

**THE LONELY VOYAGE**  
**Support or Isolation**  
**For Gay Men With AIDS?**

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THE LONELY VOYAGE:  
SUPPORT OR ISOLATION  
FOR GAY MEN WITH AIDS?

by

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(ABSTRACT)

Twenty-five gay men, 20 with Acquired Immune Deficiency Syndrome (AIDS) and 5 with either AIDS Related Complex (ARC) or who tested positive for the AIDS virus, were asked in semi-structured interviews whether they felt supported or isolated. Areas covered included society in general, employment, housing, health care, insurance, religion, families of origin, ex-wives, children, friends and lovers. Subjects indicated that fear of AIDS, homophobia, and death anxiety were all present in certain circumstances, but there was no attempt to differentiate between these three possible causes of social isolation in this exploratory study.

Unpublished Work

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## From the interviews

This is a very lonely voyage. It's too bad you have to become sick and die of a disease to feel those things in life we all strive for and reach out for. You learn a lot of humanity with this disease.

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In the last 2 1/2 weeks he always emphasized life. He had already surrendered to the dying. He wanted to be involved in everything that happened to him... We'd bring him his pills, and he wanted to know exactly what those pills were. It was his way of maintaining control. His sense of humor never left him. He remained conscious up until a half hour before he died... That morning we knew he had taken a radical change, and we called the hospice nurse. We never kept anything from him. After she examined him, we asked her, "What can we expect?" She said, "\_\_\_\_\_ is entering the death phase and he probably will go in the next 48 hours." He just sort of nodded. As the day went on he went downhill very quickly. Near the end, he looked up at us and said, "Isn't this the pits?"



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To \_\_\_\_\_ partners in Wide World Publishing, I offer my thanks for their belief that this study is worth a wider readership. It will be published in Spring, 1988, under the title AIDS: The Lonely Voyage.

I truly understand the meaning of the term "helpmate" when applied to my husband \_\_\_\_\_ who taught me word processing, made many valuable editing suggestions, and understood when, at times, our lives seemed taken over by this project. Our three children and their spouses, \_\_\_\_\_ and \_\_\_\_\_ and \_\_\_\_\_ also offered understanding and encouragement.

Finally, I offer heartfelt gratitude to the 25 men who were willing to make themselves vulnerable so that others might learn more about them and the way in which this disease has affected their lives and the lives of their loved ones.

Nancy Shands

October, 1987

Dedicated to the 25 Men  
Whose Generosity of Spirit, Wisdom, and Courage  
Live in these Pages

## Table of Contents

	Page
Abstract.....	ii
Acknowledgements.....	v
Dedication.....	vii
Table of Contents.....	viii
List of Tables.....	x
Introduction.....	1
AIDS.....	7
Methods.....	11
Demographics.....	14
Self-Image.....	16
Health Prior to AIDS.....	20
When Diagnosed.....	21
First Symptoms.....	21
Medical Care.....	22
Covering the Cost of Care.....	28
Employment.....	33
Housing.....	38
Religion.....	40
Relationships.....	42
General Public.....	42
Friends.....	44
Families of Origin (Parents).....	52
Families of Origin (Siblings).....	63

Families of Origin (Extended Family).....	79
Children.....	70
Ex-Wives.....	70
Lovers.....	71
What Would They Change.....	79
References.....	84
Appendix A: Interview Guide.....	90
Appendix B: Informed Consent.....	95
Vita.....	97

## List of Tables

Table	Page
1 Demographic Characteristics.....	17
2 Health Care Providers and Support Staff Excellent Ratings by Men with AIDS.....	24
3 Housing Arrangements.....	39
4 Person/s Closest.....	46
5 Which Family Member is Closest.....	55
6 Family Reaction to Diagnosis.....	59
7 Contact with Siblings.....	65
8 Homosexuality and Family.....	66

THE LONELY VOYAGE:  
SUPPORT OR ISOLATION FOR GAY MEN WITH AIDS?

"Nothing is untouched by this illness in terms of what makes up our humanity." That is how a young man with AIDS (Acquired Immune Deficiency Syndrome), still in his 30s, described the all-encompassing nature of his disease.

He is one of 25 gay men who participated in this study, which is intended to look at people and institutions touched by this fatal illness and to see how the reactions of these outside forces affect the person with AIDS. In short, how does AIDS affect our collective humanity?

As often as possible, the story is told in the words of the individuals interviewed who are suffering from one form or another of the disease.

INTRODUCTION

"If I'm going to fight this thing, I need all the help I can get from friends and relatives as well as good prayers and thoughts and support," finally decided one person with AIDS after isolating himself for 6 months following the shock of the diagnosis. How available are the "good prayers and thoughts and support" he spoke of?

Persons with AIDS who are gay men endure several kinds of social isolation and rejection, according to professional journals and the popular press.

First, it appears that a significant portion of the population fears people--whether gay or not--who have AIDS (Cassens, 1985; Christ & Wiener, 1985; Forstein, 1984).

Possible contagion with the fatal disease is the overriding factor.

"AIDS inspires fear," said one man who tested positive for the virus, "so people with AIDS are mistreated. People with AIDS are sick. There's too much emphasis on blame. This is a health problem and it is up to healthy people to stop this disease, not up to sick people who are burdened enough. They are going to die from this terrible disease."

Although somewhat extreme, an example of unbridled fear is a letter to the editor in a local newspaper suggesting that all AIDS patients be banished to the Antarctic in order to "save the human race" (Smith, 1985).

One 31-year-old who has AIDS responded to the idea that persons with AIDS be quarantined with visible anger. "Some people believe people with AIDS should be quarantined or put away in some kind of concentration camp or something. The mere idea that someone would even suggest that here in America! It shouldn't even be suggested, it shouldn't even be spoken, it shouldn't be dignified... because it is so ridiculous. It's so against everything we are. If we are going to do that, we might as well send Russia here to take our country... because that's exactly what happens in a country like Russia where people disappear."

Homophobia, an irrational fear of homosexuals, can result in overt and/or covert discrimination toward gay

AIDS sufferers. (Holland & Tross, 1985; Morin & Batchelor, 1984). People with AIDS are often seen as people who have engaged in frequent anonymous sexual activities and ingested a variety of mind-altering drugs (Abrams, Dilley, Maxey & Volberding, 1986).

One of the men interviewed disagreed. "A person's sexuality is only a part of that person," he declared. "The fact that I'm homosexual and someone else is heterosexual doesn't tell you anything about what kind of people we are."

Another individual described the public's reaction to homosexuality this way: "Many people perceive that homosexuals decided to be homosexuals. And now we've all decided to get AIDS and give it to each other. Like I sat down one night and said to myself, 'Oh, I'll be a queer. Oh, let me go out and screw around.' And this is God getting even."

Because of these two factors -- fear of the disease and homophobia -- AIDS has become a political issue (Barnes, 1985), as is evidenced by the example of a Minnesota political candidate who proposed that no funds be allocated for AIDS research because it would "only encourage irresponsibility" (Maxa, 1985). A mayoral candidate in Texas came under strong criticism from the gay community after a comment, meant to be off-microphone, that one way to control AIDS would be to "shoot the queers" (Engel & Sawyer, 1985).

Another more recent gaffe occurred when Vice President George Bush was booed by scientists and health providers at the Third International Conference on AIDS after he endorsed the administration's call for expanded AIDS testing. As he returned to his seat, Bush asked, "Who was that, some gay group out there?" The remark was recorded by a number of news organizations and elicited some sharp rebukes by several respected scientists (Boodman & Specter, 1987).

A sense of isolation also may be engendered in people with AIDS by the fact that AIDS is a terminal illness (Abrams et al, 1986). Although the growth of the hospice movement has made some inroads in the past 10 years, the topic of death still is avoided or romanticized in the United States. Elizabeth Kubler-Ross (1969, p. 9), who has pioneered compassionate care of the dying, suggests that "the suffering face of another human being...remind[s] us once more of our lack of omnipotence, our own limits and failures, and last but not least perhaps our own mortality."

It may be that some health care providers are affected by fear of AIDS, prejudice against homosexuals, and anxiety over death (AIDS: Fear, 1983; Zuger, 1987). Are the reports that suggest gay AIDS patients are subjected to unnecessary isolation procedures -- to say nothing of total rejection -- by health care providers accurate? (Holland & Tross, 1985; Steinbrook, Lo, Tirpack, Dilley, & Volberding,

1985). A New York physician, who has dealt with several hundred AIDS patients, states that "Many professionals continue to protect themselves from patients in inappropriate ways, such as excessive masking and gowning, handling patients' documents with tweezers, and calling for quarantines" (Nichols, 1985).

Finally, is it true that persons with AIDS are ostracized by the persons closest to them -- their own families of origin, friends and lovers? (Cassens, 1985; Christ & Wiener, 1985; Curran, 1985; Engel & Sawyer 1985). A person with AIDS may be deserted by his lover and/or friends because of fear of contagion. Upon turning to his original family, from whom he may be estranged because of his homosexuality, he often is rejected again (AIDS: Coping, 1983).

A number of studies show that persons receiving ongoing support which provides them with a sense of self-esteem and security are better able to withstand stressors (Shumaker & Brownell, 1984; Mount, 1983; Holland & Tross, 1985; Nichols, 1985; Cassel, 1979). Furthermore, there is some evidence that social isolation can lead to severe depression and even exacerbation of an illness (Cassel, 1979; Forstein, 1984; Holland & Tross, 1985; Irish, 1987).

Social isolation is found by one author to bring about a disorder he terms "bereavement of the dying." This is described as a condition of depression, loneliness, and regression found among terminal patients who have been

emotionally isolated and abandoned during the final period of life. The patient is said to be grieving for his own survivors (Weisman, 1978). A dying patient unable to put some kind of closure on his social/interpersonal relationships is subject to a passive-depressive set of symptoms (Woodson, 1979).

In a manual prepared for the National Cancer Institute, it is suggested that an ill person and his loved ones face seven tasks in order to cope with a disease (Porter, Novelli, & Associates, 1978):

1. Dealing with pain and incapacitation
2. Dealing with the hospital environment and special procedures
3. Developing adequate relationships with professional staff
4. Preserving a reasonable emotional balance
5. Preserving relationships with family and friends
6. Preserving a satisfactory self-image
7. Preparing for an uncertain future

Social isolation, described as generating feelings of frustration, meaninglessness, loneliness, estrangement, powerlessness and lack of self-esteem, relates directly to most of these tasks and has an influence on each one of them.

The various kinds of social isolation -- isolation from society, health care providers, family of origin,

friends and lovers -- are tied to these seven tasks. Admittedly, being shunned by medical staff and abandoned by a lover are very different, but the resulting feeling of isolation, whether from one cause or the other, influences the patient's ability to cope with a disease.

### AIDS

AIDS is a highly lethal epidemic first reported in 1981. The disease causes a breakdown in the body's immune system leaving an individual vulnerable to certain types of cancer and to a wide variety of opportunistic infections which produce minor or no symptoms in people with normal immune systems, but are fatal to those inflicted with this disease. There presently is no cure for AIDS, nor is there a vaccine to prevent AIDS.

A total of 42,354 individuals in the United States have been reported diagnosed with AIDS as of September 28, 1987, according to the Federal Centers for Disease Control (CDC). Of these, 24,412 persons (58%) have died (U. S. Centers for Disease Control, 1987).

AIDS is caused by infection with the Human Immunodeficiency Virus (HIV). It is estimated by the Public Health Service (Koop, 1986) that 1.5 million individuals in the United States, all of whom are capable of transmitting the disease, are infected with HIV.

The CDC (Koop, 1986) predicts that there will be 270,000 cumulative AIDS cases by 1991, with 74,000 newly diagnosed cases in that year alone. In that same year, it

is expected that 179,000 persons will have died of the disease during its 10-year existence. A total of 54,000 are expected to die in 1991 alone.

These figures are conservative. Projections by local health departments are considerably higher (Inova, 1987). It is impossible to estimate the exact number of persons who will become infected, those who will develop AIDS, or how long it will take for this transition to occur.

The projected numbers by CDC do not include people with AIDS Related Complex (ARC), which may be fatal or transient, and is characterized by swollen lymph nodes and constitutional symptoms. The CDC estimates that there are 5 to 10 ARC patients for every one AIDS patient and that approximately 10 to 20% of these persons may go on to develop AIDS.

Studies indicate that the AIDS virus can be transmitted only by intimate contact with the body fluids of an infected individual. This can occur through sexual contact, sharing of contaminated needles, transfusion of blood and some blood products, and from an infected mother to her baby in the prenatal or delivery period (American Council on Science and Health, 1986). There is no evidence of contagion via casual contact exposure (Bennett, 1985; Koop, 1986; U.S. Medicine, 1985).

About 66% of those inflicted with AIDS have been gay or bisexual men, and an additional 8% have been both homosexual males and IV drug abusers. Another 16% have

been IV drug users. Hemophiliacs have accounted for 4% of all adult cases, while 5% of all pediatric cases have been hemophiliacs. A total of 2% of all adult cases and 12% of pediatric cases have resulted from contaminated blood transfusions. Heterosexual sexual contact so far has accounted for 4% of AIDS cases in the United States, but the incidence is rising (U. S. Centers for Disease Control, 1987).

Pneumocystis Carinii Pneumonia (PCP) is the most common opportunistic infection in AIDS patients. This is often the immediate cause of death of persons with AIDS.

Kaposi's Sarcoma (KS), a type of cancer, also occurs frequently among individuals with AIDS. It is characterized by purple lesions on the skin, and sometimes on the lymph nodes and internal organs.

As many as one-third of AIDS patients develop a degenerative brain disorder, termed AIDS dementia, that can be traced to infection of brain cells by the AIDS virus or by opportunistic organisms. This is characterized by diminished ability to concentrate, by memory loss, by partial paralysis, and progresses to severe mental deterioration (American Council on Science and Health, 1986).

In early 1987, Azidothymidine (AZT), became the first medication made available to persons with AIDS and those with an HIV positive diagnoses who met certain criteria. The drug, which appears to prolong life although it is not

a cure, costs an average of \$10,000 per year for each patient.

As of October 8, 1987, there have been 1411 reported cases of AIDS and 783 deaths in the Washington Standard Metropolitan Statistical Area (SMSA), which includes Washington, D.C., northern Virginia and suburban Maryland. Included in this figure is 860 (489 deaths) in the District, 263 (136 deaths) in the Virginia suburbs, and 288 (158 deaths) in the Maryland suburbs. The Washington area ranks fifth in the number of cases among cities in the United States behind New York, San Francisco, Los Angeles and Houston (Julie Druker, personal communication, October 9, 1987).

The Whitman-Walker Clinic in Washington D.C., one of the oldest non-profit gay clinics in the nation, offers a variety of services for people with AIDS, their families and significant others. Programs include an AIDS hotline, an education component, legal services, financial aid through the AIDS Foundation, housing for displaced persons with AIDS, a confidential AIDS testing program, a dental clinic, and support groups and counseling (Whitman-Walker Clinic, 1987). The "buddy" program, which trains and provides volunteers who work directly with persons with AIDS, involves more than 310 individuals. At the time of the study, 850 people were serving as volunteers at the clinic (Joseph Ripple, personal communication, October 9, 1987).

METHODS

The purpose of this study was to evaluate the availability of support systems for gay men with AIDS. Do these men suffer social isolation, or is social support available? Specifically, do these individuals feel supported by society in general, by health care providers, by their families of origin, and by their friends and lovers? Answers to these questions will help people who provide care for persons with AIDS to do so with better understanding.

This was not a quantitative study. The sample was not random. The information provided was qualitative in character, was intended to provide preliminary information on this subject, and was undertaken to identify possible topics for quantitative research. It was assumed that fear of AIDS, homophobia, and death anxiety are all present in certain circumstances. There was no attempt made to differentiate between these three possible causes of social isolation.

Data for this exploratory analysis on social support for persons with AIDS were gathered through the use of 4 population samples. They were:

1. Interviews with 20 gay men with AIDS
2. Interviews with 5 men who had been diagnosed with ARC or who tested positive for the HIV antibody
3. Chart reviews of 30 gay men with AIDS who had

been patients at Hospice of Northern Virginia prior to January, 1987

4. A review of insurance coverage records of all of the AIDS patients (45) who had died in the Hospice of Northern Virginia program prior to August, 1987

The primary focus of the study was the group of 25 men in the first two sample populations (20 with AIDS and 5 with ARC or an HIV positive antibody test) who participated in semi-structured interviews. (See Appendix A for sample of interview guide.) These interviews were conducted during a one-year period between August, 1986, and August, 1987. Institutional review boards and boards of directors at Whitman-Walker Clinic, Washington D.C., and at Hospice of Northern Virginia, Arlington, Virginia, approved the project, and interview referrals were made through the former director of the AIDS program and other staff at the clinic and through nurses at the hospice. Individual subjects and other persons also made referrals. Most of the interviews were conducted at residences of the subjects though a few were conducted at Whitman-Walker Clinic or at the interviewer's home. Because rapport was different with each individual, the shortest interview took 30 minutes, and the longest took 2 hours and 45 minutes. The average length of time was 1 hour and 40 minutes.

All subjects agreed to having the interviews tape recorded, and each individual signed an informed consent

statement. (See Appendix B for sample of informed consent form.) To assure confidentiality, the forms and the cassette tapes were kept in a secure place and seen and heard only by the person doing the study.

Semi-structured interviews are used when interviewing people who have all experienced the same event. Although the wording of questions is not fixed in advance, the content of questions is. Like the structured interview, semi-structured questions allow for flexibility and unanticipated responses, but there is the additional benefit of probing into relevant subjects (Bailey, 1982).

In addition to the 25 interviews, charts of 30 gay men who had been Hospice of Northern Virginia patients prior to January, 1987 (all but one of whom had died), were examined in order to gather additional information on various components of social support/isolation. Specifically, 7 variables (age, marital status, household arrangements, primary caregiver/s, involvement of sisters, involvement of parent/s, and simultaneous disclosure of AIDS and homosexuality) were reviewed.

It is important to keep in mind that, in general, Hospice patients whose records were reviewed for this study were at a much later stage of the disease than the men who were interviewed. Average length of stay for Hospice patients with AIDS is 29.3 days, which means that most of the information charted was taken less than a month before death.

One last sample, the total number (45) of Hospice of Northern Virginia patients with AIDS who had died prior to August, 1987, was used to supplement information on health insurance. Financial records of these patients were reviewed in order to gain more specific information on health insurance coverage of persons with AIDS.

#### DEMOGRAPHICS

AGE -- The 20 men with AIDS who were interviewed ranged in age from 23 to 49 years old. The median was 35.5. This correlated closely with the gay Hospice patient population whose age range was 21 to 53 years of age, with a median age of 34.5. In general, the five men with HIV positive diagnoses or ARC were older than the other 2 groups, with ages ranging from 40 to 45, and a median age of 42.

OCCUPATION -- Most of the men interviewed in both the AIDS and the ARC-HIV positive groups were professionals, and some of the occupations included were musician, doctor, lawyer, librarian, accountant, dentist, chef, hotel manager, mortician, waiter, writer, salesperson and editor. Three of the men worked or had worked for the federal government. Two professionals had turned to landscaping, which they described as a less stressful occupation, following their diagnoses.

EDUCATION -- Of the 20 men with AIDS who were interviewed, 85% (17) of them had B.A. degrees. At least 6 of these had graduate degrees. A total of 100% or all of

the 5 men with ARC or HIV positive diagnoses were college educated, and 3 of these had advanced degrees.

MARITAL STATUS -- A total of 70% (14) of the men with AIDS had never been married, 25% (5) individuals were divorced, and 1 person was widowed. Three of the ARC-HIV positive group had been married. Four of the AIDS group had children, as did all 3 of the formerly married ARC-HIV positive group. Charts of the 30 Hospice patients show 27 single men, 1 divorced, 1 married, and 1 with marital status not specified. However, these Hospice statistics fail to indicate if a person had been married and divorced since 2 of the men listed as "single" were being cared for by their children. Unless subjects were asked specifically whether they had ever been married, it is very likely they would simply list themselves as single, or perhaps the person doing the admission simply assumed a gay man had never been married.

RESIDENCE -- Eighteen of the 20 men with AIDS lived in the metropolitan Washington D.C. area. The 2 men who lived outside the area commuted to Washington D.C. or environs for treatment and/or support groups. All 5 of the ARC and HIV positive group lived in the area. It is unclear exactly how many of the Hospice patients lived in the area prior to admission, but Hospice personnel indicate that a number moved here in the latter stages of illness to be with their families.

RACE -- A Total of 18 of the 20 persons with AIDS in

the study were white, 1 was black, and 1 was Hispanic. All 5 of the ARC-HIV positive group were white. Of the 30 men in the hospice sample, 28 were white, 1 man was black, and 1 individual was Hispanic.

This is in contrast to national statistics which indicate that minorities account for more than one-third of AIDS cases, while minorities make up less than one-fifth of the country's population. However, IV drug abuse is a key factor. While 12% of white men with AIDS abuse intravenous drugs, some 40% of black and Hispanic men with AIDS abuse drugs (Thompson, 1987). Virtually all of those interviewed for this study indicated they contracted the AIDS virus through sexual contact, not IV drug use. (See Table 1 for a summary of demographic characteristics for the 3 populations.)

#### SELF-IMAGE

The interviews were constructed so that the interviewer first provided introductory information, then asked the subject to tell about himself. Self-descriptions were coded as to the sequence in which they told of age, occupation, place of residence, personal history (including homosexuality), family history, AIDS, and name. Nine of the men with AIDS gave their age first, 3 persons said they had AIDS, 3 individuals gave their name, 2 men gave their place of residence, and 1 person each gave his occupation, personal history, or family history first. In the ARC-HIV positive group, none of the men gave their age first.

Table 1. DEMOGRAPHIC CHARACTERISTICS

Characteristic	AIDS		ARC-HIV		Hospice	
	No.	%	No.	%	No.	%*
<b>Age</b>						
21 - 25	2	10	-	-	2	6.7
26 - 30	2	10	-	-	5	16.7
31 - 35	6	30	-	-	8	26.7
36 - 40	5	25	1	20	7	23.3
41 - 45	3	15	4	80	5	16.7
46 - 50	2	10	-	-	1	3.3
51 - 55	-	-	-	-	2	6.7
Total	20	100	5	100	30	100.1
<b>Education</b>						
High school	3	15	-	-	-	-
College	17	85	5	100	-	-
Total	20	100	5	100	-	-
<b>Marital Status</b>						
Never married	14	70	2	40	27	90.#
Divorced	5	25	3	60	1	3.3
Widowed	1	5	-	-	1	3.3
Not specified	-	-	-	-	1	3.3
Total	20	100	5	100	30	99.9
<b>Residence</b>						
Wash. D.C. area	18	90	5	100	-	-
Outside D.C.	2	10	-	-	-	-
Total	20	100	5	100	-	-
<b>Race</b>						
White	18	90	5	100	28	93.3
Black	1	5	-	-	1	3.3
Hispanic	1	5	-	-	1	3.3
Total	20	100	5	100	30	99.9

\* Percentages may not add up to 100% due to rounding

# Figures probably unreliable. See p. 15.

Three first offered their personal history, 1 person told his occupation, and 1 man told his place of residence.

The men with AIDS mentioned the disease in this order: first, 3 men; second, 2 men; third, 7 men; fourth, 2 men; fifth, 3 men; and not at all, 3 men. "I'm 34 years old, I'm a gay man, and I have AIDS" was a typical opening statement.

Understandably, a diagnosis of AIDS became, for many of the men, a burden so heavy that all else was driven from mind. One man who had been diagnosed fourteen months prior to the interview offered this description of AIDS, "It's like it used to be this huge thing on my back and now it's more like it's on a leash and I can lead it around, rather than it leading me...It's like part of my identity now, rather than the overriding factor of my identity."

"I feel like I'm standing in the middle of 17th and K, and saying, 'Okay, hit me -- from any angle -- with anything.' Because people control you and the disease controls you," said another person, in describing the loss of control over one's life that comes with an AIDS diagnosis.

Another man told of how he reacted to being told he had AIDS. "Although generally gregarious, I really felt like a leper -- not because other people made me feel that way but because that was what was happening to me. I couldn't talk. I really became pretty tongue-tied, and it lasted for quite a while. First of all, being gay is one

thing. You're living a double life. You take on friends who are also gay because you can share common interests and activities. Now all of a sudden I had a disease I couldn't even share in that subgroup of people...I felt like I didn't want to talk to anybody -- or see anybody. I wanted to be alone. Let me be -- I'm all right -- but let me be."

An individual with ARC described his perceptions of the differences between AIDS and ARC. "Someone who has AIDS right now has his future pretty well mapped out," he said. "Some can accept that easier than others... Being ARC, you don't know what's going to happen. You don't know if you should make plans or what kind of plans you should make. So you teach yourself to start living day by day -- always wanting to set some real goals for yourself. Then you assume you're not going to come down with it and you're going to be very positive about this whole thing. You say I'm not going to come down with this, you set your goals and you make your plans, and a week later you have a bout with fatigue or the thrush [sore patches in the mouth caused by a fungus and one of the most frequent early symptoms of an immune disorder] comes back..."

AIDS, in the case of gay males, often compounds a lifetime of "feeling different," resulting in low self esteem. The most recent Gallup polls show that the public's attitude toward homosexuals has deteriorated since the AIDS epidemic. In 1977, 1982, and 1985, the public split evenly on the question "Do you think homosexual

relations between consenting adults should or should not be legal?" In 1986, respondents said they should not be legal, 54 to 33% (Schneider, 1987).

"I'd cut myself in two and damned both halves," said one man with AIDS telling about his "closeted" life as a gay man.

#### HEALTH PRIOR TO AIDS

Most of the individuals who were interviewed indicated they had enjoyed excellent or good health before contacting AIDS. Of the 20 men with AIDS, 50% (10) indicated their health prior to AIDS was "excellent," "real good," "very good," or they had been "the healthiest thing on two feet." A total of 20% (4) indicated their health had been "fine," or "good," and 25% (5) said their health had been "fair," "okay," "pretty good," or "average." One reported "poor" health prior to AIDS. Of the five ARC-HIV positive group, 60% (3) reported in the excellent category, and 40% (2) in the good category.

However, more than half the men reporting excellent health then proceeded to list numerous illnesses, some quite serious, that they had had before AIDS. Perhaps this paradox is explained by the comment of one man who had previously suffered two life-threatening illnesses. He said, "AIDS is totally different from any other disease because of the stigma attached to it." Another described being told he had AIDS "as if somebody had struck all ten

fingers on a piano -- on my back -- and it stayed with me for a long time."

"My life was not perfect, but I felt pretty comfortable where I was," explained another. "I had a niche. Then... it felt like I had broken into all these different pieces -- like Humpty Dumpty. It took some time to put those pieces back together. After a little waiting, a little doing, and a little AZT, things felt integrated again."

#### WHEN DIAGNOSED

The 20 men with AIDS had been diagnosed on average 11.1 months prior to the interview. The median was 9 months before the interview, and the range was from 3 to 33 months. Persons in the ARC-HIV positive group had been diagnosed on an average of 21.2 months prior to the interview with a median of 15 months. The range was from 7 to 42 months.

#### FIRST SYMPTOMS

Pneumocystis Carinii Pneumonia, the most common opportunistic infection in AIDS patients, also was the most common first symptom among the 20 men with AIDS interviewed. Pneumocystis Carinii Pneumonia was reported as the first symptom by 55% (11) men; Kaposi's Sarcoma, 20% (4); fatigue, 15% (3); cough; 1% (2); other, 20% (4). (More than 20 answers appear because some men gave more than 1 answer.)

Several of the men indicated they denied admitting to

themselves that they might have AIDS, and thus delayed getting medical care. One admitted watching a Kaposi's Sarcoma lesion for two months before seeing a doctor. "Every morning I'd wake up and hope it would have disappeared overnight," he told the interviewer. He described his reaction as ranging from "denial to absolute panic."

Another man told of suffering for about seven weeks with "symptoms that are compatible with this disease -- fatigue, loss of weight, low grade fever, night sweats and depression -- and growing weaker and weaker." He went to his family doctor who did a series of tests, and he told the interviewer, "Everything came out negative." This occurred 2 1/2 weeks prior to emergency hospitalization and a diagnosis of AIDS. When asked by the interviewer whether he had been tested for AIDS in the first instance, he replied, "No, he [the doctor] took blood and he asked if I wanted to have that run, and at that time I didn't feel... (pause) I was afraid. I didn't want to know."

#### MEDICAL CARE

A total of 85% (17) of the 20 men with AIDS had been hospitalized. Of that number 6 persons had been hospitalized once, 6 were hospitalized twice, 4 were hospitalized 3 times, and 1 individual had been hospitalized 8 times. No one in the ARC-HIV positive group had been hospitalized.

In general, medical care providers were perceived by

the individuals interviewed to have shown supportive behavior. When the men with AIDS were asked to indicate whether medical care they had received was provided in an accepting or rejecting manner, 55% (11) said that medical care was offered in a supportive atmosphere and 35% (7) said that they felt they had received a mix of accepting and rejecting care. In the ARC-HIV positive group of 5 men, 80% (4) gave accepting ratings and 20% (1) gave a mixed rating to outpatient medical caregivers.

When the individuals with AIDS were asked to rate hospital health providers by specific occupation, doctors and nurses were rated excellent 79% of the time, social workers were rated excellent 82% of the time, and nursing assistants were judged excellent 69% of the time. In contrast housekeepers were said to be excellent only 16% of the time, and food service workers only 22% of the time. (Some of the subjects reported on more than one hospitalization. Those men who had not been hospitalized reported on physicians only.) (See Table 2 for data on health care providers and support staff ratings.)

Most of the stories about poor hospital care concerned food service workers who were afraid to come into the room and left food trays in the hall, and about housekeepers who overgowned and/or failed to clean AIDS patients' rooms. This kind of behavior often was excused by the men being interviewed because of the "poor salaries paid these

Table 2. HEALTH CARE PROVIDERS AND SUPPORT STAFF  
EXCELLENT RATINGS BY MEN WITH AIDS

<u>Positions</u>	<u>No.</u>	<u>%*</u>
Physicians	15	79
Nurses (R.N.s)	15	79
Social Workers	14	82
Nursing assistants	11	69
Food service workers	4	22
Housekeepers	3	16

\*Percentages dependent on total no. of answers for each position. All men did not have experiences with people in each category.

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workers," and because "these people are not educated about the disease."

As one man expressed it, "They were afraid of me, and they didn't know enough not to be."

Humor often was used as a defense against rejecting behavior. One story, which has gone the rounds of the gay community, is about a hospitalized AIDS patient who, when a frightened food service worker left his food tray on the floor, "leaped out of bed, chased her down the hall, and threatened to kiss her if he caught her."

But humor didn't always chase away the pain. One man has a copy of a letter which states that a local hospital board "does not want people of his kind" treated in the hospital. Scheduled for surgery on a Monday for an extremely painful condition, he was notified by telephone on the previous Friday that the surgery had been abruptly canceled. His phone calls to his doctor went unanswered, and finally in frustration, he had his friends bundle him into a car, and he went himself to demand the doctor speak with him. At first he was told the doctor was too busy to see him, but when he threatened to sit all day in the waiting room, the doctor found time, called him in and advised him that he had decided to refer him to the National Institutes of Health (NIH) -- no reason given.

One individual said his doctor's attitude caused a "traumatic experience." He explained that his physician was "very, very abrupt. My friend was with me and he asked

my friend to leave... I thought, 'Why chase him out? He's my strength.' Then he said, 'I'm sure you already know your specimen was positive and that you have pneumocystis.' It's not that I didn't know because I was expecting the worse, but it scared me so much... And the other thing was he announced this from the doorway, like he was afraid."

Another person said he thought he had cancer [not AIDS] when his doctor told him over the telephone that he had Kaposi's Sarcoma. The next day he saw the doctor who tried to tell him what he had without using the word AIDS. Finally the man guessed that's what he had, and he said "like AIDS?" "That's what I'm trying to tell you you have," said the doctor.

There were many stories about health care workers overgowning and showing fear of AIDS patients. One man reported that "one of the nurses -- at least she was introduced as my nurse -- looked like a space cadet and she would not come into the room. She just stood by the door. I felt very rejected. I could see it in her face. I could see the fear. I started crying. That's how badly it was affecting me."

Dentists were mentioned by several of the men when they were asked if they had had problems with medical caregivers. A number of them said that their dentists refused to treat them when it was known or even suspected they had AIDS. One individual's dentist had treated him regularly 4 times a year for 15 years prior to AIDS.

These accounts of rejection by health providers have led some of the men, particularly those who are HIV positive, to be very cautious about revealing their diagnoses. One person interviewed was scheduled to undergo minor surgery the following day. He explained, "I have been going through an internal debate as to what I should say to the surgeon because the surgeon doesn't know... For the most part I am not informing people unless I find there is a need to know. If the surgeon wears gloves I'm not sure I'm going to tell. If the surgeon starts to do anything without gloves, I will... I wonder if I'm exercising social responsibility here, but I feel I know more about the disease than even these health care professionals and I'm not sure there's a need for them to know this. When there is a need to know, I'll let them know."

Hospice care received good marks from the patients and from the men interviewed who had had lovers and friends in the program. One man compared hospice care to hospital care as "the difference between heaven and hell."

But many of the men told of caring and competent health care providers outside of hospice -- nurses who "took the time to give me a hug" and social workers who "really cut through the red tape."

Doctors also were praised. "I moved back home to be close to my family after I quit working," explained one man. "I hadn't been in touch with my doctor back there and

he had no way to contact me here. He had tried to get me in the AZT program at NIH last fall, and the other day I heard from him, and he'd gone back to NIH and tracked me down. He called my father's office to see how I was doing."

Another man, without insurance and unable to bear the high cost of AZT, reported that his doctor was planning a fundraiser to cover the patient's pharmacy bills.

#### COVERING THE COST OF CARE

The economic impact of AIDS -- for the individual person with AIDS and for the nation -- is significant. Although it is illegal in the District of Columbia and California, some insurance companies in the rest of the nation presently refuse to cover persons with AIDS or persons who test positive for the virus, and many people with AIDS are without insurance coverage because of AIDS paranoia (Christ & Wiener, 1985). Approximately 1/2 of all insurance companies now require AIDS-antibody testing before a policy is granted (Iglehart, 1987). In addition, insurance coverage often is lost when a person is fired from his job or resigns of his own accord. Inevitably, the cost of health care for the thousands of AIDS patients will be borne by the general public, whether through higher insurance premiums, federally subsidized programs like Medicaid and Social Security, an increase in hospital, outpatient and home care rates, or increased charitable giving.

The Health Insurance Association of America estimates that the cost of AIDS -- not counting the cost of the new drug AZT or the care of AIDS-related illness -- will total \$40.5 billion between now and 1991. Of that, 35% will be paid by Medicaid and Medicare, 22% by private insurers, 19% by Blue Cross-Blue Shield, and 24% by individuals (Colburn, 1987).

These facts are borne out in this study. Of the 20 men with AIDS, 55% (11) of them were covered by private health insurance companies and 45% (9) were not. Of these 9 men not covered by private carriers, 55% (5) reported they had lost their health insurance with the AIDS diagnoses. Also of those same 9 men, 78% (7) were on Medicaid and 22% (2) had applied for it at the time of the interview.

One of the men in the ARC-HIV positive group was fired from his job -- and thus lost his insurance -- when it became known that his lover had died of AIDS. One of the four in this group who had insurance reported he was in danger of losing it.

"I have no health insurance, and I'm basically uninsurable," said the man who had lost his health coverage. "I know what I'm going to do if I get AIDS... I've seen too much. I'm not going to die in a hospital, so in a sense, I don't care that I don't have insurance."

The study did not include a question about suicide, although persons with AIDS are at risk (Abrams et al, 1986;

Faulstich, 1987; National Institute of Mental Health, 1986). One of the men interviewed told of a suicide attempt. "I was in a support group where we sat around talking about each others' illnesses and about friends and lovers who had died," he said. "I became so depressed and so frightened. I thought, 'Tomorrow's not going to come anyway. What's the difference? Why put this burden on everyone?'" A few months after his attempt at killing himself failed, this particular individual was involved in a holistic healing program.

When the records of 45 former AIDS patients at Hospice of Northern Virginia were reviewed, they indicated that 51% (23) were covered by private companies, 31% (14) by Blue Cross-Blue Shield, 11% (5) by Medicaid, 2% (1) by Medicare, and for 4% (2) persons, the cost was borne by Hospice.

While about 4% of AIDS patients at Hospice of Northern Virginia had no insurance, this compared with only 1% of non-AIDS patients, according to hospice records. An additional 13% were covered by Medicaid or Medicare which fails to cover the full cost. The average cost of hospice inpatient or home care for persons with AIDS is \$9000, 50% higher than the \$6000 average cost for non-AIDS patients. This is still a small percentage of the estimated average cost of medical care which ranges from \$50,000 to \$150,000 per patient (Colburn, 1987).

One of the young men at hospice whose care was paid for by a combination of Medicaid and hospice patient care

funds, money raised in the community to cover costs for indigent patients, was in the program for 160 days, more than five times longer than the 29.3 day average length of stay. Total cost of his care came to more than \$77,000, considerably more than the \$9,000 average.

Most of the men who were interviewed expressed anger at the nation's health care system and frustration at the complexities of applying for help. Even if they had not been directly affected, they all seemed to know someone who had suffered at the hands of the bureaucracy.

"Time is not an element to them, but time is of the essence to us," said one man. "We all know it's a terminal disease. It's not a question of the federal government taking on someone who is going to be on the dole for the next 20 to 30 years... They might have 5 if they're lucky."

AZT, described as "obscenely expensive" by one of the men with AIDS, was made available to certain AIDS patients about half way through the year the interviews were conducted.

One individual, still in his early 20s, told of his inability to pay for AZT. "My biggest gripe is the cost of medical care. In this land of supposed opportunity, you can't afford health care. The only drug that has any hope costs \$10,000 a year. I just feel someone in my situation should not have to worry about the cost of getting medical care." He explained that, although he has insurance that will reimburse 80% of the AZT cost, he still would need to

come up with \$800 to pay the pharmacist in advance of reimbursement -- money he does not have.

"I can't get AZT because I can't afford it. I want to leave this job, but I can't do that because if I do I'll lose my insurance," he lamented.

"It's not a long term commitment we're asking for," declared another man. "It's immediate assistance to sustain what quality of life we still have left and to allow us to improve that, if possible, until such time that something better comes along and we again can be contributing members of society."

Another young man who changed jobs and then discovered he had AIDS -- a pre-existing condition not covered in his new health plan -- described his experiences. "The people that deal with you have no compassion. All they want is their money and you get all kinds of letters and telephone calls and they hunt you down...You're dealing with a disease, but at the same time you're being constantly badgered."

Encountering the red tape of the Social Security bureaucracy, well known to the poor and the elderly, was a new experience for most of these young men who, until AIDS, had been part of an upper socio-economic class.

One man became extremely agitated as he told about his experiences. "I took a form to social security following my first appeal for reconsideration and presented it to my case worker who lost it fifteen minutes after I gave it to

her. She then brought out another form for me to fill out -- a form I'd spent hours going over with my lawyer. I said, 'Please go back and look and see if you can locate that form'. She located it at the water cooler. I was called the following week by her supervisor who advised me the form had yet again been lost. These people are playing with people's lives... The inhumanity of the whole thing is what appalls me."

One of the men termed his case worker "absolutely heartless, and mindless too." His Whitman-Walker Clinic buddy (a volunteer assigned to assist a person with AIDS) and his mother now deal with the case worker because as he explained, "She did me a lot of damage because she would get me so upset and worked up and I didn't know what the hell was going to happen next."

#### EMPLOYMENT

The individuals who participated in this study were working, contributing members of society prior to AIDS, but 80% (16) of the 20 men with AIDS were not working at the time of the interview. All but 1 of the 20 men with AIDS were employed when diagnosed, as were all 5 of the ARC-HIV positive group. At the time of the interview, 40% (8) of the men with AIDS had resigned, 25% (5) had been fired, 20% (4) were still at their jobs (1 -- part time), 1% (2) had taken a leave of absence, and .5% (1) was on sick leave. Of the 5 ARC-HIV positive group, 60% (3) were still at

their same jobs and 40% (2) had been fired, but were working at other jobs.

Of the 16 men with AIDS who were not working, 50% (8) said they would like to be employed, but only 19% (3) of those specified that they would like to be back at their former jobs. "It was drastic enough being told I had AIDS," said one man "but stopping work was even more drastic because I was a real workaholic." Five individuals made the point that they were not well enough to be working in their old jobs. Another 5 persons mentioned that they were working as volunteers in AIDS service organizations.

The experience of having persons at places of employment learn about the disease had mixed reviews with an equal number of persons reporting accepting and rejecting behavior by people at work. While 35% (7) of the men with AIDS said that people at their place of employment were supportive, another 35% (7) reported people were non-supportive. A total of 30% (6) had situations where the question was not applicable (mostly the people at work were unaware the person had AIDS). A total of 40% (2) of the ARC-HIV positive group reported they were accepted, another 40% (2) were rejected, and the situation was not applicable for 20% (1 man).

In general, the men with AIDS felt their employers were supportive. Half (10) of the men with AIDS described their bosses as caring when they were told of the disease, while 25% (5) did not tell their bosses of the specific

illness. A total of 15% (3) of bosses shunned the person with AIDS, 5% (1 boss) exhibited anger, and for 5% (1) the question was not applicable because the individual was self-employed. In the ARC-HIV positive group, one boss was angry, one was caring, and three didn't know of the diagnoses.

Co-workers were rated higher in caring than employers. A total of 50% (10) of the men with AIDS reported that their co-workers knew about the illness, 20% (4) said that some co-workers knew, and 30% (6) said that none of them knew. All of the men whose co-workers knew of the AIDS diagnoses (14) said that the vast majority of fellow employees were caring, but 10% (2) indicated that at least some fellow workers shunned them. In the ARC-HIV positive group, 40% (2 men) stated that co-workers were caring and 20% (1 person) reported a mixed reaction. The other 40% (2) said co-workers did not know of the diagnoses.

Three men reported they tried to avoid letting people at work know they had AIDS by telling them they had cancer instead. "I told everyone I had cancer," admitted one person. "I found it real easy to talk my way out of 'what kind of cancer?' questions. I found that I could change the subject in an instant, and people, in respect to my interest, wouldn't pry."

One person who tested positively for the virus described his co-workers as "enlightened," then added that he wasn't sure whether they were even aware of his immune

status. "There is kind of a conspiracy of silence... Somehow, if we talk about it, we'll get it," he explained.

Some stories were heartwarming. "My boss was very conservative, very straight arrow -- a very macho man," explained one man. "When he found out I had AIDS, I couldn't have had a warmer, more caring person. He was heartbroken, but he was very supportive. He told me 'if I can do anything for you.' I was leaving work. He told me my job was there, 'if you feel like coming back to work at any time... We'll keep you on the insurance.' I said 'if you keep me on the policy, I'll pay the premiums.' He said, 'the hell you will. We'll pay the premiums.' And they do to this day."

A large corporation placed one man with AIDS on executive loan to the Whitman-Walker Clinic. The man was paid his full salary while working at the clinic.

For others, the responses by associates and bosses were much different. One individual who had resigned his job following a diagnosis of AIDS, returned to his office to see some friends. His former supervisor, abruptly told him that there are "too many strangers walking in the hall up here. It would be better if you waited in the lobby downstairs."

Another man called his boss from the hospital where he was recovering from a bout with pneumocytis pneumonia. His employer's reaction was "We're not going to cover you on your insurance and you no longer work for us." It was only

after the man with AIDS went to the Washington Blade (a gay community newspaper) with the story that the employer backed down on the insurance.

Job terminations were not only a problem for persons with AIDS, but also for men in the ARC-HIV positive group. One man held a responsible position for ten years prior to the diagnosis, which was known to the corporate personnel office. "I was so well established there that discrimination never crossed my mind. At the same time we were going through a reorganization. We got new corporate officers and a lot of people were asked to leave. It was shortly after I got sick that the pressure was put on me to, quote, 'move on', and eventually they abolished my position -- rather conveniently. Now this is in light of the fact that I had been doing a really good job, especially from the point of financial administration. Did my illness have anything to do with them wanting to push me out or was it part of the corporate reorganization? I really don't know."

Another man in the ARC-HIV positive group appeared on television after the death of his lover and subsequently was fired from his job. "That really devastated me," he said. "I had lost my friend and I had lost my job and all I really did was take care of him. And I was frightened, too. I didn't know anything about AIDS. I felt like I was a victim of AIDS too."

HOUSING

Although only 20% (4) of the 20 persons with AIDS who were interviewed indicated that they had suffered housing discrimination, a total of 45% (9) had moved to a new place of residence since being diagnosed. A total of 40% (8) were living in group homes specifically provided for persons with AIDS. Of these, 30% (6) were living in housing provided by Whitman-Walker Clinic. The clinic provides 6 houses accomodating 37 people who are displaced from their homes, in economic need and willing to live in a group setting. Another 10% (2 individuals) in the study were living in housing provided by Damien Ministries, a Roman Catholic group dedicated to providing care for people with AIDS. One person had moved back to the home of his parents after being on his own for more than 15 years. A total of 35% (7) of the men were living with their lovers and 20% (4) lived alone.

In the ARC-HIV positive group, 40% (2 men) lived alone, another 40% (2) lived with one other person, and 20% (1 person) lived with several people. Hospice of Northern Virginia charts of the 30 men with AIDS, indicated that 77% (23) of them lived with a friend, lover, or family member/s, and 23% (7) lived alone. (See Table 3 for housing information.)

The fact that 20% of the men with AIDS who were interviewed (24% if one factors in the men in the ARC-HIV positive category) and 23% of the Hospice AIDS patients

Table 3. HOUSING ARRANGEMENTS

LIVING ARRANGEMENTS	No.	<u>Men</u>	<u>Men</u>
		<u>With</u>	<u>With</u>
		<u>AIDS</u>	<u>ARC-HIV</u>
		%	No. %
Live alone	4	20	2 40
Live with one other	7	35	2 40
Live with several people	-	-	1 20
Live in group home	8	40	- -
Live with family of origin	1	5	- -
Totals	20	100	5 100

lived alone points toward a major problem in the delivery of health care to persons with this disease. Most hospices and many home health agencies require that a patient have a primary caregiver, a person who takes responsibility for the patient. In the case of the seven hospice patients who lived alone, Whitman-Walker clinic volunteers and staff took on this obligation. In addition, they served as primary caregivers in three of the other cases. At the present time volunteer resources are stretched to the limit. As the case load increases, the only alternative for persons with the latter stages of AIDS will be hospitalization, a much more expensive option.

Some experts suggest that this problem might be solved by an intermediate nursing facility for chronically ill AIDS patients who don't need to be hospitalized but need nursing care (Colburn, 1987; Inova, 1987).

#### RELIGION

Religion, but not necessarily organized religion, was important to the majority of the 25 men interviewed in both the AIDS and ARC-HIV positive categories. A total of 36% (9) of the people interviewed reported that they belonged to a specific denomination. Of these, 6 said they were Roman Catholic, 1 said he was Methodist, 1 Muslim, and 1 Jewish. Of this group of 9 persons who claimed alliances with specific denominations, 2 men said religion played a minor role in their lives. Two individuals with AIDS and 1 man in the ARC-HIV positive group (a total of 12%) said

they were agnostic. Two men with AIDS and 1 man in the ARC-HIV positive group (12% of the total) stated they were active in the non-denominational Metropolitan Community Church which ministers to gay and lesbian persons.

These 3 were among 9 of the men with AIDS and 3 persons in the ARC-HIV positive group who specifically stated that they had spiritual values and beliefs of their own (48% of the 25 men interviewed), but that they were not part of "organized religion." It appears that part of this antipathy toward organized religion is based on the church's historic rejection of homosexuality.

"If Jesus came down today he would not be condemning homosexuals and PWAs (persons with AIDS)," claimed one man.

"I believe in a God," explained an individual who had been brought up in the Roman Catholic Church. "I believe in a loving God. Yet I have a lot of problems with organized religion. I feel the need to worship in a Christian community, but I feel the Catholic Church has sort of made me an orphan."

Another man spoke of his "disenchantment with organized churches." He added, "Part of that was being homosexual. They didn't exactly approve of me so it was like -- the hell with you."

Several persons spoke of trying to find religious solace since contracting AIDS, ARC or the virus. One of the individuals with AIDS, brought up in a fundamentalist church, had converted to the Roman Catholic faith a few

days before the interview.

"My faith has carried me through," said another man. "I don't believe that AIDS is punishment from God for being gay. My Lord, there are murderers and rapists out there. The fact of the matter is, I'm responsible for where I am right now. I didn't know at the time that this is a consequence of my behavior, but, nevertheless, it is. I am what I am because of things that I did. It's just a biological fact."

Another individual who had been brought up in the Episcopal Church said that as he got older, he came to think of himself as an agnostic. "AIDS changed a lot of that," he explained. "I still have many reservations about organized religion, but I'm a much more religious person than I used to be. I believe in God and I didn't use to. I believe in an afterlife and I didn't know about that before. I think of myself as much more religious."

Others questioned their beliefs after contracting AIDS. "Before the AIDS scare, a friend of mine used to say that God looks after gay people," said one man. "I kind of felt there was something to that. Now I'm having a few doubts about having any special treatment from God."

#### RELATIONSHIPS

GENERAL PUBLIC -- Three-quarters of the men with AIDS in this study felt that the general public was extremely fearful of the disease. While 75% (15) of those interviewed identified fear as the main reaction of the

public, 40% (6) of those individuals noted a geographic difference. People on both coasts and urban areas were reputed to be more knowledgeable about the disease while people in the "hinterlands" and rural areas were said to be uninformed and frightened. A total of 20% or 4 of the men indicated that the general public's attitude has improved, 10% or 2 persons said that the public doesn't care about AIDS, 5% (1 individual) said that the public saw AIDS as a gay disease, and another 5% (1 man) said he didn't know how the public reacted.

While none of the people with AIDS concurred, 40% (2) of the men in the ARC-HIV positive group indicated that the general public's reaction to AIDS was realistic. Another 40% or 2 men said that the public was frightened, and an equal 40% or 2 persons said that the public perceived the disease as a gay disease, 20% (1 man) said that the public's attitude had improved, and 20% (1 individual) reported that the public didn't care. (Some of the men in both groups gave more than one answer.)

Because the media's treatment of an issue may reflect the general public's perception, or, in the reverse, may influence the public's perception of an issue, persons in the study were asked to give their reactions to media treatment of AIDS. Of the 20 men with AIDS, 40% (8) indicated press coverage of AIDS had improved over time, 30% (6) said they viewed media coverage as a negative factor, 20% (4) called it positive, and 10% (2) had mixed

reviews. In the ARC-HIV positive group, 60% (3) said coverage had improved, 20% (1) perceived the press as a negative factor, and another 20% (1) gave a mixed review.

While a few of the men had immersed themselves in news about AIDS, more said that they avoided news about the illness. "It's very painful to be told over and over that you're going to die," explained one man.

Another commented, "The type of person who agrees to go on TV is unlike any gay man I know. I wish I could speak out publicly, but it would hurt my family."

FRIENDS -- While most of the men in the study indicated they had kept their old friends following diagnoses of AIDS, virtually all of them said they had gained a coterie of new friends -- other men with the disease.

When asked whether they still saw the same friends as they did prior to the disease, 75% (15) of the men with AIDS said they did, 10% (2) said they did not, and 15% (3) indicated they saw some of the same friends. In the ARC-HIV positive group, 20% (1) stated he still saw the same friends and 80% (4) reported they still saw some of the same friends.

Most friends had been told about the diagnosis, and the overwhelming majority were supportive. Of the men with AIDS, 65% (13) reported that friends knew about the diagnosis, 30% (6) said close friends knew, and 5% (1) said he had not told his friends. A majority of 85% (17)

indicated their friends were supportive, and 10% (2) indicated their friends had mixed reactions. In the ARC-HIV group, 40% (2) had told friends, 60% (3) had told close friends only. A majority of 80% (4) of the men said their friends were supportive and 20% or 1 man said his friends had mixed reactions.

When men with AIDS were asked who they were closest to, more indicated they were closest to male friends than to any other category. While there were 23 (46%) indications that lovers, family members and professionals were closest, there were 27 (54%) indications that friends of both sexes and Whitman-Walker Clinic buddies, were closest to men with AIDS. In the ARC-HIV positive group, 4 (57%) people chose friends and 3 (43%) chose others. (Some of the men in both groups gave more than 1 answer.) (See Table 4 for data on persons closest to men interviewed.)

"Friends are very important," reported one man with AIDS. "You know how sincere they are when they stay with you."

"It's a relief to get this kind of conversation out in the open" declared one man. "It's terrifying to share it, but I think the benefits of sharing it are much, much better than trying to hold onto it and go through it yourself. And the embarrassment of having your friends know -- my friends have been wonderful. They've been there for me. They haven't moved away. Some of them had some initial fear, but I don't detect any distancing."

Table 4. PERSON/S CLOSEST

CATEGORIES	<u>Men With AIDS</u>		<u>Men With ARC-HIV</u>	
	No.*	%#	No.*	%#
<u>Friends</u>				
Male friends	13	27.6	3	42.8
Female friends	4	8.5	-	-
Whitman-Walker buddies, other support system persons	10	21.3	1	14.2
Totals	<u>20</u>	<u>57.4</u>	<u>4</u>	<u>57.</u>
<u>Lovers/ex-lovers</u>				
Lovers	8	17.	3	42.8
Ex-lovers	2	4.2	-	-
Totals	<u>10</u>	<u>21.2</u>	<u>3</u>	<u>42.8</u>
<u>Family of Origin</u>				
Father	1	2.1	-	-
Mother	4	8.5	-	-
Brother	2	4.2	-	-
Sister	2	4.2	-	-
Totals	<u>9</u>	<u>19.</u>	<u>-</u>	<u>-</u>
<u>Professionals</u>				
Therapist	1	2.1	-	-
Totals	<u>1</u>	<u>2.1</u>	<u>-</u>	<u>-</u>
Grand total	<u>47</u>	<u>99.7</u>	<u>7</u>	<u>99.8</u>

\* No. of answers are greater than the number of the men interviewed because some men gave more than 1 answer  
# Percentages may not add up to 100% due to rounding

Describing his new relationships, another man said, "I've developed a small but close circle of friends who have AIDS. I'm pretty much a closeted AIDS victim. There are not very many people I've told -- my lover, my lawyer, and Whitman-Walker Clinic and AIDS support groups -- so I have plenty of people to talk to about it if I need to, and I don't think I need to lean on people who would rather not hear it."

Another man who tests HIV positive and whose lover has AIDS reported that he has a "new group of friends, including people with AIDS and people who care for people with AIDS."

"At times I can't believe I have been so lucky," said a man with AIDS. "So many people have taken an interest in me."

Often relationships had become more intense. "Nothing is casual anymore," explained one man. "Nothing is taken for granted. There are consequences to everything... Relationships are closer and more meaningful. AIDS changes everything."

Another man's words were nearly identical. "In terms of people, my life is more intense. I don't take any situation for granted anymore, and I don't take anybody or anything for granted. I am physically much more dependent on people if I want to do something that requires an activity... but the intensity of the relationships I'm involved with right now is really wonderful."

"This is a very lonely voyage," said another. "It's too bad you have to become sick and die of a disease to feel those things in life we all strive for and reach out for. You learn a lot of humanity with this disease. My relationships have never been as full and rich and compassionate. The love among my friends who have formed a support network for me is just very deep, and it's affected their lives. One of them has changed his career as a result and is going into the field of AIDS. You get a deeper appreciation for the moment in life and you really grasp it. Strangers who come compassionately to help you are just amazing."

Many of these strangers are directed to people with AIDS by the Whitman-Walker Clinic to which all of the men in the study were connected in some way. "It's like a second family here," said one man. "We'll do anything for each other."

One individual described his gay friends who have AIDS as the "only ones who understand what it's like for me."

"There's been a bonding in the gay community," said another. There's a totally different atmosphere -- a coming together -- really responding to each other's needs. It's wonderful to be a part of it."

"We resent being ignored for so long," one individual said. "We spent more in a week on Legionnaire's Disease than we did in 4 years on AIDS research... Also in the real -- at heart -- gay community, there's an intense desire to

know and to beat this disease. We don't want anyone to have it."

Still another man declared that he wanted to compliment those "who are making such a significant effort to conquer this disease in the sense of volunteering... I'm one of the people who can say -- I have felt that effort."

One young man described his support system at the clinic. "I have very good people in my life -- people who care about me. They don't pity me. They care about me. They like me."

This is the same young man who described the "false friendships" he had endured since his diagnosis. "I stopped hanging out in bars, and some people I thought were my friends never call me. This really hurt."

One individual visited a friend who did not know about the diagnosis. "I thought he had a right to know I had AIDS because I was staying at his place. So I sat down and told him. We'd been very close. We'd worked together and spent a lot of time together. It was never a sexual thing, but we'd been very close. He turned on me and told me to get the hell out of his apartment. He didn't want to be associated with me. If other people found out I had AIDS, it was going to wreck him socially and at work."

Another man felt rejected when his friend left him. "My best friend moved away -- far away," he said... "It was a time when I depended on him -- a time when I was very vulnerable... I think there was an element that he couldn't

-- that he didn't -- want to deal with me anymore."

Some men who were interviewed offered reasons other than AIDS for the rejection of friends. "It's not so much the AIDS thing," said one. "It's the death thing. I have one real close friend who just kind of backed away, but I knew even before I was sick he had trouble dealing with death, period."

Still another blamed himself. "I tend to be very cautious in dealing with other people on an emotional level," he declared. "I probably shun more people than have shunned me -- rejected them before they rejected me. I knew what could happen if people found out."

"So many people have been supportive and call me and write me," began one man. "The diagnosis has pulled us closer together." Then he added, "I've got support all around me and I still feel isolated."

Other men said they had become more selective about friendships. "With some people, I'd rather have them remember me the way I was," said one. "I used to be very energetic. I could dance all night. I just don't see these people that much because my life has changed so much, but, strangely enough, I've grown closer to other people and I've made a lot of new friends."

Many men in the study discussed the impact death has had on the gay community and their relationships. "Have my relationships changed?" asked one man. "Yes, they have. Not so much because I'm HIV positive, but because so many

of my friends have died. The friends with whom I used to do a lot with -- the friends with whom I had a lot in common -- are no longer there."

Another indicated he had known 80 people who had died of AIDS. "I used to go into a gay bar five years ago and know everyone," he said. "Now I'd be surprised if I knew five people there. Plus, the disease as it strikes people my age has really wiped out a large part of my social circle. And I'm sure there are a tremendous number of people who are sick and I don't even know. Or they're dead. These are the people who just drop out. Unless you see an obituary or hear about it from friends, you don't know. They move or go back home to die. They get embarrassed about any of their friends seeing them... They actually pick up stakes and move somewhere."

"Sometimes I wonder if I'll have friends left to come to my own funeral," mused one person.

Another declared that he tried "not to become obsessed with death, but when you've been with good friends when they die or when your social life starts revolving around memorial services to the tune of three a month, it's hard not to be conscious of death."

This same man told a poignant story about the death of a friend. "In the last 2 1/2 weeks he [the friend] always emphasized life," explained the man being interviewed. "He wanted to be involved in everything that happened to him... We'd bring him his pills, and he wanted to know exactly

what those pills were. It was his way of maintaining control. His sense of humor never left him. He remained conscious up until a half hour before he died... That morning we knew he had taken a radical change, and we called the hospice nurse. We never kept anything from him. After she examined him, we asked her, 'What can we expect?' She said, ' \_\_\_\_\_ is entering the death phase and he probably will go in the next 48 hours.' He just sort of nodded. As the day went on he went downhill very quickly. Near the end, he looked up at us and said, 'Isn't this the pits?'"

"I'm walking around so full of grief," said another person. "A good friend of mine died 2 weeks ago, and I was in a car on the way to his funeral, and I found myself turning around and going shopping. I just found myself turning around and going the other way. I didn't even question it. I said this is what I need to do right now."

FAMILIES OF ORIGIN (PARENTS) -- Men who participated in the study came from all kinds of families, and most reported that their families were supportive. "I don't know what substitute there is for a family," said one man who lived alone. "Who else is going to love me the way my family does?"

"My dying is the issue, not AIDS," said a 27-year-old who, a few months after the interview, returned to his family home to die.

"There is a great similarity in our lives right now,"

declared another man, speaking of his parents. "Lots of their friends are dying -- of old age; lots of my friends are dying -- of AIDS. These common experiences have brought us closer together."

Thirteen men with AIDS had both parents still living, the mothers of 2 men had died, the fathers of 4 men had died, and one man had lost both parents. The father of 1 man in the ARC-HIV positive group had died. Parents of 3 men with AIDS and parents of 1 individual who was HIV positive were divorced. One man with AIDS and one with the virus had been adopted. Two persons with AIDS said they had been abused as children.

Parents of half of the men with AIDS lived in the Washington, D.C. area or within 500 miles of the person interviewed. Parents of 5 men lived approximately 1000 miles away, parents of 4 men lived about 2000 miles away, and parents of 1 lived 3000 miles away. Three of the people with ARC-HIV positive had parents living in the Washington, D.C. area, and 2 had parents living about 2000 miles away.

The majority of individuals in the survey indicated they were much closer to their mothers than they were to their fathers. Men in both groups were in closer contact, in person or by phone or letter, with their mothers than with their fathers. A total of 55% (11) of the men with AIDS chose their mothers as the closest family member. Only 5% or 1 man selected his father, and that was an

instance when the individual said he could not choose between his parents and a sibling -- that all were equally close. In the ARC-HIV positive group, 60% (3) named their mother and 20% or 1 person named his father as the closest relative. A total of 30% (6) of the men with AIDS said they were least close to their father and 5% or 1 individual said he was least close to his mother. People in the ARC-HIV positive group did not name parents as the least close, but named other relative/s. (See Table 5 for data on which family member/s closest to men in study.)

Mothers generally were described as nurturing and supportive. "When I started AZT" said one man, "Mom knew more about it than I did."

"My mother wants to understand," declared another. "She takes my [AIDS] literature. She talks to me. She comes to visit me. I ask her, 'Mom, are you afraid to stay with me -- knowing my lover and I have AIDS?' She says 'no'."

"When my mother bought cemetery property, she bought a plot for me," explained another. "She doesn't want me to be alone. Even if I die, at least there's a place for me."

Fathers were often described as distant, and the introduction of AIDS into the relationship had either lengthened that distance or, conversely, shortened it.

One man abruptly interrupted a statement on how well he was doing and said, "There is a non-happy point in that sometimes you lose some of the things you thought that you

Table 5. WHICH FAMILY MEMBER IS CLOSEST

RELATIONSHIP	<u>Men With AIDS</u>		<u>Men With ARC-HIV</u>	
	No.*	%	No.*	%
Father	1	4	1	14.3
Mother	11	44	3	42.8
Brother	4	16	1	14.3
Sister	8	32	2	28.6
Female cousin	1	4	-	-
	—	—	—	—
Totals	<u>25</u>	<u>100</u>	<u>6</u>	<u>100.</u>

\* Some men named more than one relative

had before -- such as maybe my father's love. I shouldn't say my father's love -- his love is still there. It's just his closeness. My father didn't suspect I was gay and then had a double blow. It was a big shock. When I see him he'll talk about any subject except AIDS"

One of the men in the study said his father assured him that he wouldn't disown his son, but that he was "terribly disappointed" in him. The man continued, "He doesn't want any of his friends or relatives to know about it. I know it's the issue because they live in a small town. In fact, if I have to go to a hospital when I'm visiting, I have to go to [a nearby city]. He feels that I led a life of sin."

One of the men said that his father was embarrassed and very much afraid that people he knew would see his son on a television program about AIDS. "I feel very distant from him," the son explained. "There is a coldness between us. It's so hard to talk to him. I've tried in birthday cards and stuff to say 'Dad, I really do love you.'"

Another man with AIDS told of his father's death. "I feel cheated because my father and I have never been close," he said. "I really feel cheated because after I told my father (about AIDS) -- two months later he died. I feel -- not really guilt -- I feel cheated and I feel like I cheated him. I really feel cheated by him leaving me. I really feel he shouldn't have done that to me. I'm already dying, so why is he going to die before me? It was the

first time I ever heard my father say 'I love you.' I really feel cheated out of my daddy. I think I could deal with things better right now if I still had my daddy."

He was not the only man who told of his father showing affection for the first time. "My dad's not an emotional person at all," explained one. "He came to the hospital. One of the nurses had just put a thermometer in my mouth, and he held me, and I almost lost it. It was such an uncharacteristic thing for him to do. I almost broke the thermometer... It was a very emotional experience. We had never touched before."

"AIDS has definitely opened new doors with my father," said another man. "We had a lot of unfinished business. We were able to get through it and put some of it aside and go on, although it was very, very, very painful. He was very disapproving while I was in the hospital. In the therapy session he admitted he didn't like the part of me that was gay and I didn't like it either some of the time, but we both had to go on from there. We told each other 'I love you.' We had never done that before."

Virtually all the men said that telling their loved ones (lovers, children and families of origin) that they had AIDS or a form of AIDS was the most difficult thing they had ever had to do. Many men cried as they told the interviewer about telling their parents. All but 1 man with AIDS had told families of the disease, but 2 had only told certain members. One man in the ARC-HIV positive

group had not told his family, and the other 4 had only told certain members. (See Table 6 for information on family reaction to diagnosis.)

One individual expressed anger that he had not had the option of telling his parents. Another relative had done it for him. "It's all right to ask advice or it's all right to ask someone to be there when you tell your family," he said. "It's even all right to ask someone to tell your family for you if you can't handle it. But it's my decision. It is not up to anybody else to make that decision. You're telling your parents you're going to die and nobody else has that right unless you give them that right."

"I remember when I was in the hospital and I was diagnosed," related one of the men with AIDS. "My lover was there and my father was in the room. And the doctor said 'pneumocystis.' My lover and I immediately realized what that meant, but my father was sort of confused. He didn't know and I had to tell him. That was probably the worst day of my whole life... My dad was totally stunned. He sat there hitting his forehead with the palm of his hand -- crying -- saying 'I can't believe this' over and over again. That was a really terrible feeling, thinking my parents would have to bury me rather than the other way around as it should be."

Another man said, "I would do anything not to hurt my mother, but I can't help having been born this way. I was

Table 6. FAMILY REACTION TO DIAGNOSIS

RELATIONSHIP	<u>Men With AIDS</u>		<u>Men With ARC-HIV</u>	
	accept	reject	accept	reject
Father	10	4	3	-
Mother	14	2	3	-
Brother	13	6	2	-
Sister	23	1	3	-

never promiscuous -- I always had to have an emotional attachment. She's had so much sorrow in her life. I hate to add to it."

One of the men had called his family together a week before the interview to tell them that he had been diagnosed with the virus. "There were some tears," he said, "but also a lot of support. I'm really concerned about what the long term effect is going to be. I've been on the phone to each of them three or four times this week just checking up -- saying 'are you okay?'"

Another man with AIDS wrote his family a letter. "I told them I was gay. I told them I didn't believe God was punishing me. I told them that they shouldn't feel guilty about this because God isn't punishing them either. I told them I didn't choose to be gay. I told them that I had to escape [hometown] -- That it was a restrictive society and it was driving me crazy. It was driving me to the edge of suicide." Although he hears from his parents now and then, they have never mentioned the letter.

Sometimes there is a more kindly conspiracy of silence. "My mother is very supportive, but it's still something we don't talk about," reported one person. "My impression is that it's not that she doesn't want to talk about it, it's that she just doesn't know how to bring up the subject."

"I think they're [the interviewee's parents] blocking it," said another man whose lover has AIDS. "They know

he's on Interleukin-2 [a cell growth factor used in the medical treatment of people with AIDS]. They know he's on AZT. I think there's a barrier they're not comfortable going beyond. For me, that's okay."

Perhaps this conspiracy of silence about AIDS is a carry-over from an atmosphere of silence surrounding the men's homosexuality. Although all but one of the men previously had told at least some family members about their homosexuality, "it was just something we never discussed," explained one man.

"I told my mother I was one -- gay, and two -- had the virus," said one individual. "I asked, 'Mom, did you know I was gay?' and she said 'of course.' She knew all along. It was just something we never talked about."

"Why don't you start dating some women and stop going around with these men?" one man's mother asked -- as close as she ever came to a discussion of her son's sexual orientation.

"Yes, they know I'm gay, but we don't talk about it," said another. "At one point, Mother said 'I don't know what your relationship to [lover] is.' I said, 'We're lovers, Mother,' and she quickly added, 'and I don't need to know.'"

One individual who said he had never had a conversation about his homosexuality with his parents, reported, "They just know and they tolerate it." He went on to tell how he and his lover have entertained his

parents as houseguests on numerous occasions.

Six of the men with AIDS said they had told their parents that they had AIDS and that they were gay men at the same time, known as the "double whammy" in the gay community. Charts of the 30 gay men with AIDS who had been hospice patients reported that 2 had told parents simultaneously, however hospice personnel indicate that this information might not be included on patient records.

"I was dying," one individual explained in the interview. "I told the doctor in intensive care to tell my parents. He told them I had AIDS and I was dying which meant that I had had homosexual relationships -- so they had to get all three things... They couldn't believe it, but my dad said, 'You've been a devoted son all these years. You're our son and we love you'."

Another man told a similar story. "I was in the hospital," he related. "The doctor said, 'What do you want to do? Your mother and father are here. Your sisters are here. Your wife is here. They want to know why you're not responding to treatment. We know what the problem is...' I was very close to death at the time. If I hadn't dealt with some of those issues then, I would have lived my whole life not knowing who I am or what life is about. So at that moment I said 'tell them.' That simple statement -- 'tell them' -- was a tremendous relief."

Parental involvement with the hospice patients ranged from reports of "very supportive" to notes that "family is

estranged" or "family not involved, caring or interested." Parents were involved in 53% (16) of the 30 cases, there was minor involvement in 10% (3) cases, no involvement in 33% (10) cases, and one patient's parents were dead. Both parents were listed as primary caregivers 6 times, mothers were listed 6 times, and fathers were not listed.

FAMILY OF ORIGIN (SIBLINGS) -- All of the men interviewed had siblings. Of the 20 men with AIDS, 16 had sisters and 17 had brothers. There was a total of 28 sisters and 24 brothers. In the ARC-HIV positive group, 4 had sisters and 3 had brothers, and they totaled 6 sisters and 6 brothers. The number of children per family ranged from 2 to 8 in the AIDS group and from 2 to 4 in the ARC-HIV positive group. Of the men with AIDS, 9 were youngest, 7 were middle children, and 4 were eldest. Of the ARC-HIV positive group, 2 were eldest and 3 were youngest. (Half brothers and stepbrothers and sisters were counted in the sample if they lived with the family of origin.)

The majority of men in this study tended to be closer to their sisters than to their brothers. "She's the first one I told because she knows the most about the politics of the family -- How to tell people things and how to communicate well," said one man with an HIV positive reading, talking about his sister. "There is no problem communicating on any subject. I just call her up. She's volunteered to go to Israel for me to pick up a breakthrough drug the Israelis are working on."

When individuals were asked which family member they were closest to, 40% (8) said a sister and 20% (4) said a brother. Another man described being closest to his female cousin who he said "was just like a sister." In another part of the interview, the majority of the men indicated they were in much closer contact, in person and by phone and letter, with sisters than with brothers. Men with AIDS were least closest to a sister 20% or 4 times, and least closest to a brother 35% or 7 times. In the ARC-HIV positive group, men said they were least close to a sister 60% or 3 times and least close to a brother an equal 60% or 3 times. (See Table 7 on contact with siblings.)

When asked whether family members were supportive since learning of an AIDS diagnosis, men reported that more sisters (23) were supportive than brothers (13), although their total numbers were almost equal. Four of the men with AIDS volunteered that their sisters had offered to care for them. Only 1 sister was reported to have shown rejecting behavior, while 6 brothers had been non-supportive.

More of the individuals in the study divulged they were gay to their sisters than to any other family members, and sisters were far more supportive of this fact than other relatives. (See Table 8 on homosexuality and the family.)

This closeness between men with AIDS and their sisters is borne out in the review of the 30 hospice charts.

Table 7. CONTACT WITH SIBLINGS \* #

	<u>Men With AIDS</u>	<u>Men With ARC-HIV</u>
<hr/>		
Saw Within Past Month		
Brother	9	2
Sister	13	2
Contacted by Phone, Letter Within Past Month		
Brother	12	2
Sister	25	5
Saw or was in Contact with More that 12 Times in Past Year		
Brother	10	3
Sister	22	5

\* Of 20 men with AIDS, 16 had sisters, 17 had brothers.  
Of 5 men with ARC-HIV, 4 had sisters, 3 had brothers.

# In the AIDS group, there were 28 sisters and 24  
brothers. In the ARC-HIV group, there were 6 sisters  
and 6 brothers.

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Table 8. HOMOSEXUALITY AND FAMILY

	<u>Men With AIDS</u>	<u>Men With ARC-HIV</u>
<b>Who First Told</b>		
Father	-	1
Mother	3	1
Both parents simultaneously	3	2
Brother	4	1
Sister	7	3
<b>Supportive Reactions</b>		
Father	5	3
Mother	5	4
Brother	9	1
Sister	20	4

Sisters of 13 patients (out of 20 patients who were shown to have sisters) were involved to some extent in the care of their brothers. This care varied from being the only primary caregiver to one notation that the patient's sister was the "most involved in the family." Sisters were listed as primary caregivers 3 times, brothers once.

Professionals in the field of AIDS also have noted that sisters are deeply involved with men with AIDS. Dr. John Patten of New York City's Ackerman Family Institute, which is pioneering family therapy with people with AIDS, their families, lovers and friends, told a 1986 Networker Conference workshop on AIDS that he had observed this phenomenon (March 21, 1987). William Ceyrolles, social worker at Whitman-Walker clinic, said that staff had noted that many sisters were supporting their brothers emotionally, and clinic personnel were even thinking of starting a special support group for sisters (personal communication, April 28, 1987).

Judging from the experience of many of the men interviewed, sisters serve not only as confidants and support persons to the person with the illness, but as pipelines and support to other family members. "When I was diagnosed, I didn't want to tell my parents on the phone," explained one man. "So I told my sister and asked her to tell my parents." "I told my sister first so she could support my mother," said another.

One individual, who listed his sister as the family

member to whom he was closest, explained, "It may be the closeness of generations. [We] grow apart in different directions, but share something of the past. You have more in common than with your parents. My sister came to my first support group. She loved it. She loved meeting the people. It was like an education. This illness, my sister says, is really affecting a lot of people -- What they've done with their lives and how they've treated people and some of their own actions -- It's a catalyst for change -- a very positive catalyst."

"Even before the disease, my sister and I had become much closer," said one man. "And the disease has made it even more of a bonding."

"My sister gives me full and total support," still another man reported. "But I am deeply, deeply hurt about my older brother." The brother and his wife, described as being members of a "very conservative church," refused to allow the younger brother into their home because of concern about possible contagion. The sister became so angry that at the time of the interview, she was not speaking to the older brother.

Some men felt their brothers just did not care. One of the men who tested positive for the virus said that he had not told his family. When asked how he thought family members would react, he replied, "For my brothers, it would be non-concern. They probably wouldn't be upset about it one way or the other." Another man told of writing his

brother. "He's the one person I have lost. I wrote to him and told him I have AIDS, and I haven't heard from him."

Even if brothers were seen as supportive, they were not always open in their discussions. The conspiracy of silence, which existed between some men with AIDS and their parents, also sometimes existed between siblings.

"I have discussed my sickness most with my brother and his wife," said one. "I've told them essentially what I have without using the words 'AIDS' and 'K.S.' They know that I have an immune deficiency factor and that that was a factor in the neuro-muscular troubles that I had. [They know] that now I have skin cancer, which is not being treated and that I have maybe a couple of years to live unless things change. They may be smart enough to put two and two together and figure out what I have."

FAMILY OF ORIGIN (EXTENDED FAMILY) -- Sometimes extended family members were as important to the men as immediate family, and their words had either soothed or wounded. Four persons described incidents where they were barred from homes of relatives because of the fear that they might transmit the disease to children.

One man said that his aunt "told me I shouldn't be at my father's funeral. She told me she would be glad when I died. She told me I was an embarrassment to the [family] name."

Another man's aunt told him "homosexuals were worse than murderers."

"My grandmother calls and asks me how I am," said another. "Before I have a chance to answer, she says 'you sound a lot better.' So why does she ask?"

CHILDREN -- Among the 7 fathers in the study (4 in the AIDS group and 3 in the ARC-HIV positive group), there was considerable variation in their relationships to their children. One of the fathers took on the job of custodial parent when his wife left him and their infant children. The adolescent son of another man lived 1/2 time with his father and the other 1/2 with his mother. On the other hand, one father had not seen one of his children for more than 6 years, and another had not seen his daughters for more than 10 years. The children of another man had died as infants.

"AIDS makes you face your own mortality," said one individual. "I am trying to reestablish contact with my children."

Only one of the fathers had told his children about the illness, but another suspected that his ex-wife had done so. Other fathers said they dreaded telling their children. "My son knows that I've been exposed," said one. I intend to tell him on [a specific date]. That's going to be the most difficult thing of all."

EX-WIVES -- Most of the men in this study who had been married had remained close friends with their ex-wives. Five of the 8 ex-wives (one had died), on being told of the diagnosis, had offered to care for their former husbands.

Only 2 of the men said they were never in contact with their ex-wives. The men had married at an early age, 20 years old median. The range was from 17 to 31 years of age. Median duration of the marriages was 8.5 years, and the range was 4 to 20 years. (These figures exclude one marriage in which the wife died after a year of marriage).

LOVERS -- "He's family," said one man about his lover who was dying of AIDS. "Ever since I knew I was gay, I always wanted to have someone to love me."

Of particular concern to those in the field of family therapy are those family systems which are significantly stressed with this disease and its devastating toll. The term "family" must be looked at in a new perspective when considered in its relationship to gay men who have AIDS and its associated diseases. While it has been estimated that approximately 10% of the population is gay or bisexual (Gong, 1986, p. 179), a recent 5-year field study suggests that gay men comprise 4 to 5% of the U.S. population and indicates that this figure is stable in all societies and over time (Marmor, 1985). Despite a lack of social sanction and support, gay males are capable of forming long term relationships (Testa, Kinder & Ironson, 1987). More so, the AIDS epidemic has brought new impetus to gay men to protect themselves by forming partnerships (Carl, 1986; Witt, 1986, p.126).

More than half of the men in the study had lovers at the time of the interview. Of the men with AIDS, 10 were in

relationships (1 with 2 lovers, 1 on each coast), 10 were not. Of the ARC-HIV group, 3 were in a partnership, 2 were not.

The 10 men with AIDS had been in relationships with the same person for periods ranging from 3 weeks to 15 years. The median length of time was 6.5 years. The mode was 1 year with 3 men having started relationships within the year prior to the interview.

The 4 partnerships in the ARC-HIV positive group had lasted from 1 year to 11 years. The median length of time was 4 years. Again the mode was 1 year with 2 men having begun relationships in the year preceeding the interview.

One of the men in the ARC-HIV group said that he was in a relationship but added, "That is ending. We are breaking up, but we are doing it in an adult fashion. We've been through so much together, but our relationship is changing. I'll be single again, and you know how much I'm looking forward to that." Later in the interview, he named his lover as the person closest to him.

While this relationship was ending, another was beginning. One man with AIDS explained, "I even have a romantic interest going on with someone else who's a PWA [person with AIDS]. I never thought I'd have that again... We courted each other. There might be something good about AIDS. It has brought romance back. So we've been seeing each other for a few weeks now... It's so nice to have someone special. I have close friends, but it's nice to

have someone to cuddle up to... I thought, 'we'll just handle this like normal people and take our time'. Then I thought 'wait a second, our days are numbered'."

The devastating stress of AIDS was evident as men in the study described the strains in their partnerships. The overwhelming grief of facing the loss of a lover was foremost. One of the men whose lover died of AIDS and who later died of AIDS himself said, "God, if people could only know what it's like to lie there and hold your lover and to let him cry when he's afraid -- or to reach over in the middle of the night to touch him and to feel his ribs. It's not easy when you're 24 years old."

"I was pretty much destroyed," said another person whose lover had been diagnosed with AIDS. "It was tremendously difficult. Fear, incredible fear. Panic. Not for myself. No, definitely for myself. The fear of losing him and the fear of the rapid progression of the disease... The doctor told him he had two years to live... The first year I frequently cried myself to sleep. Very softly, so he didn't hear."

Financial concerns also created stress for lovers. An individual in the ARC-HIV positive group who had taken a lesser paying job since his illness, explained, "We're carrying over a lot of debts from a lifestyle which was once very easy to maintain... We're barely getting by right now... I guess what hurts me a lot about it is he never had much as a kid and this is the best he ever had it. Now he

has to give up things and that hurts me because I see myself at the center of all of this. He keeps reassuring me and says that we're both at the center of this. He's very supportive... And if I were to get sick, it's going to get even worse. I've been with a number of my friends. You slowly have to give up everything. The financial burdens become more and more... Whenever I think about AIDS in my own life, that's what I think about. I don't think about the dying or suffering -- any of that -- I think about what it's going to mean to \_\_\_\_\_ and me and our relationship."

Some of the men with AIDS felt that emotional support was not forthcoming. "Sometimes I don't think the sympathy I would like to get is there," explained one man with AIDS. "My problem is I used to be overly dependent. If I try to rely too much on him for my support, I'm not going to get it. So I've stepped back from that relationship... We're still together and we're still friends, but we're more like roommates now than lovers."

This was not an unusual statement. Most of the men with AIDS indicated that they had lessened or withdrawn entirely from sexual activity. "Our relationship has changed," said one man whose lover has AIDS. "It is largely, although not entirely, asexual... Despite that, we are a lot closer than before. There's always a question in homosexual relationships, based on statistics, about how long a relationship is going to last. It's clear to me

that this one is going to last until one or the other of us dies. It may change in some ways, but it's not going to change in ways it may have before the diagnosis."

Withdrawing sexually was not the only way men with AIDS distanced themselves from their lovers. They told of disengaging in many ways from the intimacy of a monogamous relationship.

"My lover of 10 years is having a hard time of it," said one of the men with AIDS. "Not that he rejects me... but I think our relationship over 10 years has changed. I'm not sure where to pin it. It's become old after 10 years or AIDS is playing a part in it. It doesn't seem as intimate and close as it was before. The friendship is the same, but the intimacy and being able to tell someone everything is not."

Another man with AIDS indicated that he didn't tell his lover [he had AIDS] for several weeks following diagnosis. He then asked a friend to be there for support when he did. "My lover [who is HIV positive] is in a never-never land waiting for the other shoe to fall," he said. "'I know where I'm at and I have support. He doesn't know where he's at. He doesn't have any support."

This man and two other men with AIDS who had longtime lovers took extended vacations without their lovers about a year following diagnoses. "Having done that on my own, now I feel like I can do anything," said one.

One individual told of buying a condominium in

Florida. "It will separate me from my lover in the winter months," he said, "but I've been wanting a place in Florida for years."

Another man said he spends half the year in another part of the country with a new lover who was described "as a very, very good friend who came to my rescue when I was diagnosed."

While some of the men with AIDS told of "stepping back" or distancing themselves from relationships, some partners of men with AIDS expressed hurt and resentment that they were being excluded from their lovers' lives.

"He just locked everything inside," said one man whose lover had died of AIDS a year prior to the interview. "He was really tortured psychologically. I felt a lot of guilt because he wasn't able to trust me. His financial picture was a disaster. He'd been married and divorced. There were lots of things about his life I was ignorant of. I don't know how he did it. I don't know how he juggled all that. He was one of those individuals who can keep everything all separate. I guess you'd have to say he lied a lot and told different people different things to keep all those different factions separate... It was just exhausting. So I think by the time he got to the hospital it was just give-up time. That's the hardest part of my grief -- To think that you know someone so well and you really don't."

Another lover of a man with AIDS expressed his

frustration at not being taken into his lover's confidence. "At the time it didn't bother me (pause) a whole lot," he said. But I just found out that a friend -- a very, very close friend who had a masectomy a year ago -- has discovered growths in her other breast. She didn't tell me... So I'm beginning to wonder. What character fault do I have that my closest friend and my lover see in me that they withhold this information from me?"

The lovers of two men had died and the lover of another was near death at the time of the interviews. These men were not only dealing with all the ramifications of grief over the loss of a loved one, but with fear of contacting the disease themselves.

"I was terrified for myself and I was terrified for him," said one man who now tests positive for the virus. "I really didn't believe he could die until 3 or 4 days before he did. He knew much earlier than that, I found out in retrospect. But he died, and that was the introduction to all sorts of things happening after that. It was my first experience with death... I only lived with him for 6 months, I only knew him for a year, but the impact on my life is such that I've never been the same."

A young man told about his guilt. "I feel so guilty because sometimes I wish I wasn't there. It's so damn stressful watching him die."

There are many stories of animosity between lovers and the families of partners with AIDS, but survivors in this

small sample report differently. Most of the men with lovers said that they interact with their "in-laws" just like heterosexual couples -- sometimes in harmony and sometimes with friction. Two individuals said that they had stayed with their lovers at the parental home while recuperating after hospitalization.

A lover of a man who died had never met his partner's parents. "It was all very surprising. Everyone from his colleagues, his peers, his family [were supportive], and there never had been any clearcut discussion in his family about his sexual preference, his lifestyle, or his illness. In one day, in one fell swoop, he's in the hospital, he's not going to make it. You'd better get here. I had never met any of his family before or any of his colleagues, but they were all wonderful. They couldn't do enough. They accepted me and they did everything they could for him. They could not have been more supportive." This man, more than a year after his partner's death, remained in touch with the family and said he expects to continue to do so.

Another man told of the circumstances following the death of his partner. He said that his lover had asked that his body be cremated and that his ashes be scattered in a favorite city. "His parents insisted on a traditional open casket funeral and viewing," he explained. "The funeral directors gave instructions to the family not to touch the body [because of AIDS]. At the viewing when I knew the funeral people weren't looking and his parents

were watching, I went up and kissed him on the forehead so that his parents would know that this was bullshit. I felt great sorrow for his parents. They were devastated. The funeral was difficult because it wasn't what he wanted, and there was no way I could stop them from doing it."

#### WHAT WOULD THEY CHANGE

At the conclusion of the interview, each person was asked, "If you could change one thing, what would it be?" Understandably, to be rid of AIDS was the most frequent answer (12). However 9 men in the AIDS group of 20 gave other replies. In the ARC-HIV group of 5 men, there were 3 men who wanted to be rid of AIDS and the virus and 3 men who offered other replies. (One man in each group suggested 2 changes.)

The answers varied tremendously. Some dealt with finances. "I'd probably want to be rich," said one. Another named doing away with AIDS but added that he would like to change his financial circumstances.

Other men wished that they were not homosexuals. "I would be a heterosexual," was one very succinct comment. Another fantasized: "I'd be married with kids and living in a community somewhere instead of having all that comes with this. I wish I'd gotten straightened out so I didn't have this disease." Another explained, "If one had a choice, being gay is not something one would rationally choose in this society in the time in which we live. Both things [AIDS and homosexuality] are beyond my control."

One of the men told of his unhappy childhood. "I suspect I'd change something in regard to the pain in which I grew up," he said. "I didn't come out until I was about 25 years old. Until then I lived a life of isolation. In a sense a different kind of isolation, but along the same line as the isolation I feel right now., So if there were something I would like to change it would be that kind of isolation -- that kind of pain... Yes, that's something I'd like to change. I'd like to look back and say, 'No, I didn't have a painful childhood'. And that would have changed the course of my entire life."

Another man spoke of his adulthood. "Speaking selfishly, I wish I hadn't gotten sick," he declared, "but I don't have any guilty feelings or remorse over that. I've had a lot of guilty feelings over the course of my life over things that have happened, and I've had to work hard to turn that guilt into something a little more constructive. When my wife and I were divorced, which was directly related to my being gay, I had a lot of guilt about leaving my family and my children. It was a tough period. But I can't say I want to change that. I wouldn't want to say I wish I hadn't gotten married and had a family. It was one of the best things in my life. I wouldn't want to say I wish I weren't gay because I've known a lot of wonderful people and had some wonderful experiences. I wish I hadn't gotten sick, but what can you do?"

"Get rid of the virus," said a man who has it. "That's definitely it. Years ago I wouldn't have answered it that way. I would have said I want to be a more effective charity fundraiser, or maybe I would have said I want more time with my son, but I'm not even sure that's the answer because we're close and the time we spend is real good time."

A man who tested positive for the virus and whose lover died of the disease said he would prefer not knowing he has the virus. "I guess I'm a fatalist in many ways. I've got the virus, and it's obvious how I got the virus, but there were a lot of beautiful wonderful people that I've met. In the course of my life I don't regret anything. But knowing has made life more difficult for me."

"One thing is, I have no regrets," concurred another person. "There might have been a couple of things I could have done differently, but I'm not going to sit around and worry about it... I wish I'd pursued the piano more than I did, and I think I probably would have liked a longer relationship -- an ongoing relationship. But you know the song Edith Piaf does, No Regrets? That's my song."

Another man had many regrets. "I wish I'd known then what I know now... in the sense that I've turned my life around," he explained. "I've become very religious. I have a strong faith in Jesus Christ. I've grown a lot spiritually and emotionally. I'm just so sorry that for so

many years I was so confused. I was lost in a world so many people are lost in -- success and making money. I've really found out what life is about. I wish I could have found out earlier. I would have enjoyed so many more years of knowing who I was and what I wanted to be."

The world would change if one individual had his wish. "Do away with national chauvinism, which I guess would change human nature," he said. "Have a more peaceful population, end war and conflict -- they are so counterproductive. We could have cured this thing by now if there weren't the jealousies and big military budgets and conflicts we have to deal with. We would have been aware of it much sooner. We would have known what was happening in Africa... AIDS is a symptom of what can happen when you lack global unity."

As grim as the prognosis is, some saw positive aspects. It was not unusual for the men to talk about the "benefits" of AIDS, and how their lives had changed for the better. "My first inclination is AIDS," said one man whose lover had died of the disease, "but there have been many beneficial aspects. I'm a better person because of AIDS. The pain is overwhelming sometimes, but I don't know if I would change anything."

One man said he would change the "fact of AIDS", then declared, "However, I don't think I've ever been happier in my life. I feel like I have a calling to educate other people. I feel very fulfilled and if I die tomorrow, I

feel like I've lived for everything I've wanted."

"AIDS offers an opportunity for compassion," explained another individual. "It's not a word I would have used years ago, but compassion has become very important. Just to be able to listen to other people. Just to be there and to be partners with people as they go through life."

"I'd change the amount of energy that I have so I could go out and become more active in the AIDS ministry," offered another. "There have been so many changes already that have been positive since [the diagnosis] that I'm a different person now."

"I wish I didn't have to die," said another. "Now I'm looking at life with so much to live for. When you have what the media calls a death sentence, you look at things so differently. You look at places you go. Every trip I take I look at it as maybe being there for the last time, and I enjoy it to the fullest. I look at the birds and what they're doing. I may not see that again."

Another man agreed, "The interesting thing about confronting mortality is that birds sound fabulous."

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**APPENDIX A**  
**Interview Guide**

INTERVIEW GUIDE

1. Can you tell me a little about yourself? age \_\_\_\_\_  
 (Ask, if he fails to mention any of first three) occupation \_\_\_\_\_  
 residence \_\_\_\_\_  
 personal history \_\_\_\_\_  
 AIDS \_\_\_\_\_ family history \_\_\_\_\_
2. What was your health prior to the AIDS diagnosis?
3. When were you diagnosed?
4. Can you tell me about the history of your illness?
5. There has been a lot in the papers and television about AIDS. Do you think it's been positive or negative?
6. Can you think of positive examples?
7. Can you think of negative examples?
8. How do you think the general public is reacting to AIDS?
9. Have you personally had any reaction from the people outside your immediate circle of friends and family since you were known to have AIDS? Were people supportive or non-supportive of you in: job \_\_\_\_\_  
 housing \_\_\_\_\_  
 medical \_\_\_\_\_  
 social \_\_\_\_\_
10. Have you been hospitalized? If so, how many times and where?

11. What has been your experience with health care workers?  
doctors \_\_\_\_\_ MSWs \_\_\_\_\_ food serv \_\_\_\_\_  
R.N.s \_\_\_\_\_ ass'ts \_\_\_\_\_ housekeepers \_\_\_\_\_
12. Do you have health insurance?
13. If not, why not? AIDS \_\_\_\_\_ not AIDS \_\_\_\_\_
14. Were you employed when you were diagnosed?
15. If so, tell me what happened.
16. How did your boss react?
17. How did your co-workers react?
18. If you are not working now, would you like to do so?
19. In your former job? In another job?
20. Can you describe your family of origin? (Do genogram.)



38. Their reactions?
39. Are you in a relationship with one person?
40. For how long?
41. How has AIDS affected that relationship?
42. Were you in a relationship with one person?
43. For how long?
44. Who broke it off?
45. Why?                      AIDS \_\_\_\_\_ not AIDS \_\_\_\_\_
46. Who is the person closest to you today?
47. Is it a different person from before the diagnosis?
48. Can you tell me about any experiences, good or bad, with other people reacting to your illness which we have not covered.
49. If you could change one thing in your life, what would it be?
50. Is there anything else I ought to know?

**APPENDIX B**  
**Informed Consent Form**

INFORMED CONSENT

I hereby authorize Nancy L. Shands to interview me and to record that interview as part of a Master's thesis study on the psychosocial impact of Acquired Immunodeficiency Syndrome (AIDS).

I understand that my name will not appear in the study or in the documentation for the study. I understand that my participation is completely voluntary and that I may terminate the interview at any time.

If I have any questions about the study, I can contact Ms. Shands at (703) 256-7215; James Ringer, AIDS program director, Whitman-Walker Clinic, (202) 332-5939; or Dr. Linda Little, director of VA Tech Graduate Center Department of Family and Child Development, (703) 698-6035. Counseling is available through Whitman-Walker Clinic (202) 332-5295 or VA Tech Center for Family Services, (703) 698-6033.

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Nancy L. Shands  
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Interviewee

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Date

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