

Utah State University

DigitalCommons@USU

---

All Graduate Theses and Dissertations

Graduate Studies

---

5-1986

## The Psychological and Social Consequences of HTLV-III Infection: Homosexuals in Orange County, CA

Kenneth Burton Kaisch  
*Utah State University*

Follow this and additional works at: <https://digitalcommons.usu.edu/etd>

 Part of the [Psychology Commons](#)

---

### Recommended Citation

Kaisch, Kenneth Burton, "The Psychological and Social Consequences of HTLV-III Infection: Homosexuals in Orange County, CA" (1986). *All Graduate Theses and Dissertations*. 5603.  
<https://digitalcommons.usu.edu/etd/5603>

This Dissertation is brought to you for free and open access by the Graduate Studies at DigitalCommons@USU. It has been accepted for inclusion in All Graduate Theses and Dissertations by an authorized administrator of DigitalCommons@USU. For more information, please contact [digitalcommons@usu.edu](mailto:digitalcommons@usu.edu).



THE PSYCHOLOGICAL AND SOCIAL CONSEQUENCES OF HTLV-III INFECTION:  
HOMOSEXUALS IN ORANGE COUNTY, CA

by

Kenneth Burton Kaisch

A dissertation submitted in partial fulfillment  
of the requirements for the degree

of

DOCTOR OF PHILOSOPHY

in

Psychology

Approved:

UTAH STATE UNIVERSITY  
Logan, Utah  
1986

## ACKNOWLEDGMENTS

When I began my doctoral studies, I was under the misapprehension that one's dissertation was a solitary venture. Experience has proven that assumption to be in error. Without the participation and cooperation of many people, this dissertation would never have come into being.

I wish to thank those who taught me about research. I want to thank Drs. Sebastian Striefel and James Shaver who helped me, on my first research proposal, to think more clearly about research questions and procedures. I owe a tremendous debt of gratitude to Dr. Keith Checketts, who was willing to take on a "long distance" dissertation and the concomitant problems that ensued. His calm demeanor and clear thinking helped me through many a crisis. I want to thank my committee members, Drs. Elwin Nielsen, Phyllis Cole, Richley Crapo and Brent Miller for their encouragement, criticism, and support.

I wish to acknowledge my gratitude for the assistance of Dr. Hoda Anton-Guirgis. I came to her for assistance with a proposal on the

psychosocial aspects of cancer. When that proposal could not be implemented, she said, "All right, now how else can I help you". Without her willingness to extend herself, even though I was not her student and not in her field, I would never have done this research. She put me in touch with representatives of several homophile organizations, and helped me to refine the proposal so that it was workable. Without her help, and generous financial assistance, this project would not have been possible.

I owe a special debt to those representatives of Orange County homophile organizations who contributed so greatly to me and to this research. I want to give special thanks to Lino Zambrano, who sacrificed countless hours to prepare and analyze the test materials. I also want to thank Dr. Don Hagan, Frank Newman, Dr. Lee Garlington, Dr. Bill Pike, and Steve Peskind for their generous assistance. Their interest and willingness to give of their time and to share their perceptions with me allowed me a much richer understanding of the homosexual community. I want also to thank those anonymous homosexual donors, without whom this research would have failed for lack of funds.

I owe a special debt to Dr. Peter Ebersole of Fullerton. He helped me, while I was searching for a topic, to think through matters clearly. His emotional support and intellectual clarity were most gratefully received. Also I wish to thank Barbara Throckmorton.

Without her assistance with the data analysis, I would have lost more hair than my balding pate can afford.

I also need to thank my wife, Suzanne, and my son, Samuel. They have patiently born my absences, and have loved me even when I neglected them. Without their love, I would not have survived this process.

Finally, I want to thank those men who responded to this survey--especially those with positive results on their HTLV-III antibody tests. To participate in this project was, for them, an act of courage. I hope that the information gained here might help them and others. I also want to apologize for using the term "HTLV-III positives" when mentioning those with positive results on the HTLV-III antibody test. Often people are insulted by this kind of short-hand notation. I did not mean to offend, nor do I confuse the person with the illness; I just had trouble coming up with another term.

Kenneth Kaisch

## TABLE OF CONTENTS

	Page
ACKNOWLEDGMENTS . . . . .	ii
LIST OF TABLES . . . . .	viii
ABSTRACT . . . . .	x
CHAPTER	
I. INTRODUCTION . . . . .	1
Purpose and Objectives . . . . .	5
Research Questions . . . . .	6
II. REVIEW OF THE LITERATURE . . . . .	9
The Medical Literature Regarding HTLV-III Infection . . . . .	12
Etiology and Natural History . . . . .	15
Immunology . . . . .	22
Epidemiology . . . . .	27
The HTLV-III antibody test . . . . .	35
Epidemiologic analysis using the HTLV-III antibody test . . . . .	37
Psychosocial Dimensions of HTLV-III Infection . . . . .	39
Psychosocial sequella experienced by AIDS patients . . . . .	41
Psychosocial sequella experienced by HTLV-III infected patients who have not developed AIDS . . . . .	53
Summary . . . . .	56
Parallels with Other Life-Threatening Diseases . . . . .	57
The Male Homosexual Population . . . . .	70
Incidence of Male Homosexuality . . . . .	71

Determinants of Homosexual Behavior . . . . .	72
The Question of Psychopathology . . . . .	74
Describing the Population of Male Homosexuals . . . . .	77
Methodological Problems of Homosexual Studies . . . . .	79
Summary . . . . .	84
Ethical Considerations in AIDS Research . . . . .	85
III. RESEARCH PROCEDURES . . . . .	93
Population and Sample . . . . .	93
Response Rate . . . . .	100
Description of the Sample . . . . .	107
Design . . . . .	110
Instrumentation . . . . .	112
Questionnaire . . . . .	113
Coping Strategy Inventory . . . . .	115
IPAT Anxiety Scale Questionnaire . . . . .	118
IPAT Depression Scale . . . . .	120
Data Analysis . . . . .	122
IV. RESEARCH FINDINGS . . . . .	124
Research Questions . . . . .	124
Demographic Differences . . . . .	124
First Reactions to Positive Test Results . . . . .	126
Comparison of Initial and Subsequent Reactions . . . . .	129
Measurements of Anxiety . . . . .	131
Measurements of Depression . . . . .	133
Utilization of Coping Strategies . . . . .	135
Utilization of Coping Behaviors . . . . .	138
Coping Strategies Associated with Anxiety and Depression . . . . .	140
Coping Behaviors Related to Anxiety and Depression . . . . .	142
Needs for Psychological Assistance . . . . .	143
Reliability of the ASQ and DS . . . . .	144
Response Bias . . . . .	146
Other Findings Regarding HTLV-III Positives . . . . .	146
The Question of Suicidal Ideation and Suicide Attempts . . . . .	146

Changes in Sexual Activities . . . . .	147
Changes in Social and Occupational Functioning . . . . .	148
Openness Regarding HTLV-III Infection . . . . .	150
Estimated Incidence of Adjustment Disorders . . . . .	151
Comparison of CSI Responses of AIDS Patients and HTLV-III Positives . . . . .	153
Other Findings Regarding the Entire Sample . . . . .	155
A Comparison of Subjects With and Without HTLV-III Antibody Testing . . . . .	155
Reasons Given for Not Taking the HTLV-III Antibody Test . . . . .	158
Levels of Anxiety and Depression Among 488 Male Homosexuals . . . . .	159
Comparison of Levels of Anxiety and Depression Between Male Homosexuals and Male Norms . . . . .	160
V. SUMMARY AND DISCUSSION . . . . .	162
Methodological Limitations . . . . .	167
Speculations . . . . .	170
Implications Regarding the Counseling Needs of HTLV-III Positives . . . . .	174
Recommendations for Further Study . . . . .	178
REFERENCES . . . . .	180
APPENDIXES . . . . .	195
Appendix A. Cover Letters . . . . .	196
Appendix B. Optional Consent Form . . . . .	200
Appendix C. Questionnaire . . . . .	201
Appendix D. Coping Strategies Inventory . . . . .	211
Appendix E. Categories for Coding Open Ended Questions . . . . .	213
Appendix F. First Emotional Reactions of HTLV-III Positives . . . . .	221
Appendix G. Current Emotions Regarding HTLV-III Infection . . . . .	223
Appendix H. First Cognitive Reactions of HTLV-III Positives . . . . .	226
Appendix I. Current Thoughts Regarding HTLV-III Infection . . . . .	228
VITA . . . . .	230



## LIST OF TABLES

Table	Page
1. Centers for Disease Control Criteria for the Diagnosis of AIDS . . . . .	14
2. Mortality Rates of Patients with AIDS . . . . .	22
3. AIDS Risk Groups . . . . .	34
4. Psychological and Social Issues of Homosexual AIDS Patients . . . . .	49
5. Psychological Reactions to Physical Illness . . . . .	67
6. Demographic Comparison of HTLV-III Positives and Negatives . . . . .	125
7. Initial Emotional Reactions of HTLV-III Positives . . . . .	127
8. Initial Thoughts After Learning of Positive HTLV-III Test Results . . . . .	128
9. A Comparison of Initial and Subsequent Emotional Reactions: The First Ten Subjects . . . . .	130
10. Current Emotional Reactions of HTLV-III Positives . . . . .	131
11. Current Cognitive Reactions of HTLV-III Positives . . . . .	131
12. A Comparison of Anxiety Scores Between HTLV-III Positives and Negatives . . . . .	132
13. A Comparison of Anxiety Scores Between HTLV-III Positives With and Without Physical Symptoms . . . . .	133
14. A Comparison of Depression Scores Between HTLV-III Positives and Negatives . . . . .	134
15. A Comparison of Depression Scores Between HTLV-III Positives With and Without Physical Symptoms . . . . .	135

16.	Distribution of Coping Strategies of HTLV-III Positives as Measured by the CSI . . . . .	136
17.	The Most Important Coping Behavior of HTLV-III Positives . . . . .	139
18.	Changes in Other Common Coping Behaviors . . . . .	140
19.	Correlations Between CSI Responses and ASQ and DS Scores . . . . .	141
20.	Correlations Between Common Coping Behaviors, ASQ Scores and DS Scores . . . . .	143
21.	Test-Retest Correlation Coefficients . . . . .	145
22.	Changes in Sexual Behavior of HTLV-III Positives . . . . .	147
23.	Changes in Social and Occupational Functioning . . . . .	149
24.	Comparison of CSI Responses of AIDS Patients and HTLV-III Positives . . . . .	154
25.	Demographic Comparison of Subjects With and Without HTLV-III Testing . . . . .	155
26.	The Occurrence of Symptoms Related to HTLV-III Infection . . . . .	156
27.	A Comparison of ASQ and DS Scores Between Subjects With and Without HTLV-III Testing . . . . .	158
28.	Reasons for Not Taking the HTLV-III Antibody Test . . . . .	159
29.	Levels of Anxiety and Depression Among 488 Male Homosexuals . . . . .	160
30.	A Comparison of ASQ and DS Scores Between Male Homosexuals and the Male Normative Sample . . . . .	161

## ABSTRACT

The Psychological and Social Consequences of HTLV-III Infection:  
Homosexuals in Orange County, CA

by

Kenneth Burton Kaisch, Doctor of Philosophy  
Utah State University, 1986

Major Professor: Dr. Keith Checketts

Department: Psychology

The purpose of this study was to identify the psychological and social consequences experienced by homosexual men who learn that they have positive results on the HTLV-III antibody test, but who have not yet developed AIDS or ARC. Employing a census survey of the membership of three California homophile organizations (n=1905), 30 HTLV-III positives and 55 negatives completed a biographical questionnaire, the IPAT Anxiety Scale Questionnaire, the IPAT Depression Scale, and the Coping Strategies Inventory. Results indicate that HTLV-III positives show considerable disorganization after hearing test results, have clinically high levels of anxiety (n=10), and clinically high levels of depression (n=14). Positives were also quite guarded about sharing the results of their testing,

and experienced negative effects in social (n=15) and occupational functioning (n=10), and reported pervasive changes in their sexual activity (n=30). Twelve subjects reported suicidal ideation after they heard the results of their testing, but only one subject reported a suicide attempt. The methodological limitations of the study were examined, with an emphasis on the limitations of the survey method and difficulties with the follow-up procedures. Speculations to account for the reported behaviors, implications for counseling HTLV-III positives, and suggestions for future research with this population were also discussed.

(241 pages)

## CHAPTER I

### INTRODUCTION

In early 1985, a blood test was marketed to screen donated blood and plasma for antibodies to the Human T-Cell Lymphotropic Retrovirus III (HTLV-III)--the virus that causes Acquired Immune Deficiency Syndrome (Centers for Disease Control, 1985a). The HTLV-III antibody test (Popovic, Sarngadharan, Read, & Gallo, 1984) provides a screening tool that measures the presence of an antibody to the HTLV-III virus. A positive result on the HTLV-III antibody test may be due "to subclinical [AIDS] infection, to immunity, to an active AIDS carrier state, or may represent cross-reactivity to antigens or other viruses" (Centers for Disease Control, 1985a, p. 1). The HTLV-III antibody test is currently being used to screen donated blood, and as an initial screening device for those concerned about the possibility of infection with the AIDS virus (R. Greenwood, personal communication, June 4, 1985). In this latter usage, the HTLV-III antibody test is combined with other, more expensive blood tests. Together, these tests reliably measure exposure to the virus that causes AIDS (Greenwood & Hamm, 1985). The most recent information indicates that positive findings on these tests "should be

considered presumptive evidence of current infection and infectiousness" (Centers for Disease Control, 1985d, p. 742). This use of the HTLV-III antibody test permits an early detection of the disease in its prodromal state, prior to development of the full clinical syndrome of AIDS.

In an early study using the HTLV-III antibody test to identify immunological characteristics of homosexual men, a population that has been identified as a high risk group for AIDS, Dr. Anton-Guirgis and her colleagues (1985) at the University of California--Irvine (UCI) observed that subjects who had positive results on the HTLV-III test frequently had severe psychological reactions to this information. These reactions included reported suicide attempts, fainting, hysterical behavior, and apparent nonchalance (Dr. Anton-Guirgis, personal communication, May 20, 1985). These reactions appeared to be different from the responses of other individuals to being informed of life-threatening illness, in both the frequency and the intensity of the reaction. This observation has also been reported by individuals associated with a local testing site which offers the HTLV-III antibody test to the community without charge (J. Shelley, personnel communication, October 15, 1985). They found that male homosexuals with positive results would often have to be referred to a mental health agency immediately upon learning of these results because

of the severity of their psychological reaction to this information. However, although these men would typically make appointments for further counseling, very few of these appointments were kept.

Thus, the information that one has been exposed and probably infected with the AIDS-causing virus appeared to have a marked effect on many homosexual men. The information that one has been infected with the HTLV-III virus has two components. First, one is informed of a potentially life-threatening situation. Second, the message that one's life is threatened is ambiguous, since only 10 to 20 percent of those infected develop AIDS. Further complicating this ambiguity is the long latency of the HTLV-III virus within the host organism. Current information suggests that the infected individual may wait for seven years or more before developing any clinical manifestations of the infection (Centers for Disease Control, 1986). This long wait is typically characterized by uncertainty and anxiety. The marked psychological reactions that occur after this dual message is communicated are corroborated by empirical data (Tross et al., 1985) and by the observations of other clinicians (Morin, Charles, & Malyon, 1984).

As a result of the apparent severity and frequency of these psychological reactions, members of the homosexual community in

Orange County have become concerned about the mental health of those with positive HTLV-III antibody test results. They approached Dr. Anton-Guirgis and asked for a study which would identify the psychological and social consequences of knowing that one is seropositive on the HTLV-III antibody test. Under the direction of Dr. Anton-Guirgis of UCI and Dr. Keith Checketts of Utah State University, the present study has been formulated to address these concerns. The purpose of this study is to determine the psychological and social consequences of knowing that one is seropositive for the antibody to the HTLV-III virus. It is hoped that the resultant information will assist in the development of counseling programs which can address the needs of these homosexual men.

Of those men in the homosexual community who have positive results on the HTLV-III test, it is reasonable to expect a range of adaptive and maladaptive reactions. What is unknown is the percentage of homosexual men who have maladaptive reactions to this information, and the type of reactions that they experience. In addition, there are no data describing what an adaptive reaction to this information might be. As a result, there is no data base that can be used to facilitate the psychological treatment of these individuals. This research focused on the problem of gathering this information, so that the counseling



needs of homosexual men who have been infected with the HTLV-III virus can be met more effectively and efficiently.

#### Purpose and Objectives

The purpose of this study was to identify the psychological and social consequences experienced by homosexual men who learn that they have positive results on the HTLV-III antibody test. The objectives of this research were:

1. Identify the biographical and relevant medical characteristics of the sample.
2. Identify in a systematic fashion the subjects' initial reaction to learning of exposure to the HTLV-III virus. Identify how that reaction changed over time.
3. The literature on the psychosocial reactions of patients with AIDS suggests that a depressive reaction typically ensues (Dilley, Ochitill, Perl, & Volberding, 1985; Perry & Tross, 1984), while an anecdotal description of HTLV-III infected patients who have physical symptoms but who have not yet been diagnosed with AIDS suggests increased anxiety (Morin et al., 1984). This study therefore:
  - a) tested for both anxiety and depression;
  - b) compared the levels of anxiety and depression between the group

with positive HTLV-III test results and the group with negative results;

c) within the group with positive HTLV-III test results, compared the levels of anxiety and depression for subjects with and without physical symptoms.

4. Identify the behaviors used by subjects with positive HTLV-III results to minimize the stress caused by this knowledge.

5. Identify the kinds of psychological assistance that individuals with positive HTLV-III test results perceive that they need.

#### Research Questions

In order to achieve the purpose and objectives of this research study, specific research questions have been formulated. These questions provided the focus for data collection, and were used in Chapter IV to organize the discussion of the findings.

1. Are there differences between the group having positive HTLV-III test results and the group having negative HTLV-III test results with regards to age, education, employment, income, sexual orientation, and relationship status, as measured by a biographical questionnaire?

2. What are the self reported first reactions to positive HTLV-III test results, as measured by open-ended questionnaire items? Can

these self reported first reactions be reliably categorized?

3. Is there a relationship between initial and subsequent emotional and cognitive reactions to the information that one has positive HTLV-III test results, as measured by open-ended questionnaire items?
4. Are there differences in group mean scores, as measured by the IPAT Anxiety Scale Questionnaire (ASQ), between the groups with positive and negative HTLV-III test results? Within the group with positive HTLV-III test results, are there differences in group mean scores between those with and without physical symptoms?
5. Are there differences in group mean scores, as measured by the IPAT Depression Scale (DS), between the groups with positive and negative HTLV-III test results? Within the group with positive HTLV-III test results, are there differences in group mean scores between those with and without physical symptoms?
6. What coping strategies were endorsed by those with positive HTLV-III results on the Coping Strategies Inventory (CSI) (Bauman, 1984)? Within the group with positive HTLV-III test results, are there differences in the distribution of scores on the CSI between those with and without physical symptoms?
7. What are the most important coping behaviors identified by HTLV-III positives, according to their self-report? Can these self reported coping behaviors be reliably categorized?

8. Within the group with positive HTLV-III test results, is there a relation between CSI scores and scores on the ASQ and DS?
9. Within the group with positive HTLV-III test results, is there a relation between scores on the ASQ and DS and common coping behaviors such as eating, sleeping, using tobacco, alcohol, and prescription and non-prescription drugs?
10. Within the group with positive HTLV-III test results, are there differences in the kinds of psychological assistance requested by subjects with symptoms and those without symptoms?
11. Are the ASQ and the DS reliable over time for the accessible population?
12. Is there a systematic response bias in the completion of the questionnaires, as determined by comparing the frequency of response by zip code areas?

## CHAPTER II

## REVIEW OF THE LITERATURE

The focus of the present study is to identify the psychological and social consequences of HTLV-III infection, in order to provide information relevant to the counseling needs of homosexual men who are infected with the HTLV-III virus. The HTLV-III virus has only recently been identified as the causitive agent of AIDS. In March 1985, the Food and Drug Administration licensed tests which detect the antibody to the HTLV-III virus. Thus, the early course of HTLV-III infection--i.e. the course of the infection prior to the development of the AIDS or AIDS Related Complex (ARC)--has been readily identifiable only since this time. To date, no study has been published which has addressed the psychosocial needs of those with positive antibody test results. Thus, there is, as yet, no literature that has direct bearing on the questions posed in this study. However, early reports (Anton-Guirgis, Culver, Spindler, & Kleinman, 1985; J. Shelley, personal communication, September 10, 1985) regarding those taking the HTLV-III antibody test indicated that individuals who have positive results on the test experience a variety of psychological and social trauma subsequent to receiving this

information. This experience appears to be similar to those diagnosed with ARC or generalized lymphadenopathy, in which those with non-AIDS diagnoses experienced considerable uncertainty, anxiety, and depression (Morin et al., 1984; Tross et al., 1985).

The major focus of this study is the psychosocial needs of those with HTLV-III infection who have not yet developed AIDS. Because there are no published studies that directly pertain to the questions of this study, the literature from several related areas will be examined, in order to provide the context for the present study. In order to familiarize the reader with the course of HTLV-III infection, the medical literature in this area will be reviewed. Because most of this literature focuses on patients with AIDS, the review will necessarily concentrate on the effects of AIDS. This will give the reader an understanding of the end-point of HTLV-III infection, and thereby set the context for the psychological reactions of those who test positive for the HTLV-III antibody. This section will include the current definition of AIDS, what is known about the natural history of the disease, the manner in which it attacks the immune system of human beings, the epidemiology of the disease, and the risk factors associated with the disease. This section will conclude with a review of the few psychosocial studies which have been conducted with AIDS patients.

Unfortunately, very little empirical material has been generated regarding the psychosocial needs of AIDS patients. In order to supply this needed information, and to place this disease in a theoretical perspective which includes other life threatening diseases, the second section of this review will examine the psychosocial impact of cancer. Of all the major life threatening diseases, cancer has generated the most psychosocial research. The review of this literature will prepare the reader to understand the range of psychosocial adaptations which are typically made in the presence of life threatening illness.

The third section of this review will concentrate on the scientific literature describing the psychological makeup of homosexual men--the population on which this study is focused. The values of the larger American culture within which this study has taken place are quite negative with respect to homosexuality. As a result, numerous misconceptions and outright fallacies persist. These misconceptions and fallacies might easily distort the reader's understanding of this research. In order to address this problem, the psychological and sociological research regarding homosexuality will be critically examined. In particular, the problems of research with homosexual populations will be described.

Finally, the last section of this review will examine the

literature which has described the ethical obligations of the AIDS researcher to his/her subjects. Ordinarily, a section such as this would be unnecessary. However, because of the extraordinary public reaction against AIDS patients, those infected with the HTLV-III virus, and the homosexual population in general, a number of procedures must be adopted if the psychologist is to fulfill his/her ethical obligations to the research subject. These procedures are unusual, when placed in the broader perspective of most psychological research. In order to describe these procedures, and to put them in perspective, this section is included.

#### The Medical Literature Regarding HTLV-III Infection

In June of 1981, a new and unexplained disorder which attacked and damaged the human immune system was recognized when the Centers for Disease Control detailed the cases of five young male homosexuals from Los Angeles who died of *Pneumocystis carinii* pneumonia (Centers for Disease Control, 1981a). This was followed by reports of the deaths of 26 other homosexual males who had developed an aggressive form of Kaposi's sarcoma--a rare cancer of the blood vessel (Centers for Disease Control, 1981b). It was soon apparent that these cases represented the first reports of a new, unitary disease process. This disease was called Acquired Immune



Deficiency Syndrome (AIDS), because it was apparently acquired as the result of a then unknown agent, because it depressed the functioning of the immune system, and because the disease presented a syndrome of symptoms which made its identification possible (Peskind, 1984).

A clinical description of the disease was formulated by the Centers for Disease Control in 1982 (Centers for Disease Control, 1982), based on clinical criteria, rather than on the, as yet, non-existent laboratory criteria. This description allowed an epidemiological surveillance of the disease, and marked the formal beginning of scientific study of the disease. The current Centers for Disease Control criteria for the diagnosis of AIDS are listed in Table 1, below (Centers for Disease Control, 1985b).

Table 1  
Centers for Disease Control Criteria for the Diagnosis of AIDS

=====

AIDS is present when a previously healthy patient between the ages of 28 days and 60 years meets of the following criteria:

1. No known cause of immunosuppression, such as neoplastic disease, corticosteroid therapy or renal failure.
  2. The occurrence of a disease that is predictive of a defect in cell-mediated immunity, including:
    - a. Kaposi's sarcoma, in subjects less than 60 years old.
    - b. Primary lymphoma limited to the central nervous system.
    - c. Meningitis, encephalitis, pneumonitis due to:
 

Pneumocystis	Cryptococcus	Candida
Toxoplasma	Aspergillus	Strongyloides
Cytomegalovirus	Nocardia	Mucormycosis agents
    - d. Esophagitis due to herpes simplex, cytomegalovirus or Candida.
    - e. Progressive multifocal leukoencephalopathy.
    - f. Chronic (one month) mucocutaneous herpes simplex.
    - g. Chronic (one month) cryptosporidiosis enterocolitis.
    - h. Disseminated or central nervous system coccidioidomycosis, histoplasmosis, atypical mycobacteriosis.
  3. In the absence of opportunistic diseases, any of the following diseases will be considered indicative of AIDS if the person has a positive serologic or virologic test for HTLV-III:
    - a. Disseminated histoplasmosis.
    - b. Isosporiasis, causing chronic diarrhea.
    - c. Bronchial or pulmonary candidiasis.
    - d. Non-Hodgkin's lymphoma of high-grade pathologic type.
    - e. Kaposi's sarcoma in patients 60 years or older.
  4. Patient's will be excluded as AIDS cases if they have a negative result on testing for serum antibody to HTLV-III, have no other type of HTLV-III test with a positive result, and do not have a low number of T-helper lymphocytes or a low ratio of T-helper suppressor lymphocytes. In the absence of test results, patients satisfying all other criteria in the definition will continue to be included.
- =====

The characteristic feature of AIDS is the dysfunction of the patients' cell mediated immune system (Gracie, Froebel, Madhok, Lowe, & Forbes, 1985). In essence, there are two stages in the disease process (Cesario, 1985). First, the host organism suffers an infection of the HTLV-III virus, which attacks and destroys the helper cell subset of the T lymphocytes. This trophism for helper T-cells has a profoundly disruptive effect on the immune functioning of the host. Second, the immunocompromised host is challenged by a variety of opportunistic bacteria, fungi, and virus organisms which are normally destroyed by the immune system. The host dies, not from HTLV-III infection per se, but rather from the opportunistic infections which occur as a result of the HTLV-III infection.

#### Etiology and Natural History

The etiology of AIDS has recently been linked to the HTLV-III virus by Montagnier and his co-workers in France, and by Gallo and his colleagues at the National Cancer Institute. The HTLV-III virus was first isolated from a patient with the prodrome of AIDS by Montagnier and his colleagues at the Pasteur Institute of Paris (Barre-Sinoussi, et al., 1983). They called the virus the

Lymphadenopathy Associated Virus (LAV), because it was found in immunodepressed patients suffering from lymphadenopathy--a syndrome that was thought to be the prodrome of AIDS (Domingo & Chin, 1983). Gallo's group reported the isolation of an HTLV virus from two AIDS patients in 1983 (Gallo et al., 1983). Shortly thereafter, Essex and others (1983) reported antibodies to HTLV in both AIDS patients and lymphadenopathy patients. The breakthrough came in May of 1984, when Gallo and his group published the results of their extensive work on the HTLV-III virus (Gallo et al., 1984; Popovic et al., 1984; Sarngadharan, Popovic, Bruch, Schupbach, & Gallo, 1984; Schupback et al., 1984). They isolated a virus of the HTLV family of viruses, and clearly demonstrated that this virus caused AIDS. Further work has shown that the LAV virus, identified by Montagnier, is identical with the HTLV-III virus of Gallo (Goedert & Blattner, 1985).

As a result of the research which has identified the causative agent of AIDS, a test has been developed which detects antibodies to the HTLV-III virus (Weiss et al., 1985). Antibodies are developed by the immune system to destroy particular infectious agents. The presence of an antibody specific to a particular infectious agent means that the subject has been infected, at some previous time, with that agent. Studies have shown that almost 100 per cent of AIDS patients and 89 percent of

patients with generalized lymphadenopathy were seropositive on the HTLV-III antibody test (Cheingsong-Popov et al., 1984).

When the HTLV-III antibody test was first developed, there was considerable controversy about whether the test measured exposure to, or infection with, the virus. At the present time, positive results on the HTLV-III antibody test, when confirmed by positive results on the Western blot test, are considered "presumptive evidence of current infection and infectiousness" (Centers for Disease Control, 1985d, p. 724).

Since the development of an antibody test which can detect the early stages of HTLV-III infection, it has been possible to describe with more certainty the different forms taken by the infection. Five distinct clinical stages of HTLV-III infection are currently recognized (Prendergast, 1985; Valle et al., 1985). These include: 1) transient infection, experienced by those hosts who mount a successful defense against the virus; 2) a chronic provirus state, experienced by those who are unable to defend against the virus; 3) the asymptomatic virus producer state, or 'carriers' of the virus; 4) those who develop a few clinical or laboratory symptoms of the infection, including those who develop ARC and generalized lymphadenopathy; and 5) those who develop AIDS--the end point of HTLV-III infection.

Very little is known about the first three forms of the

infection. Of those infected with HTLV-III virus, an unknown percentage of hosts have been able to successfully defend against that infection (Prendergast, 1985). These hosts are antibody positive, but do not carry the live virus, and are not infectious. It is not known, at this time, how these subjects manage to overcome the HTLV-III infection.

The second group of infected subjects is composed of those who have been unable to overcome the infection. These are symptomless individuals who are antibody positive, but who are not currently producing the virus--a proviral state. They may, at a later time, become active virus producers, but the reasons for this change of status, and the percentage who make this transition are currently unknown.

The third stage of HTLV-III infection consists of active viral production within the host. These subjects are 'carriers' of HTLV-III, and have the live virus in their systems (Prendergast, 1985). These hosts do not experience any physical symptoms, but can transmit the virus.

The fourth group is composed of hosts who develop some of the clinical or laboratory symptoms associated with AIDS (Prendergast, 1985). The symptoms experienced by members of this group are the result of a lowered immune response. Clinical symptoms might include lymphadenopathy, unexplained diarrhea, persistent fever,

fatigue and weight loss. Laboratory symptoms included depressed levels of T4 cells, inverted T4:T8 ratios, elevated serum globulin, and depressed blastogenesis. Current estimates suggest that 25 to 40 percent of those with positive HTLV-III antibody tests develop clinical or laboratory symptoms (Prendergast, 1985). Patients with two clinical and two laboratory symptoms are diagnosed as having AIDS Related Complex (ARC) (Centers for Disease Control, 1982). The presenting complaints of ARC patients include swollen lymph nodes, flu-like illness, and chronic fatigue (Ziegler & Abrams, 1985). As the research data on this stage of the infection has grown, there has been some discussion of differentiating this stage into several levels. However, this has not yet occurred.

Approximately half of the symptomatic patients, or 10 to 20 per cent of those originally infected with the HTLV-III virus enter the fifth stage of the infection and develop AIDS (Peskind, 1984; Prendergast, 1985). The reasons for movement from Stage 4 of the infection to Stage 5 are not known. Since not all Stage 4 hosts develop the full syndrome of AIDS, it is clear that intervening variables exist. However, research has not yet been able to identify these variables.

The natural history of HTLV-III infection appears to move through five periods, which are related to the development of the

infection, as described above. After infection, there is a pre-antibody period lasting four to eight weeks (Gupta, 1985). No assays have yet been developed which can reliably detect HTLV-III antigens in sera or plasma at this stage (Goedert & Blattner, 1985). Seroconversion, which occurs during the second clinical phase of HTLV-III infection, takes place between two and eight weeks after inoculation with material from patients with AIDS (Gajdusek et al., 1985; "Needlestick transmission", 1984). However, detectable antibodies have not developed in some infected, asymptomatic individuals for more than six months (Centers for Disease Control, 1985a; Salahuddin et al., 1984). "These virus-positive, antibody negative persons may represent the earliest stage of HTLV-III infection, with active viral replication and very little or no antibody response" (Landesman, Ginzburg, & Weiss, 1985, p. 522).

Following infection and seroconversion, there is a preclinical incubation period of two to five years (Goedert & Blattner, 1985). There is evidence from some currently reported AIDS cases that HTLV-III exposure occurred up to seven years prior to the diagnosis, and "the possibility of a longer incubation period cannot be excluded" (Centers for Disease Control, 1986, p. 20). During this incubation period, detectable antibodies to the HTLV-III virus are present. At this stage, there is a slight



decrease in the efficiency of the immune system, as the helper T-cells are infected and their functioning impaired. For reasons yet to be discovered, HTLV-III infection runs a fulminant course following this incubation period. In the clinical period of the disease--the fourth phase of HTLV-III infection--clinical symptoms associated with decrements in immune functioning appear. During this phase, ARC is typically diagnosed. In the fifth and final phase, the immune system of the host is destroyed, with the total destruction of helper T-cells, and the thymus which produces them. This is the phase in which AIDS is diagnosed.

Once the HTLV-III infection has progressed to AIDS, the outlook for the host is grim. The immune system is in such disarray that the usual armamentarium of drugs that are used to fight these opportunistic infections are ineffective (Gupta, 1985). At this time, it appears that AIDS is fatal. As of September 24, 1984, about 45 percent of all persons meeting the Centers for Disease Control criteria for AIDS in the U.S. have died. The death rates are described in Table 2, below (Peskind, 1984).

Table 2  
Mortality Rates of Patients with AIDS

Cases diagnosed three years ago.....	87 percent mortality
Cases diagnosed two years ago.....	72 percent mortality
Cases diagnosed one year ago.....	54 percent mortality
Cases diagnosed less than a year.....	30 percent mortality

These mortality statistics indicate the severity of the compromise of the immune system by HTLV-III.

### Immunology

In order to understand the effects of HTLV-III infection in the host organism, it is necessary to describe the normal functioning of an immune system in human beings. The function of the immune system is to identify and destroy foreign substances (antigens) such as bacteria, virus, and fungi, which enter the host (Taylor, 1984). There are two systems which carry on most of the immunologic activity: the system of cell mediated immunity, which revolves around the participation of lymphocytes and macrophages; and the system of humoral immunity, which results from the presence of immunoglobulins produced by B-cells. Recent research has demonstrated a series of complex interconnections between these two immune systems (Gupta, 1985).

Cell mediated immunity focuses around the activity of T-cells, which are lymphocytes which have been processed through the thymus (David, 1985). These cells react directly to the antigen and destroy it. They provide cellular immunity, which means that they protect the individual cells of the host. T-cells make up about 80 percent of the body's lymphocytes. There are two kinds of T-cells. The T4 or helper T-cells have a central role in coordinating the response of the entire immune system. The T4 cells can stimulate the production of antibody by B-cells, generate suppressor T-cells, generate Natural Killer (NK) cells, stimulate the general activity level of lymphocyte-antigen interactions, and a host of other growth and differentiation factors for other lymphoid cells (David, 1985; Marwick, 1985a). A.S. Fauci, who heads the immunologic research on AIDS with the National Institutes of Health, has described the helper T-cell as "the true conductor of the immune orchestra" (Marwick, 1985a, p. 3375). The other kind of T-cell, the T8 or suppressor T-cell, has a more limited function. T8 cells suppress the functioning of the T4 cells, after an infection has been successfully overcome.

Humoral immunity, on the other hand, is focused around the activities of B-cells, which are lymphocytes which have been processed through the bone marrow (David, 1985). B-cells produce immunoglobulin, and retain these substances on the cellular

surface. The humoral system functions by producing antibodies (immunoglobulins) that are specific to a particular antigen. Activated B-cells have specific surface sites which attach to the antigen, permitting the B-cell to identify and destroy the particular antigen. B-cells make up approximately 15 percent of the body's lymphocytes.

The HTLV-III virus exhibits a marked tropism for the helper T-cells (Barrett, 1984; Bowen, Lane & Fauci, 1985). The virus attaches to the cell wall of the helper T-cell, comes out of its protein coat, and releases its RNA into the cytoplasm of the cell (Taylor, 1984). Ultimately, the virus destroys the host cell (Gupta, 1985). Prior to complete destruction, the HTLV-III virus seriously interferes with the normal functioning of the helper T-cell. Specifically, the HTLV-III virus inhibits the production of and response to interleukin-2 (IL-2) (Marwick, 1985a). IL-2 amplifies the immune response by enhancing the cell function of T4, T8, and NK cells (Fauci & Lane, 1984; Gupta, 1985; Sinkovics, Gyorkey, Melnick, & Gyorkey, 1984). Because of the central role of the helper T-cell in orchestrating the response of the host's immune system, HTLV-III infection of the host's T4 cells compromises the functioning of the entire immune system.

During the course of HTLV-III infection, the T4 cells of the host organism are altered in function, and then are gradually

destroyed. In the final stages of their illness, AIDS patients can exhibit the complete absence of T4 cells. By this time, the thymus--where new T cells are processed--is atrophied and depleted of lymphoid elements, thus resulting in the inability to generate new T4 cells (Reichert, Kelly, & Macher, 1985). In these cases, there may also be a great reduction in the amount of HTLV-III virus--a paradoxical finding not uncommon in AIDS patients in the last stages of infection (Safai et al., 1984; Steis & Broder, 1985).

In addition to infecting T4 cells, the HTLV-III virus also infects brain glial cells, macrophages, and B-cells (Gupta, 1985). These are relatively recent findings, and little is presently known about the effect of HTLV-III infection on these cells. However, the presence of HTLV-III in brain glial cells probably explains the high incidence of neurological complications that appear in AIDS patients (Marwick, 1985b; Snider et al., 1983; Tross et al., 1985). In addition, HTLV-III infection of B-cells increases the level of activity in these cells (Fauci, 1984). They "spontaneously proliferate and secrete immunoglobulin, compared to B-cells from normal controls" (Fauci, in Marwick, 1985a, p. 3375). This reaction and what it means is not understood at the present time.

Understanding how the immunologic system of the host is

compromised by HTLV-III infection permits a larger understanding of the course of AIDS. The first physical symptoms of HTLV-III infection are usually swollen lymph glands and a low grade fever (Gajdusek et al., 1985; "Needlestick transmission", 1984). Given that T4 cells are found in highest concentration in the lymph nodes, it is reasonable that the lymphatic system would be the first to demonstrate clinical signs of infection. Also, there have been some reports of neurologic change, with neuropsychiatric symptoms, in the early course of the illness (Gapen, 1982; Tross, 1985; Tross et al., 1985). This may be explained by the infection of brain glial cells.

As the HTLV-III infection progresses, the immunocompromised host is beset by a variety of neoplasms and opportunistic infections. The occurrence of neoplasms may be due to the reduction of NK cells, which are thought to be involved in cancer surveillance (Witti & Goldberg, 1983). Many of these opportunistic infections are endemic in the human population, but are rarely seen in acute form because the immune system controls them. In addition to a lack of immune response to endemic antigens, AIDS patients demonstrate a failure to produce antibodies to antigens not previously encountered (Siegal, 1984).

In a host infected with HTLV-III virus, the usual immune defenses have been impaired or destroyed. Hence, the host is

susceptible to a wide range of infections. Further, because most pharmacological treatments function in conjunction with the immune system of the host, these treatments are either ineffective or significantly less effective in the HTLV-III infected host (Cesario, 1985).

These factors result in the high mortality rate seen in AIDS patients. Because there is, as yet, no cure for HTLV-III infection, the best that medicine can presently offer are treatments which respond to the opportunistic infections and neoplasms. These treatments will only gain time for the AIDS patient. Because of the total destruction of the T4 cells and the resulting disarray in the rest of the immune system, there is no real hope for recovery for the AIDS patient with present treatments.

### Epidemiology

Information about the HTLV-III virus can best be understood in the larger context of research on human retroviruses. Retroviruses were labeled because of the unique way in which they reproduce. While most organisms code genetic information in DNA, the retrovirus encodes its genetic information in RNA, and then

uses an enzyme called reverse transcriptase to copy its genome into DNA (Broder & Gallo, 1984). Retroviruses were first linked to cancers and immunodeficiency states in animals, but investigators questioned the existence of human retroviruses. Evidence for their existence did not emerge until reverse transcriptase was isolated independently by Baltimore (1970) and Temin and Mizutani (1970). Another factor influential in the discovery of human retroviruses was the development of molecular and biologic approaches which allowed the detection of low levels of retroviruses in human tissues.

In 1980, Gallo and his co-workers were able to culture the first retrovirus cells from patients with T-cell lymphoproliferative disease (Poiesz et al., 1980; Poiesz, Ruscetti, Reitz, Kalyanaraman, & Gallo, 1981). At this time, the virus was named the 'human T-cell leukemia/lymphoma virus'. This virus was found to be endemic in southern Japan, the equatorial belt in Africa, and certain parts of the Western hemisphere. A second HTLV virus was identified, and connected with hairy cell leukemia (Kalyanaraman et al., 1982). The two viruses were distinguished by labeling them HTLV-I and HTLV-II. Both HTLV I and II cause helper T cells to undergo malignant transformation and uncontrolled growth (Marx, 1985), resulting in two different kinds of leukemia.



In contrast, the HTLV-III virus causes the death of the T-cells it infects (Marx, 1985). In addition, HTLV-III "produces a factor with trans-activating abilities in infected cells. The virus is about ten times more active in this regard than HTLV-I or -II. This 'exuberant' trans-activation may help to explain why this virus kills infected cells, whereas infection with HTLV-I and -II causes transformation" (Marx, 1985, p. 157). Trans-activation is caused by the production of a protein which increases " the expression of genes attached to appropriate viral control sequences" (p. 156). This process is believed to control cell division.

Researchers now hypothesize that the HTLV family originated in Africa. A virus that is closely related to HTLV-I has been widely found in many species of Old World monkeys (Saxinger et al., 1984). This virus is distinguishable from HTLV-I only by molecular analysis (Saxinger et al., 1984). HTLV-I is widely distributed in humans throughout the equatorial belt in Africa (Gallo, 1984; Fleming et al., 1983). It is speculated that the virus mutated and was passed from the animal population into the human population. This HTLV-I virus then passed into the Americas by way of the slave trade, and into Japan by way of Portuguese mariners in the 16th century (Gallo, Sliski, & Wong-Staal, 1983).

The HTLV-III virus is believed to have originated in the

middle equatorial region of Africa. The virus has been found in some of the poorest and most isolated people in east-central Africa (Goedert & Blattner, 1985). However, the clinical syndrome of AIDS is not found in these people, suggesting that a long exposure to the virus has resulted in some kind of environmental adaptation to the virus. "Some geographically restricted tribes do have HTLV-III antibodies with seroprevalance rates as high as 50%" (Goedert & Blattner, 1985, p. 23). Recent population shifts in central Africa, away from remote villages and towards urban environments, may have been the factor responsible for the appearance of AIDS at this time.

There is further speculation that the first cases of AIDS--infection with HTLV-III virus with the now, well-known symptoms--occurred in Zaire in 1976 (Piot et al., 1984). This appearance of HTLV-III infection occurred about two years before the first cases in Haiti and the United States (Gracie et al., 1985). HTLV-III may have entered Haiti through immigrant workers from Haiti, who traveled to Zaire to find work. Because Haiti was used as a holiday resort by American homosexuals, it is suspected that the disease entered this country via that route. Transmission to Europe occurred in two ways: to European homosexuals from contact with infected American homosexuals, and to European heterosexuals by means of sexual contact with

immigrants from Zaire in Belgium. From Belgium, it was further spread into the European heterosexual population through prostitutes (Prendergast, 1985).

The hypothesis that a member of the HTLV family caused AIDS was stimulated by the finding that retroviruses in animals could induce immunodeficiency states (Hardy et al., 1976). In addition, the T-cell tropism of these viruses was congruent with the clinical findings in AIDS patients of depressed levels of helper T-cells. The hypothesis that an HTLV virus caused AIDS received direct empirical support in 1983 (Barre-Sinoussi et al., 1983; Essex et al., 1983; Gallo et al., 1983). Researchers found a heretofore unrecognized retrovirus in AIDS patients. Further examination revealed structural similarities with HTLV-I and -II, so this new virus was called HTLV-III (Gallo, Essex, & Gross, 1984).

The HTLV-III is covered with a relatively fragile protein envelope (Gupta, 1985). The fragility of the virus inhibits its transmission among human hosts. It is currently estimated that the attack rate of the virus--the number of exposures to an infected host necessary for virus transmission--is between 1:100 and 10:100 (Wiley, 1985). This is further evidence of the fragility of the virus, and the difficulty of transmitting the virus.

The HTLV-III virus "has been isolated from blood, semen, tears, breast milk, and urine, and is likely to be isolated from other body fluids and secretions" (Centers for Disease Control, 1985c, p. 682). There is evidence, however, for only two transmission routes: through semen, and through certain blood products (Centers for Disease Control, 1985c). While the blood factors in which the HTLV-III virus is carried have been identified, details of the sexual transmission of the virus are not known at this time. While intimate sexual contact is necessary for transmission, the extent of such contact, and the mechanics of transmission have not been identified (Landesman et al., 1985).

As a result of this accumulation of data regarding the transmission of the HTLV-III virus, it is currently hypothesized that there are only four vectors of transmission (R. Parker, personal communication, December 5, 1985). These include: 1) sexual contact with an exchange of semen or blood; 2) sharing intravenous needles; 3) blood or certain blood products; and 4) transmission from mother to child in the prenatal period.

While the transmission of HTLV-III is difficult, the long incubation period of the virus complicates its spread. Current estimates of the incubation period range from two to seven years or more (Centers for Disease Control, 1986; Lawrence, Lui,

Bregman, Peterman, & Morgan, 1985). This long incubation means that the host organism can carry the disease-causing virus without symptoms, and thus without any reason to consider that s/he is infected. If the mean incubation period is in fact five years, then the carrier host may be spreading the disease for some five years before becoming aware of his/her own infection. This facilitates the transmission of the disease.

The current epidemic status of AIDS is due to an interaction between the long incubation period of HTLV-III, a social environment which does not overtly censure multiple sexual contacts between different partners, considerable covert intravenous drug abuse, and a medical environment in which blood transfusions are common (Prendergast, 1985). Thus, the HTLV-III virus, which may have existed in Africa for centuries previously, has become a problem at the present time because of an environment which facilitates the transmission of the virus more readily.

Between June 1, 1981, when a surveillance program was established in the United States, and January 13, 1986, 16,458 patients (16,227 adults and 231 children) have met the criteria for a diagnosis of AIDS (Centers for Disease Control, 1986). Of these, 8,361 have died. Of those who have been diagnosed with AIDS, 60 percent were white, 25 percent black, and 14 percent Hispanic. Ninety percent were 20-49 years old, and 93 percent

were men. The race, age, and sex distributions have remained relatively constant over time (Centers for Disease Control, 1986).

There are currently six major risk groups for infection with the HTLV-III virus. These groupings have been derived from an analysis of the possible means of disease acquisition. Ninety-four percent (15,243 patients) of AIDS patients can be placed in these groups, which are detailed in Table 3 (Centers for Disease Control, 1986).

Table 3  
AIDS Risk Groups

	% of total	Cases
Homosexual/bisexual with IV drug use . . . . .	8%	1,310
Homosexual/bisexual without IV drug use . . . . .	65%	10,600
Heterosexual IV drug user . . . . .	17%	2,766
Persons with hemophilia . . . . .	1%	124
Heterosexual sex partners of persons with AIDS or persons at risk for AIDS . . . . .	1%	182
Recipients of transfused blood or blood products . .	2%	261

The remaining 984 patients have not been classified by recognized risk factors. Past experience suggests, however, that many will later be found to fit the classification above.

From the epidemiologic data, it is clear that homosexual and bisexual men constitute the largest risk group in the United States at the present time. Intravenous drug users with no history of homosexual behavior account for 17 percent of the

total. Hemophiliac patients who became infected as a result of the Factor VIII blood products which they receive to facilitate blood clotting, and others who have received transfused blood constitute another major risk group. Originally, immigrants of Haitian descent were thought to constitute a risk group. However, further data collection from the Haitian patients has found that homosexual contacts or intravenous drug use account for HTLV-III transmission in these cases. In June, 1985, the Centers for Disease Control removed the Haitian category from the list of groups that are at high risk to contract AIDS (Prendergast, 1985). Of interest to the present study is the statistic that approximately 95 percent of those with AIDS on the West Coast of the United States are homosexual or bisexual men (Prendergast, 1985).

The HTLV-III antibody test. In 1984, Gallo and his co-workers (Sarngadharan et al., 1984) developed a test to detect antibodies to the HTLV-III virus. This test is based on the finding that, after HTLV-III infection, the host develops antibodies to combat this virus. The HTLV-III antibody test is an enzyme-linked immunosorbent assay which detects antibodies to the HTLV-III virus (Landesman et al., 1985). Because this test is quite new, based on a relatively new technology, the full meaning of HTLV-III seropositivity has not yet been determined. At this

time, researchers are certain that a positive result means that the subject has, at some previous time, been 'exposed' to the HTLV-III virus (Landesman et al., 1985). It is now accepted that a positive result on the HTLV-III antibody test, when confirmed by a positive result achieved from the Western blot test, means that the person has, at some previous time, been infected with the HTLV-III virus (Centers for Disease Control, 1985d).

The meaning of positive results on the HTLV-III antibody test is complicated by the presence of false positive results (Fischinger & Bolognesi, 1985; Weiss et al., 1985). This means that the test identifies a small percentage of those who do not have the antibody as having the antibody. In addition, cross reactivity with other antigens has not yet been determined. Thus, someone with antibody "X" may be mistakenly identified as having the HTLV-III antibody, because antibody "X" cross reacts with the enzymes used to identify HTLV-III (Centers for Disease Control, 1985a). To handle these problems, patients with positive results on the HTLV-III antibody test are routinely tested with the Western blot technique. This more expensive procedure interacts with the HTLV-III antibody test in such a way that it reliably rules out false positives and cross reactivity (Fischinger & Bolognesi, 1985). However, one of the shortcomings of these two procedures is that they do not distinguish between those who have



overcome the virus and those who are still infected with the virus. Epidemiologists currently estimate that 85-90 percent of those in high risk groups with positive HTLV-III antibody test results are still infected with the virus (Prendergast, 1985).

Epidemiologic analysis using the HTLV-III antibody test.

Using previously obtained, frozen blood samples from high risk populations, seroepidemiologic studies have been conducted to estimate the spread of the HTLV-III infection. In San Francisco, the prevalence of HTLV-III antibodies among homosexual men applying for treatment at a clinic for sexually transmitted diseases rose from 1 percent in 1978, to 25 percent in 1980, to 65 percent in 1984 (Centers for Disease Control, 1984). In nonepidemic cities, the disease is also spreading. For example, a study in Pittsburgh found that seropositivity rose from 10 percent in 1983 to 28 percent in 1984 (Landesman et al., 1985).

Of concern is the data which indicates that the difference between the high rates of HTLV-III seropositivity in major coastal cities and the relatively low rates of seropositivity found in inland cities is diminishing (Landesman et al., 1985). This and other data indicate that the infection is rapidly spreading among the high risk groups (Wiley, 1985).

This does not mean that heterosexual men and women who are not members of high risk groups are not at risk for AIDS. Because

AIDS is a sexually transmitted disease, intimate sexual contact with an infected person may result in HTLV-III infection in the healthy person. In Africa, AIDS is primarily a disease in the heterosexual population (Goedert & Blattner, 1985). In this country, in New York City and Orange County, California, the virus has been found in prostitutes (Prendergast, 1985). Spread of the infection into the heterosexual population in this country is likely to occur through this source, through infection passed by bisexual men, and through infection passed by heterosexual intravenous drug abusers.

Although no empirical data have been gathered, projections regarding the current status of the AIDS epidemic have been made. At the end of 1984, it was estimated that at least 400,000 people are positive for HTLV-III antibodies (Landesman et al., 1985). The potential for the spread of the disease is much larger. Even if the spread of the disease is hypothetically limited to the risk groups identified above, the numbers are difficult to comprehend. For example, the population of intravenous drug abusers is estimated at 400,000 persons (Ginzburg, 1984). An additional 1,000,000 people occasionally inject cocaine and heroin (Ginzburg, 1984). Further, using Kinsey's estimate that 10 percent of the male population is homosexual for three years or more during their adult lives, then there are approximately 8 million homosexual men

in the United States who are 18 or older (Landesman et al., 1985). With the rapid spread of the HTLV-III infection among these high risk populations, the implications for the health care system in this country are staggering. Should the infection spread widely into the larger population, the implications in terms of human suffering and medical costs simply cannot be estimated.

#### Psychosocial Dimensions of HTLV-III Infection

Given that AIDS is an apparently fatal disease with no known cure, psychiatric and psychosocial sequella are to be expected. However, because of the newness of this syndrome, there has been little research effort in this area to date. Compared to the thousands of medical and epidemiological studies focusing on AIDS, there are only a handful of articles dealing with the psychosocial concomitants of the disease. Most of these psychosocial articles are either anecdotal accounts of those working with AIDS patients, or case studies, which look at a few subjects. Presently there are only five empirical studies on the psychosocial impact of AIDS. The validity of the results of these studies is compromised by the small number of subjects that were used, and by problems of design and sampling. Finally, there are few empirical studies focusing on the psychosocial effects of those infected with the HTLV-III virus who have not yet developed AIDS. The existent

studies have focused on subjects with generalized lymphadenopathy--now recognized as a stage of HTLV-III infection preceding AIDS.

A variety of psychological and social concomitants could be expected to accompany AIDS. One would expect that patients with AIDS and their close friends would experience the problems associated with dying from a terminal disease at a relatively young age. In addition, the public outcry and fear regarding AIDS would be likely to result in an increased social isolation felt by AIDS patients. But added to these situations is the fact that the preponderance of AIDS cases in this country--over 70 percent--have occurred among homosexual men. Given the social and economic discrimination against homosexuals in this country, and the common public perception that AIDS is a disease of homosexuals, one would expect that the psychological and social problems of AIDS patients and their friends would be intensely exacerbated. It is within this social context that the researcher can begin to consider what is occurring among those who have been diagnosed as infected with the HTLV-III virus but have have not yet developed AIDS.

However, because there is little empirical literature regarding this infected population, the psychological and social consequences for this group are poorly understood at the present time. At best, one can detail what little is known about the

psychosocial problems of AIDS and ARC patients and relate this to the larger infected population. The anecdotal evidence from patients with ARC suggests that infected men experience much greater anxiety and depression than AIDS patients. Morin and his colleagues (1984) talked with an infected man who described his situation as "life in the gray zone". Issues for those in the "gray zone" include "intense isolation,...poor social and occupational functioning due to fatigue, loss of initiative and frustration of achievement and productivity needs" (Morin et al., 1984). In addition, many experience a sense of shame and a fear of being stigmatized.

In order to review the psychosocial consequences of HTLV-III infection, the psychosocial research on AIDS patients will be examined first. There is currently more information about this subset of the infected group than about any other. Following a review of the information on AIDS patients--the 'end point' of this disease continuum--the anecdotal accounts of infected patients who have not yet developed AIDS, and the meager empirical literature on this population will be examined. This sequence will reveal the spectrum of the psychosocial sequella to HTLV-III infection.

Psychosocial sequella experienced by AIDS patients. To date, the most rigorous empirical study in this area compared the

psychological distress experienced by 67 homosexual men diagnosed with AIDS with 150 asymptomatic homosexual controls, using the Symptom Check List 90-R (SCL 90-R), a self report inventory which assesses psychological symptom patterns of psychiatric and medically ill patients. Hirsch and Dworkin (1985a) found significant differences between the two groups on scales measuring somatization, obsessive compulsive behavior, depression, anxiety, phobic anxiety, psychoticism, and an index of general severity. The scores of the patient sample for depression, anxiety and global severity were particularly elevated. Of interest was the finding that AIDS patients had varying patterns of psychological distress, and that some respondents reported symptom levels that were not within the clinical range of severity.

A second study by Hirsch and Dworkin (1985b) examined the effectiveness of coping strategies on measures of psychological distress. The researchers hypothesized that coping behaviors modulate the psychological response to the stressor of being diagnosed with AIDS. Using another sample of 60 homosexual AIDS patients, they administered the SCL 90-R to measure psychological distress, and the Coping Strategies Inventory (CSI) to evaluate coping responses. They found that eight coping strategies were frequently endorsed by their sample. No coping strategy was found to correlate with significant reduction in measures of

depression. Three strategies were significantly correlated with reductions in measures of anxiety and the general severity index. These included comparison with others who were viewed as less fortunate, active relaxation, and resigned acceptance.

Only one other study has examined the effect of coping strategies on patients with AIDS. Alumbaugh, Namir, and Boxley (1985) looked at the relation between coping styles and social support systems, using a sample of 50 homosexuals from the Los Angeles area. Using a self-developed coping scale that was apparently not tested for validity, Alumbaugh and her co-workers found that active coping behaviors such as political activist work and physical exercise were positively correlated with all measures of social support. A cognitive coping strategy, such as seeking more information on AIDS, "was not related to any support measures, and avoidance coping [such as trying to deny or forget about the illness] was negatively related to all support measures, although not at a significant level" (1985; p. 6). Unfortunately, not enough data were presented in the Hirsch and Dworkin (1985b) study to compare the responses of these two samples.

Perry and Tross (1984) conducted a retrospective examination of the charts of 52 AIDS patients at New York Hospital to determine the prevalence of recorded psychiatric complications. These investigators found that neuropsychiatric complications were

pervasive clinical features in hospitalized AIDS patients. About 83 percent had mood disturbances, and 65 percent showed signs of organic mental syndromes, according to DSM-III criteria.

"References to neuropsychiatric complications--such as being depressed, anxious, lethargic, or withdrawn--appeared in the charts of all 52 patients" (p. 202). However, relatively few psychiatric consultations were seen with this group. Only 10 of the 52 patients received psychiatric consultation, and when this occurred, it was always done because the patient was a management problem for the hospital staff.

There are several problems with this study. As a retrospective study, it did not allow key constructs such as depression and anxiety to be defined in the same way by all raters. In addition, this study examined only those AIDS patients who were in acute stages of illness, which may bias the results towards psychological disturbance. The fact, however, that all patients had some psychological problems appears significant. Also significant is the fact that the hospital staff underutilized psychiatric consultation, except when the staff had a problem. This suggests that care givers may have avoided the emotional issues of these patients.

One other study in this area also examined hospitalized AIDS patients in an acute stage of illness. Dilley and his colleagues



(1985) examined 13 out of 40 AIDS patients admitted to San Francisco General Hospital. The 13 patients seen by the psychiatric consultation service were referred from the general medical wards of the hospital. Eleven of the 13 were homosexual, and two were bisexual. "Twelve of the 13 received psychiatric diagnoses" (p. 83). Seven were diagnosed with adjustment disorder with depressed mood; two were diagnosed with a major depressive disorder; one was diagnosed with a panic disorder; one with dementia; and one with delirium. None of the patients had previously been hospitalized for a psychiatric disorder.

There is a curious anomaly between these results and those of Perry and Tross (1984). They found that 65 percent of their sample suffered from organic mental syndromes, according to DSM-III criteria. Dilley and his colleagues found only one case of dementia and one of delirium--approximately 15 percent. Other researchers who have focused on the neurological manifestations of AIDS have found that about one third of AIDS patients develop neurological complications prior to death (Levy, Bredesen & Rosenblum, 1985; Namir, 1985). Thus, the results of Perry and Tross and Dilley appear to be statistically unusual in comparison with other, more focused studies which have used larger samples.

Dilley and his co-workers were able to document recurrent psychological themes in their sample. These included: pervasive

feelings of anxiety due to uncertainty about the illness and the experimental nature of the treatments; social isolation; and a sense of guilt regarding their homosexual lifestyle. These patients also evidenced responses typical of those diagnosed with life threatening illness such as fear, anger, depression, sadness, and a search for an explanation. These responses are consistent with the responses found by Hirsch and Dworkin (1985a) and Perry and Tross (1984).

The Dilley study avoided some of the problems inherent in a retrospective study such as that of Perry and Tross. However, a major deficit of the Dilley study is that they looked only at patients who were referred to psychiatry. One wonders about the psychological condition of those AIDS patients that Dilley did not examine. In addition, there was no specification of the stage of the disease in either study. This makes the results difficult to interpret and compare. For example, the differences in the frequency of organic mental syndromes between these studies may be simply an artifact of the stage of illness. It may be that the Perry and Tross study examined patients with more advanced stages of the disease, thus explaining the finding of more organic mental syndromes. Without more controls on the data gathering, issues of this sort cannot be resolved.

It is significant, however, that Dilley was able to give

psychiatric diagnoses to 12 of his 13 patients, and Perry and Tross found evidence of psychological problems in all of the 52 patients they examined. From these two empirical studies, one can hypothesize that: 1) adjustment disorders are the most prevalent psychiatric disorder in the population of hospitalized AIDS patients; and 2) depression is likely to be the predominant mood in this population. It is not known how these hypotheses fit the staging of the disease.

Although there are only five empirical studies of the psychosocial needs of AIDS patients, there is a considerable case study and anecdotal literature. David Rubinow (1984), Chief of the Psychiatry Consultation-Liaison Service for the National Institute of Mental Health, characterized the psychosocial situation of AIDS patients as one of "catastrophic loss". This loss includes loss of "health, job, financial autonomy, normal life style,... friends, social supports, harmony with family and lover....[In addition, there is] loss of sexual activity for some, and the sexual act is corrupted as it becomes identified as the mode of transmission of the illness. Patients experience loss of self-esteem, privacy, control of life's activities, and ultimately, of life" (p. 27).

The pervasive loss experienced by AIDS patients comes not only from the debilitating physical effects of the disease, but

also from the rejection and social isolation that many patients experience. The attack on the patient by the disease process from within, is paralleled by the social rejection of others. Both experiences are stressful and debilitating. One psychologist characterized the AIDS patient as "the modern-day, 20th century leper" (Fisher, 1983).

Several organizations are currently providing psychosocial assistance to AIDS patients. The Gay Men's Health Crisis (GMHC) in New York has detailed the psychological and social trauma that accompanies AIDS in homosexual men (Wein & Lopez, 1984). This information is summarized in Table 4, below.

Table 4  
Psychological and Social Issues of Homosexual AIDS Patients

- =====
- I. Social isolation
    - A. Withdrawal of social supports, due to:
      1. Fear of mortality among friends, family.
      2. Helplessness; inability to effect change.
      3. Overidentification with patient.
      4. Fear of contagion.
    - B. Isolation among hospital patients, due to:
      1. Severe infection control precautions.
      2. Occasional homophobic reactions among hospital staff.
  - II. Alteration in Patient's Quality of Life.
    - A. Crisis, disruption, disorganization in thinking and habits.
    - B. Experiencing 'bankruptcy', boredom, isolation:
      1. Patients often too sick to work, too well to stay home.
      2. Fatigue limits vocational, social participation.
      3. Medical restrictions
      4. View of self as leper in social, sexual world.
  - III. Drop in Self-Esteem
    - A. Stigma of AIDS:
      1. AIDS is a sexually transmitted disease.
      2. Patients begin to feel guilty, dirty.
    - B. Internal dialogue: "What did I do to deserve this?"
      1. Surfacing of internalized homophobia.
      2. Self-condemnation concerning 'life in the fast lane'.
    - C. View of self as toxic to others.
  - IV. Intensity of Emotion
    - A. Obsessive cognitive style:
      1. Absence of customary diversions, distractions, daily habits.
      2. Void filled by ruminative thinking.
    - B. Emotional vacillation:
      1. Anger, guilt, rage, depression, fear, easy tears.
      2. Fluctuations frequent within course of day.
    - C. Anger:
      1. At lack of justice, righteousness in life.
      2. In response to realistic, concrete frustrations.
  - V. Issue of Control
    - A. General sense of lack of control over disease, body, life:
      1. Reinforcement of passive, helpless patient role by medical establishment.
      2. Lack of effective treatments.

- B. Struggle to regain control:
  - 1. Scrambling from doctor to doctor.
  - 2. Perceived sense of urgency to select treatment option.

C. Relevance for counseling

VI. Denial

A. Defense mechanism:

- 1. "Not me, it can't be true".
- 2. "I'll be the first to overcome this disease".
- 3. Denial as primitive but healthy buffer.

B. Importance of denial in keeping patients intact, helps patients to maintain positive quality of life.

VII. Financial Stressors: cost of treatment usually ranges from \$50,000 to \$100,000, and may range as high as \$500,000.

---

---

The information presented in Table 4 above was developed out of clinical experience derived from counseling AIDS patients. Thus, while there is no information regarding the incidence or prevalence of these problems, it is clear that these problems are experienced with enough frequency to rate inclusion in the GMHC training materials for new counselors. The information presented in Table 4 is corroborated by other anecdotal reports from a variety of sources (Deuchar, 1984; Hausman, 1983a, 1983b; Lopez & Getzel, 1984; Morin et al., 1984).

One investigator (Forstein, 1984) has compiled this anecdotal information into four stages which describe the typical reaction to the diagnosis of AIDS. The initial stage, beginning with the diagnosis, is usually one of shock, numbness and disbelief. To date, most of the AIDS cases have struck relatively young homosexual men. These men are given a terminal diagnosis in the prime of their life, in the midst of successful careers and in their prime earning years. The shock of a terminal diagnosis is considerable.

The second stage conceptualized by Forstein is that of denial: the "attempt to ignore or forget the diagnosis or pretend it is wrong or not real" (1984, p. 78). This may include self-destructive behavior, including drug and alcohol abuse, sexual exploits or excessive risk taking. This stage may last

until the physical symptoms are so severe that the reality of the illness can no longer be ignored. One writer (Peskind, 1984) has described this stage of denial as "terror management"--a way of coping that allows the patient to meet the changes involved in the diagnosis at the patient's own speed.

The third stage is characterized by the question, 'Why me?' This often involves considerable anger and attempts at bargaining. Clinicians and counselors working with AIDS patients have reported finding a large reservoir of anger in many of these patients (Morin & Batchelor, 1984; Peskind, 1985). This anger appears to be a function of the relatively early stage of life in which the illness was diagnosed. Observers have also noticed, in some homosexual patients, the development of homophobia, a sense that one is being punished for a deviant lifestyle, and internalized self hatred (Forstein, 1984; Peskind, 1985).

"Depending on the person's premorbid personality, ego structure, and level of sophistication in his relationships, the individual with AIDS will either struggle to remain engaged with others emotionally, or may give up fighting and accept the reality of his own demise" (Forstein, 1984, p. 78). This final stage of acceptance leads to a sense of peace for some, and an orientation towards preparing for death.

In light of the empirical research in this area, there is a



curious omission in Forstein's stages. Although other researchers mention the frequent occurrence of depression in AIDS patients, it is not part of Forstein's stages. Forstein's stages seem to be a reworking of Kubler-Ross's stages of dying (1969). Kubler-Ross's stages include: denial, anger, bargaining, depression, and acceptance. Forstein's stages of shock, denial, 'why me', and acceptance seem to add little to the work of Kubler-Ross, and in fact, miss one of the stages reported by most other observers of AIDS patients.

A final criticism of Forstein is one leveled at Kubler-Ross. A review of the empirical literature on dying patients found no evidence for Kubler-Ross's stages of psychological adaptation (Schulz & Aderman, 1974). The data showed that "the process of dying [is] less rigid and even stageless. There is some consensus among all researchers that terminal patients were depressed shortly before they die, but there is no consistent evidence that other affect dimensions characterize the dying patient" (Schulz & Aderman, 1974, p. 137). This suggests that Forstein's stages, while they may have some heuristic value, are not supported by the empirical data.

Psychosocial sequella experienced by HTLV-III infected patients who have not developed AIDS. The information on those patients infected with HTLV-III virus, but who have not yet

developed AIDS is considerably less well developed than the literature described above. At this time, this literature consists of those psychosocial studies or reports that have examined those with generalized lymphadenopathy or AIDS Related Complex (ARC).

There is one empirical study which contrasts the psychological characteristics of healthy homosexual men against those with AIDS, and those with a generalized lymphadenopathy syndrome (Tross et al., 1985). Using an interview format with trained personnel, this study found a pattern of ascending magnitude of distress, in which the patients with generalized lymphadenopathy syndrome were more distressed than those with AIDS, who in turn were more distressed than the asymptomatic homosexual controls. Statistically significant group differences were obtained on measures of depression, fatigue, anxiety, somatization, hostility, global distress, intrusive and avoidant thinking, work function, and social-leisure function. Of interest is the data that shows that those infected but not diagnosed with AIDS had the most severe disturbance. The most frequent psychiatric diagnoses were adjustment disorders with depressed and/or anxious mood. This finding corroborates the finding of Dilley and his co-workers (1985).

This finding of Tross and her colleagues (1985) is also

corroborated by the anecdotal report of Morin, Charles and Malyon (1984). These psychologists found that the uncertainties of being in a group that is at high risk to develop AIDS led to greater psychological distress than that exhibited by AIDS patients. Knowing that one is at great risk (some 10-20 percent of those infected develop AIDS), but not knowing whether they will develop the disease results in the development of a variety of anxiety disorders. Complicating this is the hypothesis that psychological distress may further contribute to immune suppression, and thus facilitate the further development of the disease (Coates, Temoshok, & Mandel, 1984; Kemeny, 1985).

These data suggest several conclusions. First, the psychological distress experienced by the infected group is even greater than that of the AIDS group. Second, anxiety appears to be the most common psychological concomitant in the infected group, with depression more prevalent in the AIDS group. Third, the most common psychiatric diagnosis in both the infected and the AIDS groups is adjustment disorder with anxious or depressed mood. And fourth, the social isolation experienced by those with positive HTLV-III tests, whether AIDS patients or not, can be quite severe.

### Summary

This completes the section of this review which deals with HTLV-III infection. In this section, the infection has been defined by reference to the medical literature. The etiology and natural history were then examined, reviewing how HTLV-III infection is caused and the course of the typical infection. The effects of this infection on the immune system were examined next. It was shown that the HTLV-III virus has a tropism for the T4 cell, which is a critical element in the immune system. The disruption of the functioning of this cell has the effect of disrupting the entire immune system, leaving the host open to a variety of opportunistic infections and neoplasms. The spread of HTLV-III infection was then explored, in the section on epidemiology. Factors that inhibit and promote the spread of the organism were examined. The development and use of the HTLV-III antibody test was described here. Finally, the psychosocial literature on HTLV-III infection was examined. Although there are few empirical studies at the present time, the existent studies have generated remarkably similar findings with respect to most of the psychological findings. These findings indicate that those

with HTLV-III infection who have not developed AIDS have the most severe levels of psychological distress. In addition, various coping styles have been correlated with modulations of the psychological responses to the disease. Finally, anxiety and depression are the most prevalent psychological symptoms.

Based on the existent empirical and descriptive literature, the present study has examined a sample of homosexual men. This sample included AIDS patients, men with positive antibody test results, men with negative antibody test results, and men who have not taken the antibody test. The present study measured levels of psychological symptoms, coping strategies, and social adjustment, and determined what relations exist among these variables.

#### Parallels with Other Life-Threatening Diseases

As the review above has demonstrated, there is very little empirical data regarding the psychosocial concomitants of AIDS. There is, however, information from parallel sources--research that has investigated the psychosocial impact of other life-threatening diseases. While this body of information does not carry the same weight that data developed from AIDS patients might carry, nevertheless these data can be useful--especially in these beginning stages of psychosocial research in AIDS. There

are two ways in which these related data can be useful. First, they provide an information source from which specific hypotheses can be generated which may assist the AIDS researcher. Second, the compilation of information from several related sources may provide the theoretical base from which the psychosocial concomitants of all life-threatening diseases can be understood.

The usefulness of this related information is contingent upon the inference that the psychosocial concomitants of one life-threatening disease will be similar to the psychosocial concomitants of other life-threatening diseases. In this section of the review, the psychosocial impact of two parallel diseases--cancer and AIDS--will be examined. Both diseases are life-threatening, both are present in epidemic proportions, and both have resulted in high mortality rates. However, at the present time, cancer is relatively socially acceptable. That is, others do not shun the cancer patient--cancer is not typically considered to be a communicable disease. Thus, while there is considerable psychosocial research regarding the effects of cancer, this disease is not directly parallel to AIDS because there is no element of social ostracism that is similar to the ostracism experienced by AIDS patients.

To find that social ostracism, one must go back in time to when tuberculosis (TB) was not yet curable. In the last century

and the early part of this one, after TB was identified as communicable but before a vaccine had been found, TB patients were treated in a manner similar to that of AIDS patients today (Krause, 1984). They were socially isolated, removed to different parts of the country, and put into sanitariums. Unfortunately, no one kept psychosocial data on the effects of this process, so it is not possible to include this disease as a parallel to AIDS.

There are currently no published epidemiologic surveys which have identified the incidence of psychological symptoms or the range of psychosocial adaptations in the population of cancer patients. However, there are a number of studies which have examined parts of these issues. These studies seem to fall into three categories: 1) those dealing with the patient's emotional reaction to cancer; 2) the psychosocial impact of cancer on areas of life functioning; and 3) the course of psychosocial adjustment during the course of the disease (Freidenbergs et al., 1981-82).

The diagnosis of cancer is often associated with increased levels of psychological distress in the patient. This distress appears to be caused by three classes of variables: 1) the emotional effects of knowledge of the disease, 2) the physical effects of the disease process; and 3) the effects of such standard treatments as surgery, radiation therapy, and chemotherapy. The effect of knowing that one has cancer tends to

have a powerful negative effect on the patient's emotional state (Feinstein, 1983). This intuitive hypothesis is supported by considerable empirical evidence. Roberts, Furnival and Forrest (1972) assessed the morbidity of 112 women with breast cancer using interviews and questionnaires. They found that half of the sample admitted being either very anxious or depressed. Craig and Abeloff (1974), using the Self Report of Symptoms Inventory, found that more than 50 percent of thirty leukemia and lymphoma patients were clinically depressed, and 30 percent were clinically anxious. Using the Beck Depression Inventory, Plumb and Holland (1977) found that only 23 percent of the 97 cancer patients they examined were clinically depressed. Supporting this finding, Worden and Weisman (1977) found that only 20 percent of breast cancer patients and 18 percent of other cancer patients were depressed, when tested with the MMPI Depression scale.

These studies provide the primary epidemiologic data upon which psychological interventions to cancer patients are based. However, as the knowledge of the relevant variables which effect the course of the disease has increased, several methodological shortcomings have been noticed in these studies. Factors such as the site of the cancer, the staging of the disease, and the type of medical treatment administered have not been related to the type or incidence of psychological symptoms. Psychosocial



variables such as age, religion, and gender--variables which have been shown to have an important mediating role on the impact of the disease (Freidenbergs et al., 1981-82)--have not been utilized in these studies.

In addition to the patient's emotional reaction to the knowledge of the disease, there is also a physiologic reaction to the disease process which can mediate radical shifts in psychological functioning. For example, cancer can have profound physical effects on the brain and nervous system (Brain, 1963; Norris, 1972). When cancer develops in the brain, organic brain syndromes and toxic states are often psychiatric concomitants (Holland, 1982). Cancer seems to be correlated with psychiatric problems in other sites as well. For example, Frascino, Litin and Pearson (1967) found that 76 percent of pancreas tumor patients exhibited psychiatric symptoms, whereas controls with cancer of the colon showed that 17 percent of the sample displayed these symptoms. Roth (1973) found that certain physiological syndromes are related to psychological symptoms. These include metabolic syndromes, endocrinopathies and hematological changes. In addition, Mitchell (1967) found that neoplastic disease can result in psychiatric symptoms when malignancies of nonendocrine tissues produce hormones which affect the nervous system. For example, bronchogenic, thymic, pancreatic and renal carcinomas have been

reported to cause Cushing's syndrome (Mitchell, 1967).

The third class of variables which mediate the psychological distress of cancer is connected with the traditional treatments of cancer: surgery, radiation therapy, and chemotherapy. Peck (1972) used psychiatric interviews to study the affective reactions of 50 cancer patients undergoing radiation therapy. He found that 98 percent of those interviewed complained of anxiety, and 75 percent complained of depression. Extending this finding, Peck and Borland (1976) found, in a sample of pre-radiation patients, that 62 percent were depressed and 66 percent were anxious. In an interview following the radiation treatment, they found all but one showing at least mild to moderate emotional reactions, and 80 percent showing a significant degree of anxiety.

Meyerowitz, Sparkes and Spears (1979) studied the psychological effects of chemotherapy in women with breast cancer, using a structured interview. They found that most women experienced adverse reactions, including a decrease in activities, and a negative impact on their family life. Unfortunately, there is no other literature which examines the psychological effects of chemotherapy.

A number of studies have examined the psychological effects of surgery on cancer patients (Brown, Haddox, Posada, & Rubio, 1972; Deitz, 1969; Rosillo, Welty, & Graham, 1973; Roberts et al.,

1972; Worden & Weisman, 1977). These studies indicate that the psychological impact of surgery is dependent upon premorbid attitudes towards the management of stress, the severity of the illness, and the amount of disfiguration caused by the surgery.

The research which has explored the psychosocial impact of each of the classes of variables reviewed above indicates that each variable tends to produce a psychological impact on the cancer patient. In view of the functional similarities between the effects of a diagnosis of AIDS and cancer, it is likely that these variables will have a similar impact on the AIDS patient. Thus, one would expect that the AIDS patient would have a pronounced emotional reaction following diagnosis of AIDS--perhaps even more extreme than that of the cancer patient since AIDS is, at the present time, incurable. Furthermore, one would expect the typical emotional reaction to involve depression and/or anxiety. According to the clinical literature on AIDS, this phenomenon is exactly what occurs.

Second, one would expect that AIDS might have some particular physical effects which would impact psychological functioning. Again, this is what happens. The HTLV-III virus attacks the nervous system, resulting in a variety of neurological changes which often present to the clinician as psychiatric syndromes (Perry & Tross, 1984). In addition, the host organism is

particularly susceptible to microorganisms which flourish in the central nervous system, also resulting in neurological changes with psychiatric presentation.

The third class of variables concerns the effect of treatment on the psychology of the patient. AIDS patients are typically treated with chemotherapy specific to the opportunistic infection or neoplasm. To date, no research has been conducted in this area with AIDS patients, and no clinical observations have been published. Clinicians and counselors who work with AIDS patients indicate that some kinds of chemotherapy result in major changes in psychological functioning, including dementia and major depression (Peskind, 1985). These reports are unsubstantiated by empirical investigations at this time.

In each case, AIDS patients have reactions to similar phenomena as cancer patients, and in ways that are similar to cancer patients. This suggests that there exists a common structure to psychological reactions to facing life-threatening illnesses, and support the inference upon which this part of the review is based. But there are other elements in the psychosocial reaction to cancer that do not seem to have as strong a connection. These include both the impact of the disease on areas of life functioning, and the course of psychosocial adjustment. Both of these differences appear to be related to peculiarities

that are specific to AIDS.

In cancer patients, the areas of psychosocial difficulty most frequently reported, independent of the cancer site, include: dissatisfaction with medical treatment, family problems, difficulties in social relations, and difficulties with activities of daily living (Gordon et al., 1977). In addition, cancer patients frequently have difficulty in resuming their work activities. Feldman (1978) found that 13 percent were denied work because of their cancer history, and 35 percent experienced some form of job-related discrimination. Gordon et al. (1977) found that one third of his sample of cancer patients had some form of vocational difficulty.

With AIDS patients, this situation is acutely exacerbated by the fears surrounding the disease, and the incurable course of the disease. There is no possibility of long term occupational rehabilitation with AIDS patients because the disease is incurable. And, once the patient tells his employer of his condition, the anecdotal evidence reported in the newspapers and popular press indicates that many are terminated from their employment. The discrimination is apparently so pervasive that Los Angeles and other city governments recently passed an ordinance prohibiting discrimination against AIDS patients by employers and landlords.

With regard to other variables in this class, such as social relationships, family problems, and difficulties with daily living, in each case the problems are likely to be more acute with AIDS patients than with cancer patients. Because of the communicable nature of AIDS, the fears surrounding it, and the fatal course of the disease, the reactions of others to the AIDS patient are probably more extreme than those experienced by the cancer patient.

Thus, while similarities in the psychological and psychosocial reactions to the two disease processes exist, these reactions are not identical. They appear to be mediated by variables particular to each disease, including the prognosis and course of the disease, the effect of the disease upon physiological functioning, and the social reaction to the disease.

In 1977, Lloyd attempted to codify the psychological reactions to physical illness. He isolated the following variables:

Table 5  
Psychological Reactions to Physical Illness

- 
- 
- A. Factors influencing psychological response:
1. Premorbid attitudes and personality traits, especially with regards to the management of stress.
  2. The severity of the illness, or the significance and value of the affected body part to the patient.
  3. The social environment, including cultural background, close friends, family, and relationships with the treatment team.
- B. Patterns of psychological response:
1. Therapeutic adaptation, including active cooperation with treatment, and a positive attitude toward the illness.
  2. Anxiety becomes prominent when the illness is seen as a potential threat.
  3. Depression is probably the most common psychiatric disorder that accompanies physical illness. It occurs when "the illness signifies a loss, which may be anatomical, functional, or symbolic" (p. 356).
  4. Paranoid reactions occur with patients who are inclined to use projection as a mechanism of defense against the illness.
  5. Denial of illness, which includes coping strategies such as outright denial to the tendency to minimize the importance or impact of the illness.
  6. Preoccupation with the illness, the opposite of denial, occurs when the patient actively seeks out all information about his/her illness and treatment.
  7. Prolongation of the sick role, which occurs to maximize the secondary gain which accompanies illness.
- 
-

These factors appear to summarize the psychological reactions to physical illness, and apply to both cancer and AIDS patients. There are, however, differences in the intensity with which these variables occur, depending upon the circumstances particular to the disease. In addition, there are a variety of social factors which Lloyd did not examine in A.3. above, but which will have an effect on psychological functioning. These social factors include: the communicability of the disease, the effect of the disease on social and occupational functioning, and difficulties with daily living brought on by the disease, such as shopping and housecleaning. As with the psychological variables, the social variables impact both cancer and AIDS patients, but in different ways because of the circumstances unique to each disease process.

The occurrence of common psychological and social factors between the two diseases suggests some directions for future AIDS research. Hypotheses that are suggested by these common factors include:

1. What is the degree of social isolation experienced by those with HTLV-III infection, and how does this impact their adaptation to the infection? How is this different from cancer patients' adaptation?
2. How do intervening variables, such as the staging of the infection, the type of medical treatment, age, and religion effect the



patient's adaptation to the infection?

3. What are the emotional reactions of those with HTLV-III infection during the different stages of the illness? Are they similar to the emotional reactions of cancer patients?
4. Do cancer and AIDS patients with similar premorbid personality traits exhibit similar adaptations to their illnesses? To coping with stressors?
5. Is stress associated with the progression of HTLV-III infection from one stage to the next, more critical stage?
6. What are the coping strategies used by those with different stages of HTLV-III infection?
7. What is the degree of anxiety and depression experienced by those in different stages of HTLV-III infection? Can maladaptive emotional reactions be predicted by other variables?
8. Do patients who undergo different treatments have different psychological reactions?

These hypotheses are beyond the scope of the present study, which is more exploratory in nature. However, as data accumulate regarding the psychological effects of HTLV-III infection, it will become necessary to investigate these questions.

### The Male Homosexual Population

In the United States, HTLV-III infection is found primarily in male homosexuals. Because of the pervasively negative social opinion towards this population, relatively little is known about this group. As a result, a variety of misconceptions have arisen about male homosexuals. The purpose of this section of the review is to describe briefly the population of male homosexuals, and to delineate some of the problems involved in doing research with this group.

The first problem that the researcher encounters is that of defining this population. A search of the literature reveals a wide range of opinion on this issue. Homosexuality has been variously defined as overt sexual behavior with same sex partners (Ford & Beach, 1951) and as a phenomenon that can be 'latent', with no behavioral expression (Rado, 1940). Kinsey and his colleagues (1948) defined sexuality as a continuum, ranging from heterosexuality to homosexuality, with seven identifiable divisions. A prominent investigator of homosexual behavior, Judd Marmor, defines the homosexual "as one who is motivated in adult life by a definite preferential erotic attraction to members of the same sex and who usually (but not necessarily) engages in overt sexual relations with them" (1980, p. 5). Marmor notes,

however, that homosexuality does not exclude the capacity for heterosexual arousal.

#### Incidence of Male Homosexuality

In a study of 76 modern cultures, Ford and Beach (1951) found that 64 percent of these cultures considered homosexual activity either normal or socially acceptable. In some cultures, such as the Aranda of Australia and the Siwans of North Africa, male homosexual activities were universal, although these activities did not preclude heterosexual relationships. Among the remaining 36 percent of cultures where homosexual activity was either censured or prohibited, there was evidence in many cases that homosexual activity occurred covertly. In those societies with attitudes towards homosexuality which are similar to those in the U.S., it is clear that the study of those who engage in a censured behavior is very difficult. Actual numbers are virtually impossible to obtain, due to the threat of punitive action by other members of the culture. Thus, it is reasonable to assume that the actual incidence figures present in these cultures are probably higher than the obtained figures.

Kinsey and his colleagues (1948) surveyed 5300 white American

males in an effort to measure the actual sexual practices of our culture. They found that 10 percent were more or less exclusively homosexual for at least three years between the ages of 16 and 55, and 4 percent were exclusively homosexual throughout their adult lives. "The Kinsey reports represent the most thorough and extensive surveys done to date" (Marmor, 1980, p. 7). A number of smaller surveys have been conducted in Europe and all are in approximate agreement with the Kinsey findings (Gebhard, 1969; Marmor, 1980). On the basis of these studies, one can conservatively conclude that the incidence of relatively exclusive homosexual behavior ranges from 5 to 10 percent of the male population. If bisexual behavior is included, the incidence may be twice these figures (Marmor, 1980). "It is clear that the propensity for homosexual reactivity is a widespread one even in societies such as ours which strongly discourage it" (Marmor, 1980, p. 7).

#### Determinants of Homosexual Behavior

A variety of theories have been presented to account for homosexual behavior. Three classes of hypotheses have been put forward, suggesting that homosexuality is caused by: 1) biological

factors; 2) family background; or 3) social and cultural factors.

There are currently two major hypotheses which emphasize biological factors. The first of these is based on the finding that homosexual behavior is found in most species throughout the animal kingdom (Denniston, 1980; Weinrich, 1982). This argument suggests that homosexual behavior is a natural genetic variant, similar to hair color and other genetic variants. At this time, an impressive array of data supports this hypothesis.

The second hypothesis which emphasizes biological factors argues that homosexual behavior is due to intrauterine or early postnatal influences. Specifically, Dorner and Hinz (1968) argue that a deficiency of male hormone during certain critical periods predisposes the fetus to effeminate patterns of behavior. This has been demonstrated in an animal model, and in experiments with adult male homosexuals (Dorner, 1975).

The most prevalent theory of male homosexual development attributes this development to a particular family constellation. Bieber and his colleagues (1962), in a study of 106 male homosexuals, found a parental constellation which included a detached, hostile father and a close-binding, seductive mother who dominated the husband. This theory of etiology probably originated with Freud (1905), and has had a pervasive influence in psychiatry and psychology.

The final class of etiological theories of homosexuality emphasizes social and cultural factors. While these factors have been minimized in research to date, "there is substantial reason to believe that the social and cultural contexts of human development are relevant to the genesis of some homosexual behavior" (Marmor, 1980, p. 12). For example, gender-role patterns appear to vary considerably from culture to culture. In addition, cultural attitudes regarding the acceptability of homosexual behavior probably have a bearing on the development of homosexual behavior. Finally, economic factors may play a part in some homosexual development. For example, Opler (1965) indicated that the high incidence of homosexual behavior among the Chukchee appears to be related to the difficulty in accumulating enough wealth with which to acquire a wife.

At this time, no single theory of homosexual development has accumulated convincing support. In all probability, homosexuality will be found, at a later time, to have multiple determinants, as is the case with most complex human behaviors.

#### The Question of Psychopathology

Many of the early studies of homosexuals drew samples from

legally or psychiatrically involved homosexuals (Gonsiorek, 1977). Often, the homosexual patient/prisoner group was compared with a heterosexual non-patient/non-prisoner group, as in Cattell and Monroney (1962). Given the current understanding regarding research in the behavioral sciences (Borg & Gall, 1979), it is clear that such comparisons will reveal little information that is useful. Furthermore, neither the legally nor the psychiatrically involved homosexual can be considered to adequately represent all homosexuals. Recent data derived from psychological testing of non-patient homosexuals supports this contention.

Morin (1978) identified three key studies which have called into question much of the previous behavioral research on homosexuality. The first and most influential was the work of Kinsey and his colleagues (1948), which indicated that homosexual behavior was much more widespread than previously believed. Kinsey and his co-workers stated that "37 percent of the total male population has at least some overt homosexual experience to the point of orgasm between adolescence and old age" and "an additional 13 percent...react erotically to other males without having overt sexual contact after the onset of adolescence" (p. 650).

These data indicate that homosexual behavior is widespread in our culture. Some 50 percent of the males have had homosexual

experience or been aroused sexually by other men. Some 10 percent have been homosexual in their sexual preference for a significant part of their adult lives. Some 5 percent retain a homosexual preference for all of their adult lives. The large numbers indicated by these percentages suggest that either: 1) homosexuality is within the 'normal' range of human sexual experience; or 2) homosexuality is a perversion of immense magnitude.

The second major study identified by Morin is that of Ford and Beach. "Three years after the Kinsey report, Ford and Beach (1951) published data which indicated that homosexual behavior was found in almost all species and in almost all cultures, thus strongly challenging the notion that homosexual behavior was unnatural" (Morin, 1978, p. 2). These findings have been replicated by later researchers (Kirsch & Rodman, 1982; Weinrich, 1982).

The third key study identified by Morin was that of Hooker (1957). Addressing more directly the notion that homosexuality is indicative of psychopathology, Evelyn Hooker (1957, 1958) "demonstrated that trained clinicians could not differentiate the sexual orientation of homosexual nonpatients from that of nonhomosexuals...by the use of standard projective techniques" (Morin, 1977, p. 631). Subsequent research (Gonsiorek, 1982) and



clinical evidence (Coleman, 1982a, 1982b; Hencken, 1982) supports Hooker's findings. The conjunction of the findings of Ford and Beach with those of Hooker appears to rule out the notion that homosexuality is a perversion. The conclusiveness of this evidence is indicated by the recent change in the status of homosexuality in the psychiatric nomenclature. With the appearance of the third edition of the diagnostic manual (American Psychiatric Association, 1980) homosexuality, per se, has been removed from the list of mental disorders.

Describing the Population  
of Male Homosexuals

Kinsey and his colleagues (1948) noted, "Males do not represent two discrete populations, heterosexuals and homosexuals. The world is not divided into sheep and goats. It is a fundamental of taxonomy that nature rarely deals with discrete categories" (p. 639). This comment suggests the hypothesis that a description of the male homosexual population may not be very different from a description of a male population. In a large Kinsey Institute study, this hypothesis was confirmed. Bell and Weinberg (1978) studied 686 homosexual males, carefully recruited to characterize the population of male homosexuals as closely as possible. They found that male homosexuals, in comparison to heterosexual controls, were: 1) somewhat more promiscuous; 2) less religious;

and 3) slightly more liberal in their political views. In all other areas, Bell and Weinberg found no difference between the male homosexuals in their study and the heterosexual controls. This includes the stability of work history, job satisfaction, and self-acceptance.

By means of self-reported mood measures, male homosexuals tended to be somewhat more depressed, tense, and worried than heterosexual controls. However, when homosexuals were differentiated into five naturally occurring groups, the differences in mood between homosexual and heterosexuals were explained. Most of the increase in the homosexual group mean scores resulted from the increases found in the "dysfunctional" group. The dysfunctional homosexuals were the group "which most closely accords with the stereotyped of the tormented homosexual. There were troubled people whose lives offer[ed] them little gratification....As a whole, the Dysfunctionals displayed poorer adjustment" (Bell & Weinberg, 1978, p. 225). It was apparent that the dysfunctional homosexuals accounted for most of the differences in reported mood states. As a result of this analysis, Bell and Weinberg suggested that future research should probably compare dysfunctional homosexuals against dysfunctional heterosexuals, in order to arrive at a truer understanding of the two groups.

On reflection, the finding that male homosexuals and heterosexuals share more similarities than differences is not unexpected. Given the sheer magnitude of the number of male homosexuals, one would expect that homosexuals would be a diverse population. And, considering that all homosexuals come from heterosexual families, it is likely that homosexual males would be identical to heterosexual males on most variables. The evidence supports the notion that "homosexuality is not a unitary phenomenon, but rather represents a wide variety of phenomena which take in a wide spectrum of overt behaviors and psychological experience" (Livingood, 1969, p. 2).

#### Methodological Problems of Homosexual Studies

There are a number of serious problems in conducting rigorous research with the population of male homosexuals. The single overriding problem in all studies of homosexuality has been the difficulty in obtaining an adequate sample. In any study of human behavior, if the investigator wishes to generalize the results of the study from the sample tested to a larger population, then the investigator must use a sample that 'represents' that population (Campbell & Stanley, 1963). After considerable trial and error, the procedure of random sampling has been found to most adequately 'represent' larger populations. However, before random sampling

can occur, all of the members of the target population must be identified. If the members of the target population are not identified, then the investigator cannot be certain of selecting a sample in which every member of the target population has an equal chance of being selected, and thereby violates the criterion for randomness. If the sample is not randomly chosen, then it is much more difficult for the investigator to demonstrate that the small and intensively studied sample is equivalent to the larger population about which the investigator would like to make claims.

In studying homosexuality, it is impossible--in the present social climate in this country--to obtain a random sample of homosexuals (Bell & Weinberg, 1978; Gonsiorek, 1977). Homosexuals are mostly an 'invisible' population (Gonsiorek, 1977). Because the social climate has been so negative towards homosexuals, it has been risky to identify one's self in this way. Because the population cannot be identified by the researcher, a random sampling procedure is not possible. This means that all of the published data regarding homosexuals must be considered applicable, in a strict sense, only to the sample from which the data was derived. Thus, unlike most psychological and sociological research, it is not possible to speak with confidence about the larger population.

Another of the difficulties faced by the researcher who wants to describe the homosexual population is that, despite the large numbers of homosexuals, there are few, if any, instruments which have been normed on homosexual populations. This means that data gathered by most standardized psychological instruments cannot be used without some cautionary note. Thus, not only must the conclusions from each sample be qualified as not representing the population, but each test used must also be qualified as having questionable validity when used to measure a homosexual sample. Fortunately, with the work of Bell and Weinberg (1978), it seems reasonable to assume that the norms applicable to men will also be applicable to homosexual men, on the grounds that the two populations are sufficiently alike in most cases, although with the qualifications noted above.

These difficulties are compounded by the perception among homosexuals of the biases that heterosexual researchers bring to their research with homosexual populations. Morin (1985) defines heterosexual bias as "a belief system that values heterosexuality as superior to and/or 'more natural' than homosexuality". According to Morin, this bias has resulted in the posing of research questions which are subtly biased against homosexuals, and in the biased interpretation of data. This heterosexual bias is "most clearly seen in the research that begins with the

assumption that homosexuality is per se indicative of psychopathology" (Morin, 1977, p. 629).

The results of this heterosexual bias of which Morin speaks include a reluctance among some homosexuals to participate in psychological research. Research is often seen by homosexuals as another tool which can be used against them. This is a further complication in the sampling process.

A final difficulty in researching this population has to do with the ways in which homosexual men, in this culture, tend to view the world. With some cause, they tend to perceive the world as a somewhat hostile environment. As with any minority group, there arises an 'in-group/out-group' categorization. This perceptual framework tends to limit social intercourse between homosexuals and heterosexuals.

There appears to be a circular mechanism here: the researcher cannot identify the homosexual population because it is dangerous for the homosexual to be identified as such. Those who can be identified as homosexual and persuaded to participate in a research project, cannot be validly measured, because norms have not been developed for this population. These norms have not been developed, in part, because it is impossible to obtain a random sample of the population. These factors make the study of the homosexual population very difficult.

Two factors are currently present which seem to have an ameliorating effect on these difficulties. First, due to the pioneering work of homosexual researchers, a more rational research stance has been developing towards this population over the last fifteen years. This has permitted the accumulation of usable data which--despite the problems noted above--allows some picture to be constructed which describes homosexual behavior better than either the picture arising from previous research, or the picture arising from popular misconception.

The second factor which has had a positive influence is, paradoxically, the epidemic of AIDS in the homosexual population in this country. The widespread occurrence of this disease has resulted in the recognition, on the part of some homosexuals, that more needs to be known about their lifestyle in order to facilitate treatment of homosexual AIDS patients. This has had a positive impact on the willingness of many homosexual subjects to participate in research.

However, the occurrence of AIDS also gives rise to particular problems. For example, there is a widespread attitude of denial, anger and fear among male homosexuals with regards to AIDS (L. Zambrano, personal communication, June 5, 1985). As a result, while many homosexuals are inclined to participate in AIDS research, others are likely to reject participation solely on the

grounds that they do not want to deal with anything having to do with AIDS.

### Summary

According to recent research, homosexual behavior in this country is widespread. This behavior probably has multiple determinants, as would be expected of any complex social behavior. A variety of recent studies have provided some support for the notion that homosexuality is not indicative of psychopathology. A major attempt to describe the homosexual population found that male homosexuals were very similar to heterosexual controls on almost all measures. Given the large numbers of male homosexuals in this country, this finding is not unexpected. Finally, a number of methodological problems that are particular to research with this population were identified.

These include:

1. The impossibility of obtaining a random sample of male homosexuals at the present time, and the subsequent limitations on generalizing information from the sample to the population.

2. The lack of appropriate norms for the homosexual population, because psychological tests have not been standardized



using homosexual samples. This creates some question regarding the validity of these measurements. However, because of the Bell and Weinberg study (1978), the inference can be made that norms for male homosexuals will be similar to those for males in general.

3. The difficulty in obtaining the cooperation of homosexuals for research purposes, due to the history of heterosexual bias in psychological research.

#### Ethical Considerations in AIDS Research

While a consideration of ethical obligations is important in any study involving human subjects, it is of paramount importance in AIDS research. The two populations who are most at risk for developing AIDS are male homosexuals and intravenous drug abusers. Members of these groups are subject, by virtue of group membership, to legal sanction, social stigma, and occupational discrimination. Furthermore, disclosure that one carries an AIDS diagnosis, or is a subject involved in AIDS research "carries a stigma that can adversely affect a person's interests socially, politically, and economically" (Bayer, Levine, & Murray, 1984, p. 2). This confluence of two stigmatizing group memberships presents special challenges to the AIDS researcher.

#### The Preamble of the Ethical Principles of Psychologists

(American Psychological Association, 1981) states that the psychologist's primary duty is to "respect the dignity and worth of the individual and [to] strive for the preservation and protection of fundamental human rights" (p. 633). In addition, researchers are bound to consider the welfare of the research participants (Principle 6), to protect the legal and civil rights of research participants (Principle 3c), and to respect the confidentiality of research participants (Principle 5). In AIDS research, these ethical obligations are competing directly with the needs of other organizations and agencies who want to know who has AIDS, and who is infected with the HTLV-III virus. These organizations include departments of health, blood collection centers, health and life insurance companies, schools, and employers.

In 1983, the Centers for Disease Control was charged with violating the confidentiality of patients with AIDS when they released, on three separate occasions, the names and other confidential information to a blood collection center and several health departments (Marwick, 1983). In commenting on this breach of confidentiality, a gay rights lobbyist "pointed out that once information is passed on to private institutions such as the...blood center, the Centers for Disease Control no longer has control over it" (Marwick, 1983, p. 945). Subsequent to the

revelation of this breach of confidentiality, there has been a serious rupture in the relations between the Centers for Disease Control and members of the homosexual community.

Prior to the release of the HTLV-III antibody test, most homosexual publications were advising male homosexuals to refrain from taking the test (L. Zambrano, personal communication, June 5, 1985). The Lambda Legal Defense Network, a homophile publication, detailed three major risks to a male homosexual involved in taking the antibody test in the February, 1985 edition. First, "if a positive antibody test becomes part of your medical record, it could become justification for denial of life or health insurance" ("The Test", 1985, p. 4). Second, "a positive antibody test could also become a reason for denying employment" (p. 4). Third, "the psychological pressure of knowing that one has tested positive to antibodies is one of deep concern to our community" (p. 4). These risks are not projections without substance, but rather were stated as the result of a long history of discrimination against homosexuals in this country.

Thus, there is considerable need for the researcher to take steps to preserve the confidentiality of research subjects involved in AIDS research. For this reason, guidelines for preserving confidentiality and maintaining an ethical posture with regards to AIDS research will be reviewed in this section.

The first area of ethical concern has to do with the necessity of the research and how it is conducted (American Psychological Association, 1985). Because any breach of confidentiality in AIDS research carries possible adverse consequences for the research participant, it is important for the psychologist to deliberate with peers and with the public regarding the necessity of the proposed research. In addition to standard review procedures such as consideration by an Institutional Review Board, the APA has suggested an 'extraordinary review' by utilizing an advisory group drawn from the population to be studied (American Psychological Association, 1985). This is particularly important when sampling a homosexual population. Morin (1977, 1985) has talked at length of the heterosexual bias of psychological researchers. Review by male homosexuals would permit this bias to be identified and corrected before the offending material is sent to the research subjects. In addition, these procedures are likely to facilitate the research in other ways, such as recruitment, and improved response rate.

A second area of ethical concern in AIDS research revolves around the notion of confidentiality (American Psychological Association, 1985). This area gives rise to the most acute ethical problems, because of the competing needs of other organizations to

have access to the names of research subjects. Thus, extraordinary measures must be taken to insure that the confidence of the research subjects is not abused.

The most secure way of maintaining confidentiality is to make responding anonymous. The use of this method insures that confidentiality cannot be broken. However, because of the need to gather longitudinal data, the use of this method may not always be possible. In these cases, the researcher "should adopt methodological strategies...and take legal steps...before a study is conducted, in order to minimize the possibility of involuntary disclosure of data" (American Psychological Association, 1985, p. 7). Methodological strategies would include designing the test materials so that personal, identifying data is not placed on them. Rather, a coding device is utilized, in which identifying data is kept in a key that is isolated from the testing material and stored in a secure place. Legal steps include obtaining protective orders or confidentiality certificates prior to initiating the research. Unfortunately, such legal steps have not yet been tested in the courts, and it is unclear whether they offer adequate protection at this time (American Psychological Association, 1985).

In addition, research subjects should be informed of the limits of confidentiality. It is also suggested that the

requirement of a signed consent form be waived, if such a consent form is the only way of linking a particular subject to a research protocol (Bayer et al., 1984).

A third area of ethical concern revolves around the intrusiveness of measures used in the research (American Psychological Association, 1985). For high risk groups, any talk or reflection on the topic of AIDS is likely to be stressful. "In general, researchers should minimize the unnecessary intrusiveness of their studies" (American Psychological Association, 1985, p. 4). This includes limiting recruitment to volunteers, warning potential participants when the content of an interview or questionnaire might be stressful, and making explicit that a participant can withdraw from the study at any time.

A fourth area of ethical concern has to do with carefully debriefing participants and conducting appropriate followup (American Psychological Association, 1985). This includes informing participants of any information developed as a result of the study which may impact the participant's physical or emotional health. In addition, "participants need to be made aware of the uncertainty or ambiguity in the meaning of particular findings" (American Psychological Association, 1985, p. 8). Finally, debriefing should entail uncovering other concerns that participants may have with regard to the subject of the

investigations, and the researcher should take appropriate steps to address these concerns.

The fifth and final area of ethical concern identified by the APA revolves around the careful reporting of results. Because of the public desire for new information on the subject of AIDS, there is added pressure on the researcher to report findings quickly. However, no gain will result from premature reporting of data that are inadequately analyzed, or that are based on a biased sample. "Mistaken reports, even if well intentioned, can result in unwise public policy, public alarm (or undue complacency), and stigma for affected groups" (American Psychological Association, 1985, p. 9). Thus it is especially important, when reporting results in this area, to indicate "the limitations of the study, and to emphasize points of uncertainty or alternative interpretation" (American Psychological Association, 1985, p. 10).

These five areas have been identified as areas of special concern for AIDS researchers by the Committee for the Protection of Human Participants in Research for the American Psychological Association. They represent an attempt to apply the Ethical Principles of Psychologists (American Psychological Association, 1981) to the specific challenges of AIDS research. As such, any psychological research that examines some aspect of AIDS should

shape the research to conform to the demands identified in this material. This will, insofar as it is possible to do so at this time, protect the welfare of the participants of the study.



CHAPTER III  
RESEARCH PROCEDURES

Population and Sample

The target population for this study consisted of homosexual men who have had the HTLV-III antibody test. The accessible population consisted of homosexual men resident in Orange County, California, who have had the HTLV-III antibody test, and who were on the mailing lists of at least one of the three homophile organizations in Orange County that participated in this study. The participating organizations included the Elections Committee County of Orange, Laguna Outreach, and the Gay and Lesbian Community Center.

The ideal sampling procedure for this study would have been a random sampling of all homosexual men who have had positive results to the HTLV-III antibody test in a given geographical area. There were, however, several factors which precluded this. First, the population of homosexual men was difficult to identify (Batchelor, 1984). This was due to the negative social climate with respect to homosexuality, and the fears of homosexuals regarding social rejection and economic discrimination (L. Zambrano, personal communication, June 5, 1985). Thus, because of

the difficulty in identifying the population, it was not possible to draw a random sample (Morin, 1977). Second, there was a problem in gaining the trust of the homosexual community, due to decades of psychological research with either an explicit or implicit homophobic bias (Joseph et al., 1984). Finally, because of the prevailing fears surrounding AIDS (Kalish, Ostrow, & Phair, 1983) homosexual men who were being tested engaged in a variety of procedures which prevented their identification. These procedures included insistence on the use of code numbers rather than names for identification when using public health facilities, and making arrangements with private physicians to hold the data in strictest confidence (S. Peskind, personal communication, June 5, 1985). These three factors complicated the sampling procedure of the present study. In order to gather data in this area, it was clear that procedures other than random sampling of an identifiable population would have to be utilized.

As a result, the decision was made to sample a specific and identifiable subset of the population of male homosexuals--those who were on mailing lists of homophile organizations in Orange County, CA. Homosexuals who belong to homophile organizations typically are different in some respects from the larger population of homosexuals. Unfortunately, there is no reliable information in the literature about these differences, due to the

sampling problems described above. However, according to representatives of the participating homophile organizations, their members--when compared to homosexuals who are non-members--characteristically tend to be more politically and socially active. They tend to be less defensive about their sexual orientation, and are likely to have 'come out' to more people. As a result, they are also likely to have more social support than 'closet' homosexuals (D. Hagan, F. Newman, personal communication, August 24, 1985).

In addition to the biases inherent in using members of homophile organizations, there were also biases which resulted from the geographical area from which the sample was drawn. Orange County tends, in general, to have wealthier and older residents, and to have fewer minorities than other areas in this country.

During the time frame in which this study was conducted, there was no way to reach and test directly those homosexual men who had positive antibody test results because of the anonymity procedures being used by those who conducted these blood tests. As a result, the current study mailed test materials to a broad spectrum of homosexual men, knowing that most had not yet taken the test, and that a much smaller number had taken the antibody test. As a result, the sample included men with positive antibody

test results, men with negative antibody test results, and men who had not taken the antibody test. Because the sampling procedure included more than the target population, those men with negative test results and those who had not taken the test served as control groups to the population of interest in this study. Thus, this sampling procedure had the advantage of also recruiting comparable control groups.

As a condition of access to their mailing lists, the homophile organizations involved in this study insisted on preserving the anonymity of the respondents. The rationale for these procedures was that numerous cases of social and economic discrimination have occurred against those identified as AIDS patients ("AIDS spreads", 1985). This meant that the procedures for the study were constructed so that the experimenter did not know, and could not reconstruct in any way, who the respondents in this study might be.

As the result of funding from the Department of Community and Environmental Medicine at the University of California--Irvine (UCI), and funding from anonymous homosexual donors, the sampling procedure was able to utilize a census approach, with test materials being mailed to all homosexual men who had given their name and address to a participating homophile organization in Orange County. The test materials were mailed to 1952 subjects on

October 17, 1985. The subjects were instructed to return the test materials to the Department of Community and Environmental Medicine by November 15, 1985. To preserve anonymity, the mailing lists of the participating homophile organizations were collated by members of these organizations. In addition, volunteers from the participating homophile organizations were used to address and mail the test materials.

The response rate was identified as a critical variable early in the proposal process. In order to maximize the response rate, efforts were made to publicize this study and to promote participation by the sample through the homosexual media. This involved publishing articles in the newsletters of participating organizations before the research materials were sent. Further, the research materials were accompanied by cover letters from leaders of each of the participating organizations (Appendix A) indicating both their strong endorsement of the study and representing the study as being sponsored by these organizations. In addition, a follow-up prompt letter was planned, to be sent to all subjects two weeks after the research materials were sent.

However, as a result of the kinds of inquiries which were received as a result of sending the test materials, the determination was made not to send a follow-up prompt for ethical reasons. Numerous angry phone calls and letters were received by

the Department of Community and Environmental Medicine at UCI--in excess of 100--in which those who received the test materials expressed concerns regarding how their name and address had been procured. These inquiries occurred despite the fact that the newsletters of the participating homophile organizations disseminated the information that members could expect these test materials in the mail. In addition, this information was included in the cover letter in the packet of test materials.

This volume of calls was not expected and, as a result, no formal procedures for dealing with these inquiries had been developed. Hence, when a number of people called demanding that their names be removed from these mailing lists, no procedure was implemented to record these names. This meant that we were unable to delete these names from any follow-up mailing. Given the high emotional intensity of some of the callers, it was judged that any follow-up to these subjects might cause undue and severe emotional distress, and would be viewed by them as an unwarranted invasion of privacy. For example, one caller stated that he was married and that his wife did not know of his homosexual orientation. The test materials had been sent to him at his home, and she had opened them. This caller was quite upset, did not want to participate in the study, and wanted his name removed. A number of callers and letter writers expressed themselves in a similar

fashion. However, because of the anonymity procedures, those at UCI did not have a mailing list from which to remove names, and did not record names of callers in order to preserve their anonymity. In retrospect, not taking the names of these callers was a mistake, because it prevented us from sending any follow-up materials.

This unexpectedly high rate of angry response suggested that the mailing lists of the participating organizations were not limited to active homosexuals who were willingly participating in these organizations and receiving their literature. The phone calls and written responses indicated that not all of the subjects saw themselves as members of these organizations. Further, the number of phone calls indicated a very high degree of concern among the research participants about being identified as homosexual. Although almost all were satisfied by our response that we had no contact with the mailing lists, their concern about identification was striking. It is likely that these factors had a negative impact on the response rate of subjects for this study.

### Response Rate

An AIDS-related study that sampled this population in Orange County in the winter of 1984 achieved a response rate of approximately 20% (Anton-Guirgis et al., 1985). A similar response rate was expected for the present study. Of the 1952 packets of test materials which were sent, 47 of those returned were invalid. These included materials sent to: 1) lesbian women (n= 22); 2) non-homosexual males (n= 13); 3) double mailings (n= 5); and 4) undeliverable questionnaires (n= 7). When these 47 invalid responses were subtracted from the total, 1905 valid questionnaires were sent.

Of the 1905 valid questionnaires mailed, 524 were returned, resulting in a response rate of 27.5 percent. A total of 503 subjects completed the research materials; 16 subjects chose not to participate in the study, and 5 subjects returned questionnaires that were not complete enough to be useable. Of the 503 responses, 30 were positive on the HTLV-III antibody test, 55 were negative, and 19 did not know the results of their testing. These 19 were participants in one of several area research studies, and had not received the results of their blood



tests.

There are two possible ways that these men could have received HTLV-III antibody testing in Orange County at the time of this study. Either they were tested as part of the UCI study in the winter of 1984 or they were tested at the alternative testing site at the Public Health Department in Santa Ana, California. The UCI study tested 162 male homosexuals and found 49 HTLV-III positives. As of November 1, 1985, the alternative testing site had tested 596 homosexual men, finding HTLV-III positive results in 182 cases (R. Alexander, personal communication, December 13, 1985). Thus, in the geographical area in which this study was conducted, a total of 645 homosexual men had been tested for the HTLV-III antibody, and 231 were found to be positive for antibodies to the virus. It is known that an indeterminate number of men were tested at both UCI and the alternative test site, which would reduce the number of HTLV-III positives. It is also known that some homosexual residents of Orange County have been tested outside of the county, which would increase the number of HTLV-III positives. However, for the purposes of this study, it was assumed that the sum of the UCI and alternative test site antibody testing gave an accurate figure of the number of male homosexuals tested and the number of homosexual HTLV-III positives in Orange County.

In order to obtain a base rate for HTLV-III testing of male homosexuals in Orange County, the Kinsey (1948) figure that four percent of the male population is exclusively homosexual throughout their adult life was used. According to Marmor (1980), a prominent researcher of homosexuality, the Kinsey data provides the most accurate estimate of the incidence of male homosexuals to date. Thus, it is likely that there are approximately 35,000 homosexual men in Orange County. The estimated base rate for known homosexual seropositives in Orange County is  $231/35,000$  or .0066. The present study sent questionnaires to 1905 homosexuals, slightly more than 5 percent of the estimated male homosexual population in the county. Of 1884 subjects who completed the materials, 30 reported that they were antibody positive, giving a comparable rate of .0159. This is more than two and one half times the estimated base rate of the homosexual population in Orange County. Although one would expect a somewhat higher rate of seropositives among members of homophile organizations because their members are more likely to know of testing facilities, there is no reason to believe that they are being tested at twice the rate of the rest of the homosexual population. From these data, it seems that the present study has achieved a higher than expected rate of HTLV-III positives.

The overall response rate, however, was less than what was

hoped for, given the efforts of the homophile organizations to secure participation. Historical events at the time of the research may have had a negative impact on the response rate of this study. At the time of the data collection, there was an upsurge in the amount of negative publicity surrounding AIDS and the consequences of HTLV-III antibody testing. Although the effects cannot be quantified, it is highly likely that this information had a negative impact on the response rate of the study. Between the time the research materials were mailed and their due date, the following events received considerable attention in national and local media:

1. Transamerica Insurance Company announced that it would require HTLV-III testing prior to selling medical insurance, and that it would not insure HTLV-III seropositives;
2. The city of San Antonio, Texas banned sexual intercourse and blood donations by HTLV-III seropositives;
3. State legislators in Texas began discussions about quarantining HTLV-III seropositives;
4. The Armed Forces initiated an HTLV-III screening program, with the intent of identifying and discharging any seropositives; and
5. A Houston, Texas mayoral candidate ran on an anti-homosexual,

anti-AIDS platform.

Another factor which contributed to the relatively few seropositives that responded was that fewer homosexual men were tested for the HTLV-III antibody than was expected. When the study was originally conceived and planned, representatives from the homophile organizations had the impression that a very large number, perhaps up to 50 percent of their membership would be tested by the data collection phase (D. Hagan, F. Newman, personal communication, June 5, 1985). This did not occur. By the time that data collection was finished, only 645 homosexual men had been tested in Orange County--slightly less than 2 percent of the estimated number of male homosexuals in the county.

One hypothesis that has been advanced to explain this low rate of HTLV-III antibody testing among homosexuals is the use of denial to keep from awareness anything having to do with AIDS. The leadership of the participating homophile organizations indicated that many of their homosexual acquaintances steadfastly refuse to talk about these matters. Thus, it is likely that many, if not most of those who received the research materials simply discarded them in order to protect themselves from a deeper awareness of the problem of AIDS in the homosexual community.

The need to use denial to defend against a problem suggests the presence of a pervasive and intolerable anxiety surrounding

this topic among male homosexuals at the time of this study. This anxiety is likely to have been an intervening variable which also contributed to the relatively low response rate among the entire sample.

Another hypothesis that has been put forward to explain the overall response rate is that the results achieved by this study accurately reflect the sample. To test this, I proposed a telephone survey to randomly sample the membership of the participating homophile organizations to determine if these findings were typical of the sample. However, after reviewing this proposal with the participating organizations, it was discarded for the same reasons that a follow-up letter was discarded.

In order to address the lower than expected response rate in a constructive way, each of the participating homophile organizations was contacted and asked to publish a follow-up notice in their newsletters. One organization, Laguna Outreach, sent a personal letter at their own expense to their membership. Being a smaller organization with more frequent mailings, they felt that such a letter would not be offensive or distressing to their membership. The two larger organizations were unable to put follow-up notices in their newsletters because of timing. The earliest that these materials could appear was January and

February, respectively. By this time, most of the research materials held by non-respondents would have been discarded or lost, and funding constraints did not permit the purchase of more materials.

During these contacts to address the follow-up problem, it was learned that the Gay and Lesbian Center was developing a counseling program for HTLV-III positives. The director of this program, Mr. Steve Peskind, was contacted and asked to help gather more men to participate in the study. He was instructed to limit the distribution of test materials to men who were members of the participating homophile organizations, in order to preserve the integrity of the sampling procedure.

In total, sixteen additional responses were gained during the follow-up period of this study. Of these, seven responses were from men who were positive on the HTLV-III antibody test, and two responses were from HTLV-III negatives. Thus, the study elicited responses from 30 HTLV-III positives, 55 HTLV-III negatives, and 399 subjects who had not yet been tested.

As with any survey, interpreting the results with certainty is problematic. Because of the low response rate of 27.5 percent, it is not possible to determine if the respondents accurately represent the entire sample. Because of restraints imposed by concern for the subjects' welfare, follow-up procedures which

might have tested the representativeness of the sample could not be employed. Of interest is the finding that twice as many subjects as one would expect from the estimated base rate reported that they had positive HTLV-III antibody test results. Also of interest is the datum that, of those who took the antibody test and knew their results, 35 percent were positive. This compares favorably with the positive rate of 31 percent found by the alternative test site in Santa Ana (R. Alexander, personal communication, December 13, 1985), and the rate of 30 percent found in an earlier Orange County study (Anton-Guirgis, Culver, Spindler, & Kleinman, 1985). This rate of concurrence suggests that the data collected by this survey may accurately represent both the sample and the accessible population of homosexuals in Orange County. However, given the inability to test this hypothesis, it must be considered somewhat tenuous.

#### Description of the Sample

Descriptive data were collected from all of the respondents regarding age, education, occupation, income, sexual orientation, and relationship status. The subjects ranged in age from 19 to 68 years, with a mean age of 36 years, and a standard deviation of

10.7 years. Not counting kindergarten, subjects attended school for an average of 16 years. Only 16 subjects did not complete high school. A total of 295 subjects completed college, and 181 of these went on for one or more years of graduate education. Thus, the sample was composed for the most part of very well educated, middle aged men.

The high level of education of this sample was reflected in the choice of occupation. Over half of the sample, 263 subjects, identified themselves as working in a professional capacity; 133 identified themselves as white collar workers; 53 identified themselves as blue collar workers; 17 were retired, and 30 were unemployed. It is likely, however, that not all who identified themselves as professionals are actually professionals. For example, one respondent identified himself as a "professional waiter". Although this subject was not coded in the professional category, it is likely that others identified themselves as professionals without providing this discrepant additional information. However, given the high level of education of this sample, these data are likely to represent the true occupations of the sample with high validity.

The respondents also indicated a high average level of income. Of the 485 subjects who responded to this questionnaire item, 24.5 percent indicated incomes of \$50,000 or more; 19.4



percent indicated incomes between \$35,000 and \$49,999; and 17.3 percent indicated incomes between \$25,000 and 34,999. Only 5.8 percent had incomes of \$9999 or less, and the remaining 33 percent were relatively equally distributed between \$10,000 and \$24,999.

With regard to sexual orientation, 413 respondents identified themselves as exclusively homosexual, constituting 82 percent of the sample. An additional 80 subjects identified themselves as primarily homosexual with some heterosexual interest. Thus, 98.2 percent of the sample considered themselves exclusively or primarily homosexual. Only 7 subjects described themselves as equally bisexual, and only 2 subjects identified themselves as primarily heterosexual with some homosexual interest. About half of the sample, 256 men, indicated that they were not currently in a primary homosexual relationship-- which is, roughly speaking, the homosexual equivalent of heterosexual marriage. Of the 236 men in a homosexual relationship, the years in a relationship ranged from less than one year to 35 years. The great preponderance of these relationships had been in existence for five years or less (n=156); and only 42 had relationships lasting 10 years or more. Of interest was the finding that 3 men were engaged in both heterosexual marriage and homosexual primary relationships, and 5 men were currently in heterosexual relationships only.

Compiling a composite picture of this information, the average respondent in this sample was a man 35 years of age, with a college education, professional employment, and an income over \$30,000 per year. He would describe himself as exclusively homosexual, and was equally likely to be in a primary homosexual relationship as not.

#### Design

The purpose of this study was to determine the counseling needs of homosexual men who have positive HTLV-III test results. In order to accomplish this purpose, a census survey design was used, using questionnaires to collect descriptive information that would pertain to the purpose of the study.

Because of the sensitivity of the subject matter, and because of the previous difficulties that psychologists have experienced as they have gathered data regarding homosexuals, this study was subjected to a series of review procedures. The proposal for this study was reviewed by the human subjects committees of both Utah State University and the University of California at Irvine. In addition, the proposal and questionnaire were reviewed by representatives of the participating homophile organizations. One of the organizations, Laguna Outreach, gathered a panel of three homosexual psychologists to evaluate the study and the test

materials. From these extraordinary review procedures came a number of changes in the questionnaire which made that instrument more sensitive to the lifestyles of male homosexuals. However, even with these review procedures, the subjects of the study identified several questions which they found offensive. For example, question 8 (Appendix C) asked about sexual "preference", but several subjects wrote in the margin that the question should have been phrased as sexual "orientation". In explaining this response, they indicated that "preference" implies choice, but they felt they had no choice in determining the direction of their sexuality. This seems to underscore the need for sensitivity and close collaboration between the non-homosexual researcher and members of the homosexual community when doing research in this area.

The test materials included an introductory letter from Dr. Anton-Guirgis, introductory letters from leaders of each of the participating homophile organizations (Appendix A), an optional consent form (Appendix B), a questionnaire designed to gather demographic information and personal reactions to antibody testing (Appendix C), the Coping Strategies Inventory (CSI) (Appendix D), the IPAT Depression Scale (DS), the IPAT Anxiety Scale Questionnaire (ASQ), and a self-addressed, stamped return envelope. These materials were mailed to the subjects on October

17, 1985. They were instructed to complete the questionnaires, and return them in the return envelope by November 15, 1985.

As mentioned above, a follow-up prompt letter was also planned. It was to be sent to all subjects two weeks after the original mailing. However, because of considerations for the welfare of the research subjects, this letter was not sent. Instead, Laguna Outreach sent a follow-up letter to their membership, and the Gay and Lesbian Center solicited subjects from a group of HTLV-III positives in their membership. A total of sixteen additional responses were gathered by means of these procedures, including an additional seven HTLV-III positives.

#### Instrumentation

In order to address the research questions posed in this study, several kinds of data were collected: biographical data; medical data; data regarding levels of anxiety and depression; data regarding coping behaviors; and data regarding perceptions of self. All of the data were based on self report, and thus, these data and the conclusions that are based on these data are subject to the kinds of limitations inherent in self report data.

### Questionnaire

A questionnaire (Appendix C) was developed to collect biographical data, medical data regarding the presence of physical symptoms associated with AIDS and HTLV-III antibody testing, and data regarding self perceptions and current needs. This questionnaire was not a validated test instrument. However, considering the kind of information that was collected by this instrument, validation did not appear to be essential.

Data regarding the coping behaviors of respondents were collected using several methods, due to the lack of conceptual and methodological clarity which surrounds the current understanding of this construct. Despite considerable research in this area (see Bauman, 1984 for a review), there is still no commonly accepted operational definition, no commonly accepted list of coping behaviors or strategies, and no accepted theoretical model in which to place an understanding of coping behaviors. As a result, it is not possible to ground the use of this construct on a solid theoretical and empirical base. Thus, for the purposes of this study, coping refers to "the things that people do or believe that are intended to protect against stressors" (Bauman, 1984, p.

26). The term 'coping behavior' refers more specifically to things that people do; and 'coping strategy' refers to things that people believe.

Of those in the sample with seropositive results on the HTLV-III antibody test, it was hypothesized that a range of psychological reactions would be found, from adaptive reactions to maladaptive reactions. One variable that was hypothesized to modulate the psychological reaction to this information was the coping strategies or behaviors used by the subject. Because there is presently a lack of agreement regarding the definition and measurement of these constructs, a variety of measures were used in this study. These included the Coping Strategy Inventory (CSI) (Bauman, 1984) to measure beliefs used in coping, and several close-ended and open-ended questions to measure coping behaviors. For example, an open-ended question, "What have you done to cope with the information that you have been exposed to AIDS?", was asked. This question was utilized in order to: 1) force the respondents to choose the coping strategy or behavior which they thought was most useful; and 2) detect any unique coping strategies or behaviors used by homosexuals or by HTLV-III infected people. Also, a set of close ended questions was used, which tapped common coping behaviors such as eating, tobacco smoking, use of alcohol, prescription and non-prescription drugs,

and sleeping. The use of these behaviorally oriented questions permitted some conclusions to be drawn about the effect of the information about HTLV-III infection on overt behaviors.

#### Coping Strategy Inventory

The CSI (Appendix D) is a measure of coping strategies, and consists of eleven questionnaire items, with four Likert-type response possibilities. This scale taps the cognitive strategies used in coping, and was developed from research stemming from breast cancer patients. In many ways, breast cancer patients are similar to AIDS patients. Both patient populations face life-threatening, disfiguring illnesses, and both populations are seen in a medical setting. These similarities dictated the choice of this instrument over other coping measures. In addition, the use of this instrument allowed a comparison between the findings of this study and a sample of New York AIDS patients.

Because there was an inadequate theoretical basis from which to measure coping, the CSI was developed to describe what coping strategies were actually used by breast cancer patients. There was no information in the dissertation from which this scale was drawn which described the psychometric properties of the test. In

addition, the procedures used to develop the test were difficult to understand. Apparently, a review of the relevant literature was used to generate a list of possible coping strategies. These items were administered to a sample of breast cancer patients, and 'marginal items' were eliminated. In addition, three other items were eliminated because "they were too much like the dependent variables we were trying to explain" (Bauman, 1984, p. 127). In the Hirsch and Dworkin study (1985b) which used this measure with a sample of AIDS patients, these three items were reinstated. In order to preserve the comparability of results between this study and that of Hirsch and Dworkin, these items have been retained in the present study.

In addition, another item was added to the CSI at the suggestion of Hirsch (personal communication, September 11, 1985). The only item on the CSI to tap the use of religion in coping reads, "I believe that prayer and religious faith can cure me of my illness". This statement is likely to be affirmed only by practitioners of Christian Science and religious fundamentalists. Because homosexuals seldom belong to fundamentalist groups, such a question has poor discrimination value with a homosexual sample. To address this lack, another item was added which read, "I look to God or a higher power for help and comfort in my illness".

While there were advantages to using the CSI, the lack of



psychometric data regarding reliability and validity were of great concern to the investigator. This concern was moderated by several factors. First, the research from which the CSI was derived was dissertation research at Columbia University. As such, the scale was developed under considerable supervision, and this increases the likelihood of validity. Second, there is no coping scale of which the investigator was aware which was normed on a homosexual sample. Thus, all coping scales--no matter what reliability or validity coefficients--were relatively equivalent psychometrically for use with this population. Thus, although there were problems with the CSI, it was judged to be the best coping instrument available, for the purposes of this study.

To collect data regarding anxiety and depression, the IPAT Anxiety Scale (Krug, Scheier, & Cattell, 1976) and the IPAT Depression Scale (Krug & Laughlin, 1976) were used. These tests were originally developed from the 16 Personality Factor Questionnaire (Cattell, Eber, & Tatsuoka, 1970). Both the ASQ and the DS were developed using factor analytic methods, with the DS utilizing "additional evidence provided by the empirical keying or contrasted groups approach...so the resulting scale can be thought of as blending these two independent methods of test construction" (Krug & Laughlin, 1976, p. 4).

### IPAT Anxiety Scale Questionnaire

The ASQ is a 40 item questionnaire that provides an objective measure of a subject's anxiety. "It is a brief, non-stressful, clinically-valid questionnaire...applicable to all but the lowest educational levels and appropriate for ages of 14 or 15 on upwards throughout the adult range" (Cattell & Scheier, 1963, p. 5). The test can be self-administered, has clearly written instructions, and takes 5 to 10 minutes to complete. According to one reviewer, the test reliability is .86 over many different studies (Lanyon, 1978). Another reviewer found that test-retest reliability ranged from .82 to .93, and split half reliability ranged between .78 and .92 (McReynolds, 1978). Test validity has been determined by correlations with other anxiety measures. The ASQ correlates .70 with the Taylor scale and .73 with the Eysenck neuroticism scale. A wide range of studies show a satisfactory degree of construct validity (Lanyon, 1978).

Both of the reviewers cited above found that the norms for the ASQ were inadequate. There are three sets of norms: for the general population, for college students, and for high-school students. There are separate norms for men and women, but there

are no age norms. Thus, the scores of 18 year olds are in the same group as those who are 50. This makes interpretation of scores difficult. While this is an important criticism of the test, it does not invalidate the usage of this test in this study. For the purposes of this study, a test that could validly discriminate between levels of anxiety was necessary, so that a range of scores can be developed from which judgments can be made regarding adaptive and maladaptive levels of anxiety. The ASQ fulfilled this requirement. Unfortunately, there were no norms for male homosexuals, which means that the use of this test with a homosexual population is questionable. However, this is true of most psychological tests.

For the purposes of this study, the ASQ had several important strengths. First, it validly measured (insofar as it is possible to determine with a homosexual population) the construct of anxiety. This was of critical importance. Second, it was relatively non-stressful to the test taker--an important factor given the high level of stress surrounding the topic of AIDS with homosexual men. Third, it was self-administered and quickly completed. The sum of these factors made this the test of choice for measuring anxiety in this study.

### IPAT Depression Scale

The DS is also a 40 item, self-administered questionnaire. It too is non-stressful, and can be completed quickly--similar to the ASQ. This test has split half reliabilities measured from .85 to .96. There is no test-retest data available. Krug and Laughlin (1976) report a correlation of .88 between the DS and a "pure depression factor" (p. 28) which they identified but did not define. They suggested that "this [correlation of .88] represents the upper limit of the test's predictive efficiency" (p. 28), since reliability is not 1.00. They also found that there were statistically significant differences between the responses of normals and diagnosed depressives on every test item. They concluded that the test is a valid measure that can distinguish between normals and depressed patients.

This contention was challenged by LaVoie (1978) and Lykken (1978). They criticized the test as having no construct validity. LaVoie stated that the combination of the factor analytic method and the empirical approach used in the construction of this test resulted in a methodological jumble. In addition, both reviewers pointed out that the test correlated .31

with the MMPI Depression scale, and .62 with the ASQ. While these reviewers are correct to note the oddity of the test's construction, in my opinion, too much was made of it. To assert that the test has no construct validity is to ignore the data presented in the test manual. Further, the low correlation with the MMPI is to be expected, considering the differences in construction between the two tests. Finally, while the correlation with the ASQ is high, it is not so high that one might suspect that they measure the same construct.

The combination test construction of the DS was undertaken in order to suppress the high correlation between the ASQ and the DS, when both were administered simultaneously. Four items, developed empirically, were added to the 36 items which were factor analytically pure. The additional four items act as a correction factor, similar to the MMPI K factor. To conclude that four items of a 40 item test make methodological hash of the test seems to this writer to be an overgeneralization.

Reviewers (LaVoie, 1978; Lykken, 1978) note that the norms for the DS are inadequate. Norms are provided for men and women, but no information is given regarding the sample size or characteristics. However, for the purposes of this study, this information is not critical. For the purposes of this study, a test that could validly discriminate between levels of depression

was necessary, so that a range of scores could be developed from which judgments could be made regarding adaptive and maladaptive levels of depression. The DS fulfilled these requirements. However, as with the other tests used in this study, no norms for homosexuals were available.

#### Data Analysis

When the research materials were returned, they were hand scored. Ten percent of the ASQ and DS were then randomly chosen and rescored to check reliability, and an error rate of .00375 percent was found for the ASQ and 00.0 percent for the DS.

The questionnaires were then coded for computer entry. All of the questionnaires of the HTLV-III positives and five percent of the remainder of the sample were checked for coding reliability, and an error rate of less than 2 percent was found. The data were then assembled by subject on an 80 column data coding form. The reliability of this data assembly was checked for all ASQ and DS data, all of the HTLV-III positives, and 10 percent of the remainder of the sample. Thus, all of the HTLV-III positive data were corrected. Of the 10 percent of the remainder of the sample, there was one error detected in 3650 characters of data that were checked, resulting in a data entry error rate of .0003. After the data were entered into the computer, all of the

data were checked against the entry sheet and corrected. The error rates of the scoring, coding and data entry procedures were considered negligible and unlikely to affect the results of the study in any significant fashion.

Following data entry, the data were processed on two Cyber computers, models 710-730 and 177-830, at the California State University at Fullerton, using the Statistical Package for the Social Sciences (Nie, Hull, Jenkins, Steinbrenner, & Bent, 1975). The data analysis procedures involved the computation of descriptive statistics, t-tests, chi-square tests, Pearson product-moment correlations, and point-by-point agreement ratios. These tests, with the exception of the point-by-point agreement ratio, are commonly known, and the reader is referred to other sources (Hinkle, Wiersma, & Jurs, 1979) for a review. The point-by-point agreement ratio (Kazdin, 1982) was utilized to compute reliability between observers in categorizing responses to the open-ended questions of the questionnaire (Appendix C). This method assesses the amount of agreement between observers on each response, and is computed by the formula:

$$\frac{A}{A + D} \quad \text{where } A = \text{interobserver agreements for the trial} \\ \text{and } D = \text{interobserver disagreements for the trial}$$

Three independent observers were utilized in this procedure.

After a period of instruction, they each categorized the subjects' responses to the open-ended questions of the questionnaire. The minimum criterion to affirm the reliability of the categories was .80.



## CHAPTER IV

### RESEARCH FINDINGS

In this chapter, the results from the analysis of variables directly related to the research questions posed in Chapter I are described. Because of the exploratory nature of this research, a relatively large number of questions were formulated. In order to preserve some organization and clarity in this description of the findings, each research question has been addressed in sequence. Each research question has been restated, and the findings which are pertinent to that question described. Finally, two additional sections which describe other findings of interest conclude this chapter. The first of these two sections describes other findings regarding HTLV-III positives; the second describes other findings regarding the entire sample.

#### Research Questions

##### Demographic Differences

In this section, the findings resulting from the first research question are addressed, concerning differences between the group having positive HTLV-III test results and the group having negative HTLV-III test results with regards to age, education,

employment, income, sexual orientation, and relationship status. Chi square tests were used because the data were in the form of frequency distributions.

Table 6  
Demographic Comparison of HTLV-III Positives and Negatives

Variable	Chi Square	Degrees of Freedom	Significance
Age	35.58	33	.3478
Education	24.03	15	.0646
Employment	16.34	4	.0026*
Income	16.80	7	.0187*
Sexual Orientation	3.29	3	.3497
Years in Homosexual Relationship	6.42	10	.7786

With the exception of employment and income, there were no statistically significant differences between HTLV-III positives and negatives on the above variables. With regards to employment, however, 7 of the 30 positives were unemployed at the time of the survey as compared with 1 of 55 negatives. There were also fewer professionals among the positive group as compared with the negative group. As one might expect, given this finding regarding employment, the income reported by the positives was significantly lower than the income reported by the HTLV-III negatives.

Some serendipitous information gathered from the data suggests an interpretation for this pattern of findings. Questions were asked about the presence or absence of physical symptoms related to AIDS. Those with positive HTLV-III antibody

test results indicated a much greater frequency of debilitating symptoms than those with negative results. Thus, it is likely that the infection has contributed to or caused the unemployment and low income experienced by the positive group.

#### First Reactions to Positive Test Results

In this section, the question which asked about the self reported first reactions to positive HTLV-III test results will be addressed. In order to ascertain the first reactions to positive HTLV-III test results, respondents were asked to list both their most important emotional feeling, and what they thought about at that time. Given the retrospective nature of these questions and the variable time between hearing the test result and responding to these questions, the results are not likely to be totally accurate. However, these responses do provide some information which may be helpful to counselors.

Table 7  
Initial Emotional Reactions of HTLV-III Positives

Category	Frequency
Numb or shocked . . . . .	2
Fear or dread . . . . .	7
Anxiety . . . . .	4
Anger . . . . .	4
Depression or sadness . . . . .	2
Guilt or shame . . . . .	1
Disappointment . . . . .	2
Not codeable . . . . .	8

Many respondents reported several feelings. Only the first feeling was coded, however, on the assumption that the first feeling mentioned would be the most important feeling. From reading the responses, this inference generally seemed to be justified. Most of the sample reported emotional responses of fear or dread when they heard their test results. These emotional responses are consistent with what has been reported anecdotally by those who work in HTLV-III testing sites. In order to preserve the qualitative nature of these data, the subjects' verbatim responses to this question can be found in Appendix F.

Table 8  
Initial Thoughts After Learning of Positive HTLV-III Test Results

Category	Frequency
Thoughts of dying or catastrophe . . . . .	5
Disbelief or denial . . . . .	2
Self-condemnation . . . . .	1
Thoughts of confirmation of expected results . . . . .	1
Hopeful thoughts . . . . .	3
Thoughts regarding social relationships . . . . .	7
Thoughts about what the future might hold . . . . .	6
Not codeable . . . . .	5

Most of the sample thought about the impact of this information on their social relationships. Given the pariah status of AIDS patients in our culture, this is an expected response. Others wondered about the future or thought that they would die. In order to preserve the qualitative nature of these data, the subjects' verbatim responses to this question can be found in Appendix H.

The categories into which these data have been placed were devised after inspecting the raw data. These categories were then used in a preliminary way and then revised, in order to increase the reliability of the coding. A point-by-point agreement ratio was used (Kazdin, 1982) to compute reliability, on the grounds that it provided a more rigorous test than the Pearson product-moment correlation which is often used to compute inter-observer reliability. The criterion of .80 was established

as the minimum necessary level of agreement between raters.

The three independent coders achieved agreement ratios of .90 for the emotions categories and .83 for the thought categories.

#### Comparison of Initial and Subsequent Reactions

In this section, the third research question was addressed, which asked if there was a relationship between initial and subsequent emotional and cognitive reactions to positive HTLV-III test results.

The emotional and cognitive reactions of the subjects did change over time. However, it was not possible to determine statistically if there was a relationship between initial and subsequent reactions, because the data came in an unexpected form. In order to utilize a chi square test, there must be an equal number of categories. In both the emotional and cognitive areas, however, there was a constriction in the number of categories used as the subjects described their subsequent reactions. In addition, there were a large number of uncodeable responses, since many subjects gave thoughts on the emotion questions and emotions on the thought questions. Thus, relationships between initial and subsequent reactions could not be measured statistically.

Utilizing a visual inspection, there did not appear to be any

consistent relationships between the initial and subsequent reactions for either the emotional or cognitive areas. This seemed to be a function of two variables. First, subjects had some difficulty in differentiating between thoughts and feelings, and often used these terms interchangeably. This factor resulted in many uncodeable responses. Second, there appeared to be a great variability between initial and subsequent reactions. Table 9 below illustrates these problems.

Table 9  
A Comparison of Initial and Subsequent Emotional Reactions:  
The First Ten Subjects

Subject	Initial Reaction	Subsequent Reaction
1	Fear	Acceptance
2	Depression	Not codeable
3	Anxiety	Acceptance
4	Not codeable	Depression
5	Anxiety	Not codeable
6	Not codeable	Fear
7	Shock	Depression
8	Anger	Fear
9	Disappointment	Not codeable
10	Fear	Optimism

The lack of consistent relationships between the initial and subsequent emotions and thoughts is not surprising, given the disorganizing effect that life-threatening information might have on a person. However, as time passes, one would expect that each subject would develop a relatively enduring stance towards this information. Tables 10 and 11 present the current emotional and

cognitive reactions of the infected subjects.

Table 10  
Current Emotional Reactions of HTLV-III Positives

Category	Frequency
Fear . . . . .	8
Anxiety . . . . .	3
Anger . . . . .	2
Depression . . . . .	4
Acceptance . . . . .	3
Optimism . . . . .	1
Not codeable . . . . .	9

Table 11  
Current Cognitive Reactions of HTLV-III Positives

Category	Frequency
Want more information or counseling . . . . .	4
Positive thoughts about one's self . . . . .	3
Thoughts about social relationships . . . . .	5
Waiting with no mention of hope . . . . .	8
Waiting with mention of hope . . . . .	4
Distracting self, keeping busy . . . . .	1
Thoughts of self-condemnation . . . . .	2
Not codeable . . . . .	3

#### Measurements of Anxiety

In this section, several questions regarding differences in the level of anxiety between groups was addressed. T tests were used in addressing these questions, to compare the group mean scores. The first question asked if there were differences in group mean scores as measured by the IPAT Anxiety Scale Questionnaire (ASQ) between the groups with positive and negative HTLV-III test



results. The findings are presented in Table 12, below.

Table 12  
A Comparison of Anxiety Scores Between  
HTLV-III Positives and Negatives

Group	Number of Cases	Mean	Std. Dev.	Std. Error	T Value	Significance
Positives	30	34.13	16.81	3.05	2.02	.047*
Negatives	54	27.78	11.99	1.63		

There is some difference between the ASQ scores of HTLV-III positives and negatives--a difference between the raw score means of more than 6 points, and a difference of one point using Cattell's standard sten scores. This difference does not seem likely to be a chance occurrence. Thus, one can answer this question in the affirmative: there is a difference between the group mean scores on the ASQ between those with positive and negative results on the HTLV-III antibody test. The second question in this section asked if there were differences in the level of anxiety between HTLV-III positives with physical symptoms and those without symptoms.

Table 13  
 A Comparison of Anxiety Scores Between  
 HTLV-III Positives With and Without Physical Symptoms

Group	Number of Cases	ASQ Mean	Std. Dev.	Std. Error	T Value	Significance
Any Symptoms	24	35.50	16.75	3.42	.89	.379
No Symptoms	6	28.67	16.68	6.81		
Swollen Glands	21	34.57	17.27	3.77	.22	.830
No Glands	9	33.11	16.16	5.39		

In addressing the question about differences between the groups with and without physical symptoms, the data were analyzed in two ways. In the first analysis, those with and without any symptoms were compared. However, because the physical symptoms associated with HTLV-III infection are so similar to symptoms of the common flu, another analysis was made. In the second analysis, those with swollen glands--lymphadenopathy--were compared to those without swollen glands. Lymphadenopathy is the characteristic physical symptom of HTLV-III infection. Contrary to expectations, there were no statistically significant differences found in these two analyses.

#### Measurements of Depression

In this section, several questions regarding differences in the level of depression between groups were addressed. Again, t tests

were used in order to compare group mean scores. The first question asked if there were differences in group mean scores as measured by the IPAT Depression Scale (DS) between the groups with positive and negative HTLV-III test results. The findings are presented in Table 14, below.

Table 14  
A Comparison of Depression Scores Between  
HTLV-III Positives and Negatives

Group	Number of Cases	Mean	Std. Dev.	Std. Error	T Value	Significance
Positives	30	29.70	18.29	3.34	3.83	.000*
Negatives	53	17.62	10.51	1.45		

There was a considerable difference between the DS scores of HTLV-III positives and negatives--a difference between the raw score means of more than 12 points, and a difference of four points using Cattell's standard sten scores. This difference is not likely to be a chance occurrence. The second question in this section asked if there were differences between HTLV-III positives with and without physical symptoms.

Table 15  
 A Comparison of Depression Scores Between  
 HTLV-III Positives With and Without Physical Symptoms

Group	Number of Cases	DS Mean	Std. Dev.	Std. Error	T Value	Significance
Any Symptoms	24	31.58	18.91	3.86	1.13	.267
No Symptoms	6	22.17	14.53	5.93		
Glands Swollen	21	31.33	19.43	4.24	.74	.465
Glands Normal	9	25.89	15.67	5.22		

As above, the data were analyzed in two ways. In the first analysis, those with and without any symptoms were compared; and in the second, those with and without lymphadenopathy were compared. Contrary to expectations, there were no statistically significant differences found in these two analyses.

#### Utilization of Coping Strategies

In this section, several questions regarding the utilization of coping strategies by those with positive HTLV-III results was addressed. The distribution of CSI endorsements is presented in Table 16, below. The reader may wish to turn to Appendix D for the full text of the coping strategies.

Table 16  
 Distribution of Coping Strategies of HTLV-III Positives  
 as Measured by the CSI

	Strongly Disagree (%)	Disagree (%)	Agree (%)	Strongly Agree (%)
DO THINGS	3.3	46.7	33.3	16.7
COMPARE	3.3	30.0	50.0	16.7
FORGET	14.3	60.7	14.3	10.7
ASK OTHERS	41.4	44.8	13.8	0.0
JOKE	13.8	31.0	31.0	24.1
HELP OTHERS	7.1	35.7	42.9	14.3
CALM	0.0	24.1	44.8	31.0
PRAYER	51.9	25.9	14.8	7.4
QUE SERA	0.0	24.1	48.3	27.6
CRY	11.1	25.9	44.4	18.5
SEEK INFO	0.0	10.3	44.8	44.8
BRIGHT SIDE	0.0	6.9	55.2	37.9
BEAT IT	0.0	10.3	55.2	34.5
LIVE TODAY	6.9	34.5	31.0	27.6
GOD	28.6	21.4	39.3	0.0

This pattern of responses indicates that the most frequently endorsed coping strategies include BRIGHT SIDE, SEEK INFO, and BEAT IT. These three strategies are likely to be endorsed by people who have a relatively optimistic view of the outcome of their illness. The second most frequently endorsed group of strategies--CALM and QUE SERA--are more indicative of a stoic resignation. Two of the strategies that were least frequently endorsed--ASK OTHERS and PRAYER--indicate some degree of social isolation. These subjects apparently do not feel comfortable in talking with others about their illness, nor do they have a fundamentalist religious faith that might provide some support. The other item that was infrequently endorsed--FORGET--indicates that it is difficult for these men to ignore their illness.

In order to address the question about differences in the distribution of scores between those with and without physical symptoms, the data were again analyzed in two ways: first those with any symptoms were compared to those without physical symptoms; then those with lymphadenopathy were compared to those without this symptom. In the thirty computations involved, there was one item that was statistically significant at the .05 level. However, because of the number of computations, it is likely that this statistically significant result is, in fact, due to chance.

### Utilization of Coping Behaviors

In this section, other findings regarding coping behaviors used by HTLV-III positives was addressed. The coping behaviors of the HTLV-III positives were measured in three ways: by means of the CSI, as described above; by an open-ended questionnaire item which asked "What have you done to cope with the information that you have been exposed to AIDS?"; and by a series of questions which tapped behaviors such as smoking, drinking and drug use. The open-ended questionnaire item forced the subjects to limit what they have done to cope to a single response. The results are found in Table 17. Using the point-by-point agreement method of computing inter-observer reliability, the reliability of sorting the subjects' responses into the above categories was .86 among three independent observers.

Table 17  
The Most Important Coping Behavior of HTLV-III Positives

Category	Number	Relative Frequency
Getting more information about AIDS	8	26.7%
Changing lifestyle in some way	6	20.0%
Changing sexual practices in some way	3	10.0%
Getting closer to other people	2	6.7%
Preparing for death	2	6.7%
Accepting the illness	2	6.7%
Engaging in some form of spiritual growth	2	6.7%
Keeping busy, distracting myself	1	3.3%
Not codeable	4	13.3%

Thus, while these subjects endorsed a number of similar coping strategies on the CSI, there was a remarkable diversity of response when they were asked to name their most important strategy.

In responding to close-ended questions regarding more behaviorally oriented coping behaviors, the subjects responded as shown in Table 18.



Table 18  
Changes in Other Common Coping Behaviors

Category	About the		
	More (%)	Same (%)	Less (%)
Food consumption . . . . .	23.3	63.3	13.3
Tobacco consumption . . . . .	16.7	61.1	22.2
Alcohol consumption . . . . .	11.1	48.1	40.7
Use of prescription medication . . . . .	20.0	64.0	16.0
Use of non-prescription drugs (marijuana, cocaine, etc.) . . . . .	8.7	47.8	43.5
Hours of sleep . . . . .	36.7	46.7	16.7

From these data, it appears that the HTLV-III test results have had some selective impacts on relatively common coping behaviors. In the six items in Table 18, the 'About the Same' category ranges from 47-63 percent. Thus, the information regarding HTLV-III infection has impacted a wide range of commonly used coping behaviors. The second conclusion that can be drawn from this information, is that the trend of these subjects is generally in the direction of more healthful behaviors. For example, there are reported decrements in the numbers using tobacco, alcohol, and non-prescription drugs such as marijuana and cocaine. Unfortunately, the amount of decrease was not measured.

Coping Strategies Associated  
with Anxiety and Depression

In this section, the CSI responses were correlated with ASQ and DS

responses in order to determine if there were coping strategies associated with high levels of anxiety and depression. The results of these correlations are presented in Table 19. Again, the reader is referred to Appendix D for the full text of the CSI strategies.

Table 19  
Correlations Between CSI Responses and ASQ and DS Scores

CSI Response	ASQ		DS	
	Correl.	Significance	Correl.	Significance
DO THINGS	.23	.12	.27	.07
COMPARE	-.15	.22	-.24	.10
FORGET	-.04	.41	-.03	.44
ASK OTHERS	.17	.19	.15	.22
JOKE	-.13	.26	-.11	.29
HELP OTHERS	.20	.16	.32	.05*
CALM	-.25	.09	-.36	.03*
PRAYER	-.21	.15	-.36	.03*
QUE SERA	.13	.24	.13	.24
CRY	.14	.24	.30	.07
SEEK INFO	-.01	.47	-.12	.28
BRIGHT SIDE	-.23	.12	-.37	.02*
BEAT IT	-.14	.24	-.17	.19
LIVE TODAY	.10	.31	.11	.28
GOD	-.03	.44	-.20	.16

For the most part, there appears to be little relation between the coping strategies endorsed by HTLV-III positives on the CSI and scores on the ASQ or DS. There appears to be a low positive correlation in four instances between CSI responses and the DS scores. Helping others is positively related to high DS scores, while keeping calm, believing that religious faith can cure, and

seeing the bright side of things are inversely related to high scores on the DS. When interpreting these relations, one must keep in mind that, due to the high number of computations and the placement of the probability level, one would expect to find that 1 or 2 of these 'significant' relations by chance.

Coping Behaviors Related  
to Anxiety and Depression

In this section, the common coping behaviors such as eating, smoking, drinking, and drug use were correlated with ASQ and DS responses in order to determine if there were coping behaviors associated with high levels of anxiety and depression. The results of these correlations are presented in Table 20.

Moderate inverse correlations were found between elevations in ASQ scores and DS scores and a number of common coping behaviors. These data indicate that higher levels of anxiety and depression among the HTLV-III positives in this sample are associated with decrements in smoking, alcohol and drug use, and sleeping.

Table 20  
Correlations Between Common Coping Behaviors,  
ASQ Scores and DS Scores

Common Coping Behaviors	ASQ Correl.	Signif- icance	DS Correl.	Signif- icance
Smoking tobacco	-.45	.03*	-.19	.23
Drinking alcohol	-.40	.02*	-.23	.13
Prescription drug use	-.40	.03*	-.47	.01*
Non-prescription use	-.45	.02*	-.29	.09
Sleeping	-.50	.003*	-.54	.001*

From these data, it appears that HTLV-III positives who are highly anxious tend to adopt health promoting behaviors. Those positives who are highly depressed also tend to adopt health promoting behaviors, but not to the same degree as those who are anxious. These findings may be something of an artifact of this geographical area. Counselors at the public health testing facility where the antibody test is administered in Orange County are advising the adoption of these behaviors. As a result, these finding may not be generalizable to other geographical areas.

#### Needs for Psychological Assistance

In this section, the data generated to answer the tenth research question are addressed. Those with positive HTLV-III test results were asked what kinds of psychological assistance would be useful in helping HTLV-III positives to cope with their situations. A t test was then used to determine if there were any differences in

the kinds of assistance requested by subjects with symptoms and those without symptoms.

The responses to this open ended question were categorized into four groups. These included: 1) wanting someone to talk to about the infection; 2) needing professional counseling to deal with the psychological concomitants of the infection; 3) needing more education regarding HTLV-III infection; and 4) other, idiosyncratic responses. Using t-tests to compare group means, there were no statistically significant differences in the kinds of psychological assistance requested between the group with physical symptoms and the group without physical symptoms. When the data were analyzed again, comparing those with and without the specific symptom of lymphadenopathy, there were again no statistically significant differences.

#### Reliability of the ASQ and DS

Because the ASQ and DS have not been normatized on a sample of homosexual males, there is some question regarding the reliability and validity of these tests for this population. The question of validity was outside the scope of this dissertation. However, the question of test-retest reliability was addressed.

The ASQ and the DS were sent to all of the HTLV-III positive subjects who consented to participate in the follow-up phase of

this study. Of the 13 positives who consented to participate in the follow-up phase, 10 subjects returned the completed retest materials. In addition, 33 of the remaining 329 subjects who agreed to participate in the follow-up phase were also contacted. Of these, 24 subjects completed and returned the retest materials. Approximately one month separated the dates of testing. Using a Pearson product-moment correlation, the following results were obtained.

Table 21  
Test-Retest Correlation Coefficients

Test	Entire Sample (n=34)	HTLV-III Positives (n=10)	Remainder of Sample (n=24)
Anxiety Scale Questionnaire	.97	.96	.93
Depression Scale	.93	.95	.88

These data indicate that these tests were reliable over time for this sample, and the test-retest coefficients compare favorably with those found in the ASQ literature of .86. There was no information regarding test-retest reliability for the DS. Of interest is the datum that the test-retest reliability coefficients were more stable for the HTLV-III positives than for the rest of the sample. This suggests that these emotions are relatively more enduring states for this population.

### Response Bias

In this section, the question regarding the possibility of response bias was addressed. The frequency of those responding to these research materials was compared with the frequency of materials sent by zip code areas, in order to determine if there was a systematic bias by geographical area. Using a chi square test to compare these distributions, there were three statistically significant differences in the frequency of response out of 77 zip code areas to which these research materials were sent. This finding is less than what one would expect by chance alone, when setting the probability level at .05. From this, it can be concluded that there was no systematic response bias in the completion of these questionnaires that can be detected by comparing frequency of response by zip code areas.

### Other Findings Regarding HTLV-III Positives

#### The Question of Suicidal Ideation and Suicide Attempts

One of the consistent anecdotal reports that has surrounded testing for the HTLV-III antibody has concerned the incidence of suicide and suicide attempts. In this sample of 30 HTLV-III

positives, 12 subjects reported thinking about suicide after hearing of the results of HTLV-III testing. Of these 12, only 1 subject reported actually making a suicide attempt. This finding, although based on a small sample, suggests that few persons are likely to attempt suicide after hearing of their testing results. However, this finding may be biased, under-reporting those who attempt suicide. Those who successfully completed a suicide attempt could not respond to the questionnaire.

#### Changes in Sexual Activities

Of interest is data regarding how knowledge of HTLV-III infection has changed the sexual activities of those infected. It was clear that the sexual behavior of those infected in this sample has been profoundly changed.

Table 22  
Changes in Sexual Behavior of HTLV-III Positives

	Number	% of Sample
Adopted celibacy . . . . .	9	30.0
Reduced frequency of sexual activity . . . . .	8	26.7
Engaged in safe sex practices . . . . .	10	33.3
Reduced activity & use safe sex . . . . .	1	3.3
Not codeable . . . . .	2	6.7

All of the subjects who were positive for the HTLV-III antibody reported some kind of change in their sexual activity, including those subjects whose responses were not codeable. For the most



part, either overall sexual activity was reduced or the preferred type of sexual activity was changed. One third of the sample has adopted "safe sex" practices; practices which inhibit or prevent the exchange of sexual fluids or blood between partners.

When one considers the importance of sexual activity among adult human beings, a change of this magnitude is of great clinical significance. Sex is used by human beings in many ways--to achieve intimacy, to relieve tension, to exert power, and so forth. Such a change in patterns of sexual activity is likely to have a profound impact on the self-image and self-esteem of those individuals who make these changes.

And yet, one would expect that changes due to HTLV-III positivity would show up here. The HTLV-III virus is typically transmitted through intimate sexual contact. Thus, one would expect that if being positive on the antibody test results in behavioral changes, it is more likely that such changes will occur in the area of sexual behavior than in activities more removed from transmission vectors such as occupational functioning.

#### Changes in Social and Occupational Functioning

Since AIDS is a fatal disease, it is clear that there are changes in the social and occupational functioning of AIDS patients.

However, there has been little data regarding prior points along the continuum of HTLV-III infection. This study asked those with positive HTLV-III test results about non-specific changes in their social and occupational functioning.

Table 23  
Changes in Social and Occupational Functioning

	Social Functioning	% of Sample	Occupational Functioning	% of Sample
Negative effect	15	53.6	10	37.0
No noticeable change	4	14.3	13	48.1
Positive effect	9	32.1	4	14.8

Of interest is the unexpectedly large percentage of the HTLV-III positives who have experienced positive changes in social and occupational functioning. Typically, those who report positive social changes indicated that they felt closer to significant others since learning of their HTLV-III infection. Those who reported positive occupational changes indicated that knowledge of their infection has led to a rethinking of their life goals, and adjustments in lifestyle resulting from this. Of those who reported negative effects on occupational and social functioning, the most common complaint was a sense of emotional distancing, caused either by themselves or others.

While all of the sample reported some changes in their sexual activities, typically reducing the frequency or changing the type

of the activity, there was considerably more variability regarding changes in social and occupational functioning. Subjects reported more changes in social functioning than occupational functioning. This datum supports the hypothesis that the areas of greatest disturbance will be those areas of functioning that are more closely related to transmission vectors.

#### Openness Regarding HTLV-III Infection

Related to the issue of social functioning is the willingness of subjects to self-disclose regarding important issues. Of the 30 subjects with positive results on the HTLV-III antibody test, no one indicated that they shared the results of their antibody test with everyone. Six subjects reported that they have told no one regarding their test results. Nine subjects reported that they have shared the results of their testing with most of those with whom they feel close. The remaining 15 subjects have shared the results of their testing with some, but not all of the people with whom they feel close.

These findings suggest that those with positive antibody test results are quite selective about whom they share those results with. It is likely that they feel some vulnerability regarding their test results, and are attempting to protect themselves by not disclosing indiscriminantly. This finding is quite at

variance with another finding of this study. A total of 359 subjects, or 71 percent of the sample, consented to participate in any follow-up research. To do this, they had to reveal their name and address. Of this group, 13 subjects were HTLV-III positive--constituting 43 percent of the positive group. These findings are somewhat discrepant with the findings regarding openness to disclosure described above.

#### Estimated Incidence of Adjustment Disorders

Previous studies (Dilley et al., 1985; Tross, 1985) have found a relatively high incidence of adjustment disorders among HTLV-III positives. In order to estimate the number of adjustment disorders in this sample, questions were asked regarding impairments in social and occupational functioning. The number of those who reported large or moderate impairments in either social or occupational functioning and who had sten scores of 9 or 10 on the ASQ was tabulated in order to estimate the number of subjects who might be diagnosed with an adjustment disorder with anxious mood. A total of 2 subjects fit these criteria. The number of those who reported large or moderate impairments in either social or occupational functioning and who had sten scores of 9 or 10 on the DS was tabulated in order to estimate the number of subjects who might be diagnosed with an adjustment disorder with depressed

mood. A total of 5 subjects fit these criteria. There was no overlap between these two groups of subjects. Thus, 7 out of 30 subjects, or 23 percent, could be diagnosed under these criteria.

It is important to qualify these diagnoses. They are made solely on the basis of self-report data, and in the absence of any clinical observation. As a result, these diagnoses must be understood as an estimate of the frequency of these disorders, and not as verifiable psychiatric diagnoses.

These results are similar to those of other studies. Tross and her colleagues (1985) compared homosexual men with AIDS, ARC, and asymptomatic controls. Although no numbers or percentages are given, the Tross study found that men with ARC had the greatest psychological disturbance, and that adjustment disorders were the most frequently given diagnosis. The subjects of the present study are roughly equivalent to Tross's ARC patients. Dilley and his colleagues (1985) examined 13 of 40 AIDS patients in a general hospital. They found 7 adjustment disorders with depressed mood--an incidence of 18 percent. This finding is comparable to the 17 percent of the present study that are tentatively diagnosed with an adjustment disorder with depressed mood.

Comparison of CSI Responses of AIDS  
Patients and HTLV-III Positives

AIDS is the end-point of HTLV-III infection. Thus, one would expect to find many similarities between those at differing points along the infection continuum. One of the advantages of using the CSI in this study is that a direct comparison between the responses of AIDS patients and HTLV-III positives is now possible. Hirsch and Dworkin (1985b) used the CSI on a sample of 60 New York AIDS patients. Their CSI responses are compared with those of this sample in Table 24 below.

Table 24  
 Comparison of CSI Responses of AIDS Patients  
 and HTLV-III Positives

		Strongly Disagree (%)	Disagree (%)	Agree (%)	Strongly Agree (%)
DO THINGS:	HTLV-III Positives	3.3	46.7	33.3	16.7
	AIDS Patients	11.5	48.1	34.6	5.8
COMPARE:	HTLV-III Positives	3.3	30.0	50.0	16.7
	AIDS Patients	7.7	19.2	57.7	15.4
FORGET:	HTLV-III Positives	14.3	60.7	14.3	10.7
	AIDS Patients	23.1	46.2	22.4	1.5
ASK OTHERS:	HTLV-III Positives	41.4	44.8	13.8	0.0
	AIDS Patients	15.4	51.9	26.9	4.5
JOKE:	HTLV-III Positives	13.8	31.0	31.0	24.1
	AIDS Patients	1.9	26.9	51.9	19.2
HELP OTHERS:	HTLV-III Positives	7.1	35.7	42.9	14.3
	AIDS Patients	5.8	46.2	40.4	7.7
CALM:	HTLV-III Positives	0.0	24.1	44.8	31.0
	AIDS Patients	5.8	13.5	57.7	23.1
PRAYER:	HTLV-III Positives	51.9	25.9	14.8	7.4
	AIDS Patients	25.0	34.6	26.9	13.5
QUE SERA:	HTLV-III Positives	0.0	24.1	48.3	27.6
	AIDS Patients	3.8	32.7	50.0	13.5
CRY:	HTLV-III Positives	11.1	25.9	44.4	18.5
	AIDS Patients	9.6	32.7	50.0	7.7
SEEK INFO:	HTLV-III Positives	0.0	10.3	44.8	44.8
	AIDS Patients	0.0	4.5	48.1	46.2
BRIGHT SIDE:	HTLV-III Positives	0.0	6.9	55.2	37.9
	AIDS Patients	1.9	5.8	50.0	42.3
BEAT IT:	HTLV-III Positives	0.0	10.3	55.2	34.5
	AIDS Patients	3.8	9.6	38.5	48.1
LIVE TODAY:	HTLV-III Positives	6.9	34.5	31.0	27.6
	AIDS Patients	11.5	26.9	42.3	19.2
GOD:	HTLV-III Positives	28.6	21.4	39.3	0.0
	AIDS Patients	<<Not asked of this sample>>			

These data were not analyzed statistically. However, from visual inspection one can see that there are very few differences between the responses of these two samples.

#### Other Findings Regarding the Entire Sample

##### A Comparison of Subjects With and Without HTLV-III Antibody Testing

One of the issues of interest that has arisen from this study is the question regarding differences between those male homosexuals who submit to testing and those who do not. It was hypothesized that demographic differences, the occurrence of symptoms related to HTLV-III infection, and the level of anxiety or depression might influence any given individual's decision to be tested.

Table 25  
Demographic Comparison of Subjects With  
and Without HTLV-III Testing

Variable	Chi Square	Degrees of Freedom	Significance
Age	50.64	47	.3320
Education	24.63	18	.1355
Employment	2.89	4	.5770
Income	3.30	8	.9139
Sexual Orientation	1.38	3	.7105
Years in Homosexual Relationship	29.65	24	.1965

Because these data were in the form of frequency distributions, a



chi square test was used. There were no statistically significant differences between those who were tested with the antibody test and those who were not tested on these demographic variables, indicating that these variables probably are not related to the decision to be seek antibody testing. However, there were significant differences in the incidence of physical symptoms between those who took the antibody test and those who did not. This suggests that the occurrence of physical symptoms may prompt individuals to seek the testing.

Table 26  
The Occurrence of Symptoms Related to HTLV-III Infection

Symptoms	Frequency in Test Takers	Frequency in Non-Test Takers
No symptoms	6	352
One symptom only	9	22
Two or more symptoms	15	9
Lymphadenopathy only	7	18
Lymphadenopathy plus other symptoms	14	7

The symptoms that are found in persons with HTLV-III infection include: profound and unexplained fatigue, persistent or recurrent low-grade fever, weight loss of 10 pounds or more that is not related to dieting, swollen lymph glands, and persistent and unexplained stomach upset or diarrhea. Not all persons with these symptoms are infected with HTLV-III. In fact, these symptoms are

common to many infections including colds and the common flu. But of these symptoms, swollen lymph glands or lymphadenopathy is the most pathognomonic for infection with the HTLV-III virus. Using a chi square test to compare these two distributions, it was found that those who had taken the test had a statistically significant greater number of symptoms than those who had not taken the test. This test was significant at the .0026 level.

This finding suggests that men who have HTLV-III testing may do so because they are symptomatic. Although lymphadenopathy is a relatively common concomitant to colds and flu, the finding that 18 of the non-tested group report lymphadenopathy may indicate that a number of men with the symptoms of HTLV-III infection are not receiving medical attention.

The final hypothesis in this area was that high levels of anxiety or depression might prompt individuals to seek testing. In order to test this hypothesis, t tests were used to compare the group mean scores of the two groups.

Table 27  
 A Comparison of ASQ and DS Scores Between Subjects  
 With and Without HTLV-III Testing

Group	Number of Cases	Mean	Std. Dev.	Std. Error	T Value	Significance
ASQ						
Test-takers	103	29.22	14.35	1.42	1.75	.080
Non-takers	382	26.75	12.23	.63		
DS						
Test-takers	102	21.22	14.38	1.42	3.07	.002*
Non-takers	383	17.34	10.36	.53		

Those subjects who took the antibody test appear to be more anxious and depressed than those who did not the test. On the ASQ, this difference could be attributed to chance. Using Cattell's standard sten scores on the ASQ, both group means fell within the same standard score. However, there were statistically and clinically significant differences on the DS. There was a difference of one standard score on this measure.

Reasons Given for Not Taking  
 the HTLV-III Antibody Test

The one factor which has had the most impact on the results of this study was the unexpectedly low percentage of the sample that had taken the HTLV-III antibody test. Table 28 below tabulates the responses to an open-ended question in which all the subjects

were asked why they did or did not take this test.

Table 28  
Reasons for Not Taking the HTLV-III Antibody Test

Number of Ss	Reason Given
105	Believed they had no reason to take the test
57	Were afraid or anxious regarding the results
49	Did not have the time
44	Did not want to know the results
42	Thought that the test was not meaningful
19	Responses were not codeable
14	Did not know where the test was being given
5	Wanted to wait for a more conclusive test
74	Did not respond to this item

Levels of Anxiety and Depression  
Among 488 Male Homosexuals

Of interest was the distribution of scores on measures of anxiety and depression for the entire sample. Table 29 presents these findings, using Cattell's sten scores. "Sten scales are standard scores with a 10-point range" (Krug, Scheier, & Cattell, 1976, p. 14). As used in the ASQ and DS, sten scores of 4,5,6, or 7 indicate the average range; sten scores of 1,2, or 3 are typical of secure, unusually relaxed subjects, and scores of 8, 9, or 10 indicate a high level of anxiety or depression.

Table 29  
Levels of Anxiety and Depression Among 488 Male Homosexuals

Sten Score	Frequency of ASQ (n)	Relative Frequency (%)	Frequency of DS (n)	Relative Frequency (%)	
Low	1	6	1.2	47	9.6
	2	23	4.7	32	6.6
	3	51	10.5	134	27.5
Mid- Range	4	88	18.0	100	20.5
	5	65	13.3	49	10.0
	6	85	17.4	10	2.0
	7	81	16.6	33	6.8
High	8	42	8.6	46	9.4
	9	28	5.7	20	4.1
	10	19	3.9	17	3.5

The distribution of ASQ scores appears to be a relatively normal distribution. However, the DS scores are skewed towards the lower end of the distribution, indicating that the male homosexuals of this sample are not as depressed as the normative sample of the DS.

Comparison of Levels of Anxiety  
and Depression Between Male  
Homosexuals and Male Norms

One of the concerns identified in Chapter II was the lack of normative data on male homosexuals for most psychological tests. In order to be able to interpret the psychological tests used in this study, it is important to determine if there are any

statistical differences between the distribution of scores of the male homosexuals of this sample and the male norms used to standardize the tests. In making this comparison, only those homosexuals who have not taken the HTLV-III test were used as a comparison group, on the grounds that those who had taken the test represented an artificial situation that was not comparable to the original norming sample and may unduly bias the results.

Table 30  
A Comparison of ASQ and DS Scores  
Between Male Homosexuals and the Male Normative Sample

Group	Number of Cases	Mean	Std. Dev.	Std. Error	T Value	T Needed for Signif at .05
ASQ						
Norm Sample	503	26.40	13.38	.596	.584	1.98
Homosexuals	382	26.75	12.23	.625		
DS						
Norm Sample	488	21.95	9.52	.519	.453	1.98
Homosexuals	383	17.34	10.36	.529		

From this analysis, there appear to be no statistically significant differences between the group means. Since there are no statistical differences, and because the original normative male samples undoubtedly included from 4 to 10 percent homosexuals, it seems reasonable to conclude that the ASQ and DS validly measure the constructs of anxiety and depression for the homosexual sample.

CHAPTER V  
SUMMARY AND DISCUSSION

The purpose of this study was to identify the psychological and social consequences experienced by homosexual men who learn that they have positive results on the HTLV-III antibody test. Previous research in this area had focused on AIDS and ARC patients--populations that are comprised of persons with more advanced stages of HTLV-III infection. The present study sampled a broad spectrum of homosexual men within a limited geographical area, and focused on those who had taken the HTLV-III antibody test, but who had not yet developed AIDS or ARC. A survey was sent to 1884 male members of three homophile organizations in Orange County, California, and included a self-developed questionnaire designed to gather biographical and medical information, an inventory designed to measure coping strategies, and standardized psychological tests which measure anxiety and depression. There were 503 valid returns: 30 from HTLV-III positives, 55 from HTLV-III negatives, 19 from men who did not know the results of their testing, and 399 from men who had not been tested.

There were a number of major findings from the results of

this study. These are summarized below.

For those who were tested with the HTLV-III antibody and had positive results, there appears to be an initial period of emotional and cognitive disorganization. This disorganization was reflected in the lack of consistency between subjects' initial and subsequent emotional and cognitive perceptions regarding the meaning of the testing for them. Initially, there appears to be a misreading of what the test results mean, and the perception of imminent personal catastrophe. Subsequent reactions were typically modified and more reality based.

In addition to this initial period of disorganization, the study found that the level of anxiety among HTLV-III positives was higher than that experienced by HTLV-III negatives and those who had not taken the antibody test. These differences were statistically significant, but there was not much clinical difference between the two groups. However, one third of the positive sample had clinically significant levels of anxiety.

Further, the level of depression among HTLV-III positives was higher than that experienced by HTLV-III negatives and those who had not taken the antibody test. These differences were both statistically and clinically significant. Approximately one half of the positive sample had clinically significant levels of depression.



It was hypothesized that those subjects with physical symptoms related to HTLV-III infection might show higher levels of anxiety and depression. In this sample, however, the presence of physical symptoms had no relation to levels of anxiety or depression. However, those with symptoms appeared to be more likely to have taken the HTLV-III antibody test.

The study found that a variety of coping mechanisms are used by HTLV-III positives. The most frequently endorsed group of cognitive strategies reflected an attitude of positive thinking, combined with efforts to learn more about the infection. The second most frequently endorsed group of cognitive strategies reflected an attitude of stoic resignation. In addition, many HTLV-III positives were adopting more healthful behaviors such as reducing the consumption of tobacco, alcohol, and drugs.

About half of the HTLV-III positives in this sample reported thinking of suicide after hearing of their antibody test results. Only one of these twelve subjects reported making a suicide attempt. This finding may be biased, however, because it does not reflect those who may have been successful in their suicide attempts.

With regards to sexual behavior, those with positive antibody test results have made profound changes, ranging from the adoption of celibacy to changing their preferred sexual activity.

Furthermore, changes of some kind were universally reported by this sample. These kinds of changes suggest that major shifts in intrapsychic and interpersonal behavior are occurring in these subjects.

In addition to changes in sexual behavior, the HTLV-III positives are also reporting changes in their other social behaviors. For example, those with positive antibody test results are being quite selective about sharing those results. Twenty percent of the sample have not shared their test results with anyone. Fifty percent of the sample have shared their test results with only a very few close friends. This may reflect an interpersonal isolation that could significantly impact the mental health of these subjects. About half of the HTLV-III positive subjects indicated that they have experienced some negative effects in their overall social functioning. These negative effects were identified by the subjects as the result of the social distancing--primarily caused by the positives themselves.

Concomitant to changes in social interactions, 37 percent of the positive subjects indicated some negative change in their work behavior. This change was identified by the subjects as the result of social distancing or increasing physical debilitation. Given the positive contribution to self esteem that working provides, one can speculate that those positives who are

negatively impacted in the area of work are likely to suffer decrements in self esteem.

When positive subjects were asked what kind of psychological assistance they perceived others in their situation might need, they identified three kinds of psychological assistance: 1) someone to talk to about the infection; 2) professional counseling; and 3) more education regarding HTLV-III infection. There was no difference in the kinds of psychological assistance requested between the groups with and without physical symptoms.

Finally, in order to compare the results of this study with other studies using AIDS and ARC patients, an estimate of the frequency of adjustment disorders was made. The estimated frequency of adjustment disorders in this sample of HTLV-III positives was twenty-three percent. Five subjects were identified with adjustment disorders with depressed mood; two subjects were identified with adjustment disorders with anxious mood. These figures, however, must be interpreted with considerable caution, because they are the result of correlating self-report data, and are not based on clinical observation. This finding represents a considerably lower rate of adjustment disorder that has been found in other studies using more seriously ill patients.

### Methodological Limitations

This study is subject to a number of limitations as a result of the methods used. Of foremost importance, when interpreting the results of the study, are the limitations inherent in a survey design. A survey can describe the occurrence of variables, it can explore relationships between variables, and it can be used to make comparisons between groups. It cannot provide information regarding cause-and-effect relationships. Thus, although a relationship was found regarding the occurrence of high levels of depression in the group of HTLV-III positives, and low levels of depression in those who tested negative, one cannot go on to state that group membership caused the depression; or that knowledge of positive test results caused the depression.

While this is an important limitation, it is also necessary to keep in mind that the questions posed in this study are not amenable to the collection of experimental evidence. It is highly unlikely that subjects could be found who would willingly submit to HTLV-III infection for the purposes of addressing these issues. Thus, while there are distinct limitations to the survey design used in this research, it is probably the most powerful design that can ethically be used to address these questions.

Another methodological limitation of this study has to do

with the inability to implement the planned follow-up procedure, and the subsequent uneven follow-up which occurred. One of the three homophile organizations, Laguna Outreach, is probably over-represented in this study, because they alone sent a follow-up letter to their membership. Further, the use of HTLV-III positives from the counseling program of the Gay and Lesbian Center probably over-represents that organization in the HTLV-III positive group. What impact this uneven follow-up has had on the findings of the study is impossible to assess.

Another concern is the relatively small number of HTLV-III positives who responded to this study. While this study received returns from more than twice the estimated base rate of those tested in the geographical area sampled, what this small number of returns from HTLV-III positives means, and what biases have been built into the results as a consequence are impossible to determine. Another concern is the relatively low response rate of 27 percent over the entire sample. This means that 73 percent of the accessible population did not respond. Clearly, the responses of this missing 73 percent could greatly influence the results of this study. Given the limitations of the data collection procedures, it is impossible to determine if these results accurately represent the accessible population of the study.

There is some reason to believe, however, that the sample

does represent the population. The rate of HTLV-III positives found in this study is equivalent to the rate found in a previous sample of this population (Anton-Guirgis et al., 1985), and equivalent to the rate found at the testing facility in Orange County (R. Alexander, personal communication, December 13, 1985). A second indicator of validity is that there were no differences in return rate across zip codes. This means that approximately the same percentage from each zip code area returned their questionnaires. There is even some indication as to one of the biases which may have occurred across zip codes. It was expected that very few of those who returned their materials would reveal their name and address for follow-up. Contrary to expectation, over 71 percent of the sample agreed to participate in the follow-up. This suggests that the more secure, self-confident individuals participated in this study. This further suggests that the levels of anxiety and depression may be somewhat conservative, compared to what actually exists in the population.

One of the temptations, given the limited data regarding HTLV-III positives at the present time, may be to attempt to generalize these findings beyond this sample to the target population of all male homosexuals who have had the HTLV-III antibody test. This is a very dangerous undertaking, given the demographic characteristics of this sample. The sample from which

these findings have been derived consists of well-educated, middle-aged homosexual men who typically are employed in professional occupations, have an income in excess of \$30,000 per year, are members of homophile organizations, and are currently residing in Orange County, California. This is clearly a unique group, and any attempt to generalize beyond the sample must keep this in mind.

#### Speculations

While there are a number of limitations about these data, there are also hints of a pattern that may be emerging. Of course, what follows is speculation--speculation that clearly moves beyond the data. However, these speculations may prove useful to other researchers.

When a person is told that he has positive results on the HTLV-III antibody test, he is told that he may be in a life-threatening situation: 5-20 percent of those with the infection will develop AIDS and die. However, what the patient hears appears to be somewhat different from this. The patient appears to receive the message that he is currently in a life threatening situation. The medical implication of this life-threatening situation is that he will develop a series of

disfiguring, debilitating physical illnesses which will ultimately result in his death. The social implication is that no one will want to be near him--all his friends will abandon him. Furthermore, sexual activities, which usually have been problematic for the homosexual, at least as an adolescent, will have to be curtailed.

The experience of hearing this message has a number of psychological consequences. First, there appears to be an initial disorganizing effect--the usual emotions and thoughts of the hearer are seriously disrupted, now begin to center around catastrophe, and do not have a direct relation to subsequent emotions and thoughts. This appears to be a very vulnerable time for most homosexuals who are told of positive antibody test results. It is likely--due to the psychological disruption and the temporary failure of ego defenses--that suicide might occur with some frequency during this initial period.

For the most part, however, patients are able to pull themselves together again fairly rapidly. For many, however, this reconstitution is not complete, because there still exists the perception of a number of ego-threatening problems: the imminent possibility of debilitation and death, and social and sexual isolation. From the limited data that presently exists, it appears that there are three major modes of responding to these



threats: depression, anxiety, and an adaptive response.

Approximately half of the sample from this study evidenced clinical levels of depression--one third of the sample was seriously depressed. It is hypothesized that this depression may be the result of cognitive distortions of the type described by Beck and his colleagues (1979) and Burns (1980). These writers have identified a number of common statements which people often make to themselves which appear to cause depression. For example, Burns (1980) describes 'all-or-nothing thinking'--"the tendency to evaluate your personal qualities in extreme, black-or-white categories" (pp. 31-32) as an example of a cognitive distortion which can lead to depression. It is hypothesized that the depressed subjects in this sample are using such cognitive distortions and causing the depression they experience.

Another likely contributory cause to their depression is the social isolation which they have engendered. These subjects often have not told others of their status. This lack of self-disclosure appears to contribute to a sense of isolation with friends and on the job. In addition, sexual relationships are curtailed or stopped. These behavior changes are highly likely to have a negative effect on the patient's self-esteem, resulting in depression. This depression is likely to contribute to a further reduction of activity, an increase in the use of cognitive

distortions, a further deepening of the social isolation, and an exacerbation of the depression.

Another response to this situation is that of anxiety. One third of the sample in this study evidenced clinical levels of anxiety. It is hypothesized that this anxiety may be the result of: 1) a failure to reconstitute after the initial threat to the ego (Fenichel, 1946); or 2) as the result of adopting dysfunctional attitudes which result in generalized anxiety states (Beck & Emery, 1985).

The Fenichel hypothesis is derived from psychodynamic theory. When an individual is faced with the threat of imminent death, his/her ego-defenses are likely to be, at least briefly, overwhelmed. Those individuals whose ego-defenses are flexible and adequate will quickly reconstitute their defenses. However, those without such protection will be faced with a continued experience of anxiety. The theory derived from cognitive-behavior therapy suggests that, in a manner similar to the creation of depression, the individual adopts certain attitudes which engender anxiety (Beck & Emery, 1985).

Whatever the cause of anxiety in these individuals, it is likely to lead to an increase in all behaviors. High ASQ scores were correlated most highly with the CSI strategy of doing things. They also had the strongest inverse correlations with

trying to stay calm, and with taking a positive attitude.

Nine of the thirty HTLV-III positives were both depressed and anxious. This suggests that some common mechanism may be causing both affective states, which would favor the hypothesis that cognitive distortions are responsible for these behaviors. Only one individual who achieved a score in the clinically anxious range did not also have a score in the clinically depressed range. However, five subjects achieved scores in the clinically depressed range without a concomitant level of anxiety.

The third common response to the information of HTLV-III positivity appears to be an adaptive reaction. Fifty percent of the HTLV-III positives in this sample had neither a depressive nor an anxious reaction. From the lack of any information to the contrary, these individuals are hypothesized to have made an adaptive response to the diagnosis of HTLV-III infection. What has led to this response is, at present, open to question.

#### Implications Regarding the Counseling Needs of HTLV-III Positives

There are a number of implications which can be drawn from the empirical findings regarding the counseling needs of the HTLV-III positives in this sample. The positive subjects themselves, when

asked to respond to a question about kinds of psychological assistance, if any, that they felt they needed, gave answers that were evenly distributed among three alternatives: 1) needing someone with whom to talk about their situation; 2) needing professional counseling to work through the psychological problems resulting from the infection; and 3) needing more education regarding the effects of HTLV-III infection and how to cope with them. These perceptions--because they are generated by those currently facing the problem--provide a starting point for this discussion.

The social isolation that many of the positives in this sample felt, and their lack of self-disclosure suggests that many do in fact need someone with whom to talk. The most cost effective means of meeting this need would entail the formation of self-help groups for HTLV-III positives. This would allow homosexuals with similar problems to gather and self-disclose, and to overcome some of the social isolation which affects them. These groups could have great positive impact during the initial period of disorganization that HTLV-III positives seem to experience. They would provide a social support system that could 'carry' the newly informed individual until his ego-defenses reconstitute. In addition, this social support would facilitate a healthy and flexible reconstitution. However, a major problem

with this notion may revolve around the formation of these groups. If it is not socially acceptable to identify one's self as a positive, who will join such a group? This problem must be addressed before self-help groups for this population can succeed.

The second alternative, professional counseling, also appears appropriate in many cases. Given that approximately 80 percent of the positives in this sample have clinically significant levels of anxiety or depression, it is clear that many appear to need professional counseling or psychotherapy. If the speculations above are accurate, the most appropriate psychotherapy may be cognitive-behavior therapy. Other problems experienced by this group also indicate the need for psychotherapy. For example, the changes in sexual behavior reported by all of the sample and the changes in occupational functioning reported by 30 percent of the sample are likely to have profound effects on self-esteem. In addition, although this study did not attempt to measure neuropsychological problems, material reported by other studies regarding the high incidence of neuropsychological problems in those with HTLV-III infections suggests that these problems are very common. Professional assistance in the assessment and management of neuropsychological problems is clearly indicated.

Finally, the need for more education, and more effective

education, is clearly indicated. Much of the initial disorganization experienced by HTLV-III positives seems to be the result of inadequate information about the outcomes of HTLV-III infection and erroneous information about the imminence of illness and death. If this initial disruption could be minimized, it is likely that the resulting psychological and social problems of those with positive test results would be greatly reduced.

To have the maximum impact, this education needs to be aimed in two directions. First, it needs to be broadcast to male homosexuals in general, so that they do not come in for testing with erroneous misconceptions. This kind of education would serve as a prophylaxis for the kinds of psychological and social problems which have been occurring with HTLV-III positives. Second, another educational effort needs to be aimed specifically at those who go in, or have already gone in for HTLV-III antibody testing. At the very least, written information should be prepared which addresses the problems and misconceptions found in this sample.

In addition to these efforts, more research needs to be done with this population, in order to facilitate the counseling described here. As yet, not enough is known about this population. For example, can some coping strategies reduce or exacerbate psychological problems with some patients? Once more

is discovered about the relationships between variables in this area, the counseling and educational efforts will be greatly facilitated.

#### Recommendations for Further Study

There is a growing need, as more and more people are infected with the HTLV-III virus, to do psychosocial research with this population. The following constitutes some suggestions for further study.

1. Replicate the current study with samples drawn from different socio-economic strata and different geographical areas, using the same measures.
2. Institute longitudinal studies with measures before and after antibody testing, in order to construct a more accurate picture of the sequence of events for those with positive antibody tests. Such studies would help determine the causation of the depression and anxiety experienced by HTLV-III positives.
3. Test the effectiveness of intervention strategies such as education, professional counseling, and self-help groups. For whom,

and under what conditions do these strategies work best? Test the effectiveness of coping strategies, such as those indicated on the CSI. Which strategies work, for whom, and under what conditions?

4. Test the hypotheses suggested in the 'Speculations' section above. Can a model be developed which explains the intra- and interpersonal reactions of HTLV-III positives?



## REFERENCES

- AIDS spreads to the courts. (1985, July 1). Newsweek, p. 61.
- Alumbaugh, M.J., Namir, S., & Boxley, R. (1985, August). Social support, coping and AIDS. Paper presented at the annual convention of the American Psychological Association, Los Angeles, CA.
- American Psychiatric Association. (1980). Diagnostic and statistical manual of mental disorder (3rd ed.). Washington, DC: Author.
- American Psychological Association. (1981). Ethical principles of psychologists. American Psychologist, 36, 633-638.
- American Psychological Association. (1985). Ethical issues in psychological research on AIDS. Washington, DC: American Psychological Association.
- Anton-Guirgis, H., Culver, B.D., Spindler, B., & Kleinman, S. (1985). [Methods to detect the carrier state of AIDS]. Unpublished raw data.
- Baltimore, D. (1970). RNA-dependent DNA polymerase in virions of RNA tumour viruses. Nature, 226, 1209-1211.
- Barre-Sinoussi, F., Chermann, J.C., Rey, F., Nugeyre, M.T., Chamaret, S., Gruest, J., Dauguet, C., & Axler-Blin, C. (1983). Isolation of T-lymphotropic retrovirus from a patient at risk for Acquired Immune Deficiency Syndrome (AIDS). Science, 220, 868-870.
- Barrett, D.J. (1984). Characterization of the acquired immune deficiency syndrome at the cellular and molecular level. Molecular and Cell Biochemistry, 63, 3-11.
- Bauman, L.J. (1984). Coping, social support and cancer: An empirical and theoretical study of the stress process. Dissertation Abstracts International, 45, 3214A. (University Microfilms No. DA8427348)

- Bayer, R., Levine, C., & Murray, T.H. (1984). Guidelines for confidentiality on AIDS. IRB, 6, 1-7.
- Beck, A.T., & Emery, G.D. (1985). Anxiety disorders and phobias: A cognitive perspective. New York: Basic Books.
- Beck, A.T., Rush, A.J., Shaw, B.F., & Emery, G. (1979). Cognitive therapy of depression. New York: Guilford Press.
- Bell, A.P., & Weinberg, M.S. (1978). Homosexualities: A study of diversity among men and women. New York: Simon and Schuster.
- Bieber, I., Dain, H.J., Dince, P.R., Drellich, M.G., Grand, H.G., Grundlach, R.H., Kremer, M.W., Rifkin, A.H., Wilbur, C.B., & Bieber, T.B. (1962). Homosexuality: A psychoanalytic study of male homosexuals. New York: Basic Books.
- Borg, W.R., & Gall, M.D. (1979). Educational research: An introduction. New York: Longman.
- Bowen, L.L., Lane, H.C., & Fauci, A.S. (1985). Immunologic features of AIDS. In V.T. DeVita, S. Hellman, S.A. Rosenberg (Eds.), AIDS. Philadelphia: J.B. Lippincott. pp. 89-109.
- Brain, R.W. (1963). The neurological complications of neoplasms. Lancet, 1, 179-184.
- Broder, S., & Gallo, R.C. (1984). A pathogenic retrovirus (HTLV-III) linked to AIDS. New England Journal of Medicine, 311, 1292-1297.
- Brown, R.S., Haddox, V., Posada, A., & Rubio, A. (1972). Social and psychological adjustment following pelvic exenteration. American Journal of Obstetrics and Gynecology, 114, 162-171.
- Burns, D.D. (1980). Feeling good: The new mood therapy. New York: New American Library.
- Campbell, D.T., & Stanley, J.C. (1963). Experimental and quasi-experimental designs for research. Chicago: Rand McNalley.
- Cattell, R.B., Eber, H.W. & Tatsuoka, M.M. (1970). Handbook for the 16 personality factor questionnaire. Champaign, IL: Institute for Personality and Ability Testing.
- Cattell, R.B., & Monroney, J.H. (1962). The use of the 16PF in distinguishing homosexuals, normals, and general criminals.

Journal of Consulting Psychology, 26, 531-340.

Cattell, R.B., & Scheier, I.H. (1963). Handbook for the IPAT anxiety scale questionnaire. Champaign, IL: Institute for Personality and Ability Testing.

Centers for Disease Control. (1981a). Pneumocystis pneumonia--Los Angeles. Mortality and Morbidity Weekly Reports, 30, 250-252.

Centers for Disease Control. (1981b). Kaposi's sarcoma and pneumocystis pneumonia among homosexual men--New York City and California. Mortality and Morbidity Weekly Reports, 30, 305-308.

Centers for Disease Control. (1982). Update on Acquired Immune Deficiency Syndrome (AIDS)--United States. Mortality and Morbidity Weekly Reports, 31, 507-514.

Centers for Disease Control. (1984). Antibodies to a retrovirus etiologically associated with acquired immunodeficiency syndrome (AIDS) in populations with increased incidences of the syndrome. Mortality and Morbidity Weekly Reports, 33, 377-379.

Centers for Disease Control. (1985a). Provisional Public Health Service Inter-Agency recommendations for screening donated blood and plasma for antibody to the virus causing acquired immunodeficiency syndrome. Morbidity and Mortality Weekly Reports, 34, 1-11.

Centers for Disease Control. (1985b). A revision of the case definition of Acquired Immunodeficiency Syndrome for national reporting--United States. Mortality and Morbidity Weekly Reports, 34, 373-375.

Centers for Disease Control. (1985c). Recommendations for preventing transmission of infection with HTLV-III virus in the workplace. Mortality and Morbidity Weekly Reports, 34, 682-695.

Centers for Disease Control. (1985d). Recommendations for assisting in the prevention of perinatal transmission of HTLV-III and Acquired Immunodeficiency Syndrome. Mortality and Morbidity Weekly Reports, 34, 721-732.

Centers for Disease Control. (1986). Update: Acquired Immunodeficiency Syndrome: United States. Mortality and Morbidity Weekly Reports, 35, 17-21.

- Cesario, T. (1985, June). Infectious diseases of AIDS. In P. Jemison-Smith (Chair), A clinical symposium on AIDS. University of California at Irvine.
- Cheingsong-Popov, R., Weiss, R.A., Dalgleish, A., Tedder, R.S., Shanson, D.C., Jeffries, D.J., Ferns, R.B., Briggs, E.M., Weller, I.V., & Mitton, S. (1984). Prevalence of antibody to HTLV-III in AIDS and AIDS risk patients in Britain. Lancet, *ii*, 477-480.
- Coates, T.J., Temoshok, L., & Mandel, J. (1984). Psychosocial research is essential to understanding and treating AIDS. American Psychologist, *39*, 1309-1313.
- Coleman, E. (1982a). Changing approaches to the treatment of homosexuality: A review. In W. Paul, J.D. Weinrich, J.C. Gonsiorek, & M.E. Hotvedt (Eds.), Homosexuality: Social, psychological and biological issues. Beverly Hills, CA: Sage, pp. 81-88.
- Coleman, E. (1982b). Developmental stages of the coming-out process. In W. Paul, J.D. Weinrich, J.C. Gonsiorek, & M.E. Hotvedt (Eds.), Homosexuality: Social, psychological and biological issues. Beverly Hills, CA: Sage, pp. 149-158.
- Craig, T.J. & Abeloff, M.D. (1974). Psychiatric symptomatology among hospitalized cancer patients. American Journal of Psychiatry, *141*, 1323-1327.
- David, J. (1985). The organs and cells of the immune system. In E. Rubenstein & D.D. Federman (Eds.), Scientific American Medicine. New York: Scientific American, pp. 1-11.
- Deitz, J.H. (1969). Rehabilitation of the surgical patient. Contemporary Surgery, *4*, 22-26.
- Denniston, R.H. (1980). Ambisexuality in animals. In J. Marmor (Ed.), Homosexual behavior: A modern reappraisal. New York: Basic Books, pp. 25-40.
- Deuchar, N. (1984). AIDS in New York City with particular reference to the psycho-social aspects. British Journal of Psychiatry, *145*, 612-619.
- Dilley, J.W., Ochitill, H.N., Perl, M., & Volberding, P.A. (1985). Findings in psychiatric consultations with patients with acquired immune deficiency syndrome. American Journal of Psychiatry, *142*, 82-86.

- Domingo, J., & Chin, N.W. (1983). Lymphadenopathy in a heterogeneous population at risk for the Acquired Immunodeficiency Syndrome (AIDS)--A morphologic study. American Journal of Clinical Pathology, 80, 649-654.
- Dorner, G. (1975). A neuroendocrine predisposition for homosexuality in men. Archives of Sexual Behavior, 4, 1-8.
- Dorner, G., & Hinz, G. (1968). Induction and prevention of male homosexuality by androgen. Journal of Endocrinology, 40, 387-388.
- Essex, M., McLane, M.F., Lee, T.H., Falk, L., Howe, C.W.S., & Mullins, J.I. (1983). Antibodies to cell membrane antigens associated with human T-cell leukemia virus in patients with AIDS. Science, 220, 859-862.
- Fauci, A.S. (Moderator). (1984). Acquired Immunodeficiency Syndrome: Epidemiologic, clinical, immunologic and therapeutic considerations. Annals of Internal Medicine, 100, 92-106.
- Fauci, A.S., & Lane, H.C. (1984). Overview of clinical syndromes and immunology of AIDS. Topics in Clinical Nursing, 6, 12-18.
- Feinstein, A.D. (1983). Psychological interventions in the treatment of cancer. Clinical Psychology Review, 3, 1-14.
- Feldman, F.L. (1978). Work and cancer health histories. American Cancer Society.
- Fenichel, O. (1946). The psychoanalytic theory of neurosis. New York: Norton.
- Fischinger, P.J., & Bolognesi, D.P. (1985). Prospects for diagnostic tests, intervention and vaccine development in AIDS. In V.T. DeVita, S. Hellman, S.A. Rosenberg (Eds.), AIDS. Philadelphia: J.B. Lippincott. pp. 55-88.
- Fisher, K. (1983, July). Stress: The unseen killer in AIDS. APA Monitor, pp. 1, 20, 21.
- Fleming, A.F., Yamamoto, N., Bhusnurmath, S.R., Maharajan, R., Schneider, J., & Hunsmann, G. (1983). Antibodies to ATL (HTLV) in Nigerian blood donors and patients with chronic lymphocytic leukaemia or lymphoma. Lancet, 2, 334-335.

- Ford, C., & Beach, F. (1951). Patterns of sexual behavior. New York: Harper.
- Forstein, M. (1984). The psychosocial impact of the acquired immunodeficiency syndrome. Seminars in Oncology, 11, 77-82.
- Fras, I., Litin, E.M., & Pearson, J.S. (1967). Comparison of psychiatric symptoms in carcinoma of the pancreas with those in some other intra-abdominal neoplasms. American Journal of Psychiatry, 123, 1553-1562.
- Freidenbergs, I., Gordon, W., Hibbard, M., Levine, L., Wolf, C., & Diller, L. (1981-82). Psychosocial aspects of living with cancer: A review of the literature. International Journal of Psychiatry in Medicine, 11, 303-330.
- Freud, S. (1905). Three essays on the theory of sexuality. In J. Strachey (Ed.), The standard edition of the complete psychological works of Sigmund Freud, Vol. 7. London: Hogarth Press, pp. 125-243.
- Gajdusek, D.C., Amyx, H.L., Gibbs, C.J., Jr., Asher, D.M., Rodgers-Johnson, P., Epstein, L.G., Sarin, P.S., Gallo, R.C., Maluish, A., & Arthur, L.O. (1985). Infection of chimpanzees by human T-lymphotropic retroviruses in brain and other tissues from AIDS patients. Lancet, 2, 55-56.
- Gallo, R.C. (1984). Human T-cell leukaemia/lymphoma virus and T-cell malignancies in adults. Cancer Surveys, 3, 113-159.
- Gallo, R.C., Essex, M., & Gross, L. (1984). Human T-cell leukemia/lymphoma virus. New York: Cold Harbor Laboratory.
- Gallo, R.C., Salahuddin, S.Z., Popovic, M., Scheiner, G.M., Kaplan, M., Haynes, B.F., Palker, T.J., Redfield, R., Oleske, J., Safai, B., White, G., Foster, P., & Markham, P.D. (1984). Frequent detection of and isolation of cytopathic retroviruses (HTLV-III) from patients with AIDS and at risk for AIDS. Science, 224, 500-503.
- Gallo, R.C., Sarin, P.S., Gelmann, E.P., Robert-Guroff, M., Richardson, E., Kalyanaraman, V.S., Mann, D., Sidhu, G.D., Stahl, R.E., Zolla-Pazner, S., Leibowitch, J., & Popovic, M. (1983). Isolation of human T-cell leukemia virus in acquired immune deficiency syndrome (AIDS). Science, 220, 865-868.

Gallo, R.C., Sliski, A. & Wong-Staal, F. (1983). Origin of human T-cell leukemia-lymphoma virus. Lancet, 2, 962-963.

Gapen, P. (1982). Neurological complications now characterizing many AIDS victims. Journal of the American Medical Association, 248, 2941-2942.

Gebhard, P.H. (1969). Incidence of overt homosexuality in the United States and Europe. In J.M. Livingood (Ed.), National Institute of Mental Health Task Force on Homosexuality: Final Report and Background Papers. Rockville, MD: U.S. Department of Health, Education and Welfare.

Ginzburg, H.M. (1984). Intravenous drug users and the acquired immune deficiency syndrome. Public Health Reports, 99, 206-211.

Goerdert, J., & Blattner, W. (1985). The epidemiology of the acquired immunodeficiency syndrome. In V.T. DeVita, S. Hellman, S.A. Rosenberg (Eds.), AIDS: Etiology, diagnosis, treatment, and prevention. Philadelphia: J.B. Lippincott. pp. 1-30.

Gonsiorek, J.C. (1977). Psychological adjustment and homosexuality. JSAS Catalog of Selected Documents in Psychology, 7, 45(MS1478).

Gonsiorek, J.C. (1982). Results of psychological testing on homosexual populations. In W. Paul, J.D. Weinrich, J.C. Gonsiorek, & M.E. Hotvedt (Eds.), Homosexuality: Social, psychological and biological issues. Beverly Hills, CA: Sage, pp. 71-80.

Gordon, W., Freidenbergs, I., Diller, L., Hibbard, M., Levine, L., Wolf, C., Ezrachi, O., & Francis, A. (1977). The psychological problems of cancer patients: A retrospective study. Paper presented at the 85th American Psychological Association Convention, San Francisco.

Gracie, J.A., Froebel, K.S., Madhok, R., Lowe, G.D., & Forbes, C.D. (1985). Acquired immune deficiency syndrome--an overview. Scottish Medical Journal, 30, 1-7.

Greenwood, J.R., & Hamm, P. (1985). HTLV-III blood testing and lab precautions. In P. Jemison-Smith (Chair), A clinical symposium on AIDS. University of California at Irvine.

Gupta, S. (1985). Immunology of AIDS/ARC. In P. Jemison-Smith (Chair), A clinical symposium on AIDS. University of California

at Irvine.

Hardy, W.D., Jr., Hess, P.W., MacEwen, E.G., McClelland, E.E., Zuckerman, M., Essex, M., Cotter, S.M., & Jarrett, O. (1976). Biology of feline leukemia virus in the natural environment. Cancer Research, 36, 582-588.

Hausman, K. (1983a, August 5). Treating victims of AIDS poses challenge to psychiatrists. Psychiatric News. p. 1, 8.

Hausman, K. (1983b, August 19). 'AIDS panic' brings lonely life to patients, gays. Psychiatric News, p. 3, 24-25.

Hencken, J.D. (1982). Homosexuality and psychoanalysis: Toward a mutual understanding. In W. Paul, J.D. Weinrich, J.C. Gonsiorek, & M.E. Hotvedt (Eds.), Homosexuality: Social, psychological and biological issues. Beverly Hills, CA: Sage, pp. 121-148.

Hinkle, D.E., Wiersma, W., & Jurs, S.G. (1979). Applied statistics for the behavioral sciences. Chicago: Rand McNally.

Hirsch, D.A. & Dworkin, R.H. (1985a, August) Psychological distress and the Acquired Immune Deficiency Syndrome (AIDS). Paper presented at the annual convention of the American Psychological Association, Los Angeles, CA.

Hirsch, D.A., & Dworkin, R.H. (1985b, August). Strategies used to cope with AIDS. Paper presented at the annual convention of the American Psychological Association, Los Angeles, CA.

Holland, J.C. (1982). Psychologic aspects of cancer. In J.F. Holland & E. Frei (Eds.) Cancer medicine. Philadelphia: Lea & Febiger, pp. 1175-1203.

Hooker, E. (1957). The adjustment of the male overt homosexual. Journal of Projective Techniques, 21, 18-31.

Hooker, E. (1958). The adjustment of the male overt homosexual. Journal of Projective Techniques, 22, 33-54.

Joseph, J.G., Emmons, C., Kessler, R.C., Wortman, C.B., O'Brien, K., Hocker, W.T., & Schaefer, C. (1984). Coping with the threat of AIDS. American Psychologist, 39, 1297-1302.

Kalish, S.B., Ostrow, D.G., & Phair, J.P. (1983). Diagnosis and treatment of acquired immune deficiency states and opportunistic infections. In D.G. Ostrow, T.A. Sandholzer, & Y.M. Felman



(Eds.) Sexually transmitted diseases in homosexual men: Diagnosis, treatment and research. New York: Plenum Medical Books. pp. 213-234.

Kalyanaraman, V.S., Sarngadharan, M.G., Robert-Guroff, M., Miyoshi, I., Blayney, D., Golde, K., & Gallo, R.C. (1982). A new subtype of human T-cell leukemia virus (HTLV-II) associated with a T-cell variant of hairy cell leukemia. Science, 218, 571-573.

Kazdin, A.E. (1982). Single-case research designs: Methods for clinical and applied settings. New York: Oxford University Press.

Kemeny, M. (1985, August). Stress and psychological factors predicting immunity and genital herpes recurrence. Paper presented at the annual convention of the American Psychological Association, Los Angeles, CA.

Kinsey, A.C., Pomeroy, W., & Martin, C. (1948). Sexual behavior in the human male. Philadelphia: Saunders.

Kirsch, J.A.W., & Rodman, J.E. (1982). Selection and sexuality: The Darwinian view of homosexuality. In W. Paul, J.D. Weinrich, J.C. Gonsiorek, & M.E. Hotvedt (Eds.), Homosexuality: Social, psychological and biological issues. Beverly Hills, CA: Sage, pp. 183-196.

Krause, R.M. (1984). Koch's postulates and the search for the AIDS agent. Review of Infectious Disease, 6, 270-279.

Krug, S.E., & Laughlin, J.E. (1976). Handbook for the IPAT depression scale. Champaign, IL: Institute for Personality and Ability Testing.

Krug, S.E., Scheier, I.H., & Cattell, R.B. (1976). Handbook for the IPAT anxiety scale. Champaign, IL: Institute for Personality and Ability Testing.

Kubler-Ross, E. (1969). On death and dying. New York: Macmillan.

Landesman, S.H., Ginzburg, H. M., & Weiss, S.H. (1985). The AIDS epidemic. New England Journal of Medicine, 312, 521-525.

Lanyon, R.I. (1978). In O.K. Buros (Ed.) The Eighth mental measurements yearbook, Vol. I. Highland Park, NJ: Gryphon Press, pp. 854-857.

LaVoie, A.L. (1978). In O.K. Buros (Ed.) The Eighth mental measurements yearbook, Vol. I. Highland Park, NJ: Gryphon Press, pp. 859-860.

Lawrence, D.N., Lui, K.J., Bregman, D.J., Peterman, T.A., & Morgan, W.M. (1985). A model-based estimate of the average incubation and latency period for transfusion-associated AIDS. Abstract of paper presented at the International Conference on AIDS, Atlanta, GA. Journal of Neurosurgery, 61, 9-16.

Levy, R.M., Bredesen, D.E., & Roseblum, M.L. (1985). Neurological manifestations of the acquired immunodeficiency syndrome (AIDS): Experience at UCSF and review of the literature. Journal of Neurosurgery, 62, 475-495.

Livingood, J.M. (Ed.). (1969). National Institute of Mental Health Task Force on Homosexuality: Final Report and Background Papers. Rockville, MD: U.S. Department of Health, Education and Welfare.

Lloyd, G.G. (1977). Psychological reactions to physical illness. British Journal of Hospital Medicine, 17, 352-358.

Lopez, D.J., & Getzel, G.S. (1984). Helping gay AIDS patients in crisis. Social Casework, 65, 387-394.

Lykken, D.T. (1978). In O.K. Buros (Ed.) The Eighth mental measurements yearbook, Vol. I. Highland Park, NJ: Gryphon Press, pp. 860-861.

Marmor, J. (1980). Overview: The multiple roots of homosexual behavior. In J. Marmor (Ed.), Homosexual behavior. New York: Basic, pp. 3-22.

Marwick, C. (1983). "Confidentiality" issues may cloud epidemiologic studies of AIDS. Journal of the American Medical Association, 250, 1945-1946.

Marwick, C. (1985a). Molecular level view gives immune system clues. Journal of the American Medical Association, 253, 3371-3376.

Marwick, C. (1985b). Neurological complications appear often in AIDS. Journal of the American Medical Association, 253, 3379, 3383.

- Marx, J.L. (1985). More progress on the HTLV family. Science, 227, 156-157.
- McReynolds, P. (1978). In O.K. Buros (Ed.) The Eighth mental measurements yearbook, Vol. I. Highland Park, NJ: Gryphon Press, pp. 857-859.
- Meyerowitz, B.E., Sparks, F.C., & Spears, I.K. (1979). Adjuvant Chemotherapy for breast carcinoma: Psychosocial implications. Cancer, 43, 1613-1618.
- Mitchell, W.M. (1967). Etiological factors producing neuropsychiatric syndromes in patients with malignant disease. International Journal of Neuropsychiatry, 3, 464-468.
- Morin, S.F. (1977). Heterosexual bias in psychological research on lesbianism and male homosexuality. American Psychologist, 32, 629-637.
- Morin, S.F. (1978). Psychology and the gay community: An overview. Journal of Social Issues, 34, 1-6.
- Morin, S.F. (1985, May). Research methodologies and heterosexual bias in AIDS research. Paper presented at the meeting of the American Association for the Advancement of Science, Los Angeles, CA.
- Morin, S.F., & Batchelor, W.F. (1984). Responding to the psychological crisis of AIDS. Public Health Reports, 99, 4-9.
- Morin, S.F., Charles, K.A., Malyon, A.K. (1984). The psychological impact of AIDS on gay men. American Psychologist, 39, 1288-1293.
- Namir, S. (1985, August). Neuropsychological assessment and intervention for people with AIDS. Paper presented at the American Psychological Association Convention, Los Angeles, CA).
- Needlestick transmission of HTLV-III from a patient infected in Africa. (1984) Lancet, 2, 1376-1377.
- Nie, N.H., Hull, C.H., Jenkins, J.G., Steinbrenner, K., & Bent, D.H. (1975). Statistical package for the social sciences (2nd ed.). New York: McGraw Hill.
- Norris, F.H.Jr. (1972). The remote effects of cancer on the nervous system. Zeitschrift fur Neurologie, 201, 201-210.

Opler, M.K. (1965). Anthropological and cross-cultural aspects of homosexuality. In J.Marmor (Ed.), Sexual inversion: The multiple roots of homosexuality. New York: Basic Books, pp. 108-123.

Peck, A. (1972). Emotional reaction to having cancer. American Journal of Roentology, Radium Therapy and Nuclear Medicine, 114, 591-599.

Peck, A., & Borland, J. (1976). Emotional reactions to radiation therapy. Unpublished manuscript.

Perry, S.W., & Tross, S. (1984). Psychiatric problems of AIDS inpatients at the New York Hospital: Preliminary report. Public Health Report, 99, 200-205.

Peskind, S. (1984). Living with AIDS: An information guide for Orange County. Garden Grove, CA: AIDS Response Program.

Peskind, S. (1985). Psychosocial aspects of AIDS. In P. Jemison-Smith (Chair), A clinical symposium on AIDS. University of California at Irvine.

Piot, P., Quinn, T.C., Taelman, H., Feinsod, F.M., Minlangu, K.B., Wobin, O., Mbendi, N., Mazebo, P., Ndangi, K., Stevens, W., Kalambayi, K., Mitchell, S., Bridts, C., & McCormick, J.B. (1984). Acquired immunodeficiency syndrome in a heterosexual population in Zaire. Lancet, July 14, 65-69.

Plumb, M.M. & Holland, J. (1977). Comparative studies of psychological function in patients with advanced cancer in self-reported depressive symptoms. Journal of Psychosomatic Medicine, 39, 264-276.

Poiesz, B.J., Ruscetti, F.W., Gazdar, A.F., Bunn, P.A., Minna, J.D., & Gallo, R.C. (1980). Detection and isolation of type C retrovirus particles from fresh and cultured lymphocytes of a patient with cutaneous T-cell lymphoma. Proceedings of the National Academy of Science, 77, 7415-7419.

Poiesz, B.J., Ruscetti, F.W., Reitz, M.S., Kalyanaraman, V.S., & Gallo, R.C. (1981). Isolation of a new type C retrovirus (HTLV) in primary uncultured cells of a patient with Sczary T-cell leukemia. Nature, 294, 268-271.

Popovic, M., Sarngadharan, M.G., Read, E., & Gallo, R.C. (1984). Detection, isolation, and continuous production of cytopathic retroviruses (HTLV-III) from patients with AIDS and pre-AIDS.

Science, 224, 497-500.

Prendergast, T., Jr. (1985). Epidemiology of AIDS/ARC. In P. Jemison-Smith (Chair), A clinical symposium on AIDS. University of California at Irvine.

Rado, S. (1940). A critical examination of the concept of bisexuality. Psychosomatic Medicine, 2, 459-467.

Reichert, C.M., Kelly, V.L., & Macher, A.M. (1985). Pathologic features of AIDS. In V.T. DeVita, S. Hellman, S.A. Rosenberg (Eds.), AIDS. Philadelphia: J.B. Lippincott. pp. 111-160.

Roberts, M.M., Furnival, I.G., & Forrest, A.P. (1972). The morbidity of mastectomy. British Journal of Surgery, 59, 301-302.

Rosillo, R.H., Welty, M.J., & Graham, W.P. (1973). The patient with maxillofacial cancer. Nursing Clinics of North America, 8, 153-158.

Roth, J. (1973). [The pareneoplastic syndromes]. Hippocrates, 44, 18-38.

Rubinow, D.R. (1984). The psychosocial impact of AIDS. Topics in Clinical Nursing, 6, 26-30.

Safai, B., Sarngadharan, M.G., Groopman, J.E., Arnett, K., Popovic, M., Sliski, A., Schupbach, J., & Gallo, R.C. (1984). Seroepidemiological studies of human T-lymphotropic virus, type III in Acquired Immunodeficiency Syndrome. Lancet, i, 1438.

Salahuddin, S.Z., Groopman, J.E., Markham, P.D., Sarngadharan, M.G., Redfield, R.R., McLane, M.F., Essex, M., Sliski, A., & Gallo, R.C. (1984). HTLV-III in symptom-free seronegative persons. Lancet, 2, 1418-1420.

Sarngadharan, M.G., Popovic, M., Bruch, L., Schupbach, J., & Gallo, R.C. (1984). Antibodies reactive with human T-lymphotropic retroviruses (HTLV-III) in the serum of patients with AIDS. Science, 224, 506-508.

Saxinger, W.C., Lange-Wantzin, G., Thomsen, K., Lapin, B., Yakovleva, L., Li, Y., Guo, H., Robert-Guroff, M., Blattner, W.A., Ito, Y., & Gallo, R.C. (1984). Human T-cell leukemia virus: A diverse family of related exogenous retroviruses of humans and old world primates. In R.C. Gallo, M.E. Essex, & L.Gross (Eds.), Human T-cell leukemia/lymphoma virus. New York: Cold Spring

Harbor Laboratory, pp. 323-330.

Schulz, R., & Aderman, D. (1974). Clinical research and the 'Stages of Dying'. Omega, 5, 137-144.

Schupbach, J., Popovic, M., Gilden, R.V., Gonda, M.A., Sarngadharan, M.G., & Gallo, R.C. (1984). Serological analysis of a subgroup of human T-lymphotropic retroviruses (HTVL-III) associated with AIDS. Science, 224, 503-505.

Seigal, F.P. (1984). Immune function and dysfunction in AIDS. Seminars in Oncology, 11, 29-39.

Sinkovics, J.G., Gyorkey, F., Melnick, J.L., & Gyorkey, P. (1984). Acquired immune deficiency syndrome (AIDS): Speculations about its etiology and comparative immunology. Review of Infectious Diseases, 6, 745-760.

Snider, W.D., Simpson, D.M., Neilson, S., Gold, J.W., Metroka, C.E., & Posner, J.B. (1983). Neurological complications of Acquired Immuno-Deficiency Syndrome: Analysis of 50 patients. Annals of Neurology, 14, 403-408.

Steis, R., & Broder, S. (1985). AIDS: A general overview. In V.T. DeVita, S. Hellman, S.A. Rosenberg (Eds.), AIDS. Philadelphia: J.B. Lippincott. pp. 299-338.

Taylor, D.L. (1984, May). Immune response: Physiology, signs, and symptoms. Nursing84, pp. 52-54.

Temin, H.M., & Mizutani, S. (1970). RNA-directed DNA polymerase in virions in Rous sarcoma virus. Nature, 226, 1211-1213.

The test: Raising concerns over civil liberties. (1985, February). Lambda Legal Defense Newsletter, p. 4.

Tross, S. (1985, August). Psychological impact of AIDS spectrum disorders. Paper presented at the annual convention of the American Psychological Association, Los Angeles, CA.

Tross, S., Holland, J.C., Metzler, A., Sidtis, J.J., Price, P.W., & Jordan, B.D. (1985, April). Psychological and neuropsychological function in AIDS spectrum disorder patients. Abstract of paper presented at the International Conference on AIDS, Atlanta, GA.

- Valle, S., Saxinger, C., Ranki, A., Antonen, J., Suni, J., Lahdevirta, J., & Krohn, K. (1985). Diversity of clinical spectrum of HTLV-III infection. Lancet, 1, 301-304.
- Wein, K., & Lopez, D. (1984). Overview of psychological issues concerning AIDS. Unpublished manuscript.
- Weinrich, J.D. (1982). Is homosexuality biologically natural. In W. Paul, J.D. Weinrich, J.C. Gonsiorek, & M.E. Hotvedt (Eds.), Homosexuality: Social, psychological and biological issues. Beverly Hills, CA: Sage, pp. 197-208.
- Weiss, S.H., Goedert, J.J., Sarngadharan, M.G., Bodner, A.J., AIDS Seroepidemiology Collaborative Working Group, Gallo, R.C., & Blattner, W.A. (1985). Screening test for HTLV-III (AIDS agent) antibodies: specificity, sensitivity, and applications. Journal of the American Medical Association, 253, 221-225.
- Wiley, J.A. (1985, August). Prevalance of sexual behavior in areas of San Francisco with high AIDS incidence. Paper presented at the annual convention of the American Psychological Association, Los Angeles, CA.
- Witti, F.P., & Goldberg, M.I. (1983). The National Institutes of Health and research into the acquired immune deficiency syndrome. Public Health Reports, 98, 312-319.
- Worden, J.W. & Weisman, A.D. (1977). The fallacy of post-mastectomy depression. American Journal of Medical Sciences, 273, 169-175.
- Zeigler, J.L., & Abrams, D.I. (1985). The AIDS-Related Complex. In V.T. DeVita, S. Hellman, S.A. Rosenberg (Eds.), AIDS. Philadelphia: J.B. Lippincott. pp. 223-233.

APPENDIXES



## Appendix A. Cover Letters

UNIVERSITY OF CALIFORNIA, IRVINE

BERKELEY • DAVIS • DARTMOUTH • LOS ANGELES • RIVERSIDE • SAN DIEGO • SAN FRANCISCO



SANTA BARBARA • SANTA CRUZ

CALIFORNIA COLLEGE OF MEDICINE  
DEPARTMENT OF COMMUNITY AND  
ENVIRONMENTAL MEDICINE

IRVINE, CALIFORNIA 92717

Dear Friend:

Leaders in the gay community and researchers at the University of California, Irvine are conducting a study on the psychological difficulties that gay men might experience as a result of the availability of the Blood tests for AIDS. We are inviting you to participate in this research.

We need your help, whether you have been tested or not. Specifically, we are asking that you complete the materials in this packet, and return them to us no later than November 15th, 1985. It is important that everyone who receives a packet complete the information and return it even if you have not been tested for AIDS.

Those who have not been tested, or who have negative test results will form the control group in this study. Without participation from everyone, the information obtained will be of limited use. So please set aside some time to complete these materials as soon as possible.

Should you choose not to participate, please tell us why, using the very first blank of the first questionnaire. Then return the research material. Your thoughtfulness will help us determine what the results of this research really mean.

Some of you are women. Our mailing lists do not distinguish between men and women. If you are female, please return the questionnaire, noting your gender.

The Gay and Lesbian Community Services Center of Orange County, the Elections Committee of the County of Orange, and Laguna Outreach have all endorsed this study. The research is being conducted under the auspices of the College of Medicine, University of California at Irvine.

The test materials are designed to ensure your anonymity. The information you supply will help us develop guidelines for needs of treatment programs for your brothers.

Sincerely,

A handwritten signature in dark ink, appearing to read "Hoda Anton-Guirgis".

Hoda Anton-Guirgis, Ph.D.  
Associate Professor  
Principal Investigator

**LAGUNA OUTREACH, INC.**

P.O. Box 1701 • Laguna Beach, California 92651

(714) 497-4237

September 16, 1985.

Dear Friend:

As you are probably already aware, over the last few months many gay men have taken the newly developed blood test which screens for the AIDS antibody. Recently we have begun to hear reports that a number of these men who have learned that their test results are positive have experienced adverse emotional reactions.


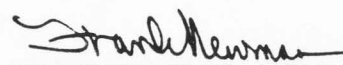
To develop effective counseling to meet the needs of gay men at risk for AIDS, we have asked Mr. Kenneth Kaisch and Dr. Hoda Anton-Guirgis to conduct a research study, under the auspices of the University of California, Irvine's Medical School, to determine what is happening to these men.

We believe that this study will be helpful to the future well-being of our community and ask you to support the research by filling out the accompanying test materials and returning them today. We also want you to know that we have taken appropriate measures to ensure your anonymity.

We need 100% participation - from everyone with positive test results, from everyone with negative test results, and from everyone who has never taken the test.

Please, give a few minutes of your time now. Your responses may provide the data that may someday help someone close to you in their time of greatest need.

Yours sincerely,

  
\_\_\_\_\_  
Karen Jones  
Co-Chair  
\_\_\_\_\_  
Frank Newman  
Co-Chair

**Co-chairs**

Carol Adams  
Don Hagan

**Board of Directors**

Amy Adams  
Treasurer  
Lyn Calderine  
Publications Chair  
Joanna Clark  
Secretary  
Nikki Deal  
Annual Dinner Chair  
Richard Elliott  
Political Affairs Chair  
Evan Fruithandler  
Finance Co-Chair  
Tom Fulton  
Voter Registration Chair  
Richard Kelly  
Finance Co-Chair  
Arlene Sontag  
Community Organizations Chair

September 16, 1985

Dear Friend:

Ray is 24 years old, a handsome surfer blond, and until a few weeks ago was on top of the world. He made an emergency call to my office asking to see me immediately. One week previously he had taken the AIDS Antibody test. He had just received word that the test was positive. He was certain that he wanted to kill himself. His life was on the edge of survival. Within a few days his roommate moved out of their apartment. Ray sat in my office crying and frightened. How do we help Ray? The roadmaps are only today being created. YOU CAN HELP!

If AIDS has not affected your life, it is only a matter of time. Orange County will surpass 200 cases this year and the number will double next year. ECCO is supporting this special AIDS study in collaboration with Kenneth Kaisch and Dr. Hoda Anton-Guirgis of UCI Medical School. THEY ARE OUR FRIENDS!

Please, don't set this questionnaire aside. We need every individual receiving it to complete it and return it in the enclosed envelope. Your response is important whether you have had the AIDS Antibody test or not. WE GUARANTEE YOUR ANONYMITY. ECCO HAS PUT THIS PACKAGE TOGETHER. ECCO HAS LABELED AND MAILED THIS TO YOU.

On behalf of our Board of Directors I thank you for your time. There will be others like Ray who will also be thankful that you care.

Sincerely,

Don G. Hagan, M.D.  
ECCO Co-Chair

---

**Elections Committee of the County of Orange**

PO Box 1745 Laguna Beach CA 92652 (714) 497-4311  
Political ID No. 822380

---



the Center

Gay & Lesbian Community Services Center of Orange County

(714) 534-0862 Administration  
(714) 534-3261 Hotline

September 16, 1985

Dear Friend,

The University of California, Irvine, Department of Community and Environmental Medicine along with several Orange County gay and lesbian organizations is now conducting an AIDS Research Study. The principal researchers are Kenneth Kalsch and Dr. Hoda Anton-Guirgis of U.C.I.; organizations include the Center, ECCO, and Laguna Outreach.

The U.C.I. study will assess the counseling needs of gay and bisexual men with respect to AIDS virus antibody testing. Since the beginning of antibody testing, severe psychological reactions have been reported among some of those with positive test results. The enclosed questionnaire was developed with the assistance of the gay community to help evaluate critical counseling needs at this time.

We believe that this study may be helpful to the well-being of our community and ask you to fill-out and return the accompanying test materials. Your anonymity and confidentiality of the responses are assured.

We are asking everyone who receives the test materials to respond - whether or not you have taken the antibody test and regardless of positive or negative result. The researchers need responses from the entire community.

So, please give a few minutes of your time now. The data you provide may someday help you or someone close to you in time of need.

Thank you!

*Steve Peskind*

Steve Peskind  
Field Coordinator  
AIDS Response Program of Orange County

*Werner Kuhn*

Werner Kuhn  
Executive Director  
Gay and Lesbian Community  
Services Center of Orange  
County

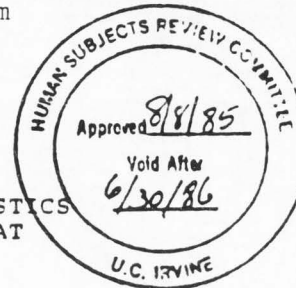
12832 GARDEN GROVE BOULEVARD, SUITE E GARDEN GROVE, CALIFORNIA 92643

## Appendix B. Optional Consent Form

UNIVERSITY OF CALIFORNIA, IRVINE  
CONSENT TO ACT AS A HUMAN RESEARCH SUBJECT

EPIDEMIOLOGIC EVALUATION OF IMMUNOLOGIC CHARACTERISTICS  
 OF A GENERAL BLOOD DONOR POPULATION AND GROUPS AT  
 HIGH RISK FOR AIDS

Hoda Anton-Guirgis, Ph.D.  
 Community and Environmental Medicine, UCI  
 (714) 856-7416



NAME OF SUBJECT: (OPTIONAL) \_\_\_\_\_

PURPOSE OF STUDY: I have been asked to participate as a subject in the investigation with the above title. In this investigation, attempts will be made to evaluate questionnaire and psychological test results, in order to ascertain the extent and type of counseling needs of homosexual men at high risk status for developing Acquired Immunodeficiency Disease (AIDS).

PROCEDURES: I understand and agree to participate in the following procedures in this investigation:

1. Complete a questionnaire to gather information on social history.
2. Complete two brief psychological tests.

RISKS: There are no known risks in these procedures.

BENEFITS: I acknowledge that the benefits of this study are for research purposes and for the development of a counseling program to treat gay men who have been exposed to AIDS.

COSTS: Costs of all of the tests will be covered by research funds.

CONFIDENTIALITY: We have designed this study to preserve the anonymity of those participants that wish to remain anonymous. To further protect confidentiality, no copy of this consent form will be retained by the study.

I have read the Experimental Subjects Bill of Rights (see attached) and have been given this consent form to keep. I consent to participate.

\_\_\_\_\_  
 Signature of Subject (Optional)

\_\_\_\_\_  
 Date

## Appendix C. Questionnaire

INSTRUCTIONS: All information will be kept in the strictest medical confidence. This questionnaire is designed so that you do not have to reveal your name or any other identifying data, if you choose not to do so. At no time will any information concerning any participant be given to anyone without your written permission. Please complete the following questionnaire by filling in the blanks, or by making a mark by the blank that best describes you. You may refuse to answer any or all questions, or stop filling out the questionnaire at any time. However, the data collected by this study will prove most useful if everyone completes and returns these questionnaires.

If you have any questions about this study or this questionnaire, you may contact the principal investigator at (714) 856-7416, or our research associate, Ken Kaisch, at (714) 447-3452 on Saturdays between the hours of 9 a.m. and noon, or most weekday evenings between 7:30 p.m. and 10 p.m.

Please complete this material, place it in the stamped, return envelope, and mail it to Dr. Hoda Anton-Guirgis, Department of Community and Environmental Medicine, College of Medicine, Irvine, CA 92717, by October 30, 1985.

FOR THOSE CHOOSING NOT TO COMPLETE THESE MATERIALS: If you choose not to participate in this study, it would be helpful if we could know why. Please give your reasons in the space provided immediately below, and return these materials in the stamped, self-addressed envelope. Thank you.

Today's date: \_\_\_\_\_  
 month--day--year

1a. Date of birth: \_\_\_\_\_  
 month--day--year

1b. If you participated in the previous UCI study, we would like to know the last digit of your social security number. This plus your birthdate will allow us to collate the information between the two studies, and still preserve your anonymity. Last digit of your Social Security number: \_\_

1c. Your zip code: \_\_\_\_\_ (This will allow us to determine the frequency of response by zip code, which will help us understand what the results of this survey mean.)

2. Current relationship status:  
 Not currently in a relationship \_\_\_\_\_  
 Same sex partner/lover for \_\_\_\_\_ years  
 Heterosexual marriage \_\_\_\_\_

3. If you are living with a partner, does your partner have any AIDS symptoms?    yes \_\_\_\_\_ no \_\_\_\_\_

4. How many years of schooling have you completed, not counting kindergarten: \_\_\_\_\_ years

5. What is your approximate annual income, before taxes are deducted: \$ \_\_\_\_\_

6. What category best describes your current employment:  
 Professional \_\_\_\_\_  
 White collar \_\_\_\_\_  
 Blue collar \_\_\_\_\_  
 Retired \_\_\_\_\_  
 Unemployed \_\_\_\_\_

7. We are interested in learning if you have received counseling or psychotherapy for any reason. Please check those that apply:  
 Anxiety disorders (phobias, panic attacks, anxiety) \_\_\_\_\_  
 Depression or thoughts of suicide \_\_\_\_\_  
 Substance abuse \_\_\_\_\_  
 Major mental disorder (schizophrenia, manic depression) \_\_\_\_\_  
 Other (please specify) \_\_\_\_\_  
 No counseling or psychotherapy \_\_\_\_\_

8. Which statement below best reflects your sexual preference:
- Exclusively homosexual\_\_\_\_\_
- Primarily homosexual, with some heterosexual interest\_\_\_\_\_
- Equally bisexual\_\_\_\_\_
- Primarily heterosexual, with some homosexual interest\_\_\_\_\_
- Exclusively heterosexual\_\_\_\_\_

Have you had any of the following physical conditions in the last 2 months? (please check all that apply)

9. Profound and unexplained fatigue\_\_\_\_\_
10. Persistent or recurrent fever\_\_\_\_\_
11. Weight loss of more than 10 lbs., not related to dieting\_\_\_\_\_
12. Swollen glands (lymph nodes in neck, armpits, groin)\_\_\_\_\_
13. Persistent and unexplained diarrhea or stomach upset\_\_\_\_\_
14. Others (please specify in the space below):

15. The HTLV-III virus has been found to cause AIDS. The HTLV-III antibody test has been developed to detect antibodies to this virus. (It is important to note that researchers have found that not everyone with antibodies to this virus will go on to develop AIDS.) Have you had the HTLV-III antibody test? Yes\_\_\_ No\_\_\_

16. What were your reasons for taking or not taking the test?

If you have had any of the following blood tests, please give the date(s) you were tested and the results of the test:

Blood Test	Date(s) Tested	Results
17. Hepatitis B Core Antibody	_____	_____
18. Hepatitis B Surface Antigen	_____	_____
19. T Helper Cells	_____	_____
20. T Suppressor Cells	_____	_____
21. T Helper/T Suppressor ratio	_____	_____
22. Other tests (please specify)	_____	_____



23. Have you ever had cancer? yes\_\_\_ no\_\_\_

If you have had cancer(s), please indicate the following:

	Type of Cancer(s)	Date Diagnosed	Current Status
24.	_____	_____	_____
25.	_____	_____	_____

If you have you ever had any major disease or illness other than cancer, please indicate the following:

	Type of Disease/Illness	Date Diagnosed	Current Status
26.	_____	_____	_____
27.	_____	_____	_____
28.	_____	_____	_____

=====

IF YOU HAVE TAKEN THE HTLV-III ANTIBODY TEST, PLEASE CONTINUE WITH THE NEXT ITEM. IF YOU HAVE NOT TAKEN THE ANTIBODY TEST, PLEASE GO TO THE LAST PAGE OF THIS QUESTIONNAIRE.

29. When, approximately, did you take the test? \_\_\_\_\_  
month--year
30. Where did you take the test?  
Public health facility\_\_\_\_\_  
Private physician\_\_\_\_\_  
As part of a UCI research study\_\_\_\_\_  
Other (please specify)\_\_\_\_\_
31. What were the results of your test?  
Positive, indicating exposure to the AIDS virus\_\_\_\_\_  
Negative, indicating probable non-exposure to the AIDS virus\_\_\_\_\_  
Inconclusive\_\_\_\_\_  
I don't know\_\_\_\_\_
32. Have you been diagnosed as having AIDS?  
Yes\_\_\_ If 'yes', who made this diagnosis\_\_\_\_\_  
No\_\_\_\_\_  
I don't know\_\_\_\_\_

THOSE WITH POSITIVE RESULTS TO THE HTLV-III ANTIBODY TEST SHOULD CONTINUE WITH THE QUESTIONS BELOW. THOSE WITH NEGATIVE RESULTS, PLEASE GO TO THE LAST PAGE OF THIS QUESTIONNAIRE.

33. When you first learned that you tested positive for the AIDS antibody, what was the major emotional feeling that you experienced?

34. And what did you think about at the time? (Please list only your most important thought)

35. What is the major emotional feeling that you now experience with regards to being exposed to the HTLV-III virus?

36. And what is your current thought with regards to being exposed to the HTLV-III virus? (Please list only the most important thought)

37. Social functioning can be defined as the interaction between you and all other individuals, including lovers, friends, neighbors, and relatives. What effect, if any, have these positive test results had on your overall social functioning?

Very large negative effect \_\_\_

Moderate negative effect \_\_\_

Slight negative effect \_\_\_

No noticeable change \_\_\_

Slight positive effect \_\_\_

Moderate positive effect \_\_\_

Very large positive effect \_\_\_

38. Please explain your answer to the question immediately above by describing the single most important thing that has happened to you:

39. Occupational functioning can be defined as how you function in your workplace. Occupational functioning would include your relationships with your employer, fellow workers, subordinates, and would also include your level of productivity. What effect, if any, have these positive test results had on your overall occupational functioning?

Very large negative effect \_\_\_

Moderate negative effect \_\_\_

Slight negative effect \_\_\_

No noticeable change \_\_\_

Slight positive effect \_\_\_

Moderate positive effect \_\_\_

Very large positive effect \_\_\_

40. Please explain your answer to the question immediately above by describing the single most important thing that has happened to you:

41. In what way, if any, has knowledge that you have been exposed to the virus that causes AIDS changed your sexual activities? Please list only the single most important change. (Be explicit)

42. What have you done to cope with the information that you have been exposed to AIDS? Please list only the single most important thing that you have done.

PLEASE RESPOND TO THE NEXT SET OF QUESTIONS BY CIRCLING THE NUMBER WHICH BEST DESCRIBES YOUR RESPONSE. YOUR RESPONSE CHOICES INCLUDE:

	1	2	3	4
	Strongly Disagree	Disagree	Agree	Strongly Agree
43. I'm trying to do many things I wanted to do, but never had time for before.....	1	2	3	4
44. When I think of the problems other people have, my own don't seem so bad.....	1	2	3	4
45. I've found that the best thing for me is to just forget I have an illness.....	1	2	3	4
46. I turn to friends and relatives to decide what I should do.....	1	2	3	4
47. If I joke and kid about my problems it helps me to deal with my feelings.....	1	2	3	4
48. I help others more than I did before my illness.....	1	2	3	4
49. I pride myself in taking things calmly. It doesn't help to get upset.....	1	2	3	4
50. I believe that prayer and religious faith can cure me of my illness.....	1	2	3	4
51. I have often found that what is going to happen will happen.....	1	2	3	4
52. It helps to get away from people and cry a little.....	1	2	3	4
53. I've tried to find out everything I could about my condition.....	1	2	3	4
54. I believe in trying to look on the bright side of things.....	1	2	3	4
55. I'm going to beat this thing. I'm not going to let it get the best of me.....	1	2	3	4
56. Nowadays, a person has to live for today and let tomorrow take care of itself.....	1	2	3	4
57. I look to God or a higher power for help and comfort in my illness.....	1	2	3	4

Since learning that you have been exposed to the virus that causes AIDS, are you: (please check all that apply)

58. Exercising more\_\_\_ or less\_\_\_ or about the same\_\_\_
59. Eating more\_\_\_ or less\_\_\_ or about the same\_\_\_
60. Smoking tobacco more\_\_\_ or less\_\_\_ or about the same\_\_\_
61. Using alcohol more\_\_\_ or less\_\_\_ or about the same\_\_\_
62. Using prescription medication more\_\_\_ or less\_\_\_ or about the same\_\_\_
63. Using non-prescription drugs (marijuana, cocaine, etc.)  
more\_\_\_ or less\_\_\_ or about the same\_\_\_
64. Sleeping more\_\_\_ or less\_\_\_ or about the same\_\_\_
65. Have you considered suicide since hearing your test results?  
yes\_\_\_ no\_\_\_
66. Have you attempted suicide since hearing of your test results?  
yes\_\_\_ no\_\_\_
67. What kinds of psychological assistance, if any, do you feel that people who have positive AIDS antibody test results need, in order to cope with their situation?

68. What two things inside yourself cause you the greatest difficulty?

a. \_\_\_\_\_

b. \_\_\_\_\_

69. What two things outside yourself cause you the greatest difficulty?

a. \_\_\_\_\_

b. \_\_\_\_\_

70. What are your two greatest personal strengths?

a. \_\_\_\_\_

b. \_\_\_\_\_

With whom have you shared your positive test results? (please check all that apply)

71. No one at all \_\_\_\_\_

72. Everyone I am close to \_\_\_\_\_

73. Everybody \_\_\_\_\_

74. Lover \_\_\_\_\_

75. Sex partners \_\_\_\_\_

76. Gay friends \_\_\_\_\_

77. Straight friends \_\_\_\_\_

78. Gay neighbors \_\_\_\_\_

79. Straight neighbors \_\_\_\_\_

80. Family members \_\_\_\_\_

81. Physician(s) \_\_\_\_\_

82. Clergy \_\_\_\_\_

83. Others (please specify) \_\_\_\_\_

84. We are considering a followup study in several months. We would like to track those who have participated in this study, so that we can learn how your psychological needs change over time. To do this, we need volunteers. We will retest the volunteers at a later date, and then compare those reactions with the reactions that we have measured today.

It will be very useful if we can follow the respondents of this study, and compare later information with the information we are now gathering. However, we cannot do this unless we have some way of connecting current responses to those we might get in the future. To have a follow-up, we need two things: 1) a way of connecting your response on these questionnaires with your response on future questionnaires; and 2) some way to get in touch with you, should you decide to participate in a follow-up phase, so that we can mail you the new questionnaires. This means, if you want to volunteer for the next phase, that we need to ask you to give us your name and address.

If you choose to participate, this page of the questionnaire will be removed from these test materials, and stored under the care of an anonymous and trusted researcher at the College of Medicine. A code number will be assigned, so that we can preserve your anonymity. When the follow-up research is completed, these names and addresses will be destroyed. In this way, we can maintain the anonymity of all who participate in future studies.

Name \_\_\_\_\_  
Address \_\_\_\_\_  
\_\_\_\_\_

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE. YOUR EFFORTS IN PARTICIPATING IN THIS STUDY WILL HELP GAYS WHO HAVE TESTED POSITIVE TO THE AIDS ANTIBODY TEST TO GET THE HELP THEY NEED! NOW PLEASE GO TO THE SELF ANALYSIS FORM AND THE PERSONAL ASSESSMENT INVENTORY, AND COMPLETE THEM. THEY TAKE ABOUT 5-10 MINUTES EACH. WHEN YOU FINISH ALL THREE QUESTIONNAIRES, PLACE THEM IN THE STAMPED RETURN ENVELOPE, AND MAIL THEM BACK TO US. WE NEED THE COMPLETED MATERIALS BY NOVEMBER 15, 1985. THANKS!

## Appendix D. Coping Strategies Inventory

PLEASE RESPOND TO THE NEXT SET OF QUESTIONS BY CIRCLING THE NUMBER WHICH BEST DESCRIBES YOUR RESPONSE. YOUR RESPONSE CHOICES INCLUDE:

	1	2	3	4
	Strongly Disagree	Disagree	Agree	Strongly Agree
1. I'm trying to do many things I wanted to do, but never had time for before (DO THINGS)....	1	2	3	4
2. When I think of the problems other people have, my own don't seem so bad (COMPARE).....	1	2	3	4
3. I've found that the best thing for me is to just forget I have an illness (FORGET).....	1	2	3	4
4. I turn to friends and relatives to decide what I should do (ASK OTHERS).....	1	2	3	4
5. If I joke and kid about my problems it helps me to deal with my feelings (JOKE).....	1	2	3	4
6. I help others more than I did before my illness (HELP OTHERS).....	1	2	3	4
7. I pride myself in taking things calmly. It doesn't help to get upset (CALM).....	1	2	3	4
8. I believe that prayer and religious faith can cure me of my illness (PRAYER).....	1	2	3	4
9. I have often found that what is going to happen will happen (QUE SERA).....	1	2	3	4
10. It helps to get away from people and cry a little (CRY).....	1	2	3	4
11. I've tried to find out everything I could about my condition (SEEK INFO).....	1	2	3	4
12. I believe in trying to look on the bright side of things (BRIGHT SIDE).....	1	2	3	4
13. I'm going to beat this thing. I'm not going to let it get the best of me (BEAT IT). 1	2	3	4	
14. Nowadays, a person has to live for today				



and let tomorrow take care of  
itself (LIVE TODAY) ..... 1 2 3 4

The following question was added by the author:

15. I look to God or a higher power for help  
and comfort in my illness (GOD)..... 1 2 3 4

Note Bene: The word or words in parentheses did not appear in the scale when it was given to the subjects. They have been added for the convenience of the reader, in order to provide a cross-reference for my comments in the body of this report.

## Appendix E. Categories for Coding Open Ended Questions

Question 33: Major Emotional Feeling  
After Learning of Positive  
HTLV-III Test Results

## Procedure:

1. Read the Ss response, and then compare it with each category before you code it.
2. If no feeling words are used (like fear, anxiety, depression, etc.) then you cannot code a feeling. Code instead #8--Other. Do not infer a feeling.
3. If several feelings are described, code only the first feeling that is described with a feeling word. If several feelings are described in one sentence, code only the first feeling.
4. If you can't decide how to code a response, then code it 'Other--not codeable in the categories above'.
5. Follow this procedure for each response.

+++++

1. Numb, shocked, immobilized.
2. Fear--a major fear, dread, horror.
3. Anxiety--less than a major fear. Nervous, upset.
4. Anger.
5. Depression or sadness.
6. Guilt or shame. This may be expressed by expressions of feeling

dirty or unclean.

7. Disappointment.

8. Other--not codeable in the categories above. E.g. thoughts; confusion; happiness.

Question 34: Major Thought After  
First Learning of Positive  
HTLV-III Test Results

Procedure:

1. Subjects were asked to describe their major thought.

We must assume that their first sentence embodies that thought. Therefore, code only the first sentence.

2. If a sentence embodies more than one thought, code only the first thought.

3. If you can't decide how to code a response, then code it 'Other--not codeable in the categories above'. Do not infer. If a response doesn't fit a category easily, it is an uncodeable response.

+++++

1. Thoughts of dying, catastrophe. E.g. "I'm going to die; I might die; I haven't lived enough yet; etc."

2. Disbelief--denial. E.g. "I can't/won't get AIDS".

3. Thoughts of self-condemnation. E.g. "I'm no good; I haven't lived my life right; etc."

4. Thoughts of confirmation. E.g. "this confirms what I had suspected".

5. Hopeful thoughts, e.g. "I won't die", positive thinking, thoughts about the potential for treatment, need for more information.

6. Thoughts regarding social relationships (lover, friends, family). These thoughts can be either positive or negative.

7. Wondering about the future, what it will hold, quality of life concerns, survival, how much time is left.

8. Other--not codeable in the categories above. E.g. feelings such as anger, fear, depression, or thought that do not fit the categories above.

Question 35: Current  
Emotional Feeling

Procedure:

1. Read the Ss response, and then compare it with each category before you code it.
2. If no feeling words are used (like fear, anxiety, depression, etc.) then you cannot code a feeling. Do not infer a feeling.
3. If several feelings are described, code only the first feeling that is described with a feeling word. If several feelings are described in one sentence, code only the first feeling.
4. If you can't decide how to code a response, then code it 'Other--not codeable in the categories above'.
5. Follow this procedure for each response.

+++++

1. Fear--a major fear, dread, horror.
2. Anxiety--less than a major fear. Nervous, upset.
3. Anger.
4. Depression or sadness.
5. Acceptance of the condition, acceptance of self.
6. Optimism.

7. Other--not codeable in the categories above. E.g. thoughts; confused feelings. Note that all sentences that begin: "I feel like..." or "I feel that..." are thoughts, not feelings.

Question 36: Current Major Thought With Regard to HTLV-III Exposure

Procedure:

1. Subjects were asked to describe their major thought. We must assume that their first sentence embodies that thought. Therefore, code only the first sentence.
2. If a sentence embodies more than one thought, code only the first thought.
3. If you can't decide how to code a response, then code it 'Other--not codeable in the categories above'. Do not infer. If a response doesn't fit a category easily, it is an uncodeable response.

+++++

1. Want more information, or counseling
2. Positive thoughts about self. E.g. "still healthy; I keep calm and avoid stress; I am hopeful I will be OK; I am doing all the right things for myself".
3. Thoughts regarding social relationships (lover, friends, family). These can be either positive or negative.
4. Waiting with no explicit mention of hope. Resignation, fate, wondering.
5. Waiting with explicit mention of hope.
6. Distracting self; keeping busy.
7. Self condemnation, guilt, shame.
8. Other--not codeable in the categories above. E.g. feelings

such as anger, fear, depression, or thoughts that don't easily fit these categories.

Question 42: What Are You Doing  
to Cope With the Information That  
You Have Been Exposed to AIDS?

In coding this material, if several responses are described, code only the most important single response. The most important response is either the first response stated or the response that is described with the most words. Code the first response unless there is substantial reason to believe that it is not the most important response. If you are uncertain which of two responses is most important, code the first response. If you can't decide how to code a response, then code it 'Other--not codeable in the categories above'.

+++++

1. Coming closer to people.
2. Gathering information on AIDS, reading, understanding more.
3. Preparing for death, catastrophe
4. Acceptance of the inevitable.
5. Keeping busy
6. Spiritual growth
7. Changing my lifestyle
8. Changing my sexual activities.
9. Other--not codeable in the categories above.

Question 67: What Kinds of  
Psychological Assistance  
Do People Need

In coding this material, if several responses are described, code only the most important single response. The most important response is either the first response stated or the response that is described with the most words. Code the first response unless there is substantial reason to believe that it is not the most important response. If you are uncertain which of two responses is most important, code the first response. If you can't decide how to code a response, then code it 'Other--not codeable in the categories above'.

+++++

1. Someone to talk to
2. Professional counseling or psychotherapy. E.g. responses that talks about the need to talk with a trained person.
3. Education. E.g. info describing what the HTLV-III test really means; the chances of getting AIDS; information about what one can do to reduce the chances of contracting AIDS; etc.
4. Other--not codeable in the categories above. E.g. responses such as anger, fear, depression.

Question 54: Effects of Positive  
HTLV-III Test Results on  
Social Functioning

In coding this material, if several responses are described, code only the most important single response. The most important response is either the first response stated or the response that is described with the most words. Code the first response unless there is substantial reason to believe that it is not the most important response. If you are uncertain which of two responses is most important, code the first response. If you can't decide how

to code a response, then code it 'Other--not codeable in the categories above'.

1. Distancing, primarily caused by others.
2. Distancing, primarily caused by self.
3. Complete social isolation
4. No change in social functioning
5. More contact with others
6. Changes in sexual practices
7. Other--not codeable in the categories above. E.g. responses such as...
8. No response made to this category--question left blank.

Be certain not to infer a response. E.g. the response, "I am spending a lot more time with my dog" does not necessarily mean there is distancing of any kind. Code this response, if it is the most important, as 'Other'.

Question 56: Effect on  
Occupational Functioning

In coding this material, if several responses are described, code only the most important single response. The most important response is either the first response stated or the response that is described with the most words. Code the first response unless there is substantial reason to believe that it is not the most important response. If you are uncertain which of two responses is most important, code the first response. If you can't decide how to code a response, then code it 'Other--not codeable in the categories above'.

1. Distancing, caused by others
2. Distancing, caused by self
3. Complete social isolation. E.g. if both kinds of distancing are present in severe form.
4. Loss of promotion or raise
5. Fired from job
6. Lowered productivity
7. No change in occupational functioning
8. Better occupational functioning in some way or ways
9. Other--not codeable in the categories above. E.g. responses



- such as anger, fear, depression.
10. No response made to this category--question left blank.

Question 57: Changes  
in Sexual Activities

In coding this material, if several responses are described, code only the most important single response. The most important response is either the first response stated or the response that is described with the most words. Code the first response unless there is substantial reason to believe that it is not the most important response. If you are uncertain which of two responses is most important, code the first response. If you can't decide how to code a response, then code it 'Other--not codeable in the categories above'.

1. No change in sexual activities
2. Celibacy
3. Increased sexual activity
4. Safe sex practices. Any listed safe sex practice is coded as safe sex if it is the major response. Thus, one need not list all safe sex activities in order to code this response. Safe sex activities include: hugging, massage, body rubbing, mutual masturbation, using a condom for anal intercourse, not getting semen or urine in mouth, avoiding fisting or rimming, keeping number of sex partners low.
5. Other--not codeable in the categories above. E.g. responses such as anger, fear, depression.
6. No response made to this category--question left blank.

## Appendix F. First Emotional Reactions of HTLV-III Positives

Those subjects who were positive on the HTLV-III antibody test were asked to respond to the question, "When you first learned that you tested positive for the AIDS antibody, what was the major emotional feeling that you experienced?" In order to preserve the qualitative nature of these responses, they are reproduced here verbatim. The subjects' responses are in order, so that the reader can compare the different reactions by subject.

1. I assumed the test was much like that for hepatitis and meant I had fought off the virus successfully, so I was not unduly concerned until I discovered I was wrong. Then I wanted to know all I could about it, and I was quite frightened by the spectre of AIDS in my life.
2. I was very depressed and sad, sometimes I think about suicide.
3. Anxiety--depression.
4. I just wanted to know more about AIDS.
5. Grip of reality--it could happen to me--anxiety rush.
6. [I found out] this month, October, 1985. Feelings were very mixed at that time.
7. Shock.
8. Anger.
9. Great disappointment--moderate depression--but at the time, no symptoms--and encouraged that I don't fit the "getting sick" type!
10. Fear.
11. Emotional distress: fear.
12. Depression, anxiety, occasional fits of crying--reevaluation of life and lifestyle. Desire to live life as fully as possible.

13. Disappointed, but not surprised.
14. Was I going to get AIDS, and if I was going to die.
15. Confusion.
16. Positive results expected since lover diagnosed with AIDS--I was not surprised nor overly concerned--positive test results among nearly 60% of gay men and do not indicate AIDS diagnosis.
17. Slight but controlled fear.
18. Trapped--unclear--didn't want anyone to touch me as I was not clean.
19. Somewhat stunned, but not fearful of my future.
20. Fear.
21. Concern for my family--uncertainty about the future.
22. Figuring out who to tell--those I thought I could trust--or not to tell a soul.
23. I expected a positive--no strong feelings.
24. Fear of dying, getting AIDS, possibly exposing others--guilt.
25. Anger--mad at myself for being so promiscuous(sic) for so long.
26. At first, disbelief--a let down feeling. Somewhat nervous, scared.
27. None--I expected it.
28. Anger and fear.
29. I was mad, though I knew it would be positive.
30. That there was no hope for me to live. I was very uninformed.

## Appendix G. Current Emotions Regarding HTLV-III Infection

The following are responses to the question, "What is the major emotional feeling that you now experience with regards to being exposed to the HTLV-III virus?" of those who were HTLV-III positive.

1. I accept exposure as inevitable. I don't see how I could have avoided it, given my life style at that time. I have somewhat returned to my original philosophy--it can't happen to me, and it won't happen to me.
2. Not knowing when I'm going to die. I feel like I'm dying. Just thinking about it.
3. Coming to terms with my finiteness--temporary. I feel anxiety and surprising motivation to experience the things I want to before it is too late. I am also angry because I might be OK in the end and maybe I'm worrying for nought.
4. I'm a little depressed because I would like to date somebody but it wouldn't be right exposing them to it.
5. "Vulnerability". To protect myself as best I can with normal good health.
6. The fear that it could go on to develop AIDS. I don't want to die!!!
7. Some depression.
8. Fear of the unknown. I just feel dirty.
9. Great perplexity at what the future holds. I now have moderately painful lymph node enlargement. I'm fearful of dealing with it medically due to possible loss of job, etc.--plus, what can be done?
10. Cautious optimism.
11. Fear--fearful of getting any sickness: flu, etc...
12. Anger and caution. Anticipation wondering if and when the

disease will strike.

13. Mild, occasional anxiety.

14. At first depressed, not wanting to have sex. Life goes on, and I take safe precautions in having sex.

15. Depression.

16. I feel little use in worrying about it because of apparent inevitability to exposure for most gay people.

17. I no longer have an emotional response to the results of the test.

18. Like a graph [graph drawn with many highs and lows]. Highs/lows wondering when will "it" happen if it does. Always try to be one step ahead of myself and wanting more life. Looking at things as if I may never see them again.

19. How can I help others I know to improve their health. Basically feeling calm, slight anxiety, live for today.

20. Anger, frustration.

21. Making the necessary "changes" and precautions. Alternative "safe sex". Social restructure.

22. My wife would have no choice but divorce me now, after being separated for 3 1/2 years.

23. That I would confer with my doctor.

24. Fear--every time I get a symptom.

25. Uncertainty.

26. My emotional feeling is still one of being scared, but as long as I don't show physical signs, I'm OK and more or less act as I always do but even take more care of myself. I also feel absolutely positive that a cure is just around the corner.

27. None.

28. Fear--whenever I get a cold, fatigue, rash, etc. I get scared and watch it closely with the fear that it may develop.

29. Death.

30. Ongoing fear of exposure to a opportunistic disease. Fear of sexual contacts. Fear of people discovering my test results.

## Appendix H. First Cognitive Reactions of HTLV-III Positives

1. As God's perfect child, AIDS could not enter my life. But I continued to worry, and read everything I could get my hands on, as well as discuss it with my physician.
2. My family! And sex partners I had been with!
3. How I haven't even lived yet and done what I wanted to do.
4. I wondered if my roommate thought I gave it to him.
5. Survival.
6. Mixed feelings.
7. Wondered how much time I had left. Feared for well-being of my former lover.
8. Getting away from everyone--I just wanted to run away.
9. Planning well for the future. Protecting my new mate--which came about before my knowledge of results--though I had over 1 year ago begun practicing safe sex. I would likely commit suicide before becoming debilitated.
10. I thought I'd die from it.
11. Parents; dying of AIDS; if partner had been exposed.
12. How much time I had left. How it would affect future relationships. If other people had been infected by me.
13. I can't recall, but I don't think I gave it a lot of consideration at the time.
14. I thought of not being able to have children.
15. Whether the steps I would have to take would reduce the quality of life to the point that it would not be worth taking them in the first place.

16. Suspicions confirmed.
17. That I might be one who gets AIDS.
18. Where--when could this have happened. If I would have lived my life different would this have happened. I don't want to have any pain or slow deterioration.
19. What can I do to improve my immune system beyond its current strength. Will I be able to have kids.
20. I was going to die.
21. Uncertainty--fear--concern.
22. How to inform others about the virus, or what I can do. Will my insurance be cancelled now that the health department has my name and address.
23. Moderate concern.
24. Trying not to cry and freak out--trying to calm down--please someone talk to me.
25. Mad at myself for being promiscuous(sic) for so long.
26. I couldn't understand how I got it. I thought of death but I look and feel fine and healthy.
27. I hope I don't come down with AIDS.
28. Will I get AIDS or more symptoms.
29. I was mad, depressed.
30. Wanted to learn more about my own situation and yet knew that I would hide it from myself.



## Appendix I. Current Thoughts Regarding HTLV-III Infection

1. I wish there had been counseling and good information for us when we were first informed. But even now, with all the information available known, there is still no real evidence as to what a positive reading means. I am particularly frightened by the social implications of being positive and the national panic about the disease.
2. Stop having sex. With anyone.
3. There really isn't any time to procrastinate. I am still very healthy.
4. What can you say but, "oh well".
5. "I'm holding my breath".
6. The same--although I try to keep myself busy and not dwell on the idea.
7. Hope they find a cure soon so that if I do develop AIDS I can be cured.
8. What's going to happen? How long do I have?
9. I was in the wrong place. I believe it primarily passed via receptive anal sex. I've practiced that once or twice prior to 1985!
10. I hope I don't have to get AIDS, but I've been "getting my life in order" in case I do.
11. Am I going to die from it?
12. Doing what will best keep me in shape to fight off the disease. Considerable worry--many friends have died in the last six months--will I die also?
13. I'll either contract AIDS or I won't. In the meantime, life goes on, and worrying about it will accomplish nothing positive.

14. Will medical science find a cure?
15. I will most likely never know a lover again in my life. I also find I can't have sexual relations, safe or unsafe.
16. One cannot deny fate in this case.
17. We really don't know what it means--it may mean nothing at all.
18. I hate it.
19. How can I help others I know improve their health. Basically feeling calm, slight anxiety, live for today.
20. Frustration from allowing myself to become labeled.
21. Hope.
22. Trying to keep myself healthy as possible (no drugs, limited alcohol, quit smoking, take vitamins, and eat a healthy diet).
23. I think I've "had" a case of AIDS and thrown it off.
24. Being careful and getting educated.
25. Not sure if I will be one of the 5% or 10% that comes down with AIDS. If I have any choice it I do or not.
26. I really still don't believe it because I show no symptoms or visible signs. However I've done thorough research to find out what there is to know about the disease, and the future research in cures!
27. I must be more carefull with myself and others.
28. I want to educate and support everyone as much as possible.
29. Death.
30. Need to educate myself on precautions of safe sex.

VITA  
Kenneth B. Kaisch  
Candidate for the Degree of  
Doctor of Philosophy

Dissertation: The Psychological and Social Consequences of HTLV-III Infection: Homosexuals in Orange County, CA

Major Field: Clinical Psychology

Biographical Information:

Personal Data: Born in Detroit Michigan, August 29, 1948, son of Kenneth R. and Marjorie Kaisch; married Suzanne Carol LePrevost August 31, 1969; son Samuel Kristopher, born June 16, 1979.

Education: Attended elementary and high schools in Fairbanks, Alaska; Frankfort, Germany; El Paso, Texas; Balboa, Panama Canal Zone; and Highland Park, Illinois. Attended Kenyon College with majors in philosophy and religion; received Bachelor of Arts degree with a major in Philosophy and Religion from San Francisco State University in 1972. Attended Church Divinity School of the Pacific and received Master of Divinity degree in 1976. Attended Utah State University and received Master of Science degree in Counseling Psychology in 1983. Elected to Phi Kappa Phi Honor Society, 1982. In 1986, completed the requirements for the Doctor of Philosophy degree at Utah State University, with a major in Clinical Psychology.

Professional Experience: Assistant hospital chaplain, St. Luke's Hospital, San Francisco, 1973; seminarian-in-charge of St. John's Episcopal Church, Logan, Utah, 1974-75; ordinand's training program, Ogden, Utah, 1976-77; ordained deacon, August 15, 1976; ordained priest, March 25, 1977; Vicar, St. Francis' Episcopal Church, Moab, Utah, 1977-80; Priest-in-Residence, St. John's Episcopal Church, Logan, Utah, 1980-84. Psychological assistant to Peter Ebersole, Ph.D., Fullerton, California, 1984-86. Psychology intern at Patton State Hospital, Patton, California, 1985-86.