirements continue. This is possible

because language in the ADA states that it does not replace

that in the Rehabilitation Act. (Kaplan, 1991)

Title I also added protection to qualified non-

disabled individuals who are related to or associated with a

disabled person. This expansion on section 504 protections

made it illegal for an employer to deny employment to a

qualified individual because of association with a disabled

individual. (Thompson, 1991) This protects those who care

for or are in relations with someone with HIV/AIDS.

In the area of health insurance, the ADA specifically

requires employers to provide equal benefits to disabled

employees that are provided for non-disabled employees. This

policy extends to pre-existing conditions clauses even

though they have a disparate impact on individuals with disabilities. (Thompson, 1991)

EEOC to Interpret ADA

The regulations used to enact Title I were developed by the Equal Employment Opportunity Commission (EEOC), the same government agency that interpreted the Civil Rights Act.

The ADA requires that :

> No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment. (Kaplan, 1991, p. 4)

According to Kaplan (1991), because the nature of each person's disability is unique in each work environment, it becomes the responsibility of the employer with the employee to consider employability and reasonable accommodation on a case-by-case basis. This is supported by the EEOC's finding that

> where that individual's functional limitation impedes such job performance, an employer must take steps to reasonably accommodate, and thus help overcome the particular impediment unless to do so would impose an undue hardship. Such accommodations usually take the form of adjustments to the way a job customarily is performed, or to the work environment itself. (Kaplan, 1991, p. 4)

In relation to employment, the ADA protects people from discrimination in the full range of employment activities, including:

-job application and recruiting procedures;

-hiring and discharge;

-employee compensation and fringe benefits;

-job assignment;

-advancement;

-annual and sick leave (or other types of leave);

-job training;

-social and recreational activities; and

-other terms, conditions and privileges of employment.

The law requires that people with disabilities receive the same protection and rights of other workers.

> It mandates that employers clearly justify the use of any employment standard, criterion or job description that tends to exclude or adversely affect disabled workers. (Nau, 1991, p. 9)

Because so much language in the ADA came from the Rehabilitation Act, understanding of terminology and of the court's interpretation of the same can be known to us from past rulings. Key concepts imported from the Rehabilitation Act include "reasonable accommodation," "undue hardship," "essential functions," and "qualified individual."

Important protection offered by the Act to people with HIV/AIDS is in the category of reasonable accommodation. The law states that an individual with a disability is protected from discrimination in employment if "with or without reasonable accommodation," that person can perform the essential functions of the employment position that he or she holds or desires. (Thompson, 1990)

The House Education and Labor Committee report on the ADA noted that the law is premised on:

> the obligation of employers to consider people with disabilities as individuals and to avoid prejudging what an applicant can or cannot do on the basis of that individual's appearance or any other easily identifiable characteristic, or on a preconceived and often erroneous judgment about an individual's capabilities based on "labeling" of that person as having a particular kind of disability. (Thompson, 1990, p. 28)

A subsection of reasonable accommodation that is most relevant to people with HIV/AIDS calls for the employers to restructure jobs, modify work schedule such as part-time, allow time for medical visits, or reassign an employee to a vacant position. It is a form of affirmative action in that it requires employers to insure individuals with disabilities the same rights as those without disabilities. (Kaplan, 1991)

Employers generally do not have to offer an individual with disabilities another job as part of reasonable

accommodation, according to court rulings, unless it is a general company policy. (Warren, 1991)

Job restructuring may however be an option the company can use. It involves the identification of non-essential functions of the job and attempting to eliminate them. The process of doing such, as outlined by the EEOC, includes the following four steps:

> 1. analyze the particular job function involved and determine its purpose and essential functions;
> 2. consult with the individual to find out how his or her disability limits job functions and how the limitations can be overcome with an accommodation;
> 3. identify possible accommodations and assess their effectiveness in helping the person perform the essential functions of the job; and
> 4. consider the employee's preferences and then select the most appropriate accommodation for both employer and the employee. (Thompson, 1991, p. 67)

Nau (1991) pointed out that this issue may become difficult for employers because of two key elements: sick leave and leaves of absence for those with HIV/AIDS. Anyone familiar with the medical progression of HIV infection knows that there are intermittent bouts of illness and wellness. The new law indicates that employers will have to leave positions available for people with AIDS to return to after a sick leave.

On a more day-to-day basis, time off from work for the various medical exams, blood tests, and perhaps clinical trials that people with AIDS participate in will create a change in normal work schedules for many employees.

Essential Functions

EEOC regulations that detail how employers are to determine essential functions of a job include:

1. the employer's judgment as to which functions are essential;
2. written job descriptions prepared before advertising or interviewing applicants for a job;
3. the amount of time spent performing the function;
4. the consequences of not requiring an incumbent to perform the function;
5. the terms of a collective bargaining agreement;
6. work experience of past incumbents in the job; and
7. current work experience of incumbents in similar jobs. (Thompson, 1991, p. 27)

Undue Hardship

Exceptions to the "reasonable accommodation" clause can be made for employers who can show that such accommodations will cause an "undue hardship" on them. Factors that contribute to this include the size of the employer, the cost of the accommodation, the financial resources of the employer and the impact of the accommodation on the employer and facility. (Thompson, 1991)

The employer must also present factual evidence that the accommodation will create undue hardship, not merely assert the fact. The burden of proof is on the employer. (Kaplan, 1991)

Testing and Medical Documentation

Another area of protection the Act will offer to those with HIV/AIDS is in the area of testing for HIV and in disclosure of medical records.

The ADA prohibits employers from asking applicants about medical status or requiring a pre-employment physical. Also prohibited are questions pertaining to past disabilities or predisposition to disabilities. Even where a disability may be apparent, the employer cannot make inquiries of the nature or extent of the disability. The employer can ask if the person will be able to perform the duties required in the position. (Kaplan, 1991)

Medical examinations are allowed only after an employee has been offered a position and must meet the following ADA criteria:

> 1. The examination is required of all entering employees in that job classification, regardless of disability;
> 2. Information gathered from the exam is treated as a confidential medical record; and
> 3. The results of the examination are used only in accordance with the ADA. (Warren, 1991, p. S4A-23)

Employers can conduct medical examinations of current employees only if there is an objective need for the information in relation to business necessity.

The use and distribution of medical records is protected and release of records requires written consent from the employee.

One challenge to employers will be the potential invisibility of HIV/AIDS as a disability. If an employee does not self-disclose, an employer may not know of the illness. Many people who are HIV positive or even with AIDS, are still healthy appearing, fairly fully functioning members of the work force. Yet, the employer will carry some if not most of the burden of fair treatment even without knowledge of the illness. This is one area where court interpretation will probably have a large impact on both employee and employer behavior and requirements.

> While the law generally will not penalize some action by an employer that did not take into account the disability status of someone who had not disclosed his or her status to the employer, a 'known or should-have-known' standard has often been applied in the area of disability rights. Further, employees' recollections of what they have and have not told their employer sometimes change once an active litigation is commenced. (Nau, 1991, p. 10)

What this will mean is that employers will have to make extra efforts to communicate with and educate employees about their policies in relations to AIDS. Clarification of the procedures for disclosure and the confidentiality of that information will have to be written and distributed.

A "landmark decision" in Massachusetts resulted in the award of $30,000 to the estate of a Boston hotel waiter who claimed that his employer discriminated against him because of the perception of his having AIDS. (Wong, 1992, p. 25)

66

"This decision means that employers can no longer mask discrimination with feigned ignorance. It is no longer sufficient to say they were never notified," (Wong, 1992, p. 29) a director of the Gay and Lesbian Advocates and Defenders' AIDS Law Project said.

The Boston Globe article pointed out the fact that even though the employer did not receive explicit information from the person that he had AIDS, in firing this person, the hotel violated his civil rights under the ADA and Boston laws. (Wong, 1992)

While this law will provide protection for the person with AIDS/HIV, it will increase the burden on employers to educate co-workers. In cases where an employee discloses HIV/AIDS status, the employer will not be able to "segregate the employee or perpetuate the discrimination of others." (Nau, 1991, p. 10)

Financial Risks for Employers

While litigation will help clarify the ADA and its implementation, it will most likely also put the employer at risk financially. With the appearance of court cases, it will probably not be long before court decisions award punitive damages for those employees who are discriminated against for reasons of disability.

Recent press coverage in *The Boston Globe* indicated that two related issues developed recently, each with financial costs to companies. The first was that a new contract with nurses at Brigham and Women's Hospital in

Boston which included a provision for the guarantee of $100,000 in disability insurance for nurses infected with the HIV virus in the course of their work. (Lewis, 1992, 1, p. 1) The second article reported on the court awarding $157 million to a sex-bias suit filed in June, 1979. In the class-action suit expected to cost State Farm Insurance Companies over $200 million by the time all payments are made, women claimed discrimination in employment practices based on gender. They all were denied access to sales jobs for no other apparent reason except their gender. It is the largest award ever won based on protection offered through the Civil Rights Act of 1964. The Equal Employment Opportunity Commission filed the claim. (Lokken, 1992, p. 2)

Again, at this point in time, considering the newness of the law and its implementation, it is hard to predict the financial impact it will on employers. However, another area of business that will be impacted in a more predictable way is that of benefits and their costs.

> A bill filed in Massachusetts
> would establish a presumption that a health-care
> worker who becomes HIV positive after reporting a
> work-related exposure was infected on the job. "This
> bill guarantees that all health care workers who
> contract AIDS because of job-related contact will be
> protected beyond workers' compensation," an aide to a
> state senator said. Under the bill, hospitals and
> other health institutions would be required to provide
> $500,000 in disability insurance to an infected worker
> as well as life insurance equal to twice the workers'
> most recent salary. (Lewis, 1992, 2, p. 11)

The ADA appears to protect those with HIV/AIDS from suffering under caps that some employers now put on benefit payments. Yet there is some debate, which will probably

continue on into the future. According to Woolsey, (1991-1, p. 83) the law may effectively prohibit both large benefit systems as well as self-insured systems from setting caps.

However, she pointed out that

some courts, though, have ruled that self-insured plans may have more leeway than insured plans to restrict health benefits for people with AIDS. (Woolsey, 1991-1, p. 83).

Self-insured plans are directly sponsored by the company, usually have less resources than other plans and the notion of "undue hardship" may make the exception allowable. Insured plans are larger and usually contracted through a vendor such as Blue Cross, etc.

"Undue hardship" would allow employers to be exempted from the policies of the ADA if the costs of treating a person with AIDS places the company in economic hardship. The company will have the burden of proof in this matter however. And, interpretation of what this will mean to employers and people with AIDS will be determined by the actions and decisions of the courts.

Considering the fact that most people who are affected by this disease are in their prime work years and have been previously healthy, this disease will impact business like other disabilities do not. Most people who currently have the infection are probably already employed somewhere. In the future, more job applicants will be HIV positive.

Employers are expressly barred by the ADA from using testing as a means of screening out potential new employees who are HIV positive.

Under the ADA, employers may require employee physicals only if the exams are clearly job-specific and consistent with business necessity and then only after an offer of employment has been made to a job applicant. (Nau, 1991, p. 9)

This means that employers can give physical exams to new hires, after they are hired, but can only use the information gained to inform them about the person's ability to perform in direct relation to their job. The exam must be justifiable for business reasons and must be given to all employees performing the same types of work.

The results of the exam must also be maintained in separate and confidential files.

If confidential employee medical information is leaked to co-workers, employers could be charged with breach of confidentiality. (Woolsey, 1991-1, p. 83)

So, the risk an employer incurs by having taken on the responsibility to maintain the confidentiality of employees' records may outweigh any benefits.

Business Cautious of Confidentiality of Records

The Fortune Magazine/Allstate Insurance survey (Lieberman, 1988) reported that most executives 60% do not wish to learn whether current or prospective employees have been exposed to HIV. Rationale against testing included:

-Testing will not provide any information related to an employee's ability to perform a job as it is not diagnostic or any physical or mental impairment.

-Several states have enacted legislation either
banning or limiting testing of employees.
-Under handicap discrimination statutes, employers
in states where no bans/limits have been place on
testing could test employees only if they could
demonstrate a link between test result and job
qualifications - rather unlikely due to test's lack
of diagnostic abilities.
-Testing could be viewed as a violation of state
common-law prohibiting unreasonable intrusion into
another person's affairs.
-Under the Employment Retirement Income Security
Act (ERISA), an employer may not fire employees to
avoid access to a benefit plan. This law could
potentially be applied if an employer fires an
individual that is known by the employer to be
infected with HIV.
-Knowledge of am employee's antibody status could
potentially enhance the employer's liability in the
extremely unlikely event of workplace transmission.
(Lieberman, 1988, p. 69)

While many states have enacted laws to protect the

privacy of individuals with HIV infection, two examples

include Massachusetts and Rhode Island. In Massachusetts,

doctors, health care providers and facilities must obtain

written, informed consent before conducting any AIDS

testing. Employers may not require HIV-antibody tests as a

condition of employment.

In Rhode Island, the Prevention and Suppression of

Contagious Diseases Act, includes provisions on AIDS

testing, confidentiality, and employment discrimination.

Testing for AIDS requires informed written consent and may

not be used as a condition of employment unless there is a

"clear and present danger" of HIV virus transmission to

others. An employer may not discriminate against a person on

the basis of an HIV-positive test result or the perception

thereof. (Schachter, 1989)

All states and the federal government require that the names of AIDS patients be reported to health authorities. However, there is growing recognition that employees' medical records should be kept confidential and not disclosed to a third party without the affected employee's consent. This requirement is embedded in a number of state statutes. These statutes make it unlawful for employers to disclose medical information about an employee without the written authorization of the employee involved, except in very limited circumstances. One such exception permits disclosure for the purpose of administering and maintaining employee benefit plans. (Schachter,1989)

As is the case with any protected status, no explicit questions can be asked of any candidate regarding that status. So questions asked during an interview about HIV/AIDS status are clearly illegal.

A large financial award resulted in a Pennsylvania federal court ruling in 1990. This case was the first time that a court defined AIDS as a non-job-related disability covered by that state's Human Relations Act. In that case, a regional partner of Hyatt Legal Services was awarded $158,000 in damages after he was fired in 1987 shortly after he had disclosed that he had AIDS. (Woolsey, 1991-1)

On the other hand, employers can also face liability suits under worker compensation laws for transmission of HIV in the workplace or even the stress created for co-workers in relation to the disease. (Woolsey, 1991-1)

Co-Workers' Concerns and Rights

This is also an area of great concern for employers. The Fortune/Allstate survey showed that 22% of executives thought that co-workers of someone with HIV infection would refuse to work alongside such an individual. (Lieberman, 1988). Legal guidance in this area can be found primarily under two Federal Laws:

-The Occupational and Safety and Hazard Act (OSHA) protects employees who refuse to work only if the employees reasonably believe there is a real danger to their health.

-The National Labor Relation Act (NLRA) protects employees who engage in "concerted activity" (joint action of two or more workers) related to terms/contract of employment - a complaint or other activity is therefore potentially protected from disciplinary actions on part of the employer.

However, based on current medical evidence related to HIV transmission, it is unlikely for co-workers to prove refusal to work with someone with HIV is protected under either act.

The HIV Virus: Impact on the Workplace

AIDS is one of the most serious health problems facing America today. Measured in terms of actual and potential costs, and in human suffering, AIDS challenges every sector of society. It calls for bold, innovative responses. It demands leadership as the nation mobilizes its resources. AIDS presents

opportunities as well as challenges, especially for
business and labor. It may challenge our ability to
do business. But we can meet this challenge by
actively dealing with AIDS as a workplace issue.
AIDS also offers us an opportunity to fulfill an
important civic responsibility. We can serve the
public interest by sponsoring education, mobilizing
communities, supporting AIDS services and programs
and actively contributing to the nation's response.
Finally, AIDS is a call for leadership in a time of
crisis.

Some companies remain on the sidelines. They are
convinced that because they and their communities
are not yet directly experiencing the impact of the
epidemic, there is no need to become involved. The
AIDS epidemic has just begun, however. The full
impact is still in front of us. The costs to
business and labor, as well as to society, could be
high. But in fact, tomorrow's costs will depend in
large part upon what businesses and labor do today.

Edward N. Brandt, Jr., chair, National Leadership
Coalition on AIDS (National Leadership Coalition on
AIDS, 2, p. 5)

With or without the ADA, HIV/AIDS is having an impact

on both employers and employees.

As with any catastrophic illness, AIDS can affect
business in many crucial ways:

-Insurance/health care costs   -Legal considerations
-Productivity   -Confidentiality/privacy
-Work disruption   -Discrimination concerns
-Customer concerns   -Disability requirements
-Employee morale   -Job accommodation
(National Leadership Coalition on AIDS, 1, p. 1)

Who Pays: Employers or Public?

While there are costs attached to this disease that

cannot have a price tag attached to them, the first response

of many is a concern for the dollars and cents of this

disease. A large part of that cost will be for health care.

74

Along with concern about the issue of cost comes the issue of who is responsible for picking up the tab. As the ADA winds its way through courts and public attention and as AIDS becomes a concern for more and more people, the issue of who pays the costs of health care for HIV/AIDS patients will continue to be asked by many, including employers and insurers. The costs attached to HIV/AIDS will be looked at in greater detail later, but the general question of the role employers pay is an important one to look at now.

Mike Isbell, staff attorney for Lamda Legal Defense and Education Fund in New York City noted that
"at the beginning of the epidemic, we felt it was key to have a job since insurance discrimination primarily affected people without employment-based insurance. Now we are seeing that employment no longer guarantees you coverage. When people are deprived of insurance coverage, the public ends up paying for it." (Woolsey,5, p. 81)

Health care that is provided through public funding may be more expensive than employer-funded health care, however. This is due in part to the nature of the costs incurred when someone depends on social funding for health care. Chances increase that the ill person waits to obtain treatment until he or she is sick with a more serious disorder that could have been prevented if he or she had obtained care earlier. In addition to this factor is the increased cost of obtaining health care through the more expensive emergency room setting. So, whether or not a person is employed, health care will be provided and costs incurred. The quality and the costs of the health care will be adversely affected by how it is provided.

Isbell asserted a long-term optimism generated by the

passage of the ADA. He said,
> "It's very clear that the ADA will offer protection to
> HIV-infected employees. By 1994, there should be
> comprehensive coverage for many more employees" with
> the disease. (Woolsey, 1991, 6, p. 82)

As employers are expected to play a greater part in

the overall management of this disease, so too are they

expected to contribute to the overall wellness of employees

by allowing them to remain on the job with HIV/AIDS. In

"Responding to AIDS: Ten Principles for the Workplace,"

business and social service providers joined in underscoring

what many may take for granted: that employment is more than

a means to earn a living; it defines an essential part of

the lives of most people. Even if we do not look at the

specific components of how employment contributes to

individual well being, the fact is that working makes an

important contribution to the physical and mental well-being

of many people dealing with serious illness. (Citizens'

Commission on AIDS, 1989)

Key issues that arise for those infected with HIV go

beyond the immediate and ever-present fear of death or

prolonged suffering to issues of one's ability to live with

the illness, to continue working, to receive health benefits

and to experience the emotional support and assistance of

friends and colleagues. In addition to this knowledge of the

overall benefit of work for those with HIV is the knowledge

that continued employment will place additional financial

burden on employers. The Citizens' Commission suggested that

the two are not mutually exclusive, however. Infected
employees can continue to make an important contribution to
their employers with relatively minor accommodations.

Planning and awareness may be the key factors for
employers to effectively deal with the cost of the illness
in terms of losses in productivity, higher insurance
expenses, and possible costly litigation. Education can
reduce co-workers' concern about AIDS and its transmission
in the workplace by decreasing fear among co-workers and
work disruption. Companies will need to develop cost-
effective health care programs, as well as strategies to
communicate information about health benefits and company
policy on HIV-infected individuals to employees. (Klosinski,
1987)

Ten Principles for the Workplace

In 1988, the Citizens Commission on AIDS addressed
what it thought was the most pressing economic issue of
AIDS: keeping people with HIV/AIDS working for as long as
they could. It developed a set of principles that could
serve as a framework for employers, unions and other
organizations that respond to the issue of AIDS in the
workplace.

In the preface to "Responding to AIDS: Ten Principles for the Workplace," co-chairs John Jacob and John Zuccotti stated that

> the ten principles developed by the Citizens
> Commission are based on the experiences--both negative
> and positive--of many individuals and corporations.
> They offer what we believe is a rational,
> compassionate, and prudent framework. They have been
> endorsed by a wide variety of business, labor,
> government, and non-profit organizations. (Citizens
> Commission on AIDS, 1989, p. iv)

The principles are the following:

1. People with AIDS or HIV infection are entitled to the same rights and opportunities as people with other serious or life-threatening illness.

2. Employment policies must, at a minimum, comply with federal, state, and local laws and regulations.

3. Employment policies should be based on the scientific and epidemiological evidence that people with AIDS of HIV infection do not pose a risk of transmission of the virus to co-workers through ordinary workplace contact.

4. The highest levels of management and union leadership should unequivocally endorse nondiscriminatory employment policies and educational programs about AIDS.

5. Employers and unions should communicate their support of these policies to workers in simple, clear, and unambiguous terms.

6. Employers should provide employees with sensitive, accurate, and up-to-date education about risk reduction in their personal lives.

7. Employers have a duty to protect the confidentiality of employees' medical information.

8. To prevent work disruption and rejection by co-workers of an employee with AIDS or HIV infection, employers and unions should undertake education for all employees before such an incident occurs and as needed thereafter.

9. Employers should not require HIV screening as part of general pre-employment or workplace physical examinations.

10. In those special occupations settings where there may be a potential risk of exposure to HIV (for example, in health care, where workers may be exposed to blood or blood products), employers should provide specific, ongoing education and training, as well as the necessary equipment to reinforce appropriate infection control procedures and ensure that they are implemented. (Citizens Commission on AIDS, 1989, p. 1)

"We believe the AIDS workplace principles can provide leadership in this complex and emotionally charged arena, in much the same manner that the Sullivan Principles offered guidance regarding investment policies in South Africa," Zuccotti, a former deputy mayor of New York City said. (Lambert, 1988, p. B11)

Reasons for Employers to Respond to AIDS

If we are to sufficiently contain the epidemic and minimize the devastation to individuals and social institutions, choices will be required of us individually and collectively which will be made at the intersection of public health policies, societal values, scientific technology, and an economic reality that includes increasing world needs and decreasing resources.

AIDS requires, for example, that we take the most difficult, most emotionally charged concerns of our civilization and within the extremes of existing values, morals, social structures, and economics cut through to the essential tasks involved in halting a sexually transmitted disease," he continued. (Forstein, 1989, p. 159-160)

Recommendations for what businesses can and are doing in response to HIV/AIDS are outlined by the United Way of Central Maryland. In a report developed in conjunction with the Health Education Resources Organization and the American

Social Health Association, their list of reasons for

employers to respond proactively to the disease included:

> 1. AIDS is a national as well as local problem which
> has already and will undoubtedly continue to impact
> upon the workforce:
>   -more than one million Americans are infected with
> HIV -- an uncertain percentage of these will
> progress to illness (25% - 100%);
>   - more than 200,000 individuals have already been
> diagnosed with full-blown AIDS; over half of these
> have already died;
>   -most people with AIDS are between the ages of 20
> and 40 -- prime work years.
>
> 2. Employers have an obligation to ensure a safe
> work environment for all employees.
>
> 3. The emergence of AIDS within the workplace has
> resulted in numerous issues and dilemmas related to
> personnel management.
>
> 4. The economic impact of AIDS on both the
> individual and employer requires careful design and
> analysis of an adequate benefits program.
>
> 5. The workplace is an ideal opportunity to reach
> individuals potentially at-risk with effective AIDS
> prevention messages. (United Way of Central
> Maryland, 1988, p. I-4)

Large and small companies alike are seeing that they

are not immune to HIV-related illness and
> education is the best prevention against spread of
> this disease as well as the best guarantee that
> workers will respond rationally and compassionately to
> a co-worker with AIDS. (Klosinski, 1988, p. 3)

AIDS and HIV is not unique in the fact that it demands

a series of responses from employers - money, education,

policies, programs, planning, etc. The history of business

is all about its response to changing needs. Whether

motivated by a concern for employee well-being, productivity

or cost control, employers have initiated new programs such

as wellness, anti-smoking, alcohol/substance abuse, weight

control, etc.

> To the extent corporate America has responded at all
> to the tough issues surrounding AIDS, it has, by and
> large, responded with considerable clarity, compassion
> and rationality. The problem is that most
> organizations have not made a response.
>
> Successful management of the consequences of the AIDS
> epidemic over the next decade will be an on-going
> challenge, not only for the public health
> establishment, but for the management of unions,
> government agencies, non-profit organizations,
> educational institutions, law enforcement agencies,
> and health care establishments. Fortunately, the
> pioneers and the managers of the organizations first
> affected by the epidemic in its earliest days have by
> now demonstrated that AIDS is manageable in the
> workplace. They have shown that certain approaches
> have a high probability for success, while others, a
> high probability for failure." (Emery, 1988, p. 13)

Business Managers Address Employer Responses

In an address to corporate executives at a Leadership

Coalition on AIDS meeting in Washington, D.C., Bob Haas,

chairman and CEO of Levi Strauss & Co. noted that

> In San Francisco, we have lost three times more of our
> citizens to AIDS than were lost as casualties from our
> city in World War I, World War II, Korea and Vietnam
> combined. The HIV virus has all of our communities on
> its travel itineraries. (McDonald, 1990, p. 1)

As the disease spreads throughout the country, more

and more companies will have to address the issues raised by

the disease. Emery said, there

> are three keys to successful management of AIDS in the
> workplace. First, companies must address AIDS in a
> compassionate, responsible, and humane manner. AIDS,
> or any other life-threatening disease, can rob its
> victims of life, work, and human contact. As employers
> we are responsible for making sure employees are
> treated with respect and dignity.

81

Second, at Levi Strauss & Co., we've seen that education is the key to building understanding and changing attitudes. By educating yourself and your employees about AIDS, you can reduce the impact the disease will have in the workplace. Education can minimize, if not eliminate, prejudice and unwarranted fear about AIDS.

Third, the impetus must come from the top. (Emery, 1988, p. xiv)

At Levi Strauss, Haas handed out AIDS information flyers in the lobby of the company to help dispel any stigma attached to being concerned or involved with the issue. That was in 1982. (McDonald, 1990)

Arthur White, President and CEO of WSY Consulting Group, listed four areas where business can assume leadership role in response to HIV/AIDS. They include:

1. Americans feel strongly that companies should help meet the health needs of their employees. AIDS is a health problem. So business has a clear leadership mandate in this area.

2. Americans believe that companies should help meet the health needs of the community, including corporate giving to hospitals, health programs, and basic medical research. Each year, companies contribute $5 billion to various causes. This must now include AIDS.

3. Americans favor joint private-public sector solutions to serious health and social problems. Americans accept the fact that government can no longer afford to be all things to all people. So government-business partnerships are even more crucial to solving the AIDS crisis.

4. Misconceptions, fears and uncertainties about AIDS abound. Businesses can take a leadership role by making AIDS part of each company's employee education strategy. (National Leadership Coalition on AIDS, 1988, p. 4)

Government Addresses Employer Issues

The Federal Government has responded to the workplace
issues generated by the HIV/AIDS epidemic. Coverage of the
disease under the ADA is certainly one response. The Report
of the Presidential Commission on the Human Immunodeficiency
Virus is another. This comprehensive report focused on
workplace policies; education and information; corporate
leadership and support; and critical policy issues such as
financing health care, prevention efforts, discrimination,
and research, vaccine and drug development. (National
Leadership Coalition on AIDS, 1988)

The report recommended that business and labor:

> -insure that HIV-infected employees are provided the
> same rights and benefits offered other employees
> with other illness and disabilities;
> -treat HIV-infected employees, as well as other
> employees with diseases or disabilities, with
> compassion and understanding and allow them to
> continue working as long as they are able to perform
> their job;
> -develop HIV-related policies and guidelines prior
> to the appearance of the first HIV-infected employee
> in the workplace in order to facilitate the
> acceptance of the HIV-infected employee and reduce
> fears;
> -provide for 'reasonable accommodations' for HIV-
> infected employees such as modified work schedules,
> adapted working environments, etc.;
> -utilize the concept of 'otherwise qualified' in
> determining whether an HIV-infected employee should
> be employed;
> -insure access and maintenance of private health
> insurance coverage for HIV-infected persons,
> particularly since the health insurance burden is
> predominantly on the public system;
> -where indicated to protect the public safety,
> provide thorough testing and evaluation of the
> employee's skills and capabilities in order to
> determine if there is a functional impairment: HIV

testing of employees is not useful in predicting the
onset of functional impairment in persons who are
otherwise healthy;
-work actively with both the state and federal
government health insurance entities to examine ways
of improving the public/private partnership
necessary to bear the cost of the provision of
comprehensive health care for HIV-infected persons.
(National Leadership Coalition on AIDS, 1988, p. 23-
24)

Barriers to an Effective Response

The ability of businesses to effectively respond to

AIDS in the workplace along these or any other published

guidelines is hindered by numerous barriers, however. Taken

together, the barriers may seem insurmountable, leading

employers to attempt to ignore AIDS, hoping it will not

become a workplace issue for them. A more realistic response

and one that is supported by businesses that have had to

deal with this disease in their workplace, is found in first

acknowledging these barriers and then beginning to plan

strategies to respond. Several of the major barriers

confronted by employers have been listed by the United Way

of Central Maryland. They include:

1. Fear of the unknown -- in spite of a relatively
high level of understanding, the newness associated
with HIV and AIDS (reporting AIDS cases began only
in 1981) invokes high levels of fear by many.

2. Concerns regarding transmission -- although the
major routes of transmission have been determined,
many individuals are confused or uninformed leading
to unwarranted fear.

3. Lack of technical knowledge about AIDS -- limited available information by employers has resulted in poor practices and/or poor policies.

4. Certain aspects of AIDS are too sensitive to address -- AIDS requires discussion of extremely personal issues such as sexual and drug-use activity, testing, death and dying -- often viewed as inappropriate in the workplace.

5. Public relations problems -- many employers may consider a focus on AIDS "bad for business" due to the associated stigma.

6. Deficiency of existing policies -- addressing AIDS-related issues often uncovers glaring gaps in other personnel, benefits, and training policies and procedures.

7. Limited time and resources -- education to overcome fears in the workplace takes time and money, precious resources for most employers.
(United Way of Central Maryland, 1988, p. I-6)

The American Management Association actually interviewed employers to see why they did not have AIDS policies. Reasons given, in descending order of frequency, included:

1. We've yet to have a case of AIDS; we'll deal with the problem if and when it surfaces.

2. Since the prevailing wisdom is to treat AIDS-related illness as one would any other chronic or life-threatening illness, no specific policy is needed. Why a policy on AIDS, but not on cancer, or cardiovascular disease?

3. The few cases we've had were dealt with on an individual basis - the situations were too sensitive to do otherwise.

4. We understand that the virus can't be transmitted casually, but our customers don't.

5. An AIDS-specific policy opens the possibility that the company could become a haven for HIV carriers seeking medical coverage.

6. Medical information changes daily. Thus, any policy would have to be temporary. (Bohl, 1988, p. 50)

Removing Barriers to an Effective Response

Yet, these barriers that prevent effective responses by employers to the issues surrounding AIDS in the workplace will probably have to be removed. They may have to be removed by legal mandate or they may have to be removed by employer choice. When that times arrives, the following steps will be helpful in implementing a successful and positive response:

1. Becoming educated about AIDS and all its aspects -- knowledge is a powerful tool for overcoming fear.

2. Being open about fears and concerns with others -- acknowledgment of concerns is often the first step toward conquering and controlling them.

3. Learning from others' experiences and perspectives -- networking with employers here or elsewhere who've already encountered situations that may help in strategy design.

4. Seeking out and using all appropriate and available resources -- realizing it is neither efficient to "reinvent the wheel" nor to address problems alone that are clearly beyond any one employer's ability to resolve.

5. Soliciting administrative support -- management up to the highest level must be sensitized and supportive of the need to respond in an efficient manner.

6. Gaining community support -- cooperation and collaboration through bridge-building with others has traditionally proven effective in responding to major issues. (United Way of Central Maryland, 1988, p I-8)

According to Terry Mulready, vice president, corporate
communications, Pacific Bell, their are five steps to help
influence the company to do the "right thing" in relation to
AIDS.

> First, realize that in your push to establish an AIDS
> program, you have allies throughout your company - some
> of them officers and directors. you need to identify
> these people and work with them.
>
> Second, you need to stress that having an AIDS
> policy is the right thing to do. Our employees, our
> companies, our communities, our country face a problem
> - and there is no excuse for inaction.
>
> Third, having said that, you need to appeal to
> the self interest of relevant departments within your
> company.
>
> You need to convince your benefits group that
> AIDS education holds down health care costs. And you
> need to convince Contributions that fighting AIDS is a
> good social investment.
>
> Fourth, you must make people aware of the fact
> that AIDS is an unusual opportunity to do well by doing
> good. The resources you devote to AIDS will more than
> pay for themselves in savings on future health plan
> expenditures and public and employee recognition.
> People want guidance - and if you give it, you'll be
> the leader.
>
> Fifth and last, people love favorable
> recognition. Few issues get more (recognition) than
> AIDS, and if you're on the right side of an issue,
> favorable attention will follow. Such attention must
> never be the reason for starting a program, but it can
> be a tool to motivate otherwise hostile or indifferent
> people. (Bohl, 1988, p. 35)

Key Issues Surrounding the Disease

Key issues that require closer consideration when
examining the existing workplace policy can be categorized

under four majors headings, according to the Maryland

report. The four headings include: *occupational risks,*

personnel management, prevention education and

employment benefits. I am going to use those four

categories to organize information regarding employers

responses to the disease.

Occupational Risks

Occupations vary in their level of potential risk of
infection with a number of infectious agents,
including HIV. Clarification of the risks within
certain occupations must be identified to insure
proper provision of a a safe working environment.
(United Way of Central Maryland, 1988, p. I-9)

"Most inquiries we receive about AIDS focus on one
question: 'How can I keep from getting it?' Workers
are anxious about how HIV is transmitted. But their
fears can be addressed by comprehensive, honest,
candid and early education," said Jordon Barab,
Occupational Safety and Health Coordinator of the
American Federation of State, County and Municipal
Employees (AFSCME).

"We learned some valuable lessons in our first efforts
to deal with AIDS as an occupational hazard. You
cannot assume that because there are worksite
standards or guidelines, people know about them. Some
workers had never heard of the hepatitis-B
precautions, and some worked in institutions where the
precautions were not enforced.

"While the importance of AIDS training in all
occupational settings seems obvious, there is a marked
absence of training programs in hospitals, mental
health facilities and correctional institutions. When
training is provided, it is often inadequate or poorly
conducted. There is also a tremendous lack of and need
for employee counseling," Barab said. (National
Leadership Coalition on AIDS, 1988, p. 9)

In November 1985, the CDC issued recommendations for

preventing transmission of HIV infection in the workplace.

The following occupational groupings were created in order

to frame the guidelines. The groupings include Health Care

Workers,(HCWs) Personal-service workers (PSWs), Food-service

Workers(FSWs), and others sharing the same work environment.
     The information and recommendations contained in this
     document have been developed with particular emphasis
     on health-care workers and others in related
     occupations in which exposure might occur to blood
     from persons infected with the 'AIDS' virus. Because
     of public concern about the purported risk of
     transmission of HIV 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. (CDC, 1985, p. 681)

HEALTH CARE WORKERS include those professions whose

work involves contact with patients, their blood or other

body fluids, or corpses. Also, any workplace operation that

requires employees to be trained in first aid or CPR should

be considered under this category and adhere to

corresponding prevention guidelines. (CDC 1985)

     "Universal Blood and Body Fluid Precautions" are

recommended for all patients thereby eliminating any need to

identify specifically those with HIV infection.

          Universal Precautions include the following
     guidelines:
          Wear gloves when:
               -Touching blood/body fluids, mucus membranes
     or non-intact skin;
               -Handling items or surfaces soiled with
     blood/body fluids; and
               -Performing venipuncture and other vascular
     access procedures.

          Additionally:

-Wash hands and other skin surfaces
immediately and thoroughly if soiled with blood/body
fluids;
-Change gloves after contact with each
patient;
-Wear masks and protective eyewear during
procedures that may generate droplets of blood/body
fluids to prevent exposure of the mucus membranes of
the nose, mouth or eyes;
-Wear gowns or aprons during procedures that
may generate splashes of blood/body fluids;
-Handle needles or other sharp instruments
with extraordinary care during procedures, cleaning and
disposal;
-Do not recap, bend or break needles. Place
disposable needles and syringes and other sharp items
in a puncture-resistent container. (Georgia, 1990, p.
16)

Personnel Management Responses

AIDS in the workplace boils down to a management
response. Planning ahead and anticipation of certain known
issues can make a positive difference in how effective
employer response to these issues will be. Terry Mulready,
vice president, corporate communications, Pacific Bell,
indicated the "primary challenge presented by AIDS is in the
hands of managers." He listed three principles to govern
their responses:

1. Education is the key to effective management.
2. Managers must maintain a discrimination-free
workplace
3. In dealing with AIDS, managers must take all
reasonable steps to keep their workers as healthy as
possible. (Bohl, 1988, p. 30)

The challenge to employers with respect to management issues is one of balance. On one hand are the concerns and rights of co-workers, customers and management; on the other are the concerns of workers with HIV/AIDS and their legal protection. A balance needs to be established in order to protect the rights and welfare of the affected employee while also respecting the concerns of co-workers and the company/agency.

Managers may encounter unwarranted fears and disruptive reactions from employees who work with persons who are either presumed or known to be infected with HIV. Managers require information and guidelines to resolve AIDS-related personnel issues that might be encountered. They also need information on laws that will be impacting on their workplace choices.

Because the "known or should-have-known" standard is often applied in applications of disability rights law, employers will have the responsibility for establishing AIDS-fair policies and procedures before they know someone within their workforce is infected. (Nau, 1991) This will impact the development of policy statements, employee education programs and protection of confidentiality of disclosure.

Nau (1991) pointed out that the U.S. Department of Justice and the federal Equal Employment Opportunity Commission (EEOC) have already begun to clarify rules relating to the ADA. As is traditional in relation to the

Equal Rights Bill, the EEOC is expected to take a very pro-employee stance in interpreting the law.

Yet, survey after survey pointed to employers either ill-informed of the laws or willing to act in ways to put themselves at risk. A survey of 3,000 businesses in Philadelphia conducted by the Philadelphia newspapers found that:

-16.5% of employers would encourage an employee with AIDS to resign;

-16% would prevent the employee from being promoted; and

-almost 10% would dismiss the employee.

The survey also indicated that:

-75% knew little of their legal obligations;

-70% believed it unlikely they would have an AIDS case in the next five years; and

-30% would inform co-workers without obtaining consent from the person with AIDS. (National Leadership Coalition on AIDS, 1988)

Statistics do not tend to change much from year to year. Even in 1991, Alan Emery, president of Alan Emery Consulting Group, an independent management and health consultant in San Francisco pointed out that

> "Probably only 10% to 15% of big businesses have addressed the issue of AIDS." Far fewer smaller companies - those with fewer than 1,000 employees - which employ 47% of working Americans-have implemented any kind of AIDS policy or education program, he said. ((Woolsey, 1991-2, p. 75)

> Prior experience in dealing with issues such as racial and ethnic discrimination and sexual harassment has

shown that disruption and crises can be minimized if
top management and union leadership provide clear
policy directives and appropriate internal policy
implementation. That is equally true in responding to
AIDS. (Citizens Commission on AIDS, 1989, p. 10)

A documented AIDS policy is the most simple and cost-
effective means to reduce a company's potential
liability. It tells managers how they should act
regarding AIDS issues, and it lets employees know what
they can expect from the company. Such a policy should
be effective before AIDS enters your workplace if you
are to avoid privacy complications. Communicate it
regularly to employees in the same manner as EEO
policies.

You can't rely on managers doing the 'right thing'
just because they understand that AIDS is not casually
transmitted. The American Civil Liberties Union has
found that even people who know the facts about AIDS
transmission sometimes prevent people from keeping
jobs, finding housing or securing insurance coverage
and medical care. And AIDS bias is growing fast.
"Many other employers, especially those in the major
cities where AIDS has exacted its greatest toll,
assume that the mass media have thoroughly educated
their employees and dependents

The National Leadership Coalition on AIDS reported
that was not true. It said two out of three adults
still erroneously believe they can contract the virus
by working near or being touched by a person with
AIDS. (Woolsey, 1991-2, p. 75)

Policy Development in the Workplace

The workplace is an excellent site for targeted

prevention efforts for those at-risk for HIV infection as

well as prevention of unnecessary fear by the workplace

population at large. This effort must be done with planning

and an overall understanding of the issues related to HIV

and AIDS in general and in the workplace. The development of

a company policy goes hand-in-hand with education and
communication.

Three essential elements to a comprehensive AIDS
program in the workplace included: 1., a written policy to
tell supervisors how to act and employees what to expect;
2., training to teach supervisors how to implement the
policy; and 3., employee education, to prevent future
infection as well as discrimination against co-workers who
have - or are perceived to have - AIDS. (Durity, 1991)

The Bank of America, headquartered in San Francisco,
approached the development of a company response to the
disease with a five-pronged approached. This included:
    -Policy
    -Benefit design
    -Communication
    -Training
    -Support and referral(Bohl, 1988, p. 26)

1. Policy: Their policy stressed continuation of work
for those who were ill, the application of reasonable
accommodation as necessary, a listing of services for those
ill, and guidelines for managers.

2. Benefit design: Benefit design included the
incorporation of medical case management - which includes
care in the home or a hospice and providing for chore
services. This model has been proven to reduce overall costs
for treating those with the illness.

3. Communication: The policy was distributed to each
manager for review in staff meetings. Others within the
company and outside it also had access to it. Articles

appeared in company publications and videos and brochures were made available. Anyone seeking further information was encouraged to contact personnel.

4. Training: Training includes the communication strategy above as well as targeted efforts for specific sites with special needs. Personnel staff received yearly training.

5. Support and referral: A network of service providers was developed in the community for both psychological and social support. (Bohl, 1988)

> "The importance of having some type of policy, or guidelines, cannot be over stressed," Nancy Merritt, vice president and director of equal opportunity programs for Bank of America, San Francisco stated. "If you don't have a policy in place, you are looking very much at the downside..." that being fear, undetected illness and anxiety, uncontrolled health costs, and discrimination lawsuits. (Bohl, 1988, p. 25)

The central purpose of the AIDS program at Digital Equipment Corporation is "to ensure that all employees feel safe," according to Paul Ross, manager of AIDS Programs. He said that Digital made it clear that employees with HIV or AIDS would receive the same level of medical, disability and life benefits as any other employee. The medical plan also includes case management.

At each company facility, training began with line managers, who then were responsible for forming a partnership with the personnel department to deliver the message to the workforce at large. The training focused on

increasing managers' knowledge of the disease and preparing

them for leadership roles. (Woolsey, 1991, 3, p. 80)

The American Management Association has developed a

"composite policy" on AIDS/HIV and other life-threatening

illness. In reporting on the policy, they noted that

> Our researchers considered both the form as well as
> the ideas presented. Only those elements which were
> deemed most suitable and practical for a broad range
> of companies - big and small, national or local, in
> the manufacturing or service categories - were
> extracted for inclusion.
>
> No policy can be installed "turnkey" fashion. For many
> organizations, policy formation has been the product
> of task force activity, involving individuals from the
> employee assistance program, benefits, employee
> relations, legal, and others. Some have added outside
> expertise in the form of consultation with medical
> experts knowledgeable about AIDS. The task force
> discussions proved helpful in integrating the policy
> with other plans, including education and benefits
> clarification.
>
> You will notice that our composite policy (See
> APPENDIX III for complete policy) tries to minimize
> the abstract third-party 'voice' that is so popular
> among policy writers. There are two basic reasons for
> this. First, AIDS is a controversial subject that has
> elicited highly emotional responses from several
> segments of society. So while we normally would expect
> managers to adjust a broad policy to fit local needs
> or circumstances, we felt that this policy should be
> sufficiently plan spoken and direct to allow it to be
> passed on directly to all employees. (Bohl, 1988, p.
> 59)
>
> Instead of developing a separate policy, employers can

also
> "add AIDS-related provisions to their current company
> policy defining how they will handle health and
> disability claims," according to Bryan Lawton, vice
> president and director of employee assistance
> services, Wells Fargo Bank N.A., San Francisco.
> (Woolsey, 1991, 2, p. 76)

Employers should also be aware of any state or local laws that may require any special requirements relative to disabled individuals or people with AIDS. (Cobb, 1989)

Education Follows Policy Development

A policy is little good in terms of informing employees or in protecting the legal position of the employer without effective communication. The policy, coupled with an educational program, can meet several goals. They include:

> 1. Improved understanding of occupational risk potential of HIV transmission.
> 2. Increased awareness of risk of infection in personal life thereby reducing risk of continued transmission in the public.
> 3. Enhanced compassion for co-workers affected by HIV infection, thereby improving work conditions.
> 4. Affirmation of employer's concerns to ensure safe work environment.
> 5. Introduction of policy related to AIDS and understanding of the framework for the rationale behind any new guidelines established. (United Way of Central Maryland, 1988, III-37)

The following framework can be used to develop and implement such a communication program within the work setting:

Step 1. Identify audience to target

> Who among the staff should receive information
>   -in most instances, it is appropriate for all staff to be provided with information
>   -support of upper level management is critical for an effective   program and therefore should be targeted first.

-middle management, specifically the human
resource staff are important conduits to line
managers and employees.
    -staff managers will allow better access and
acceptance to receive information from line
employees
    -employees will benefit personally and
professionally.

Step 2. Determine content of program

At a minimum, the following questions should be
answered in any educational program conducted:
    -What is AIDS/ARC/HIV infection?
    -How is HIV transmitted?
    -How is HIV not transmitted?
    -What is the clinical course of those infected?
    -What is the risk of exposure in the workplace?
    -What AIDS policies exist in the work setting?
    -What resources are available for further
assistance?

Depending on the target audience of a program,
content material may be weighted more heavily on
some issues versus others. The extent of discussing
sexual and other life-style issues related to risk
reduction should also be determined. A simple staff
"needs assessment" of current knowledge/concerns
might help in deciding upon the level and extent of
information presented.

Step 3. Design program delivery strategy

How an educational program is delivered is critical
to an effective intervention. Following are a few
key issues to consider when determining the delivery
strategy:

    -Keep within corporate culture
            *incorporate AIDS information into existing
programs
            *incorporate AIDS information into regularly
scheduled staff meetings
            *offer special education forums during lunch
hours
    -Offer programs on company/agency time
    -Determine who is best suited to present
information
            *in-house medical office
            *local medical professionals
            *community AIDS service agencies
    -Keep format simples and up to date
            *information can be presented in a variety of
ways ranging from simple brochure distribution to

98

full-length presentations and seminars for employees
and managers
          *live presentations usually last about one to
one and a half hours and consist of:
                --Welcome and introduction
                --goals and objectives of program
                --overview of existing AIDS policy
                --factual presentation and/or video
                    tape
                --discussion
                --closing/literature distribution
          *determine size and make-up of group (will
different levels of staff be educated separately or
mixed?)
          *decide whether program attendance will be
mandatory or voluntary.

Step 4. Evaluate impact

   -Evaluation of an educational program can be
extremely formal using such methods as pre- and
post-seminar questionnaires to determine changes in
knowledge and attitudes, or
   -Informal evaluations can be conducted through
observation of work setting "atmospheres" related to
AIDS-related issues before and after an educational
intervention is conducted. (United Way of Central
Maryland, 1988, p. III-38-40)

The cost to implement and conduct an educational

program on AIDS/HIV in the workplace can be very

inexpensive.

     For about $1,000, an employer of 300 people can have

groups of about 30 people watching two informational videos

followed by a doctor discussing the medical aspects of HIV

transmission. Questions and answers can follow that.

Separate presentations of about an hour each can then be

given to managers. (Woolsey, 1991, 2)

     A lot of information is available free from various

community and national groups as well.

"Corporate America is so concerned at this time about
the high cost of health insurance," Robert Modine,
director, employee relations, Modine Manufacturing,
Racine, Wis. pointed out. "But, if you look at
educating employees about HIV and the causes behind it
- what better approach do you have than trying to
prevent one case?" (Woolsey, 1991, 2, p. 77)

Mucha noted that the biggest expense of an AIDS

education program is pulling employees off the job.

In addition to that,
the small expense for a program is far less costly
than possible lawsuits, work disruptions, customer
relation problems or loss of valued employees in the
future. (National Leadership Coalition on AIDS, 1, p.
5)

Employee Benefits are a Major Concern

Health benefits are an assumed component of employment

for many workers. They are a rising concern for employers.

In a recent survey reported in *Employee Benefit Plan Review*

over half of the employers responding (54%) indicated that

employee benefits were their most critical concern of all

workplace problems. Benefits led other such workplace issues

as wages (52%), AIDS (48%), substance abuse (32%), stress

(31%), and wrongful discharge (30%) (*Employee Benefit Plan

Review,* 1989)

AIDS was the top concern for employees in the survey

conducted the prior year. Yet AIDS and benefits seem

inextricably connected. With the cost of treatment for AIDS

exceeding $65 billion annually, it is hard to imagine how

employers can not keep this issue top on their list.

Key facts that contribute to the significance of the issue include:

    -33% of large companies surveyed report at least
    one case of AIDS in their employee/dependent
    populations;
    -it is estimated that 35-55% of people who have
    AIDS are employed and covered by employer-sponsored
    benefits plans;
    -of those organizations with employees with AIDS,
    50% report having experienced an increase in their
    benefits costs (life, disability, sick pay, health,
    other) - the largest being in life insurance
    (27.5%);
    -group health insurance costs are expected to
    increase by an average of 16.2% costing employers
    $14 billion in benefits costs within the next five
    years;
    -self-insured organizations are at greatest risk
    for program insolvency;
    -the vast majority of employers strongly believe
    that AIDS should be covered under their
    organization's benefits plan.
    -under the Employment Retirement Income Security
    Act (ERISA), an employer cannot fire an employee in
    order to prevent employee access to entitlements
    under a benefits plan. (United Way of Central
    Maryland, 1988, p. III-42)

Other legal considerations relevant to the issue of

AIDS and benefits include:

-equal access to insurance for all employees;

-a uniform benefits package and a uniform benefit

level for each employee within an insurance group regardless

of illness; and

-for employers with 20 or more employees, federal law

(COBRA) requires that you offer continued health coverage to

employees and their dependents for specified periods of

time. The employee or dependent will pay up to 102% of the

health insurance premium cost. Some states require that an

employee be offered conversion rights from the carrier for

an individual policy as well. (National Leadership Coalition

on AIDS, 1)

To be as effective as possible in managing benefit

cost, legality and overall administration, the National

Leadership Coalition on AIDS recommended that employers

become familiar with laws and policies before an employee is

identified with AIDS. The following suggestions were made:

> 1. Be aware of laws mandating extension of benefits
> for employees leaving employment and their
> dependents; the most important of these is the
> federal COBRA legislation.
>
> 2. Understand the health and disability benefits
> offered by your insurance contract, including pre-
> existing conditions provisions. Review your benefits
> package with your insurer, broker, or administrator.
>
> 3. Determine whether additional benefits appropriate
> for people with chronic disorders might be cost-
> beneficial to you; such benefits may substitute for
> expensive hospital stays. These benefits might
> include home care, hospice, or nursing home
> services, and prescription coverage.
>
> 4. Look into the possibility of utilizing cost
> containment measures such as case management, which
> provides appropriate care at the appropriate time,
> or alternate delivery systems such as health
> maintenance organizations (HMOs). (National
> Leadership Coalition on AIDS, 1, p. 5)

Because AIDS cuts across such a variety of issues in

benefits management, a comparable variety of challenges is

created for employers. The challenges faced range from

fairness to cost-containment. To take full advantage of the

options available and to provide the most benefit for the

least amount of cost, employers will have to design the response best suited to the needs of the employee and the organization.

Legal Questions Regarding Cost Containment

Because either the costs are too high or the fear of costs getting out of control is too present with HIV/AIDS, many companies are looking for ways to limit their health benefit exposure. Primarily small companies are particularly concerned and have been the source of legal challenges and on-going court rulings in this area. The issue does not seem to be settled definitely one way or the other at this time.

The court cases are arising over Section 510 of the Employment Retirement Income Security Act (ERISA) of 1974. This section

> prohibits insured plans from denying or limiting
> benefits because the employee has a catastrophic
> illness that would be costly to the plan.

> Self-funded plans, however, which are exempt under
> ERISA from state insurance benefit mandates, have been
> given greater freedom to restrict health benefits for
> workers with AIDS. Last year (1990), in what was
> believed to be the first ruling on the issue, a
> federal court in Texas ruled that nothing in ERISA
> requires self-funded employers to provide equitable
> benefits for employees with AIDS. (Woolsey, 1991, 1, p
> 84)

There are two sections of Section 510 that provide protection to those with HIV/AIDS. The first is the continuation coverage provisions.

> The continuation coverage provisions of ERISA were
> enacted in 1986 to address the problem of employees
> losing group health insurance coverage for themselves
> and their dependents upon loss of employment.

Employees who are beneficiaries under employment
related group health plans will qualify for
continuation coverage if their employer employs at
least twenty persons. If the employee's coverage under
the group health plan would otherwise cease because of
a reduction in work hours as a result of the
employee's disability or because the employee has
become entirely unable to work, the employee is
entitled to elect to continue to participate in the
group health plan for up to eighteen months. Employers
may require their former employees to pay premiums for
this coverage. (Leonard, 1989, p. 948)

While the main purpose of these provisions seems to be
prevention of discharge on the eve of vesting dates
under pension plans, employees have invoked them
successfully under other circumstances as well. For
example, a discharge employee suffering from
degenerative arthritis was found to have a right to
sue under section 510 by the United States Court of
Appeals for the Third Circuit in *Zipf v. American
Telephone and Telegraph* in 1985. (Bohl, 1988, p. 126)

Parallels exist for those with HIV/AIDS.
ERISA section 510 states that employers cannot take
adverse actions against employees in order to deprive
them of benefits to which they are or may become
entitled, and allows persons affected by such actions
to bring a federal suit to vindicate their rights.
(Leonard, 1989, p. 949)

The Citizens Commission on AIDS for New York City and

Northern New Jersey, along with other AIDS advocacy groups,

is calling for business to review the kinds of benefits

provided
in light of the needs of employees with catastrophic
illness including: long-term disability; coverage for
prescription and experimental drugs; reimbursement for
outpatient, home, and hospice care; leaves of absence;
psychological counseling and others. (Citizens
Commission on AIDS for New York City and Northern New
Jersey, 1989, p. 14)

Business is often reviewing those benefits, but

seemingly, not with the best of intentions for employer

health.
"I haven't seen any employer changing its plan to cap
payments for other illness," Mark Scherzer, an ACT-UP
attorney in New York said. "There is something about

AIDS which makes employers feel more privileged to
discriminate. Their reaction is a prejudicial reaction
because AIDS claims are not necessarily the most
expensive. It seems employers feel that people with
AIDS are less deserving of Benefits." (Woolsey, 1991,
1, p. 84)
"The enormity of the epidemic represents an
opportunity to rethink some of the deficient policies
or practices by insurers, not just for AIDS, but for
all life-threatening illness," Mike Isbell, lawyer for
Lambda Legal Defense and Education Fund, Inc., in New
York said. (Woolsey, 1991, 6, p. 82)

Where we as a nation go with the opportunity will

probably be decided in the courts, offices and hearts of the

nation over the next few years.

CHAPTER 3

THE RESEARCH

Introduction

There was once a man named Nasreddin Hodza who lived in a small, well-knit village community somewhere in the Balkan Peninsula. One day he woke up at daybreak and went out in the yard in front of his house, bent down on his knees, and began a vigorous and meticulous search -- inch by inch -- through his well-kept garden. Soon his neighbors and other passers-by stopped and watched him. Curious, they asked him what he was doing. He looked up momentarily and said that he had lost his precious gold coin the night before and was trying to find it. Now there were not too many such gold coins around the village, and the good neighbors, sympathizing with Nasreddin, volunteered to search with him.

The search continued for hours with increasing urgency, but the gold coin was nowhere to be found. As sundown was approaching, one frustrated neighbor asked Nasreddin, "Now see here! Where approximately do you think you lost this famous coin of yours?" Nasreddin looked him straight in the eye and said, "I am sure I lost it inside the house." "Then why in Heaven's name are we searching for it out here?" snapped the exasperated neighbor. Nasreddin shook his head knowingly and muttered, "Because there is more light out here!" (Bangura, 1992, p. 7)

To shed light on the issues surrounding AIDS and HIV in the workplace, researchers too have been looking in many of the wrong places, in part because the light was better, but perhaps because the economic concerns were greater there. Research has focused on employers, insurers, and care providers, but not on those who are ill and directly affected by the disease. Despite this previous focus on the

topic, little has been written about the people who are in the workplace and HIV positive.

In reviewing the literature on AIDS in the workplace, there is an abundance of data available. Much of that data has an impact on the infected person in the workplace and so was reported in this paper. Of course, company policies, government protection, and medical facts (the bulk of the literature) have an impact on the infected person. Nowhere, however, is there a wealth of research on what impact HIV has on employees in the workplace. Nowhere do articles focus on the physical impact of AIDS on peoples' ability to perform various jobs, or the specific emotional needs of an infected person at work.

The fact that there is so little information about what people who are HIV positive and working have to deal with makes little sense in relation to the overall amount of literature available about AIDS in the workplace. Yet there appears to be no record of interviews with those trying to manage their disease and their worklife; no articles on coping skills required; and no articles on how to manage one's health care while maintaining a work schedule. And the list of possible topics could go on, but still no wealth of literature.

Because so little research has been done that focuses on this topic, there is very little to base new research on. With that in mind, the methodology for my research was based on the need to generate exploratory data. The conclusion was

that by running a series of focus groups, this purpose will

be best served.

<u>What are Focus Groups?</u>

Depending on which source one reads, the origins of

focus groups will vary. In a social science environment,

focus groups are seen as having grown
> out of the group therapy method used by psychiatrists.
> The concept is based on the assumption that
> individuals who share a problem will be more willing
> to talk about it amid the security of others sharing
> the problem. It offers a means of obtaining in-depth
> information on a specific topic through a discussion
> group atmosphere which allows an insight into the
> behavior and thinking of the individual group members.
> Rather than using a structured question-and-answer
> methodology, the procedure is to encourage a group to
> discuss feelings, attitudes, and perceptions about the
> topic being discussed. (Bellenger, Bernhardt, and
> Goldstucker, 1979, p. 13)

Focus groups are also used for research in the

business community, primarily for marketing, but also in

areas of human resources. It that field, the origin of focus

groups is traced more to motivation research conducted

following World War II. "Like most motivation research

techniques, it was instantly condemned by the conservative

research establishment as "unscientific" and therefor

"untrustworthy." (Wells, 1979, p. 2)

> According to Stewart and Sahmdasani,
> "the focused group interview had its origins in the
> Office of Radio Research at Columbia University in
> 1941, when Paul Lazarsfeld invited Robert Merton to
> assist him in the evaluation of audience response to
> radio programs." (1990, p. 2)

The first paper on the method was published in 1946

and the first book was published in 1956, both with Merton

as principal author. (Stewart and Shamdasani, 1990)

> The importance of the group as a means for eliciting
> information has been emphasized by Smith (1954) in his
> classic definition of group interviewing: "The term
> group interviewing will be limited to those situations
> where the assembled group is small enough to permit
> genuine discussion among all its members." (Stewart
> and Shamdasani, 1990, p. 10)

> Focus groups constitute one specific technique within
> the broader category of group interviewing to collect
> qualitative data. The hallmark of focus groups is *the
> explicit use of the group interaction to produce data
> and insights that would be less accessible without the
> interaction found in the group*.(author's italics)
> (Morgan, 1988, p. 12)

> Basically, there are two types of group interview
> studies. One is nothing more than a question and
> answer session: the group moderator asks questions and
> the respondents give verbal or written answers. A
> second type is the focus group interview, where a
> group of people (generally eight to twelve) are led
> through an open, in-depth discussion by a group
> moderator. The moderator's objective is to focus the
> discussion on the relevant subject areas in a non-
> directive manner. (Cox, Higginbotham, and Burton,
> 1979, p. 96)

It is the latter form that was used for this research

project.

Advantages to Using Focus Group Research

> Focus group research has been the subject of much
> controversy and criticism. Such criticism is
> generally associated with the view that focus group
> interviews do not yield "hard" data, and the concern
> that group members may not be representative of a
> larger population (because of both the small numbers
> and the idiosyncratic nature of the group
> discussion). Such criticism, however, is unfair.
> Although focus groups do have important limitations
> of which the researcher should be aware, limitations
> are not unique to focus group research; all research

tools in the social sciences have significant
limitations. (Stewart and Shamdasani, 1990, p. 12)

There are a variety of advantages to using focus
groups particularly in relation to the topic of identifying
concerns of those with HIV/AIDS in the workplace. Generally,
the advantages include:

1. The ability to generate hypotheses;

2. The ability to learn about a new field or any of
interest;

3. They are a good starting point to gather
information where little research exists;

4. They allow for the "surprise factor" to emerge from
the group which would be hidden by more structured methods.
(Biel, 1979, p. 117)

> Even when time and funds are ample for the most
> painstaking research, the researcher must get some
> background somewhere before he can cope with a problem
> in any useful way. When other information sources are
> sparse or lacking, or when the researcher needs
> immediate, personal contact with the subject matter to
> spark his own thought, group interviews are highly
> productive idea breeders."(Wells, 1979, p. 2.)

> What traditional survey research gains in sample size,
> standardization and quantification, it loses in lack
> of contact between respondent and client, rigidity,
> elapsed time, and high cost. Too often it also
> produces elegantly quantified "results" that neither
> investigator nor client understands. (Wells, 1979, p.
> 11.)

Focus groups are also supported extensively as both an
independent means of gathering research as well as part of
larger, more representative surveys of a population.
Therefore, the focus group was chosen as a stand-alone

110

research project, because of both literature substantiating

this and the nature of this study.

Stewart and Shamdasani (1990) pointed out that focus

group research is particularly appropriate when
the group of people - or population - of interest is
relatively homogeneous, at least with respect to the
issue at hand. In such cases, a small number of
respondents is all that is needed to generalize to the
larger population. (p. 17)

While this research did not result in data able to be

generalized to all people who are HIV positive and working,

the sample populations used yielded good preliminary data

relating to the issues of people who participated in the

groups. The demographic information requested of the

participants allowed a review of the characteristics of

those who participated. From that, we were able to determine

the fit of this population in relation to the overall

population of those with HIV infection in the nation.

Morgan (1988), noted that there are some who think the

focus group must be limited to preliminary or exploratory

research.
The key distinguishing feature of a self-contained
focus group is that the results of the research can
stand on their own...Focus groups are useful when it
comes to investigating *what* participants think, but
they excel at uncovering *why* participants think as
they do. (p. 25)

Compared to survey research, in which interviewers
typically encounter problems when they ask about
issues about which the participant does not have a
well-formed opinion, this example shows that focus
groups are a good way to observe the process of
opinion formation. (Morgan, 1988, p. 28)

Focus groups provide a number of advantages relative
to other types of research:

1. Focus groups provide data from a group of people much more quickly and at less cost than would be the case if each individual were interviewed separately. They also can be assembled on much shorter notice than would be required for a more systematic, and larger survey.
2. Focus groups allow the researcher to interact directly with respondents. This provides opportunities for the clarification of responses, for follow-up questions, and for the proving of responses. Respondents can qualify responses or give contingent answers to questions. In addition, it is possible for the researcher to observe nonverbal responses such as gestures, smiles, frowns and so forth, which may carry information that supplements (and, on occasion, even contradicts) the verbal response.
3. The open response format of a focus group provides an opportunity to obtain large and rich amounts of data in the respondents' own words. The researcher can obtain deeper levels of meaning, make important connections, and identify subtle nuances in expression and meaning.
4. Focus groups allow respondents to react to and build upon the responses of other group members. This synergistic effect of the group setting may result in the production of data or ideas that might not have been uncovered in individual interviews.
5. Focus groups are very flexible. They can be used to examine a wide range of topics with a variety of individuals and in a variety of settings.
6. Focus groups may be one of the few research tools available for obtaining data from children or from individuals who are not particularly literate.
7. The results of a focus group are easy to understand. Researchers and decision makers can readily understand the verbal responses of most respondents. This is not always the case with more sophisticated survey research that employs complex statistical analyses. (Stewart and Shamdasani, 1990, p. 16)

Disadvantages of the Focus Group

There are, of course, disadvantages to using the focus group method. Yet, upon review, they are not significance enough to prevent its use. Of course, many of these

disadvantages are the negative sides to the advantages above. They include:

> 1. The small numbers of respondents that participate even in several difference focus groups and the conveniences nature of most focus group recruiting practices significantly limit generalization to a larger population. Indeed, persons who are willing to travel to a locale to participate in a one- to two-hour group discussion may be quite different from the population of interest, at least on some dimension, such as compliance or deference.
> 2. The interaction of respondents with one another and with the researcher has two undesirable effects. First, the responses from members of the group are not independent of one another, which restricts the generalizability of results. Second, the results obtained in a focus group may be biased by a very dominant or opinionated member. More reserved group members may be hesitant to talk.
> 3. The "live" and immediate nature of the interaction may lead a researcher or decision maker to place greater faith in the findings than is actually warranted. There is a certain credibility attached to the opinion of a live respondent that is often not present in statistical summaries.
> 4. The open-ended nature of responses obtained in focus groups often makes summarization and interpretation of results difficult.
> 5. The moderator may bias results by knowingly or unknowingly providing cues about what types of responses and answers are desirable. (Stewart and Shamdasani, 1990, p. 17)

Why the Group?

Goldman (1979) pointed out that "The establishment of group cohesiveness is dependent in large part on the second criterion of "groupness," namely, *sharing a common interest*." (1979, p. 38) In this case, the common interest included HIV infection, sexual orientation and coping with work.

Advantages of using the group as a means of research include: the stimulation of new ideas based on group interaction, the opportunity to observe interaction between people, and the ability to have members explore and experience the dynamics and differences that exist between them regarding varying attitudes and opinions about their disease, their work or the social environment. Using the group as the means of research also allows for the generation of spontaneity and candor in response to the issue, and finally, it can provoke individual emotions in response to the topic that individual interviews could not. (Goldman, 1979)

In addition, the researcher's enrollment in a graduate program that utilizes group interaction and interpersonal communication as the primary means to teach, naturally led to the selection of a group process to conduct this research. After reviewing literature on qualitative research and assessing the researcher's primary skills and interests, the Focus Group seemed most appropriate. Because the researcher had conducted support groups for three years with HIV infected people, he was aware of the level of concern so many have regarding issues of HIV infection and work. The focus group allowed the use of a group process which was both time-limited, and topic-limited, but which generates data on what is happening for those with HIV infection in relation to a specific area - work.

> "Much is known about the interaction of small groups, and about the analysis of qualitative data. It is on this knowledge that the validity of focus group

interview as a scientific tool rests. (Stewart and
Shamdasani, 1990, p. 14)

Because of a deep-felt belief in naturalistic inquiry
and research methodologies, the focus group approach was
also a compatible method for the researcher. It was course-
work in both the ODAGS Department and Interpersonal
Communication that provided the initial cognitive structure
for him to embrace naturalistic inquiry.

The nature of this research required a more
naturalistic approach for at least two reasons. The first,
already discussed, is that so little research has been
conducted to date.

Secondly, the researcher wanted to be more personally
involved with the research and resulting data than merely
putting out a survey instrument. Lincoln and Guba (1985),
pointed out that the naturalistic researcher
        "elects to use him- or herself as well as other humans
        as the primary data-gathering instruments (as opposed
        to paper-and-pencil or brass instruments) because it
        would be virtually impossible to devise a priori a
        nonhuman instrument with sufficient adaptability to
        encompass and adjust to the variety of realities that
        will be encountered," (p. 39) among other things.

In the case of research into HIV and AIDS, there are
so many variables at work within the infected. They are
often struggling to cope with a near-always fatal disease,
at a young age. They are often dealing with the homophobia
and racism of our culture and therefore lacking generalized
support or understanding of their struggle. They are also
living with a disease that is not fully understood by the
medical community, let alone by the general public. That in

turn has created fear among many, including those who are

infected. The fear for those who are not infected relates to

contagion. The fear for those who are infected is

multifaceted.

Axelrod talked about the ability of qualitative

research to get at the emotional framework of the topic

being studied. (1979, p. 47) This topic is rampant with

emotion

The advantage of naturalistic research to allow for

inductive data analysis allowed the research to unfold as it

progressed. As there were so few reference points in

literature on this subject, the outcome of the research was

not clear at the outset. The ability of naturalistic

research to allow for "multiple realities" and the reality

that "values can be an explicit part of the analytic

structure," (Lincoln and Guba, 1985, p. 40) was therefore

conducive to this research.

Other validation for the selection of qualitative

research came from Marshall and Rossman (1989), who pointed

out that naturalistic research is used for:

> -research that cannot be done experimentally for
> practical or ethical reasons
> -research that delves in depth into complexities and
> processes
> -research for which relevant variables have yet to
> be identified
> -research that seeks to explore where and why
> policy, folk wisdom, and practice do not work
> -research on unknown societies or innovative systems
> -research on informal and unstructured linkages and
> processes in organizations
> -research on real, as opposed to stated,
> organizational goals (p. 46)

McCracken (1988) pointed out that

> A final difference between qualitative and
> quantitative approaches is the number and kind or
> respondents that should be recruited for research
> purposes. The quantitative project requires
> investigators to construct a "sample" of the
> necessary size and type to generalize to the larger
> population. In the qualitative case, however, the
> issue is not one of generalizability. It is that of
> access. The purpose of the qualitative interview is
> not to discover how many, and what kinds of, people
> with a certain characteristic. It is to gain access
> to the cultural categories and assumptions according
> to which one culture construes the world. (p. 17)

He also noted that qualitative methods are
most useful and powerful when they are used to
discover how the respondent sees the world,
(McCracken, 1988. p. 21)

and that is exactly what is intended here. This

researcher will attempt to learn more about the realities of

work for those with HIV infection

Methods of This Study

> The task for the qualitative methodologist is to
> provide a framework within which people can respond
> in a way that represents accurately and thoroughly
> their points of view about the world, or that part
> of the world about which they are talking. (Patton,
> 1980, p. 28)

Once the decision was made to gather data via focus

groups, several methodological questions remained. They

included such topics as: How many groups were necessary?,

Where would the participants be recruited?, How long would

the groups last?, How many people would be in each group?,

117

How would the groups be facilitated?, and How would the data
be analyzed and presented?

How Many Groups?

Perhaps because much of the history of focus group
research has been in the marketing field and the needs were
different there or because the issue just may not be as
significant variable, the number of groups is not often
written about. From the literature, it would appear that the
decision on the number of groups is often left to the
moderator to determine how many are necessary to do the work
required. The literature points to the significance of the
demographics as well as the issues being researcher, e.g.,
Does it have broad market appeal or narrow?. (Prince, 1978,
Peterson, 1979, Axelrod, 1979, Biel, 1979)

In the social sciences, there appears to be parallel
thinking on the number of groups necessary to gather
meaningful data.

Research goals contribute to the choice of the number
of groups conducted. Marketing researchers provide a clear
example here, varying the number of groups according to
whether the additional discussions are producing new ideas.
According to Calder (1977),

> if the moderator can clearly anticipate what will be
> said next in a group, then the research is done; this
> usually takes 3 or 4 groups. Thus research that is
> exploratory in nature or simply aimed at "getting
> someone's perspective" will probably take only a few
> groups. (Morgan, 1988, p. 42)

It became clear that the number of groups was not the

important factor, but rather the amount of new information

that came out of the groups. This conclusion is impacted by

both the topic being studied and the people being used to

gather data.

> One important determinant of the number of groups is
> the number of different population subgroups required.
> The more homogeneous your groups are in terms of both
> background and role-based perspectives, the fewer you
> will need. (Morgan, 1988, p. 42)
>
> Qualitative research is not a "quick and dirty" and
> cheap way for avoiding quantitative research. It
> serves completely different purposes and does not, in
> any way, presume to supply the same kinds of answers
> as quantitative exploration does.
>
> It cannot, for instance, give numbers or tell you how
> **many** people do this or feel this or think this. After
> a series of sessions, a feeling may develop that
> something may be a prevalent and important reaction
> and this it is something that had better be thought
> about strongly but be carefully on guard against any
> attempt to measure the **extent** of the reaction in any
> of the same terms used for a quantitative study.
> Axelrod, 1979, p. 49)
>
> In general, the goal is to do only as many groups as
> are required to provide an adequate answer to the
> research question... The best advice is to determine a
> target number of groups in the planning stage, but to
> have a flexible alternative available if more groups
> are needed. (Morgan, 1988, p. 43)

Wells (1979) puts that target at three or four groups.

He said,

> From the first interview on an unfamiliar topic, the
> analyst invariably learns a great deal. The second
> interview produces much more, but not all of it is
> new. Usually by the third session, and certainly by
> the fourth, most of what is said has been said several
> times before, and it is obvious that little is to be
> gained from continuing. (Wells, 1979, p. 6)

Bellenger, Bernhardt and Goldstucker (1979) move to

even a more minimalist approach. They said,

> the objective, of course, is to try to have as few
> groups as possible, while at the same time realizing

the necessity to replicate the focus group interviews
for each segment being studied. If there are two with
any one age group and they go in totally different
direction, a third session should be conducted. (p.
14)

With this all in mind, the researcher ran four groups.

This researcher found that the topic was one that produced

relatively similar data quickly.

Facilitation Style Chosen

Given the needs of this research - to gather

exploratory data, groups were run with low-structure, which

meant relatively low moderator involvement.
Low levels of moderator involvement are important for
goals that emphasize exploratory research. Are the
basic issues well known? Does existing knowledge come
from participants' perspectives, or is it based on
researcher-imposed agendas? If the goal is to learn
something new from participants, then it is best to
let them speak for themselves. (Morgan, 1988, p. 49)

The lack of research in this area has been pointed out

already. For that reason, low moderator involvement and high

group idea generation was important. Also, this research was

focused on hearing what those with HIV had to say about

their issues at work. Because a focus group is good at

generating participant ideas, facilitation was used to

maximize those responses. The group environment was

structured to facilitate people feeling supported in their

desire to discuss and share ideas.
For low levels of moderator involvement, the biggest
plus is te ability to assess participants' own
interest." (Morgan, 1988, p. 50)

The primary role of facilitator was to set basic

groundrules: one person speaking at a time, focus on the

topic at hand, no side-conversations, confidentiality of

information and individuals, and encouragement for everyone

to participant. (Morgan, 1988, p. 57)

Group Duration

The groups lasted about two hours. This is a typical

length of time for focus groups. (Bellenger, Bernhardt,

Goldstucker, 1979; Morgan, 1988; Wells, 1979; Stewart and

Sahmdasani, 1990; Kaden, 1979)

> Focus group interviews typically last one and a half
> to two hours, which gives the moderator sufficient
> time to develop a good rapport with respondents and
> thus get very candid answers. Often the moderator is
> able to get below the conscious level, and the
> respondents reveal their personality, emotions, and
> true feelings. This technique thus allows the
> researcher to handle sensitive areas more effectively
> via the group method than with individual interviews.
> (Bellenger, Bernhardt, and Goldstucker, 1979, p. 14)

Within that two-hour time frame, a warm-up or get-

acquainted period was included. This included time for

seating and casual talk. The intent was to get people to

relax and feel comfortable with the space and one another.

(Morgan, 1988)

Following this period, there was an introduction from

the facilitator, with an introduction of himself, why he was

there and the goals for the meeting. (See Appendix V)

Included in that was a clear statement of confidentiality -

both from the facilitator's point of view (that all

information heard at the group will be kept confidential)

and from each participants' point of view(that what they

hear at the group will be kept confidential). The opening

remarks of the facilitator also included a definition of a

focus group and fundamentals of how it operates.

Participants were given an overview of how the group would

proceed and an opportunity to ask questions.

After the opening, members were encouraged to talk

about issues that were of concern to them in the workplace.

All sessions were audiotaped and signed permission

forms (Appendix I) were obtained from all participants.

Following that, each participant was asked to introduce

himself and begin the group. The chosen format included a

brief introduction from people. This did not include full

name, as that remained an item left to the individual

discretion. People were asked to say a little about what

they do for work, what brought them to this group and a

general statement about how they feel about working. This

introduction allowed each member at least a brief period of

uninterrupted disclosure and a presence in the group.

Discussion then moved to particular items of interest to the

members. The primary role of the facilitator was to keep the

topic moving when it got stuck, bring it back to the topic

when it strayed, and to encourage clarification of ideas

when necessary.

Demographic Information Gathered

A short questionnaire was filled out by participants
at the end of the group regarding demographic information.
(Appendix II) This included: age, race, gender, years of
infection, means of infection, years of employment, symptoms
to date, type of work, status of work (full-time, part-
time), source of health coverage, hourly pay or salary,
educational level. This information helped in the evaluation
of who was in each group.

Group Configuration and Formation

In keeping with the needs of group development, group
size was targeted for from about 5 to 12 members. Five
agencies became the primary resources for distribution of
information to potential participants. These agencies
included: Project Care, New Bedford, MA; Project AWARE, Fall
River, MA; Strategem Health Care, Providence, RI; Positive
Directions, Boston, MA; and Positive Changes, Providence,
RI. Contacts at these agencies were told of the desire to
form a group of 5 to 12 working people who were HIV
positive. Flyers were mailed to them for posting and for
distribution to potential participants (Appendix IV)
Through many starts and stops, bad weather, lack of turnout,
lack of contact follow-through and various other reasons

that remain unknown, the initial rounds of group formation

remained without participants.

The researcher then decided to offer reimbursement for

expenses and a $25 stipend was offered. In the following

weeks, two groups were scheduled for Strategem Health Care

in Providence, RI. The first group had five members and the

second had six members. The next two groups were organized

through Positive Directions in Boston, MA. The first group

had seven members participating and the second had six. So,

a total of 24 people were brought through the Focus Group

process.

Data Analysis

Discussion from each group, notes and transcriptions

facilitated the analysis of data from each group. To assess

the importance of various items of discussion, both the

number of times the item was mentioned as well as the number

of people who considered the item important were indicated.

Because the facilitator was an integral part of the group,

any emotional significance attached to a particular item was

noted and referenced in the analysis. An attempt to present

items in a rank order was made if it seemed both appropriate

and possible.

This process of analysis was followed for each group.

Finally, an evaluation of the similarity across groups was

conducted. An evaluation of reasons for the findings was

then presented.

Ethnographic statements were used to both substantiate

findings as well as personalize them.

Stewart and Shamdasani (1990) talked of the differing

forms of data: emic and etic.
> Emic data are data that arise in a natural or
> indigenous form. They are only minimally imposed by
> the researcher or the research setting. Etic data, on
> the other hand, represent the researcher's imposed
> view of the situation.
>
> Focus groups - along with a few other techniques such
> as unstructured depth interviews - provide data that
> are closer to the emic side of the continuum because
> they allow individuals to respond in their own words,
> using their own categorizations and perceived
> associations. (p. 13)

Because of this bias, statistical tests were not

performed on the data because it was counter productive to

the intent and strength of the methodology. Instead, the

primary purpose of the methodology was to gather information

related to the topic being studied.

Number counting is not an integral part of a

qualitative study. The goal of qualitative research is to

learn what the people have to say and to understand what

they say and why they are saying it. It is not to find out

how many, because at best, the "population" studied is too

small to make any findings "significant" by any statistical

measure. (Axelrod, 1979)

Reporting the findings included the above information

as well as facilitator response to both the findings and

process. This included an assessment of participant

involvement, emotional state or group interaction. It

included an assessment of the researcher's learning from

beginning the process through to the end. In the final

chapter, recommendations for next steps, especially in the

employment environment, will be presented.

> It is important that clients understand that the ideal
> function of a focus group, or qualitative research, is
> to provide *direction*. Because of the small sample
> reached through focus groups (i.e. approximately eight
> to ten respondents per group), the findings from a
> focus group are not meant to be used as the "final
> word" upon which to base entire marketing plans or
> marketing strategies. Rather focus groups ideally
> should be viewed as research-vehicle that provides a
> client with findings which represent the "tip of the
> iceberg" in terms of the overall marketing research
> project. Focus groups, or qualitative research, offer
> reaction to ideas and directional information.
> (Hannah, 1979, p. 70.)

CHAPTER 4

THE FINDINGS

The Research Data

Of the 24 people attending the four focus group
meetings, 23 reported being gay males, 21 were white males,
one was Afro-American, one was Hispanic and one did not
report in this category. The average age of those
participating was 36 with a range of from 26 to 50 years of
age. The average length of diagnosis was 3.9 years with a
range of from 3 months to 8 years. Overall physical symptoms
reported by those participating were typical for those in
the early to middle stages of the disease's progression.
They included: pneumonia, skin problems, loss of memory,
tiredness, neuropathy, fever, infections, night sweats,
diarrhea and weight loss.

Of those participating in the groups, only one person
did not report working full time. Seven participants held
graduate degrees, six were college graduates, five had some
college, three were high school graduates and three did not
respond. Nineteen participants received their health care
benefits through their employer and five did not.

Table 4.1: Overall Group Demographic Information

Average Age: 36   **Gender:**   Male 24 Female 0

Race: **Sexual Orientation:**

Caucasian 21   Gay 23

African American 1   Straight 0

Asian 0   Bi-sexual 0

Cape Verdean 0   Other: NA 0

Hispanic 1

Native American 0

Average time since diagnosis: 3.9 years

Means of infection: Sexual contact 23

  (If known)   Intravenous drug use 0

                          Transfusion 0

                          Other: N.A. - 1

Symptoms to date: Bouts with pneumonia, loss of
memory, numbness, headaches, sore throat, mild skin
problems, fatigue, night sweats, anxiety, fevers,
pariotinitis, retinitis, pneumocystic pneumonia, shingles,
skin problems, diarrhea, warts, amoeba, low platelet counts,
minor infections, neuropathy, psoriasis, and weight loss

Occupations: Field consultant for government
programs, chef, nursing assistant, rehabilitation/mental
health caseworker, hotel controller, librarian,.customer

service, media librarian, hairstylist,
landscaper/horticulturist, chef, mental health counselor,
refrigeration engineer, accountant, computer
consultant/hotline manger, welder/mechanic, program
coordinator, distribution manager, social service worker,
scientist, controller, commercial designer,
telecommunications specialist, vocational instructor, and
rehabilitation counselor supervisor.

Length of employment in occupation: 8 years

Work status: Full Time 23   Part Time 1

Educational level: High School: 3

Some College: 5

College graduate: 6

Graduate Degree: 7

Other: N.A. - 3

Payment status: Hourly 9   Salary 15

Does work provide health insurance: Yes 19 No 5

Topics in the Individual Groups

Following is an analysis of each group. "X" after each
item indicates that this item was raised by other members or
that other members echoed concern when it was raised.

The items were generated from transcripts of the
meetings and from notes. They were then clustered into
categories that reflected a general theme for the group.

Many items could have fit into several themes, so context of the statement and/or relation to other items in a theme were used to sort and cluster.

Group One

A five-member group was held on January 19, 1993 at Strategem Health Care Services in Providence, RI. All five members of the group identified themselves as gay, white males who had contracted the disease through sexual contact. The average age of the men was 40.8 years with a range of 31 to 50. The average length of diagnosis for members of the group was 3 years, with a range of from 22 months to 4 years. Only one member reported symptoms to date and that included two bouts with pneumonia.

All members were employed full-time. Four earned a salary and one was an hourly wage earner. All received their medical benefits through their employer. One member held a graduate degree, two held bachelor degrees, one marked other and the fifth entered no response in the category of education.

Occupations of the members included: a field consultant for government programs, a chef and nursing assistant, a rehabilitation/mental health caseworker, a hotel controller, and a librarian. The average length of time in their occupation was 12 years. One group member did

not indicate years in occupation. The range for the other members was from 6 to 19 years.

The meeting of the group began at 9 a.m. and ran until just before 11 a.m. The group started with an introduction of the researcher and a review of the ground-rules as stated in the consent form. All participants were asked to read and sign the consent form. They were reminded that they should be attending voluntarily and that they could ask questions at any time and leave at any time.

General conversation focused on issues that they were experiencing at work. One member of the group was generally silent, the others engaged in a dialogue that resulted in the listed items that follow. There were no debates or discussions about the relative value of any item, but discussion was more a free-form discussion of events occurring at the various members' worksites. Items extracted from the discussion include the following data:

Loss of Control
-Over personal privacy ("I had to go public.")xxxx
-I'm not sure of my job security xx
-My confidentiality not protected x
-Generally feeling helpless, with no way out x
-Having to provide reasons for doctors visits
-Job duties changed for accommodation

Concern about response from co-workers

-They will think negatively of me x

-Receiving special care (don't want it) x

-Homophobic responses x

-Uncertainty of co-workers' response when they

find out

-Isolation

-Ignorance

-Policy can't regulate people's action

Comfort in support from policy statements

-Information = support = reality of disease xx

-Laws provide protection xx

Future is uncertain

-Health and/or ability to work is uncertain x

-Benefits may change x

-Physical changes might take place

Financial exposure

-Will health coverage be there x

-Can my benefits coverage be capped

-Less work = less pay

Stress

-Being exposed to the diseases of other at work xx

-Preoccupied with this disease and its impact x

-Work issues cause stress, not good for health

-Have to lie/keep secrets, not be out about the

disease

-Medications impact my ability to work

Balancing work and health is difficult

-Work/stress/health/values have to be balanced xx

-Work provides sense of purpose/health/lifestyle x

Anger/frustration

-This disease is an interruption of life

-It's work to manage the anger

Ability to change jobs is limited

-Benefits exclude pre-existing conditions

<u>Group Two</u>

Group two met on January 21, 1993, two days after the
first group at the same site. Six members were in attendance
at this meeting, which ran from 6 p.m. until 8 p.m. All six
members described themselves as gay, four described
themselves as white males and two did not respond in that
category. All six members reported contracting the disease
through sexual contact. The average age of the men was 35.5
years of age with a range of from 29 to 44.

The average length of diagnosis was 4.75 years with a range of 1.5 to 8 years. One of the members reported symptoms including loss of memory, tiredness, numbness, headaches and sore throat; a second reported symptoms of mild skin problems.

Five of the six members reported working full-time and the sixth reported part-time employment. One member held a graduate degree, two had some college, two others had high school educations and the sixth member did not respond in this category. Three members were on salary and three were hourly employees. Three members received their benefits from their employers and the other three did not.

Occupations included: customer service, media librarian, hairstylist, landscaper/horticulturist, chef, and mental health counselor.

The group began in the same manner as the first group. There was little difference in structure or flow except where personal experiences impacted group interaction. Perhaps because of educational attainment or structure of earnings and benefits, their was more emphasis on benefits in general: both health and disability.

Items discussed by the group included the following:

Feelings of vulnerability

-I feel exposed to the world xx

-Confidentiality breached x

-There will be business lost if customers know x

-If I litigate, more people will know

-I can get diseases from my co-workers

Work vs. health polarity

-I have to balance the stress of work with my

health xx

-I have to make work more enjoyable now

-Health is my top priority

-Work is no longer as important to me

-My t-cell count went down without the stress of

work

-My time for all things is less because of work

-It's hard to let time for doctors' appointments

Loss of privacy

-Medication creates complications at work xxx

-It's hard to keep this secret from co-workers xx

-My intimacy with co-workers impacted my

disclosure

Fear of isolation

-I'm hurt that no one asks me about it xxx

-I would be isolated if I didn't have my work x

-I would be isolated if people knew

-I'm concerned how people will react

-Asking me about HIV is a form of support

-I fear rejection

-I've noticed a change in peoples' behavior

-I fear a change in their behavior if they knew

-It hurts that people don't support me

Depression

-I have a sense of my own death x

-I have a loss of self-esteem x

-I feel depressed

-I feel stigmatized

-I feel guilty

-I feel a sense of loss

Physical limitations

-I lack energy

-I have an increased sense of limitation

Anger/frustration

-Work is not as important to me now x

-My employer has not taken responsibility for
        responding to this disease

-I have had to re-evaluate my goals

-This disease has interrupted the "American Dream"

-My life has been cut short

-The company has not informed me of my rights

-I would feel more comfortable if I knew the
        company policy

-There is homophobia out there

Financial concerns

-My disability benefits are not clear xx

-If I work less, I earn less; it's a slap in the
                        face x

-I lack job security

-I fear a loss of benefits

-I have lost job security

Employer response is important

-I carry the burden if people are not informed x

-A policy is supportive

-The lack of information leaves me vulnerable

-The size of the employer doesn't matter

-"What is reasonable accommodation?"

General work concerns

-Work is something to do

-Work is a way for me to contribute

-Work is good interaction

-Work is acknowledgement of my worth

Group Three

The third group was held February 25, 1993 at Positive Directions in Boston, MA from 6 to 8 p.m. Eight participants were present. Seven of the members reported being gay and one did not indicate sexual orientation. Seven were white, one was African American . All were men and all reported contracting the disease through sexual contact. The average age of the group members was 34 with a range from 26 to 39. The average length of diagnosis was 4 years with a range from 1.5 years to 6 years.

Symptoms of members of the group fatigue, night sweats and anxiety for one; fevers, pariotinitis, and retinitis for another; pneumocystic pneumonia for a third; and shingles and skin problems for a fourth.

Six of the eight members were paid on a salary and two were hourly. Seven received medical benefits through their employers and one did not. All reported being employed full time. Four members had graduate degrees (one indicating a Ph.D.); two were college graduates; one had some college and the seventh had a high school education. Members had been in their occupations for an average of 8.6 years with a range of from 3 years to 15 years.

Occupations included: refrigeration engineer, accountant, computer consultant/hotline manger, welder/mechanic, program coordinator, distribution manager, social service worker and scientist.

The participation of the African American member added
a new dimension to the groups. The expressed experience of
this member was a different from the experience of white
members in that he expressed more confidence in the
existence of laws and policies as protection for workers
with HIV infection. It was also he who stated that he was
"willing to fight for his rights."

Other then adding this dimension to the group, the
experiences of the African American member did not appear to
diverge substantially from those of white members. Each
member remained focused on their own work experiences and
once again did not become involved in debating relative
importance of issues.

What was significant for the researcher was that
following this group, he felt that the item pool had begun
to repeat itself and that as Calder (1977) noted "If the
moderator can clearly anticipate what will be said next in
the group, then the research is done; this usually takes 3
or 4 groups." This feeling was significant because of
changes in several group variables. These changes included
the facts that the group had moved to a new location, the
educational and racial diversity were different, and that it
was the third group to run.

Items generated in this group included the following:

Issues of Job Security

-Job security assurances are important xxx

-I'm not able to meet my work requirements

-Work contributes to my mental health

-Work is an escape for me

Concerns about future health

-I'm afraid of getting AIDS

Co-workers responses have an impact

-People's attitudes change

-I don't want to be labelled a "fag"

-I'm feeling targeted

-Positive responses are appreciated

Feelings of isolation

-I'm pulling inside more

-I'm feeling outside my work group

-I am socially disabled

-I'm preoccupied with the disease

-There are no other examples of HIV in the
workplace

Education is important

-Understanding and accepting gay issues is
important x

-I want to be part of the discussion of HIV

-Social issues training is important

140

Disclosing is difficult

-I dislike having to keep it a secret x

-My confidentiality has been breached x

-Harassment is real

-The burden of proving discrimination is on me

-It's like having to come out again

-it would be simpler if I could come out

-My boss is not supportive

-I don't want past discrimination repeated

-People are preoccupied with the cause

-My self image has changed

Concerns about medical care vs. work

-Will leaves result in a negative review?

-What do my absences mean to others?

-It takes a lot of time to treat this disease

-They may think I'm looking for a job

-I overcompensate with work to show I'm okay

-I feel guilty

-I feel pressure to perform

-Physical changes cause concern about my ability
   to   work

Policies/benefits are important

-I'm glad we have a good disability program

-Policies are important

-Job benefits are important

-Income is critical

-The disability plan needs to be communicated

better

Feelings of being trapped

-I can't move because of benefits

-I either work or I don't

-I can't change jobs

-My life choices are limited

Support is important

-Most of my support is outside of work

-Their are legal agencies that protect me

-I want to be treated the same as anyone with a

chronic illness

-I want to be able to talk about it

-I'm willing to fight for my rights

Group Four

Group four was held on March 12, 1993 at Positive
Directions in Boston, MA. Five members were present, all of
whom were gay, four of whom were white and one of whom was
Hispanic. Age for this group averaged 34.6 with a range of
from 28 to 49. Average length of diagnosis was 3.8 years
with a range of from 3 months to 6 years. Four members

reported contracting the disease through sexual contact and one did not respond. Symptoms reported by members included: skin problems; fatigue, diarrhea, night sweats, warts and amoeba; low platelet counts, and minor infections; mild skin problems, fatigue, and night sweats; and neuropathy, diarrhea, psoriasis, fatigue and weight loss.

All members were employed full time. One held a graduate degree, one a bachelors degree and three had some college. Two were working with a salary and three were working on an hourly basis. Four received their health benefits through work and the fifth did not. The average length of time in their occupations was 3 years with 2 members not reporting. The range of time within their occupations was from 2 years to 4 years.

Occupations for members of the group included: controller, commercial designer, telecommunications specialist, vocational instructor, and rehabilitation counselor supervisor.

A significant factor in this group was the fact that two members worked for companies that were either gay-owned or very gay-friendly. This had a positive impact on both their ability to obtain both accommodation for medical leave and flexibility in work assignments. This non-homophobic environment also appeared to provide easier access to information about policies, disability programs, etc. It did not appear to change the nature of issues that these members had to deal with however. Issues like co-worker responses,

telling co-workers and other concerns about work versus

health foe example remained constant. What became apparent

was that even though a company may have policies and

education regarding HIV infection, it can not control the

responses of all employees. Some may continue to feel

threatened or homophobic, etc.

Items generated by this group included the following:

Fear

-I was panicked when I first learned

-I'm leery of other peoples' diseases

Questions of relationship between work/health

-How much I can do at work is unclear

-My motivation is less now

-Medication has had an impact

-I feel guilty taking time off

-Rewarding work is worth less money

Concern about other peoples' responses

-I'm afraid of being treated differently

-People see the disease, not me

-People won't act the same toward me

-People will shun me

-Overcautious behavior is insulting

144

Financial issues

-I'm concerned about benefits

-I feel good that I have job assurances

-Benefits are a form of support

-Salary maintenance is important

Issues with disclosure

-I'm comforted by people knowing x

-I question who I will tell

-What is the best way to tell?

-Disclosure is difficult

Depression

-I am depressed x

-There are so many emotional issues

Frustration/anger

-There has been a lack of confidentiality xx

-How can I keep up at work? x

-I question my future

-What about my career aspirations?

-People don't understand HIV/AIDS

Lack of control

-My symptoms forced me out

-I had no choice but to disclose

-It's hard to keep this a secret

Support is helpful

-Support is coupled with acceptance of

homosexuality xxxx

-Employers are responsible to educate employees on

issues of HIV and homophobia to dispel myths xx

-Support is shown through accommodation x

-I need flexibility to go to doctors x

-Education is important for others to act with

compassion x

-Normal interaction is good

-A policy helps change behaviors of co-workers x

-Support helped me keep my incentive to work

-Working provides support in many ways

-Education alleviates fear in others

-Education needs to be updated

-Panels of HIV people are helpful in the workplace

-Work improves my self worth

-Education improves my self esteem

-Work is a symbol of who I am

-Sometimes I question who has the problem - me or

the people who hate?

What the Participants Reported

In reviewing the data reported by the group members,
eight themes were identified as being the most significant.

While it was often difficult to isolate one theme from one another, as they were often inter-related to one degree or another, the following eight themes were reported most consistently throughout the various groups. They included:

1. **The on-going balance and/or imbalance between health and work**
2. **A feeling of personal vulnerability**
3. **A concern about co-worker responses**
4. **The significance of various supports through work**
5. **Financial concerns**
6. **The importance of and difficulty with disclosing**
7. **Concerns about the future**
8. **Anger/depression/stress**

In compiling this list of themes, it is important to note that language used to discuss each theme and specific reference to situations or workplaces varied from person to person and group to group. However, it became clear to the researcher that key themes were of concern to most participants and were reoccurring. Race and age, though of significance, did not appear to be as significant a factor in individuals' responses to working with HIV infection as did progression of the disease and support in and/or out of the workplace. Issues being dealt with by some in the groups

were impacted also by whether the person had disclosed his
HIV status in the workplace and the responses he had
received. While the variables impacting responses to
disclosure were many, including, level of support, comfort
and awareness of co-workers, these responses had an impact
on the future choices of infected workers. This paper can
not begin to catalogue or describe all these variables, only
to identify what was important to individuals as expressed
in the groups.

Responses by infected individuals to disclosure ranged
from feelings of relief, satisfaction, anger, betrayal to
confusion and regret. Those who had not disclosed, could not
contribute to this discussion. Their reasons for not having
disclosed also covered a broad range and is not a topic of
primary interest in this research. Many of these reasons
show up however as concerns of participants in the
workplace.

Controlling for educational levels and/or
social/economic class, as with race, was difficult given the
research design. Data can not be divided into issues for one
group or another, even though these group memberships have
an impact on all social interaction. Generally, however, the
researcher was pleased with the level and variety of
education of the members. While racial membership was not as
diverse as it could have been, one Afro-American and one
Hispanic American were present in the population studied.
Female participation was not available and was perhaps due

to recruitment methods. There was one group planned, which had to be cancelled due to snow, at which four women were expected. They did not show up at the subsequent meeting however.

Development of Group Themes

Data was collected and analyzed independently for each group. Even though all the groups and all the data analysis was done by one researcher. The intent was to create a list of items that reflected the content of discussion in each group with as little bias from data in other groups. It became apparent to the researcher while he was facilitating the groups that participants were raising similar topics and concerns. Topics of discussion varied however, due to the circumstances of work environment, co-workers' responses and participants' ability to process information and feelings. Health status also impacted both the topics discussed by individuals as well as some personal attitudes toward themselves, co-workers or work in general.

The fact that eight primary themes were running through the various groups was not determined until after all groups had been run and the specific group data was reviewed. Conversation was recorded, ideas extracted from the statements and continually grouped to create thoughts or ideas that were running through the groups. Data was then

gathered from all four groups to be reviewed for similarity and was clustered into general themes.

Balance and/or Imbalance Between Health and Work

A pervasive issue across all groups and for all members was the issue of balancing work with their health. Some members talked about the importance and contribution of working - how it provided income, esteem, sense of purpose, affiliation, etc. Yet for all members there was a sense of having to find a way to balance meeting the demands of their work with the needs of managing their relatively recent disease. The average length of diagnosis for members of the group was 3.9 years and the longest term was 8 years. Finding answers to questions regarding how to cope simultaneously with these two issues came up time and time again. Dialogue common to the groups went as follows regarding the value of work:

-"There's a lot of people in my life right now who don't work because they can't work. Its very scary. And I like to work. I like my job. I wouldn't want to be home."

-"It's our society. How we fit into society is what we do."

-"It's also to feel productive, which is very important to one's mental health."

-"Yes, and it's a sense of purpose."

-"Yeah. If you can be productive, I'd like to be

productive."

The balance between work and stress was discussed as

follows:

-"My priority is to keep myself stress-free. And

from the other perspective, I guess my employer

might not be getting out of me what he could if I

were not negative. ...I do what I have to but I'm

not going to put myself in stressful situations to

keep the position."

-"I'm learning that in cooking I could see that I

was doing a lot of things compared to somebody else

doing less than what I was doing. I'm trying to

control my...I'm at the point now that I'm working

eight hours a day and just doing what I'm supposed

to do and I'm not trying to build stress up."

-"I've never thought of it that way, but I think

I've somewhat come to that feeling too. I'll do my

job but it's not worth letting the stress get to

me."

In another group, a member talked about how the job

prevented him from getting medical treatment:

-"It was a constant source of aggravation and

irritation (time required to leave work for clinical

trials) so it was something I had to give up because

of work. My life would be a lot simpler if I could

disclose at work and have support at work to help
carry me through this, but the second part is
missing. So I've kinda accepted the fact that unless
I get really sick or find a new work environment I'm
just not going to come completely clean at work."

Work issues often were seen as adding stress to
participants' lives and so counterproductive to health
and/or t-cell counts. Because of this relationship, work
became less important for some. This appeared to be due to a
changing set of values. Getting the most out of life, or
keeping the most important parts of life intact seemed to
increase for them. Health took on a higher priority in
general and in specific in relation to work.

Yet for others, there was a sense that work
contributed to a sense of being healthy and of being able to
maintain a healthy lifestyle. For one, a compromise was to
find work that was more intrinsically rewarding to him; for
another, to make work more fun. Still another felt that
overcompensating at work was necessary to show he was
healthy and another felt an ongoing pressure to perform.

An example of this valuing of work includes the
following dialogue:

-"I can't conceive of not working. Not just the
medical expenses. I just can't conceive of not being
able to work. I know it may happen and hopefully it
will happen slow enough if it happens."

Concerns were expressed about the ability to continue
to perform at work due to the physical changes of the
disease or the impact of medication. The need for increased
time off raised concerns about getting medical care without
being perceived as: looking for another job or receiving a
negative review. Some expressed guilt at having to take so
much time off.

> -"Exactly. And that's what I've seen people go
> through in whatever job they've lost. I'm not going
> to be sitting here 220 pounds not experiencing the
> problems related to HIV anyway. I'll probably be
> very thin, weak, tired. You know all those pictures
> come into mind. I wouldn't be able to work. And I
> think that's what the negative side is. I haven't
> seen anyone gracefully fall into full-blown AIDS."

This issue will probably continue to impact members as
they struggle with their dual role of worker and person with
a chronic illness. Certainly, policies, programs, benefits,
education, and attitude will have an affect on how they
resolve some of their concerns.

A Feeling of Personal Vulnerability

It may be apparent from the previous concern that
workers with HIV infection felt vulnerable in the workplace.
This feeling manifested itself in many ways and was
expressed by participants in direct and indirect ways.

Certainly, participants felt a loss of control over their
work lives. Many physical limitations were mentioned. HIV
infection forced many members to disclose facts about
themselves that they said they would otherwise have kept
private. This included issues surrounding their sexuality,
health status, and reasons for medical visits or other
leaves. This loss of privacy was felt by many participants
as a major loss.

>   -"No, my fear is the uncomfortableness. I know they
>   can't fire me. I know they won't fire me. It's like
>   the idea of having people know about your private
>   life."

>   -"It was hard for me because I didn't want to go
>   public. And I knew that if I really made a big stink
>   about that it would have been a public issue. And
>   whether I have a disease or I'm gay or whatever, is
>   no one's funking business. Excuse me, but that is
>   how I felt. And I didn't want to disclose that so
>   people could pick up the Providence Journal and read
>   it. And I felt really, really trapped by that."

>   -"I guess in absolute theory I know I won't have any
>   problem when everyone knows. I know I won't have any
>   problem. I work with people that are sensitive, I
>   think. And I'm not worried about the town trying to
>   find a way to fire me. It's the loss of privacy I'm
>   going to have to deal with. Just the loss of
>   privacy. They'll accommodate me easily. I take the

time off for these doctors' appointments for my own

sick time or any time I have. It's just the loss of

privacy. And that's a regret more than a fear. And

I'd like to prolong my privacy as long as I can."

Medical leaves and the need for repeated medications

often forced questions by co-workers and subsequent guessing

or disclosure by participants.

This vulnerability also spread to issues surrounding

job security. And while this topic is also related to

financial issues, it created a feeling of personal

vulnerability as well. Tied into this job insecurity was the

fear for many that disclosures to either personnel, a

supervisor or a co-worker were not kept confidential by

those persons.

> -"Well, I was working in a local hospital in Rhode
> Island going back about five or six years ago and I
> was a chef. And I had told somebody that I was HIV
> figuring that they would keep it to themselves, but
> they tell everybody else. I got transferred from
> that department into another department and I had
> asked them why. And they had told me that they
> didn't want me to cut or slice my hand and cook
> blood into the food. And I mean, I wouldn't do that.
> I think some normal person wouldn't do that."
>
> -"After three months contemplating what I should do,
> knowing he'd probably find out anyway, I figured
> that I should tell him myself so that at least he

might be afraid that if he did something like try to get rid of me, he'd have the threat of a lawsuit because I had disclosed the information. It wasn't something he heard, then very nicely got rid of me in a way that he could. So that was a big, big concern. I ended up doing it. Those were the most anxiety-ridden days of my life, not to mention afterwards. It's funny. I didn't think about it beforehand because I felt as though it was something I had to do to secure my employment, but I can't believe I had to disclose something so personal. Something that I didn't, first of all, not even know what level of understanding these persons would have about the disease. Just having to take them in a room and tell them something so personal seems unfair, ridiculous. But I felt like I was trapped into it because I needed the health care benefits. Since then, many anxiety-ridden days because I wondered what they were going to do, if they were going to find a way to get rid of me."

Another way members experienced feelings of vulnerability was with the fear of being vulnerable to the diseases of others at work. This fear has not received much public exposure, the more usual concern is that of co-workers' fear of exposure to HIV infection. It was a surprise for the researcher to hear of this concern, but it was one that was echoed by many members of the

groups.Knowledge of this concern will allow more co-workers to be sensitive and responsive to those with HIV infection.

-"One fear that I've thought of is one that I'm sure _x_ has and already brought up was working. I have to visit hospitals and doctors offices. Most recently I got panicked over having to go to my territory, which is New York City and having heard the night before that I was leaving for my trip that TB was at epidemic levels in four out of five boroughs in New York City. So it was like 'Yeah, I'm fine now, but all I have to do is be exposed to TB...Then if I was really unlucky, I could be exposed to the drug-resistant type and then I'd have no chance of surviving. And this could all happen just because of my job'. So I'm saying 'What do I want to do about this? What is more important?'"

-"We're the ones with the compromised immune systems. They're afraid, but we're the ones that are at risk."

-"Stay off airplanes, and away from small children and what next, small furry animals? It's ridiculous."

-"I also worked with children on the weekends. I'm a child care worker for adolescents. And they're always, always sick. That brought up a whole new bunch of fears. I'll be leaving my job in February. I just can't risk it."

A Concern about Co-worker Responses

Participants were very sensitive to and concerned about the responses of their co-workers upon learning of

157

their HIV infection. Those who were not "out" feared isolation, ridicule and other recriminations.

-"'Probably the best thing that could happen to me at this point is to disclose my status and let the chips fall where they may, but I just don't have the guts. I've experienced recrimination on my other jobs and I just don't want that to happen again."

-"There's no overt hostility except an occasional very bad joke. But it's (HIV status) not something I would ever discuss not would I answer the question if I were asked because I worry about job security."

-"I think it effects you socially at work. I intentionally avoid company outings...excuse the pun. There is a ski weekend coming up and a lot of the people are going to bring their spouses and children. It's not for me. I know a lot of it is a burden I put on myself. I already feel handicapped because I'm gay. I think it would be worse if I say I'm gay and oh, by the way, I'm HIV positive."

-"It's self-imposed exile."

Those who were out did at times have to deal with intolerance, uninformed behavior and talk, etc. Others who were out found a comforting sense of support among co-workers. And so, while it is difficult to categorize this concern about co-workers' responses as being any one issue, the significance of co-worker response to disclosure was clear.

-"I notice that workers that I work with that know
of my condition, some have already written me off.
I've had one person come up to me and say 'I'm
afraid to get close to you now. I'm afraid you are
going to die.' There's definitely that distance."

It may be important to note that while most were
concerned about negative responses from co-workers, some
participants did not want to receive special positive or
supportive treatment due to their illness. Instead, they
wanted to be viewed as anyone with a chronic illness,
capable of managing their illness and not to be overwhelmed
by sympathy, pity or overly expressed concern.

-"When he told some people he was HIV, they were
overly nice. They were overly solicitous. That's
much more my fear, of coming out to the people I
work with. They'll be watching every single sneeze I
have not for fear for themselves. Maybe I'm wrong,
maybe I'm deluding myself, but I think it would be
more that I'm, I don't want people worrying about
me. I don't want people looking at me each day and
trying to say 'Has his color changed or has he lost
a pound?'"

-"And my boss came in, 'How are your doing?' The
president of the company in front of twelve other
reps is patting me on the back. Jesus, just what I
need. They're going to wonder what's going on, not
to mention I felt like saying 'What do you think,

I'm was going to be dead by now?' I wonder what he

was thinking. He saw me, I looked healthy. That

feeling of knowing and he's always asking a friend

of mine that is a field rep. I hate that that

happens, but I still don't regret disclosing. It's a

nice thing but at the same time it does cause

problems. "

Homophobic responses were also a great concern to

participants. Because the groups were largely comprised of

gay men, news of their illness triggered responses to or

concerns about their sexual orientation. Not wanting to be

seen differently by co-workers because of their illness or

sexual orientation was also a major concern. The concept of

co-workers seeing or responding to the disease or the sexual

orientation instead of the person concerned many group

members.

-"It's that support we all need and we don't want

people talking behind our back about that fag. I

would have loved for the personnel people to have

said 'Don't worry we're behind you.' I work for a

company with 20,000 employees and I've never seen

the written word in any company manual and I think

that they are taking a denial approach that it

doesn't exist."

-"People weren't so concerned with his health as

with how he got it and I think we all relate to

that."

-"They want to know how you got it and it goes back
to the homophobia. I don't know what their reaction
would be if you told people you were a drug addict
because you're a second class citizen even if you're
gay. Being gay, you're not accepted, being HIV
positive you're even less accepted, I guess."

-"If you're HIV, then they assume you are gay. If
you are gay, then they assume you are HIV. It's a
double edge."

Regardless of responses in the workplace, either
supportive or not, some members found that having this
disease was disabling them socially. This occurred because
of their choice to focus more of their attention on the
disease, their health management and emotional issues. This
appeared to result in increased introversion on their part
and thus the feelings of isolation from their co-workers.

-"Well, you could see how they looked at him. I knew
there was talk going on. But because I knew this
person and, you know, tried to make him comfortable.
I can remember one day, we had an in-service and it
was on CSP. No, not CSP, CPR training. sitting there
all by himself, we were in the cafeteria, everyone's
sharing tables and he's sitting there by himself.
So, I came in, I went and sat right next to him,
basically as an attitude, like, you know, 'You
people are assholes!'"

Work stood out clearly as a pivotal form of support, sense of identity, source of financial well being and source of purpose for most of the group members. The overall concern about how co-workers would respond reflects the desire to remain an integral part of the workplace for group members.

-"Work itself is helpful because its an escape. The actual work gave me a structure to get up, to go out because of that obligation and the actual work let me focus elsewhere away from the HIV."

-"Believe it or not, I had a very good reaction. Oh God, yes. He (the boss) said that they would all be supportive and they they will work with me, and that if there was any reason why I needed to slow down, they would work with me. And they encouraged me to talk to the Personnel Director at the time and they left it up to me so that if I needed anything, that I could talk to her. And I did and she was great."

Another facet of this disease was the fact that all but one was working full-time even though many members knew they were eligible for disability leave.

"One concern I have is the way the law reads. Your employer has to make reasonable accommodation for your illness and what does that mean? I can work thirty hours per week rather than forty hours per

week. Will that effect my paycheck and if it does,
will that effect my long-term disability
entitlement? I really feel it's all or nothing. I
really have to work forty hours per week or don't
work at all."

The importance of policies and health care benefits
were brought up often. Those who had good employer policies
and benefits programs were thankful and those who weren't
sure about their own, wanted better communication about them
from employers.

-"One of the things that helped me disclose my
status to my boss was that my institution had a
whole program around AIDS awareness. They has a
contest for someone to come up with a poster. The
poster said, 'You would be surprised who could get
AIDS.' And my boss had it outside her door and it
just, it's okay to talk about it."

The desire for support at work went beyond mere policy
and benefit programs, however. Group members talked
extensively about their desire for acceptance as someone
with a chronic illness, as a homosexual, as someone with a
need for accommodation, etc.. Being able to talk openly in
the workplace about their illness helped some, being asked
about their illness helped others. Seeing workplace
educational programs helped many feel more accepted and
understood. Having an employer initiate training and
educational programs also took a feeling of responsibility

away from the infected worker. He no longer had to be the one responsible for educating co-workers or supervisors or with dealing with the hostility or ignorance of some co-workers.

> -"They incorporated a training the day I went back. They gave a lecture on AIDS in the workplace, which was good, but you got to see just how ignorant people really were. They just don't know anything about it or don't care to know about it."
>
> -"When I disclosed my status at the workplace, I felt this (HIV) has to be their issue, not just my issue. Me experience has been nothing but educational for my supervisor. They never had to deal with 'My God, this guy has to leave every day at 3 p.m.' So, by example, by working late the days I could, by doing what I could do, they said, 'My God, he's a good worker." That set an example that 'he's still productive.'"

Some members were more willing than others to obtain or take advantage of legal protections that are provided through federal or state laws. Some did not know about these protections, others were hesitant and still others were assertive in their use of legal protections. The need for accommodation to have medical leave for doctors' appointments or rest was an important factor in motivating some to learn of their legal rights.

-"I've been out on my job and even more out when the
Mass anti-discrimination law came out. I felt there
are laws about discrimination against AIDS. That I
felt that if I was discriminated against, I would
use the laws and resources I had available. Since
the government was behind me, I would use that."

-"In a certain sense, part of what I've done my
whole life is not necessarily being distrustful, not
maybe being distrustful of individuals, but not
distrustful of laws so that I keep very careful
records, so I know I can prove what I have to."

-"The law is maybe there, but I think its the
implementation of the law that could be made more
aggressive."

Financial Concerns

HIV infection is an expensive disease. It has a
financial impact in two primary ways: the first is the cost
of treatment; the second is the loss of income from
inability to work at a former pace.

The quickest way to summarize much of the concern in
this area is something one member said about the fact that
if he worked less he would be paid less. This hits at the
core of most concerns, that with a disabling disease,
inability to work results in a loss of pay.

Many members were not clear about the benefits they
would receive under their disability policy. This was
aggravated by those who were not out in their workplace.
Others feared a change in their benefits program, either
because they were ill or due to changing economic
circumstances of their employer.

-"Being aware that AIDS is in my life, they don't
know its directed at me personally. So I have a lot
of support at work for many different things. My
only concern is the benefits. They are a big
concern, although I only use them once or twice a
year right now because I don't take medication or
anything. I wonder what will happen and how
insurance will change and how policies will change
or how much they'll go up and that type of thing. So
that's a bit of stress for me, especially seeing the
unbelievable costs for people with full-blown AIDS
right now. To maintain their health and stability is
in the thousands per month."

-"I'm on AZT and its every month. I picked up the
AZT last week and it was like $262. It's a good
thing that I have benefits. I don't have benefits; I
don't have $262 a month."

-"There's people in my life who spend $5,000 a week
just on one part of their medical regimen. And
that's $5,000 a week just for that. It doesn't
include their medications. It does not include their

follow-up doctors appointments. None of the lab
work, none of that."

-"I have a friend who has spent $81,000 in six
months. Covered, thank God. But that was just basic
things to stay alive. What would he do without
coverage? Having that around you if you do really
makes you think about that. Where you could be and
what not that you're going to get there, but it just
gives you a little piece of mind. And to know not to
say that these people couldn't get it through
Medicaid or had no money or these kinds of things.
But to know that it would be so much more difficult
or the level of care would just be so much less."

Job security also fell into this category. Certainly
the fear of losing one's job raised questions about
financial security. This concern was raised for at least two
reasons. One was due to the risk of being fired upon an
employer learning and the second was due to the inability to
perform in the job.

The Importance of and Difficulty with
Disclosing

Participants talked often of the difficulty of
disclosing their illness to co-workers and supervisors.
Those who had disclosed, talked of negative experiences
because of their action. These responses included: a lack of

confidentiality, pressure to perform, the responsibility to deal with co-workers' fears, etc.

Questions remained for those participants who have not disclosed such as who to tell and how to do it in the best way. The fear of harassment surrounded this issue and many felt it was comparable to coming out about their sexual orientation, if they had. Because of the sensitivity of that issue, there was fear of continued or repeated discriminations.

> -"For me, work is the last frontier, the only place I haven't told people I'm gay or my status. I'm worried about the financial impact it might have on me. If I were considered a financial liability to my company, there might be some way I could be phased out."

However, many talked of the burden of carry this secret. They mentioned the work it took to take leaves without explaining reasons, carrying emotional concerns by themselves, or dealing with the physical symptoms at work. Others talked about the comfort they received after they disclosed. Intimacy with co-workers was cited as a reason to disclose. A non-supportive boss was cited as a reason not to disclose.

> -"I want him to know so I don't have to lie or fib, so that if I have to take a morning off for a doctor's visit I'm not out looking for another job or screwing up. I really have some major concerns

about my health. I want to take that time off and

not be questioned about it."

-"I work probably 50 hours per week, but those times

I'm gone from work, I feel guilty. I haven't been

straight forward about my condition, I've told him I

have a serious blood disorder but I won't say the

word HIV."

For many, this was a very significant, on-going issue

as they questioned their presence and role in the workplace.

Concerns about the Future

For participants between the ages of 26 to 50 to have

to deal with a chronic illness, impending disability, loss

of income and perhaps death, forced them to question what

their future will be. Health, finances, social interaction

and career advancement were all raised as concerns by

participants. The future of each appeared to be depending on

a variable none could define: the quality of their health.

Questions were raised regarding the length of time left for

them to work; the status of pay, benefits and other support

programs; and the ability to change jobs. All of these

issues fed into a central question of how to get the most

out of life and for some, the meaning and purpose of their

life. That led to questions of values.

-"When I signed up for my insurance, they gave a whole

list of things. Have you ever had this problem, that

problem? They said, 'Have you ever been treated for AIDS?'
And I wrote, no, because I haven't been treated for AIDS. In
a way that was lying but in a way it wasn't. I feel like I
have to lie about it and I don't like to lie. I feel like
the system that we currently have in place in the job world
or any part of our lives, kinda sets us up."

What was clear was that the participants represented a
population in transition. Where they would end up remained
uncertain; the fact that it would be a different place from
where they were now was more certain. Issues impacting this
sense of change included self identity, physical and
emotional well-being, and financial and social status.

-"I felt that I needed for my own stress to be out
at my job about my HIV status because I needed to be
able to talk about the fact that I wasn't feeling
well, that I was depressed about being HIV
positive."

-"Depression really affected my work at a certain
point. I'm not the type of person who puts himself
into the task when I'm depressed, I go inward, so my
work suffered, so that affected my relationship with
my boss."

-"Not to mention it was also like telling them I was
gay. I'm 31 years old and these people all know me
and there were so many personal things that came up.
I thought about it. It was after the fact. It really
bothered me later on. Then it was just not right. I

also have a fear that with them knowing, they're
going to watch the costs and as you say, they might
get a lot higher, and they might design an insurance
in my situation where they can legally put a cap on
expenses."

Anger/Depression/Stress

This emotional condition of members is appropriate for
review last. It is impacted by all of the above issues. It
is also the clearest truth to come out of the research.
People with HIV infection have a tremendous number of issues
to deal with. For those who are continuing in their work,
those issues are magnified. Hearing the stories of those HIV
infected and working means hearing the emotional pain,
confusion and helplessness.

-"I'd like control in my life too because you give

up a lot of control of your own life. When I was

diagnosed in 1989 in Rhode Island, the woman who

diagnosed me really led me to think the wrong way.

She said that I had about two years to live...I put

school off for two years, actually three years. And

said, 'Well I can't become a nurse,' and basically

just slouched around. I ended my life. My life was

over. I didn't care what happened. I didn't work at

anything. I didn't focus on anything. Anyone who

knows me knows how miserable I have been."

-"I wonder if it's the same one who told my lover at the time when I had this particular health care worker say, 'What are you doing with this person? He's going to die. You're going to be living alone and have no one to take care of you. Why don't you leave this person?' I could take her and smack her in the head because she just caused so much turmoil in my life because of that."

Statements such as "I have a sense of my own death," may be appropriate for some in their 50s, 60s, 70s, or 80s. Hearing it from people in their 20s, 30s, and 40s was striking and sad for the researcher. Some of the participants experienced a great deal of sadness as well, others experienced frustration and anger.

-"Personally, I'm angry about these things and I'm learning how to cope with that. But if I go into work and I'm dealing with psychotic people that have an angry attitude, its going to come out in my ability to help them. It's going to show in my actions. I feel like I've really jipped the people that I'm supposed to be providing services for."

-"My fear is that the people would think I'm fucking off and I'm not an alcoholic. So I told the second in charge. She's a lesbian and I thought was really sensitive and a year later she used it against me because she wanted my job."

One noted that managing the anger was a lot of work. Others questioned what had become of their career and/or life aspirations.

-"I went from telling one person to telling five. I want their confidentiality and I think the more people you tell the more chances for a slip-up. I have the concerns about being labelled the fag. Out in life, I don't mind being called gay, but at work, I don't want people to know that."

Many talked about feeling trapped in their jobs, in part because of an inability to acquire benefits in a new job or a sense of no reason to move into unknown circumstances and added stress.

-"You lose a lot of the control in your life. That's one of the aspects of control - that you end up stuck in a job you don't like because of insurance issues. They have to stay in the job they have or they are afraid that they will be out there without insurance."

-"I do feel trapped in my job, that my life choices are much more limited than someone who's HIV negative."

-"I held back on going for a job I would have loved because I was HIV positive because that's a job of greater responsibility and that means when the time comes when I would have gotten sick, I would have been letting the organization down even more."

While the fear of death was not mentioned specifically, references were made to getting sicker or getting AIDS. The feeling of being overwhelmed by the diversity of issues was certainly echoed by many of the participants in various ways. The participants' feeling of being guilty or responsible did not help alleviate depression or anger. Instead, it was a likely contribution to the sense of low self esteem some were experiencing.

-"Not only do you have the feeling of letting the group down taking time off to go to the doctors."

-"I tend to work very long hours because I have this notion, whether it's true or not, that I will be considered lax during the times I'm not around, and that's difficult. I don't imagine that given my work environment there's a niche for someone who works half as much. It's never been seen before. They wouldn't know what to do with someone who's half as able as someone else."

-"There's not a day I don't worry."

Significance of the Data

In an attempt not to overlook the emotional content from the data, a summary of the impact of this data on the researcher is necessary. The reader may have responded to the content with a variety of emotional responses, the data are highly evocative. One's view of the many issues involved

174

in the research: homosexuality, disabilities in the workplace, chronic illness, death, etc., may also color the nature of one's response.

One article that drew attention to a parallel of suffering and death, and possibly two different social/personal responses appeared in the *Boston Globe*.

A 21-year-old honor student, athlete and graduate of Malden Catholic High School was reported found dead and lodged in a chimney of a fraternity house at Cornell University. He had apparently been out drinking and for unknown reasons, climbed into the chimney of a rival fraternity house, perhaps as a prank. He became lodged and died in the chimney.(Hart, 1993)

Reading the article left this researcher with a combination of feelings. The thoughts of the student's agony of entrapment, a slow and excruciating death, unheeded calls for help, and a life ended prematurely brought feelings of waste, sorrow and compassion. For what had he died? A simple college prank? A drunken spree? All seemingly inconsequential acts.

Upon reflection, the power of the feelings struck a parallel. They were similar to ones felt for members of the focus groups. All relatively young people, all being trapped by a disease not able to be cured, all being ill for engaging in acts that might be considered a spree of youth. All having their lives cut short. Yet, the response from society does not parallel the response of many who read the

Malden youth's obituary. Seldom is there understanding,

compassion or support. Instead of people seeing the

suffering, they see the cause. Instead of compassion and

grief, there is often judgement and alienation.

Hopefully, more data on what is happening to the lives

of those with HIV infection will enlighten more people to

the reality of suffering and perhaps even their ethics.

Challenges for the Researcher

The use of focus groups to gather information

regarding the issues confronting working people who are HIV

infected was productive. For two hours, groups of men talked

about their issues and concerns. The discussion was begun

with a clear explanation of confidentiality in an attempt to

create and environment of safety and trust. From the length,

depth and intimacy of the items shared, it appears that

members felt safe enough to share information about their

current experiences at work. The researcher did not dwell on

items beyond obtaining clarity of the content. From this

facilitative behavior came one of the more difficult aspects

of conducting the focus groups. Trained as both a counselor

and educator, it was hard to gather items that reflected

either a lack of understanding of laws, or external

circumstances and not be able to try to increase the

understanding of participants. It was also hard not to try

to offer developmental options or engage the group in option

generation in response to the fact that some participants demonstrated a lack of personal development, confidence or esteem, etc. However, the basic assumption driving the facilitation of the Focus Groups was minimal involvement of the facilitator to maximize item generation by the members and to stay focused on the generation of items, rather than on their impact on the individual or his personal stage of development

Participants appeared relaxed and involved in the discussions of each group. They did not appear to hesitate to add their personal opinion of issues and revealed fairly intimate and personal comments. There were reasonable variations in member participation with only one member who remained overly withdrawn. Each group ran until items for discussion appeared to be exhausted, which in all cases kept within about ten minutes of the two hours.

As many of the group members were already members of support groups, the facilitator felt it necessary to differentiate between the goals and structure of the two groups. All participants were introduced to the focus group process as one used to generate ideas, not one where there would be debates of relative value, problem resolution or even personal growth. "We are here to generate information, not to try to solve problems," the facilitator stated before each group.

CHAPTER 5

CONCLUSIONS

<u>Review of Research Objectives</u>

In reviewing the objectives for this research project
they were:

1., To learn more about the important concerns and
needs of those who are working and HIV infected;

2., To determine the diversity of needs among various
individuals;

3., To understand better how employers can meet these
needs; and

4., To establish a basis for future research to
support employers, social service providers and those with
HIV infection as they continue to struggle with issues of
work and maintaining health.

We have gathered information that responds to
objective 1. These findings comprised the bulk of Chapter 4.
Objective 2 remained more elusive to this project, however,
and will be discussed in more detail later in this chapter
in conjunction with future research (objective 4).

Objective 3, how employers respond to the needs of
employees with HIV infection, is in part already understood
by employers and yet, needs to be redefined according to the
findings of the research.

What Employers Can Do

If employers are to effectively meet the needs of those who are working with HIV infection, they will have to go beyond the existing guidelines published by many organizations. These guidelines currently include the need for policy development and education of employees. We are not suggesting any less, but rather the acceptance of the need for more. In other words, employers have to begin to address the deep-seated biases and prejudices that prevent workers with HIV infection from receiving comparable treatment as those with other chronic illness in the workplace. Employers also need to accept the fact that workers with HIV infection feel vulnerable from a personal, financial and employment perspective. These emotional issues require both a lot of adjustment on the part of the employee and a lot of support on the part of the employer. The employment, health, social, or financial future for those with HIV infection is neither clear nor optimistic in most cases. This results from factors in both the workplace and personal life and impacts on both. The prospect of disability or even death, is not a pleasant one. The cost of health care and the uncertainty of medical benefits adds more uncertainty to the lives of those with HIV infection.

Additionally, the responses of co-workers remains an unknown variable for many with HIV infection. The fear of

isolation or ridicule resided in the minds of many of those in the groups. Yet, for most participants, work remained central to their existence. For employers, this means both increasing their understanding of the issues surrounding HIV infection in the workplace, developing programs that respect the privacy of those infected and increasing and improving the awareness of co-workers and managers. In conclusion, this means that merely having policy statements and sporadic training will not effectively meet the needs of either hose infected or their co-workers.

What's Happening for Those with HIV Infection

Conducting four focus groups and listening to the talk of 24 men who are both HIV infected and working led to several conclusions regarding their status. The participants represented various levels of education, job classifications and employer types. Racial diversity was also represented. The messages heard reflected a relatively uniform set of concerns. They have been catalogued previously. The overall result of this research informs both employers about how to respond and readers about the plight of those with HIV infection who still remain in the workforce.

The first is the realization of the turmoil that exists in these men's lives. This turmoil is promulgated by several factors. One is of course their HIV status. Dealing with a chronic illness, with no known cure, a highly

180

controversial treatment and many debilitating symptoms, results in turmoil: emotional, physical and psychological. Second, these men are dealing with social issues regarding the means of contagion, whether that be sexual behavior or intravenous drug use. Neither position receives favored treatment, general support or understanding in this society. Isolation, fear and questioning easily accompanies either position. Third, these men are dealing with an unexpected severity of disease for their age that forces them to reconsider life goals and values.

Any one of these issues would likely create turmoil for many in our society. Combined, it becomes easy to understand the stress, anxiety, depression, anger, fear and isolation that is so common for people with HIV infection. When we combine these concerns with the specific issue of work, the scenario becomes more complicated.

Work is a means of financial and personal support for many people. That remains true for those with HIV infection. It becomes more complicated however, as the number of variables these people are dealing with is greater than most. The impact of these variables (physical, emotional, psychological, financial, social, etc.) coming together can mean a lot to this researcher, social service providers and employers. Exactly how requires further consideration. Based on this research, some conclusions are as follows.

Many people with HIV infection are in need of continued support for coping with issues raised by working with HIV infection. This support in the workplace should include clear information about the specific and general policies of employers in regard to HIV infection, disability coverage, health insurance benefits and reasonable accommodation. Because of the desire of some people to keep their HIV status private, this information has to be disseminated on an on-going basis to all employees. One apparent problem with responses to HIV infection is that employers often wait until the problem appears in their workplace before providing education or supportive programming. This puts an increased burden on the infected worker to either obtain necessary information surreptitiously if he or she wanted to maintain confidentiality, or be forced to make a much more significant decision about disclosure to get that information.

Reasonable accommodation, a mandated form of workplace support for those with disabilities, is required by law and means that employers have to modify either the working environment or conditions, including hours and positions, to enable a disabled employee to continue to work. Many of those in the groups did not know their employer's policy regarding this. Nor did they know what impact a change in

job might have on their earnings. The decrease in physical vitality combined with an increased need for medical attention both require accommodation for some workers.

Another form of support can be provided on the job, but is often found off the job, and includes psychological and emotional support. Because this form of support can help infected people understand the emotional and physical challenges created by the disease, it helps them normalize it and increase or maintain their productivity.

The need for medical support requires good health benefits on the job and clear information about both what it is and how to access it.

Social Issues, Homophobia and Oppression

Part of the issue of dealing with HIV infection is wrapped up in moral and social issues. It appears that employers are still not comfortable keeping the issue of HIV infection an ongoing dialogue between management and employees, regardless of the extent of the disease. From talk of participants and an understanding of social issues, it becomes hard to separate the issues of sexual orientation or drug use from this difficulty. Members of the groups from all types of work, education and economic levels addressed the anxiety and fear they face in relation to isolation, homophobia or ignorance. This paper will not address the topics of sexual orientation or drug use in detail, but can

address the need for employers to overcome the discriminatory and oppressive tendency to keep this disease and the challenges it creates a secret. Keeping information about medical benefits, company policies and reasonable accommodation open and available is only a start. Helping managers, co-workers and infected workers understand the issues surrounding this disease and expected behaviors and support in response to it requires more work and attention.

A second area is education about HIV infection. Employers have to take this educational process proactively if they want to respond to the needs of their infected employees and their co-workers. Responding only after an employee is identified with HIV infection not only puts great emotional burden on that employee, it ignores his or her needs during the months and years that he or she is silent about the disease. A suggestion brought up in the groups was to have information updated frequently and to bring in panels of people to talk about the subject. These panels could include people who are HIV infected but not employees themselves. Participants talked of the positive level of support that they felt when the subject of HIV infection was one that co-workers felt comfortable talking about. Management can foster that talk.

It is important to remember that those with HIV infection can not be held responsible for educating their co-workers on issues surrounding HIV infection. Employer programs have to distribute information regularly as well as

keep it available to all employees and managers. The problem
with having those with HIV infection responsible for
educating both co-workers and management about the issues
surrounding the disease is that these workers then become
both the recipients of ignorant thinking, hostility or lack
of understanding plus, they can begin to feel burdened with
the responsibility for changing co-workers behaviors or
attitudes. That is an added burden at a time when these
people are bearing burden enough.

Managers and personnel also have to receive training
on legal requirements of maintaining the confidentiality of
disclosure by those with HIV infection. The topic of having
their disclosure shared with co-workers, other supervisors
or management was repeated in group after group. Currently,
many members were not assertive or clear about their legal
right to privacy of medical records, but in the future
litigation could increase if employers continue to violate
this basic right of all employees.

In responding to any social issue of oppression,
change is a long-term opportunity. Employers will benefit
from the opportunity presented them by the HIV infection to
begin to educate their employees to the diversity of their
workforce and the needs of all to become more understanding
and accepting of difference. If nothing else is done, co-
workers and managers need to understand the severity of this
disease for what it is, not for how it was caught. People in
the groups clearly demonstrated that various levels of

suffering that are occurring for them, both in and out of the workplace. Employers have a responsibility to this group, as to any group of employees to make work as productive, rewarding and enriching as possible. Ending discrimination, fear or recrimination is a significant next step.

HIV infection is not an indication of moral laxity or irresponsibility. Those who are infected are sick; their attitudes toward work, career and success do not change substantially. One message that came through repeatedly is that members of this group are often struggling to continue proving they can still be productive, creative members of the workforce. They are struggling against the odds of social and medical complications, but their motivation is still intact.

The Severity of the Disease

Employers need to recognize and respond to the vulnerability of employees with HIV infection. This speaks to the issue of privacy, but also speaks to the emotional state of these workers. The point that these employees are dealing with a chronic illness is reason alone to understand and respond to their vulnerability. We have already discussed the other elements adding to their feeling of vulnerability. Personnel offices, as well as co-workers and

managers, need to be more aware of this state and develop effective institutional and personal responses to it.

Feeling supported and understood by a manager or employer can do a lot to maintain both the morale and productivity of an infected employee.

Employers need to understand that employees with HIV will very likely have changed behaviors. This may include the need for medical leave or it may mean behaviors resulting from increased emotional stress from coping with the disease.

The difficulty which many employees have disclosing their health status may be an indication of the need for employers to be more pro-active in many areas. Education means more than knowing what the disease is and how it is transmitted. It requires an understanding of the complex issues being faced by employees with the infection and helping co-workers and managers understand this as well.

Learning to give people with HIV infection the same support we give to those with heart disease, cancer or other chronic illness may be the next big challenge for the workplace. The fact that people with HIV infection are in the workplace talks of their commitment and motivation. Most people with HIV infection are eligible for disability leave. They chose however to remain working. They expressed a lot of caring about what they do and how they do their job. They wanted to be seen as someone who continued to perform well, and in some cases be eligible for promotions and job

changes. Employers may need to keep the perspective that HIV

infection is a long-term chronic illness and disability that

does not immediately disable employees but rather one that

allows for about 14 years of continued employment.

According to Richard Williams, Manager of AIDS

Awareness Programs at Polaroid Corporation, "My experience

has been that when a person learns that a co-worker has HIV

disease, he or she often feels that he/she doesn't know what

to say or do. The purpose, therefore, of the *When a Co-*

worker has AIDS brochure is to reassure people that, in

general, they do know what to do and say by giving them

concrete suggestions and to empower people with some basic

AIDS information and resources to which they can turn."

(1993, i)

Implications

For Workers with HIV infection: Workers with HIV

infection should become more proactive in their

understanding of laws and policies in regard to workplace

issues. They should seek out support and networking with

other workers with HIV infection and they should understand

that much of what they are coping with goes part and parcel

with any chronic illness. However, they should also become

familiar with social issues, homophobia and disability to

feel less guilty, deficient or responsible for the behaviors

of others.

For employers: Much has been said already about the need for employers to become more responsive to and understanding of the issues surrounding this disease. They also need to communicate policies and benefits more assertively, rather than waiting for the issue to surface in their workplace.

For co-workers: Co-workers should become more aware of HIV infection and its impact on people both in and out of the workplace. They need to understand that HIV infection is much like any other chronic illness and respond in much the same way they would to someone with cancer, heart disease, etc. They should separate causes of the disease with impact of the disease and begin to see those with HIV infection as people who are ill.

Co-workers would benefit from understanding that while they may be frightened of catching HIV infection from those in their workplace it is highly unlikely. At the same time, those with HIV infection are genuinely fearful of catching the diseases that otherwise healthy co-workers may be carrying.

For personnel offices: Personnel offices need to respond to workers with HIV infection with more support and compassion as well as with an increased understanding of the laws protecting these workers. Support and compassion includes respecting the privacy of infected people, understanding of the complexity of the emotional and social issues surrounding the disease and providing a degree of

security around job, benefits and company policies.
Personnel staff also need to more clearly understand the
laws and how it requires reasonable accommodation,
confidentiality of medical records, disability, and the
right to employment for those with disabilities.

Future Research

Future research needs to continue to learn more about
the specifics of issues impacting those with HIV infection
in the workplace. A random survey of people throughout the
country would be an ideal way to begin to understand more
about the patterns of behavior and needs in the workplace.
Surveys targeting various work sites would begin to build
data for all of us to understand the variety of needs being
experienced by HIV infected workers. Gathering demographics
on various factors such as size of employer, type of
funding, product, benefit plans, HIV policies, educational
programs, etc., would allow us to see what and how factors
vary across these criteria. Continuing to develop this data
base can only help co-workers, educators, social service
providers, managers, personnel staff, family and friends
understand how to effectively respond to and support those
with HIV infection.

A vaccine or cure for HIV infection still appears to
be off in the indefinite future. Knowing more about what is
happening with this disease in the workplace and the impact

of these variables can inform others about how to develop,

disseminate policies; how to support both those with

infection and co-workers; social and cultural issues in the

workplace, etc.

Expanding that research to study the issues of concern

for the various other groups in the workplace in response to

HIV infection would also be helpful. Learning more about the

perceptions of co-workers, managers and personnel staff

would help to identify areas for education or dispel myths

some with HIV infection may be holding. In either case,

gathering this information would allow for a more complete

understanding of the impact HIV infection is having on the

people in the workplace.

APPENDIX A

CONSENT FORM

I am John Rich, a doctoral student at the University of
Massachusetts in Amherst and an administrator at the University of
Massachusetts in Dartmouth. The subject of my doctoral research is
"HIV Infection in the Workplace: Its Impact on the Infected Employee."
To further that research, I am conducting this Focus Group of HIV-
positive people who are also working.

Thank you for agreeing to participate in this research. After I
outline the structure and purpose of our Focus Group, we will spend
approximately two hours discussing issues and concerns you have in the
workplace as an HIV-positive individual. There will be no right and
wrong concerns, rather, all information will be considered for
inclusion in this research.

As a participant in this research project, you have several
rights. First, your participation in the group is entirely voluntary.
You should have had no pressure from anyone to volunteer; you are free
to refuse or to decline to participate at any time and to leave the
group. Secondly, all information you share will be used for research
purposes only and held in strict confidence. It will be available only
to myself and the professors who will review my work at the University
of Massachusetts in Amherst. The group will be audiotaped and the tape
will be transcribed by a person unconnected with you. Your name or the
name of your employer will not be recorded and will not appear on the
tape or be transcribed. In the final dissertation or in any subsequent
publication or presentation, I will present only group information;
any excerpts from your discussion that may be used will not include
sufficient detail about you for anyone who knows you to determine that
it was you who gave that information. In addition, as a participant,
you agree to maintain the confidentiality of information and/or
discussion you hear as a member of this group.

I will be happy to provide you with a final copy of the
dissertation abstract developed as a result of this group. If you have
any questions about this project, please feel free to ask before or
after the group or later. You may contact me at:

John Rich
45 High Street
Jamestown, RI 02835
(H) 401-423-3663
(W) 508-999-8659

I, _____, have read the above
statement and agree to participate in this Focus Group under the
conditions stated in this consent form.

_____
Signature of Participant

Please check below if you would like to receive a copy of the
following: __dissertation abstract
Address for those requesting copies of material:

_____

_____

DEMOGRAPHIC INFORMATION SHEET
(Optional Information)

Age:_____   **Gender**:   Male___Female___

Race: **Sexual Orientation:**

Caucasian___   Gay___

African American___   Straight___

Asian___   Bi-sexual___

Cape Verdean___   Other:_____

Hispanic___

Native American___

Time since diagnosis:_____

Means of infection: Sexual contact___

   (If known)   Intravenous drug use___

                      Transfusion___

                      Other:_____

Symptoms to date: None___

                      Other, please explain _____

_____

_____

Occupation:_____

Length of employment in occupation:_____

Work status: Full Time___   Part Time___

Educational level: High School___

                      Some College___

                      College graduate:___

                      Graduate Degree:___

                      Other:_____

Payment status: Hourly___   Salary___

   Does work provide health insurance: Yes___   No___

APPENDIX C

COMPOSITE POLICY

(Company) is committed to maintaining a healthy and safe work environment for all employees, as well as providing support for individual employees who may be facing the trauma of a life-threatening or catastrophic illness.

The AIDS epidemic and the spread of infection from the human immunodeficiency virus (HIV) is causing concern in many segments of society. Consequently, some employees may be experiencing anxiety about the possibility of working with a person who has become infected.

The purpose of this policy is to support the physical and emotional health of all employees, minimize disruptions to productivity and morale caused by the presence of a worker with a life-threatening or catastrophic illness, and demonstrate the company's continued commitment to our affirmative action goals related to physically handicapped employees.

As a general principle, the company recognizes that an employee facing a life-threatening or catastrophic illness may wish to continue to work as long as he or she is able. If an individual is able to work, he or she is expected to be productive; if the individual cannot work, then he or she is eligible for health and disability benefits, as specified in (other policies).

As with an handicapping condition, the company will make reasonable accommodations for an employee as long as such accommodations are practical and economically feasible, and in the best interest of the employee and the business unit.

The company reserves the right to ask its appointed physician to examine an employee with a life-threatening or catastrophic illness to determine that this individual is able to work and poses no threat to himself/herself or to others.

The policies and procedures outline herein apply to all disabilities and do not change any existing medical, benefits, or employee relations policies covering sickness or disability.

SPECIFIC ACTIONS

1. SPECIAL COORDINATOR APPOINTED

To help all employees understand and deal with problems that may arise from AIDS or other life-threatening illness, (name) has been appointed special medical coordinator. He/she has the background, experience, and training to deal with this subject, and can be contacted at (phone number). The medical coordinator will:

    a. Answer all questions that relate to these diseases;
    b. Refer employees to proper medical resources, agencies, and organizations that provide tests, treatment, assistance, and support;
    c. Discuss assistance and benefits;
    d. Consult with the employee, his/her physicians and supervisor or manager about any necessary reassignment or adjustment in duties or hours;

194

e. Circulate the most current information available on this subject to properly inform employees; and
f. Coordinate and conduct seminars or other programs for co-workers and managers of sections or department related to AIDS or other life-threatening illness.

All employees are encouraged to use the special coordinator as a resource person as needs arise.

2. CONFIDENTIALITY ASSURED

In every instance, the special medical coordinator will take every precaution to see that information about an employee's medical condition is kept strictly confidential. Supervisors and managers should also recognize that medical information is personal and confidential and take all reasonable steps to assure confidentiality.

3. AIDS SHOULD BE REPORTED.

Any employee who has reason to believe that he or she has become infected with the human immunodeficiency virus or any other condition that poses a serious threat to health should contact the special coordinator, on a confidential basis.

Any employee who has tested positive for HIV infection or is being treated for AIDS or ARC should report this fact to the special medical coordinator to ensure that he or she will be eligible to receive support and benefit programs.

A supervisor or manager who learns that an employee has HIV infection or any form of HIV-related illness should counsel that the employee contact the special coordinator. The supervisor or manager may, with the employee's permission, inform the special coordinator of the employee's condition.

4. EMPLOYMENT TIES TO PERFORMANCE

Because HIV infection may take more than five years to seriously affect a person's functional abilities, he or she may be able to work for a long time without any restrictions or problems. As long as an employer is able to perform his or her job properly and meet the standards set for performance, and as long as medical evidence shows that continued employment does not endanger either the individual or co-workers, an employee with HIV infection should and will be allowed to continue working. Employees with HIV infection are entitled to the same working conditions as others and will receive coverage under our various support and benefit programs, as eligible. If, in the course of time, a person with HIV-related illness cannot perform his or her duties, we will make whatever arrangements are necessary to allow that person to work within reasonable limits of his or her capabilities. The person may be assigned to jobs or hours he or she can work. In no case will an employee with HIV infection or any other infectious disease be automatically or summarily discharged.

5. UNDERSTANDING, NOT IGNORANCE.

Employees will be asked to be sensitive to the needs of critically ill colleagues. Continued employment for an employee who is seriously ill may be beneficial, both for personal and for financial reasons.

Next to prompt, professional medical treatment, the most important help that a person with AIDS can get is the understanding and compassion of relatives, friends, and co-workers. In many cases, it is far worse to be shunned by others and lose one's place in society than to suffer the slow progression of disabilities that come from this disease. A policy cannot order anyone to be kind and considerate to the victim of a life-threatening or catastrophic illness. However, we sincerely hope that every employee will do everything in his or her power to make each day a person with AIDS works an affirmation of all that is good and decent in human spirit. (Bohl, 1988, p. 62-65)

OUTREACH PUBLICITY

Input Sought!

Are You HIV+ and Working?

Attend one of two Focus Groups:
Friday, Feb. 26 and Friday, March 3
7 to 9 p.m.

Confidentiality Insured

$25 Reimbursement

POSITIVE DIRECTIONS
140 Clarendon Street, Suite 805, Boston

Call Jack Smallcombe at 617-262-3456 for more
information

You are invited to participate in a Focus Group as part of a research project to explore the issues of people who are HIV positive and working. There will be two groups at Positive Directions: Friday, February 26 and Friday, March 5 both from 7 to 9 p.m. Confidentiality is assured for all participants and a $25 fee will be provided as reimbursement for time and expenses. Participants will only need to attend one of the two groups, whichever is convenient.

As someone who is HIV positive and working, you know there are many issues that are facing you now that were not present before. The purpose of the group is to have participants discuss these issues to both list and clarify them. There will be no need to discuss your name, employer or any other personal information.

The groups will be run by John Rich, a doctoral student at the University of Massachusetts Amherst. John is also Director of Career Services at the University of Massachusetts Dartmouth and has run a support group for HIV positive people for three years in Providence.

Anyone interested in contributing to this research can contact Jack Smallcombe at Positive Directions 617-262-3456 or John Rich at UMass, 508-999-8659 or home at 401-423-3663.

As many involved with the issues of HIV infection may know, people who are HIV positive are often also employed in various forms of work. While HIV infection does not prohibit individuals from working, it may present that individual with new challenges, needs or interests. Much research has been done on the issues employers face in dealing with HIV infection in the workplace, not as much has been done to learn about and understand the issues faced by individuals who are HIV positive and working. To learn more about that topic, a Focus Group will be held for interested individuals.

Individuals who are HIV positive, working in some context at least part-time and are interested in participating in this confidential Focus Group should call for more information. The group will focus on the issues and concerns people who are HIV positive are facing in the workplace. It will last for about two hours and require one meeting only.

Information gained from the Focus Group will be strictly confidential and used for research purposes only. There is no need for anyone to disclose specific place of work, supervisor or any other specific information about the job. Names of individuals will also not be a part of the research project.

The group will be run by John Rich, a doctoral candidate in Organizational Development at the University of Massachusetts in Amherst. He has also run an HIV support group in Providence for three years and is employed at the University of Massachusetts Dartmouth as Director of Career Services.

Anyone interested in participating in the group should contact John Rich at 508-999-8659 during the day or 401-423-3663 evenings.

FACILITATOR'S OPENING REMARKS

"Hello, my name is John Rich and I am a doctoral student at the University of Massachusetts Amherst in organizational development and applied group studies. I am here today to conduct a focus group discussion around the topic of issues of concern in the workplace to people with HIV infection. This interest of mine has developed from my three years of facilitating a support group for HIV positive men. During that time, I heard many of the issues that HIV positive people faced in relation to working. I became interested in doing more systematic research on this subject and have included it in my doctoral program.

We will be meeting for approximately two hours. During that time each of you will have an opportunity to talk about your issues and concerns at work. To begin our discussion, each one of you will have a brief opportunity to introduce yourself to the group. This introduction can include information such as your name, what you do for work, how long you have been doing it and perhaps how long you have been HIV positive.

After everyone has had an opportunity to introduce himself or herself, we will begin to talk about issues of particular concern to you regarding work. I want to encourage you all to say what comes to mind, and think of any comment as a contribution as there are no right or wrong feelings here. I hope all of you will respect the thoughts and feelings of other members and not judge them.

As you all know, what we say here is to remain confidential. That means we agree not to share details of what a person says or even who was here.

My role will be to keep the discussion on topic and to help clarify what has been said. I appreciate only one person speaking at a time.

I have given each of you a copy of the consent form I am required to have you sign. Please read it now and ask me any questions you may have about it. Thank you for agreeing to participate and remember any of you are free to leave at any time."

BIBLIOGRAPHY

Alexander Hamilton Institute, Inc., *What Every Manager Should Know About The Americans With Disabilities Act,* Maywood, NJ.

Altman, Lawrence K., (1992), "Women Worldwide Nearing Higher Rate for AIDS Than Men," *The New York Times,* July 21, New York, N.Y. C 3.

Axelrod, Myril, D., (1979), "Marketers Get an Eyeful When Focus Groups Expose Products, Ideas, Images, Ad Copy, etc. to Consumers," *Focus Group Interviews: A Reader,* Higginbotham, James B.; Cox, Keith K., eds., American Marketing Association, Chicago, IL

Bangura, Abdul Karim, (1992), *The Limitations of Survey Research Methods in Assessing the Problem of Minority Student Retention in Higher Education,* Mellen Research University Press, San Francisco, CA.

Barr, Judith D., ScD.; Waring, Joan M.; and Warshaw, Leon J., M.D., (1991) "Employees' Sources of AIDS Information: The Workplace as a Promising Educational Setting," *Journal of Occupational Medicine,* Vol. 33, No. 2, February, Baltimore, MD.

Bayer, Ronald, Levine, Carol, and Wolf, Susan, (1989), "HIV Antibody Screening: An Ethical Framework for Evaluating Proposed Programs," *The AIDS Epidemic,* O'Malley, ed., Beacon Press, Boston.

Bayless, Pamela, (1989), "AIDS at Work in N.Y.: Fear, Evasion, Lawsuits," *Crain's New York Business,* March 20, 1,29, New York.

Behling, John H., (1984), *Guidelines for Preparing the Research Proposal,* University Press of America, Inc., Lanham, MD.

Bellenger, Danny N., Bernhardt, Kenneth L., and Goldstucker, Jac L., (1979), "Qualitative Research Techniques: Focus Group interviews," *Focus Group Interviews: A Reader,* Higginbotham, James B.; Cox, Keith K., eds., American Marketing Association, Chicago, IL

Berry, William D., & Lewis-Beck, Michael S., editors, (1986), *New Tools for Social Scientists: Advances and Applications in Research Methods,* Sage Publications, Inc., Newbury Park, CA.

Biel, Alex, (1979), "Focus Groups: The Most Abused Form of Research," *Focus Group Interviews: A Reader,* Higginbotham, James B.; Cox, Keith K., eds., American Marketing Association, Chicago, IL

Black, Paul H., and Levy, Elinor M., (1988), "The HIV Seropositive State and Progression to AIDS: An Overview of Factors Promoting Progression," *The AIDS Epidemic,* O'Malley, ed., Beacon Press, Boston.

Bohl, Don L., editor, (1988), *AIDS: The New Workplace Issues,* American Management Association, New York.

Brockhoeft, John E., (1989), "AIDS in the Workplace: Legal Limitations on Employer Actions," *American Business Law Journal,* v. 26, summer, 255-301, Austin, TX.

Brostoff, Steven, (1988), "Insurers Reject D.C. AIDS Amendments," *National Underwriter,* v. 92, N1, 1-26, Cincinnati, OH.

Carelli, Richard, (1992), "Court Asks US View on AIDS Suit," *The Boston Globe,* March 31, Boston.

Centers for Disease Control, (1993), "1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS among Adolescents and Adults," *Morbidity and Mortality Weekly Report, V.* 41, December 18, Atlanta, GA.

Centers for Disease Control, (1981), "Pneumocystis Pneumonia - Los Angeles," *Morbidity and Mortality Weekly Report,* V. 30, June 5, Atlanta, GA, pgs. 250-2.

Centers for Disease Control, National AIDS Information Clearinghouse, (1990), *AIDS and the Workplace,* Atlanta, GA.

Centers for Disease Control, (1985), "Recommendations for Preventing Transmission of Infection with HTLV type III/LAV Virus in the Workplace," *Morbidity and Mortality Weekly Report,* V. 34, 681-90, Atlanta, GA.

Centers for Disease Control, (1986), *Morbidity and Mortality Weekly Report,* V. 35: 334-339, Atlanta, GA.

Centers for Disease Control, (1987), "Recommendations for Prevention of HIV Transmission in Health Care Settings," *Morbidity and Mortality Weekly Report, Supplement,* V 36, supplement 2s, Atlanta, GA.

Centers for Disease Control, (1988), *Update: Universal Precautions for Prevention of Transmission of Human Innumodeficiency Virus, Hepatitis B Virus, and Other Blood-borne Pathogens in Health-Care Settings*, V 37. 377-382, Atlanta, GA.

Centers for Disease Control, (1991), *1992 Revised Classification System for HIV Infection and Expanded AIDS Surveillance Case Definition for Adolescents and Adults*, Atlanta, GA

Cimons, Marlene, (1992), "Few AIDS-like Virus Signs Found in New Ill," *The Boston Globe*, August 10, Boston, MA.

Citizens Commission on AIDS for New York City and Northern New Jersey, (1989), *Responding to AIDS: Ten Principles for the Workplace*, New York.

Cobb, Sharon A., (1989), "Facing Up to AIDS Issues in the Workplace," *Employee Relations Law Journal*, v. 15, n. 3, Winter 1989-90, 457-68, New York.

Cohen, Cynthia F. and Murray E., (July, 1989), "AIDS in the Workplace: Legal Requirements and Organizational Responses," *Labor Law Journal*, V 39, N 7, 411-18.

Congressional Quarterly Almanac, (1990), *Bush Reluctantly Signs AIDS Measure*, v XLVI, 582-589, Washington, D.C.

Cox, Keith K, Higginbotham, James B., and Burton, John, (1979), "Applications of Focus Group Interviews in Marketing," *Focus Group Interviews: A Reader*, Higginbotham, James B.; Cox, Keith K., eds., American Marketing Association, Chicago, IL

Cramer, David, (1989), "The HIV-Positive Individual," *No Longer Immune: A Counselor's Guide to AIDS*, Kain, ed., Alexandria, VA.

Craven, Donald, (1989) "Human Innumodeficiency Virus in Intravenous Drug Users: Epidemiology, Issues, and Controversies," *The AIDS Epidemic*, O'Malley, Beacon Press, Boston.

Crimp, Douglas, (1990), *AIDS Demographics*, Seattle, Bay Press.

Curran, William J.; Clark, Mary E.; Gostin, Larry, (1987), "AIDS: Legal and Policy Implications of the Application of Traditional Disease Control Measures," *Law, Medicine & Health Care*, Summer, Vol. 15, 27-35.

Dauer, Christopher, (1991), "Lloyd's Disavows Controversial DI," *National Underwriter*, v. 95, May 3, Cincinnati, OH.

Durity, Art, (April, 1991), "The AIDS Epidemic: As Workers Die, AIDS becomes a Business Issue," *Personnel,* V 68, N 4, American Management Association, New York, p. 1.

Eckholm, Erik, (1992), "AIDS, Fatally Steady in the U.S., Accelerates Worldwide," *The New York Times,* Sunday, June 28, New York, N.Y. E 5.

Emery, Alan R., and Puckett, Sam B., (1988), *Managing AIDS in the Workplace,* Addison- Wesley Publishing Co, Inc., Reading, MA.

Employee Benefit Plan Review, (October, 1989), "Benefits Top List of Workplace Problems", Charles Spencer, Assoc., Inc., Chicago, pgs. 26-7.

Feldman, Stuart, (1991), "Establishing an AIDS Program: A Job for Champions," *Personnel,* April, V 68, N 4, American Management Association, New York, p. 8.

Feldman, Stuart, (1991), When It Comes to AIDS, It's Survival of the Smartest," *Personnel,* April, V 68, N 4, American Management Association, New York, p. 6.

Foreman, Judy, (1991a), "AIDS' Relentless Onslaught: Infections Heading Past 10M Mark; Outlook Grim," *The Boston Globe,* November 25, Boston.

Foreman, Judy, (1991b), "Putting AIDS Scourge in Perspective," *The Boston Globe,* November 18, Boston.

Forstein, Marshall, (1989), "Understanding the Psychological Impact of AIDS: The Other Epidemic," *The AIDS Epidemic,* O'Malley, ed., Beacon Press, Boston.

Georgia Department of Human Resources, (1988), *AIDS Training Manual,* Division of Public Health, Office of Infectious Disease, AIDS Program, Atlanta, GA.

Georgia Department of Human Resources, (1990), *AIDS Training Manual, Revised,* Division of Public Health, Office of Infectious Disease, AIDS Program, Atlanta, GA.

Glaser,Chris, "AIDS and A-Bomb Disease: Facing a Special Death," *The AIDS Epidemic,* O'Malley, ed., 251-256, Beacon Press, Boston.

Goldman, Alfred E., (1979), "The Group Depth Interview," *Focus Group Interviews: A Reader,* Higginbotham, James B.; Cox, Keith K., eds., American Marketing Association, Chicago, IL

Goldman, Charles D., (1992), "ADA Compliance May Turn on
   Changing Attitudes," *ADA Monthly Bulletin,* Thompson
   Publishing Group, Washington, D.C.

Gostin, Lawrence O., JD, (1990), "The AIDS Litigation
   Project: A National Review of Court and Human Rights
   Commission Decisions, Part 1: The Social Impact of AIDS,"
   Journal of American Medical Association, Cole, Helene M.,
   ed., April 11, Vol. 263, No. 14, 1961-1974.

Green, Arlee C., (1991), "Educational Effort Seeks to Cure
   Worker Concerns on AIDS," *AFL-CIO News,* March 18,
   Washington, D.C.

Haney, Daniel Q., (1992) "Harvard AIDS Study Sees 120
   Million Infections by Decade's End," *The Boston Globe,*
   June 4, Boston, MA.

Hannah, Maggie, (1979), "A Perspective in Focus Groups,"
   Higginbotham, James B.; Cox, Keith K., eds., (1979), *Focus
   Group Interviews: A Reader,* American Marketing
   Association, Chicago, IL

Hart, Jordana, (1993), "Student from Medford Found Dead in
   Chimney," *The Boston Globe,* January 20, Boston, MA.

Higginbotham, James B.; Cox, Keith K., eds., (1979), *Focus
   Group Interviews: A Reader,* American Marketing
   Association, Chicago, IL

Hunter, Nan, (1990), *Epidemic of Fear: A Survey of AIDS
   Discrimination in the 1980s and Policy Recommendations for
   the 1990s,* American Civil Liberties Union, New York.

Kaden, Robert, J., (1979), "Incomplete Use Keeps Focus Group
   from Producing Optimum Results," Higginbotham, James B.;
   Cox, Keith K., eds., (1979), *Focus Group Interviews: A
   Reader,* American Marketing Association, Chicago, IL

Kahn, Steven C., Brown, Barbara Berish, Zepke, Brent E.,
   Lanzarone, Michael, (1990), *Personnel Director's Legal
   Guide,* Warren, Gorham & Lamont, Boston.

Kahn, Steven C., Brown, Barbara Berish, Zepke, Brent E.,
   Lanzarone, Michael, (1991), *Personnel Director's Legal
   Guide, 1991 Supplement,* Warren, Gorham & Lamont, Boston.

Kain, Craig, ed., (1989), *No Longer Immune: A Counselor's
   Guide to AIDS,* American Association for Counseling and
   Development, Alexandria, VA.

Kaplan, Rochelle K, (1991) *New Responsibilities Under the
   ADA,* The College Placement Council, Bethlehem, PA.

Kelly, Jeffrey A. and St. Lawrence, Janet S., (1988), *The AIDS Health Crisis,* Plenum Press, New York

Keye Productivity Center, (1991), *The Americans With Disabilities Act,* Kansas City, MO.

Klosinski, Lee E., ed., (1988), *AIDS Education, A Business Guide,* American Foundation for AIDS Research, New York.

Knapp, Richard, and Parente, Joseph, (1989) "Foster Higgins Survey on Employee Opinions," Foster Higgins & Co., Inc., New York

Knox, Richard A., (1990) "AIDS in Workplace a Growing Issue," *The Boston Globe,* March 11, Boston.

Knox, Richard A., (1991) "Magic Johnson Gave AIDS Prevention a Needed Jolt," *The Boston Globe,* November 10, Boston.

Knox, Richard A., (1992), "Conferees Face Grim Prognosis on AIDS," *The Boston Sunday Globe,* July, 7, Boston. Kong, Dolores, (1991), "HIV Primer: How the Virus Spreads, How to cut the Risks," *The Boston Globe,* November 10, Boston.

Kong, Dolores, (1992), "House Report Says AIDS is Rising Unchecked Among Teenagers," *The Boston Globe,* April 12, Boston.

Koop, C. Everett, U.S. Surgeon General, (1986), *Understanding AIDS,* U.S. Department of Health and Human Services, Publication HHS No. (CDC) HHS-88-8404, Washington, D.C.

Kubler-Ross, Elisabeth; Serinus, Jason, (1988) *Psychoimmunity and the Healing Process: a Holistic Approach to Immunity and AIDS,* Celestial Arts, Berkeley, CA.

Lambert, Bruce (1988), "Employers Endorse AIDS Guidelines," *The New York Times,* February 18, New York.

Lamda Legal Defense and Education Fund, Inc., (1990), *AIDS Legal Guide,* New York.

Lehman, Betsy A., (1992), "AIDS Tests for Health Caregivers?'" *The Boston Globe,* August 10, Boston, MA.

Leonard, Arthur S., (1989), *AIDS, Employment and Unemployment,* Ohio State Law Journal, Vol. 49, No. 4, pgs. 929-964, Cincinnati, OH.

Lewis, Diane E., (1992, 1) "Brigham Nurses Win HIV Policy: $100,000 Guarantee for Those Infected," *The Boston Globe,* April 29, Boston.

Lewis, Diane E., (1992, 2) "Nurses' Bill Would Benefit HIV Workers," *The Boston Globe,* July 7, Boston.

Lewis, Diane E., (1992, 3) "Fighting for Their Health, Workers Dealing with AIDS Patients Want Protection from Products," *The Boston Globe,* July 24, Boston.

Lieberman Research Inc., (1988), *Business Response to AIDS,* Fortune Magazine and Allstate Insurance, New York.

Lincoln, Yvonna S., and Guba, Egon G., (1985), *Naturalistic Inquiry,* Sage Publications, Inc., Newbury Park, CA.

Locy, Toni, (1992, 1), "Individual Rights Focus of Debate on AIDS Bills," *The Boston Globe,* April 12, Boston.

Locy, Toni, (1992, 2), "Bill Meant to Limit Workers' Exposure to AIDS is Approved," *The Boston Globe,* July 9, Boston.

Lokken, Dean, (1992), "Sex-Bias Suit Settled for $157 Million", *The Boston Globe,* April 29, Boston.

Marshall, Catherine, and Rossman, Gretchen B., (1989), *Designing Qualitative Research,* Sage Publications, Inc., Newbury Park, CA.

McCracken, Grant, (1988), *The Long Interview,* Sage Publications, Newbury Park, CA.

McDonald, Martha, (1990), "How to Deal with AIDS in the Workplace," *Intervention,* Vol. 1, No. 1, Clinical Partners, Boston.

McKenzie, Nancy F., editor, (1991), *The AIDS Reader: Social, Political and Ethical Issues,* Penguin Group, New York.

McLaughlin, Loretta, (1989) "AIDS: An Overview," *The AIDS Epidemic,* O'Malley, ed., Beacon Press, Boston

Mehring, John, (1990), "AIDS at Work: The SEIU AIDS Project," *Labor Research Review,* Vol. 9, No. 2, Midwest Center for Labor Research, East Chicago, Ind.

Men's Fitness, (1992), "AIDS, Attention Hippocrates!", Woodland Hills, CA.

Miles, Mathew B.; Huberman, A. Michael, (1984), *Qualitative Data Analysis: A Sourcebook of New Methods,* Sage Publications, Newbury Park, CA.

Monette, Paul, (1988), *Borrowed Time: An AIDS Memoir,* Harcourt, Brace, Jovanovich, New York.

Morgan, David L., (1988), *Focus Groups as Qualitative Research,* Sage Publications, Newbury Park, CA.

National Association of People with AIDS, (1992), *HIV in America: A Profile of the Challenges Facing Americans Living with HIV,* Washington, D.C.

National Leadership Coalition on AIDS, (1993), *Employee Attitudes about AIDS: A National Survey,* Washington, D.C.

National Leadership Coalition on AIDS, (1988), *Private Sector Leadership Conference on AIDS,* Conference Presentations, Chicago.

National Leadership Coalition on AIDS, (1), *Small Business and AIDS: How AIDS Can Affect Your Business,* Washington.

National Leadership Coalition on AIDS, (2), *Business and Labor Speak Out on AIDS,* Washington, D.C.

National Safety Council, (1987), *AIDS: What Workers Should Know,* Chicago.

Nau, Charles, (April, 1991), "ADA Forces Employers to Respond," *Personnel,* V 68, N 4, American Management Association, pgs. 9-10 New York.

Nelkin, Dorothy; Willis, David P.; Parris, Scott V., editors, (1991), *A Disease of Society: Cultural and Institutional Responses to AIDS,* Cambridge University Press, Cambridge, England.

Newman, Lisa, (1992) "An Elementary Respect: In Chicago, A School Rallies Around Teacher with AIDS," *The Boston Globe,* March 25, Boston.

Newport Daily News, (1992), "AIDS Redefinition Adds 160,000 People," August 21, Newport, RI

Newsday, (1992), "Gloomy Forecasts Overwhelm Optimism at AIDS Conference," *The Providence Sunday Journal,* July 26, Providence, RI.

Odets, Walt, Ph.D., (1991) "The Secret Epidemic," *Out/Look,* Fall, 45-49.

O'Malley, Padraig, editor, (1989), *The AIDS Epidemic: Private Rights and the Public Interest,* Beacon Press, Boston.

Patton, Cindy, (1990), *Inventing AIDS,* Routledge, Chapman and Hall, Inc., New York.

Patton, Michael Quinn, (1980), *Qualitative Evaluation Methods,* Sage Publications, Inc., Newbury Park, CA.

Peterson, Ida Karen, (1979), "The Influence of the Researcher and His Procedures on the Validity of Group Sessions," *Focus Group Interviews: A Reader,* Higginbotham, James B.; Cox, Keith K., eds., American Marketing Association, Chicago, IL

Positive Changes, (1992), "An Eye on the World," July, Positive Changes, Inc., Providence, RI.

Prince, Melvin, (1978), "Focus Groups Can Give Marketeer Early Clues on Marketability of New Product," *Marketing News,* September 8, American Marketing Association, Chicago, IL.

Provincetown Positive, (1991), "Enhancing the Commonalities in Survivors with AIDS greater than three years," v. 9, November, Provincetown, MA.

Pryor, John B.; Reeder, Glenn D.; and McManus, Julie A., (1991), "Fear and Loathing in the Workplace: Reactions to AIDS-Infected Co-workers," *Personality and Social Psychology Bulletin,* Vol. 17, No. 2, April, Sage Publications, Beverly Hills, CA.

Reamer, Frederic G., (1991), *AIDS and Ethics,* Columbia University Press, New York

Reuters, (1992), "Buchanan Calls AIDS 'Retribution'," *The Boston Globe,* February 28, Boston.

Ribadeneira, Diego, (1992), "Magic Strikes a Chord in Message at Burke," *The Boston Globe,* March 13, p. 1, 12, Boston

Robinson, Christine R., (1987) *AIDS: Extent of the Problem, Responses, and Needs in the Greater Boston Area,* United Way of Massachusetts Bay, Boston.

Roche Biomedical Laboratories, *AIDS in the Workplace: The Roche Philosophy,* Burlington, NC, .

Rogers, David E. and Ginzberg, Eli, (1989), *Public and Professional Attitudes Toward AIDS Patients,* Westview Press, Inc., Boulder, CO.

Ryan, Bob, (1992), "Saying the Magic Word," *The Boston Globe*, March 3, pgs 53, 57, Boston.

Ryan, Caitlin C.; and Rowe, Mone J., (1988) "AIDS: Legal and Ethical Issues," *Social Casework: The Journal of Contemporary Social Work*, June, 324-333.

Sabatier, Renee, (1988), *Blaming Others: Prejudice, Race and Worldwide AIDS*, New Society Publishers, Philadelphia.

Schachter, Victor and Geidt, Thomas E, (1989) *When An Employee Has AIDS*, Executive Enterprises, New York.

Schmalz, Jeffrey, (1992), "Two Speak as One: Those with AIDS Reach for the White House," *The New York Times*, July 10, New York, N.Y.

Schoeman, Ferdinand, (1991), "AIDS and Privacy," *AIDS and Ethics*, Reamer, F.G., ed., pgs. 241-76, Columbia House Press, New York.

Seidman, I.E., (1991), *Interviewing as Qualitative Research: A Guide for Researchers in Education and the Social Sciences*, Teachers College Press, New York, NY.

Sharp, Jude, Ph.D., (1992) "The Workplace Response to HIV Disease," *Focus: A Guide to AIDS Research and Counseling*, Vol. 7, No. 3, February, 1-4.

Shilts, Randy, (1988), *And the Band Played on: Politics, People, and the AIDS Epidemic*, Penguin Books, New York.

Stevens, George E., "Understanding AIDS: Employers Must Learn the Facts to Educate and Protect its Workforce," *Personnel Administrator*, v. 33, August, 84-88, Berea, OH.

Stewart, David W.; Sahmdasani, Pre N., (1990), *Focus Groups: Theory and Practice*, Sage Publications, Newbury Park, CA.

Stodghill, Ron, (1993), "Managing AIDS: How One Boss Struggled to Cope," *Business Week*, February 1, 48-52.

Synder, Kenneth E., (1991), "Have Your Ever Been Discriminated Against in Your Job?", *Careers and the Disabled*, Greenlawn, NY, 33-36.

Thomas, Joe G.; Moore, Robert; Brown, R. Gene, (1991) "AIDS: How Management Should Respond," *Employment Relations Today*, Fall, Vol. 18, No. 3, New York, NY

Thompson Publishing Group, (February, 1991), *ADA Compliance Guide*, Washington, D.C.

Thompson Publishing Group, (February, 1992)*ADA Compliance Guide Monthly Bulletin*, V 3, N 2, Washington, D.C.

United Way of Central Maryland, (1988), *AIDS in the Work Place: Issues and Strategies in Policy Development*, Baltimore.

Van Ness, Paul N., *Alternative and Holistic Health Care for AIDS and Its Prevention*, Whitman Walker Clinic, Washington, D. C.

Verhovek, Sam Howe, (1992), "Infected Nurse Wins $5.4 Million from New York State in AIDS Suit," *The New York Times*, July 15, New York, N.Y.

Wachter, Robert M., M.D., (1991), *The Fragile Coalition: Scientists, Activists, and AIDS*, St. Martin's Press, New York.

Ward, Gary, (1990), *What a Manager Should Know About AIDS in the Workplace*, Dartnell Corp, Chicago.

Weller, Susan C., Romney, A. Kimball, (1988), *Systematic Data Collection*, Sage Publications, Inc., Newbury park, CA.

Wells, William D., (1979), "Group Interviewing," *Focus Group Interviews: A Reader*, Higginbotham, James B.; Cox, Keith K., eds., American Marketing Association, Chicago, IL

West, Rhonda and Durity, Art, (April, 1991), "Does My Company Need To Worry About AIDS?," *Personnel*, V 68, N 4, American Management Association, p. 5, New York.

Williams, John M, (1992), "ADA and the Changing Workplace," *Careers and the Disabled*, Winter, Greenlawn, NY 37-42.

Williams, Richard, Ph.D., (1993), *"When a Co-worker has AIDS,"* Polaroid Corporation, Cambridge, MA.

Winiarski, Mark G., (1991), *AIDS-related Psychotherapy*, Pergamon Press, Inc.Elmsford, NY.

Wisconsin Department of Health and Social Services, (1986), *Prevention of the Transmission of HTLV-III In the Workplace*, Madison, Wisconsin.

Wong, Doris Sue, (1992), "MCAD Breaks Ground on AIDS: $30,000 Judgement Given in Bias Case," *The Boston Globe*, August 11, Boston, MA.

Woolsey, Christine, (Oct. 7, 1991-1) "Disability Law to Clarify Employers' Duty," V 25, *Business Insurance*, p. 83-4, New York.

Woolsey, Christine, (Oct. 7, 1991-2) "Employers ill-prepared
    for AIDS," V 25, *Business Insurance,* pgs. 1, 73-7, New
    York.

Woolsey, Christine, (Oct. 7, 1991-3) "Digital Pioneers
    Program to Fight AIDS, Ignorance," V 25, *Business
    Insurance,* p. 80, New York.

Woolsey, Christine, (Oct. 7, 1991-4) "Employers Teach AIDS
    101," V 25, *Business Insurance,* pgs. 78-9, New York.

Woolsey, Christine, (Oct. 7, 1991-5) "How to Live with the
    Costs as Workers Live with AIDS," V 25, *Business
    Insurance,* p. 81, New York.

Woolsey, Christine, (Oct. 7, 1991-6) "Broader Coverage
    Sought for AIDS," V 25, *Business Insurance,* p. 82, New
    York.

Zonana, Howard V., (1991), "The Duty to Protect:
    Confidentiality and HIV," *AIDS and Ethics,* Reamer, F.G.,
    ed., pgs. 219-27, Columbia House Press, New York.