INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

UMI
A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA
313/761-4700  800/521-0500
Speaking in voices, learning to talk: The spoken and written culture of the AIDS Foundation of Houston

Tudor, Elizabeth Jean, Ph.D.
Rice University, 1994

Copyright ©1994 by Tudor, Elizabeth Jean. All rights reserved.
RICE UNIVERSITY

SPEAKING IN VOICES, LEARNING TO TALK:  
THE SPOKEN AND WRITTEN  
CULTURE OF THE AIDS FOUNDATION OF HOUSTON

BY

ELIZABETH J. TUDOR

A THESIS SUBMITTED  
IN PARTIAL FULFILLMENT OF THE  
REQUIREMENTS FOR THE DEGREE  
DOCTOR OF PHILOSOPHY

APPROVED, THESIS COMMITTEE

Stephen A. Tyler,  
Herbert S. Autrey Professor of Anthropology & Linguistics,  
Department of Anthropology

Eugenia Georges, Associate Professor  
Department of Anthropology

Chad Gordon, Professor  
Department of Sociology

Houston, Texas

April, 1994
ABSTRACT

Speaking in Voices, Learning to Talk: The Spoken and Written Culture of the AIDS Foundation of Houston

by

Elizabeth J. Tudor

AIDS has become the most controversial issue to enter the American public discourse in the recent past. AIDS arouses a passionate response in Houston as elsewhere because it lies at the intersection between competing discourses. Contemporary debates on sexual identity, gay politics, sex education, drug use, and health care are changing the shape of public discourses on sexuality, identity, Christianity, public health, and law. The founders of the AIDS Foundation of Houston recognized the need to create a way of speaking about and understanding AIDS which could challenge unsympathetic points of view. The AIDS Foundation of Houston began its organizing and educational activities in 1981. It has become a key player in local political battles over what course Houston’s response to the AIDS epidemic would take. As part of their efforts, local groups like the Foundation use a counter-discourse which portrays PWA’s not as dangerous sources of contamination or AIDS victims but honestly represented as caring, responsible people who are actively involved in decision making and shaping public policy.

This essay explores several aspects of this counter-discourse including both its oral and written aspects. Volunteers and staff at the AIDS Foundation speak about AIDS with a Foundation “etiquette” which protects the secrecy and dignity of persons with AIDS (PWA’s) while loudly insisting on a more caring
response by the city and state. PWA's, their lovers, friends, and family publicly talk about what it is like to have AIDS in oral narratives as well as through written autobiography and biography. These narratives express the suffering and passion of people with AIDS while also speaking to the political nature of life-threatening illness. These stories confront negative representations with a language of compassion and acceptance. The AIDS Foundation also has a more conventional form of public discourse which is less emotionally intense but is persistent in demanding improved services and AIDS education. The AIDS Foundation of Houston has been successful in creating alternate forms of AIDS discourses, challenging unsympathetic discourses, expanding local services, and teaching their way of speaking to people from all walks of life.
ACKNOWLEDGEMENTS

I wish to thank the AIDS Foundation of Houston for graciously opening their doors to me and providing me with access and work space. I also wish to thank Brown McDonald, Ed Mayo, Evelyn Cox, Joyce Yost, Bart Loeser, Ed Inderwish, Bill Huvar, Bill Napoli, Gene Marcum, and the many other volunteers, staff, persons with AIDS and callers to the hotline who cannot be named. It was they who kindly allowed me to listen to their painful revelations and answered my endless questions. I also wish to acknowledge the financial and clerical support offered by Rice University during much of the research period. It would have been difficult to pay the rent without the departmental fellowships from Anthropology, the Lodieska Stockbridge Vaughan Award, and other funding.

The members of my dissertation committee, Stephen Tyler, Eugenia Georges, and Chad Gordon have been tremendously supportive throughout this project. I also want to thank Sharon Trawee who supported me in my decision to switch research topics and helped me to educate myself in cultural anthropology, discourse theory, and philosophy. Sharon has been teacher, advisor, confidant, and, most importantly, friend. I also wish to thank my teachers, advisors, employers, and co-workers over the last few years for their support and patience: Norris Lang at University of Houston-Main Campus, Doug Holmes at the University of Houson-Clear Lake, George Guilmet at the University of Puget Sound, Brigitte Jordan, Bill Clancy, Melissa Cefkin, and Melissa Francis at the Institute for Research on Learning, and Jim Edwards and Linda Fanning at Xerox.

My family and friends have been my lifeline throughout the experience. My father, Daniel Tudor, has read, re-read and proofread my
drafts and always offered cogent advice (even if I didn't always take it). My mother, Janet Tudor, kept me sane by offering me a place to escape from it all and who was always willing to listen. My friends, Terry Castaneda, Priscilla Weeks, Marcia Hall, Sunil Kukreja, Kathy Vassos, Sarah Sloane, Judy Doenges, Angelika Kindermann, and Judith Gregory have read my work, taken me out for meals, given me good advice, and offered me the encouragement I sometime needed desperately. My thanks to you all.
# TABLE OF CONTENTS

List of Tables ...................................................................................................................... ix
List of Plates ........................................................................................................................ x
Preface ................................................................................................................................... x

Chapter 1  Learning to be a Hotline Volunteer................................................................. 1

Hotline Volunteers and AIDS Talk ............................................................................... 1
Learning to Talk About AIDS ......................................................................................... 6
Foundation Etiquette ......................................................................................................... 12
Being a Hotline Volunteer ............................................................................................... 17
Caller Stories: Transmission, Testing and Fear ............................................................ 22
AFH Discourse in the Larger Context ............................................................................. 31

Chapter 2  Illness Narrative, Personal Experience, and the
Construction of Counter-Discourse.................................................................................. 35

Public Conversations and AIDS Discourse .................................................................. 35
Metaphor in AIDS Discourses ....................................................................................... 37
Theme, Motif and Narrative Structure ........................................................................... 42
Autobiography ................................................................................................................ 48
Inside/Outside ................................................................................................................ 55
Alternative Discourse: An Exemplary Person with AIDS ............................................. 59
Gary Walsh: Gay Man, Psychotherapist, Political Activist & PWA .................................. 60
Eureka? Or Things Suddenly Fall Apart ......................................................................... 65
Living with Illness ........................................................................................................... 67
Political Coming Out as Work ......................................................................................... 71
Concluding Remarks ...................................................................................................... 75

Chapter 3  Telling Tales of the Other: Biographies of People
with AIDS ......................................................................................................................... 77

Stranger, Sojourners and the Search for Enlightenment ................................................. 79
Metaphor, Theme, and Narrative Structure in AIDS:
Personal Stories in Pastoral Perspective ......................................................................... 86
"Tending the Bones": Whitmore's Tales of Being There ................................................. 92
The NAMES Project as Biography: The Houston Panels ............................................. 102
The Discursive Work of PWA Biography ...................................................................... 117

Chapter 4  The Face Turned Outward .............................................................................. 121

Lifeline: The AIDS Foundation Newsletter ................................................................. 125
Portraits of People: Poster Boys and Valiant Volunteers .............................................. 127
The Official Face of AFH: The Executive Directors .................................................... 140
Hidden Emotion and Concealed Grief .......................................................................... 151
The Interactions of Sympathetic Discourses ................................................................ 153
Final Note ......................................................................................................................... 158
Chapter 5  Conclusion: Speaking in Voices, Learning to Talk.................160

Learning to Talk the Talk..........................................................162
Discourse as a Public Conversation............................................169
People with AIDS Speak Out......................................................171
Biography as Counter-Discourse.................................................176
Conclusion..................................................................................176

List of References.......................................................................182
LIST OF TABLES

Table I: Volunteer Options .................................................. 5-6
Table II: Neuropsychiatric Effects of HIV Infection .................. 15
Table III: Metaphor and Correspondence .............................. 118
Table IV: AFH Client Services ............................................. 123-4

LIST OF PLATES

Plate I: The NAMES Quilt at the George R. Brown Convention Hall...... 111
Plate II: Robert Allen Martin’s Panel ...................................... 111
Plate III: Hal H.’s Panel .......................................................... 112
Plate IV: Aves de Houston 1990 .............................................. 112
Plate V: Michael McAdory's Panel .......................................... 113
Plate VI: Greg Moorhead’s Panel ............................................. 113
PREFACE

In Houston as in the U. S. as a whole, the AIDS epidemic represents a region of culture which is being hotly contested. What does it mean to have AIDS? Is AIDS a sign of deviance, criminality and promiscuity? Or is a person with AIDS (PWA) like anyone else who must deal with the realities of a life-threatening disease? The ways in which these and other related questions are answered reveals much about the perspective of speakers (or writers) and about how they might address issues of AIDS education and services to persons with AIDS. Those who volunteer in an AIDS organization such as the AIDS Foundation of Houston (AFH) can be assumed to have somewhat similar views about AIDS—they will consider service to people with AIDS and AIDS education a worthwhile activity. However, such a gloss conceals a great deal of diversity in beliefs and cultural backgrounds among AFH volunteers and staff. Some choose to volunteer because a family member has died or because they themselves are HIV positive. Others are active in a community outreach program of a church or university or are employed by an organization which encourages community service. Whatever the motivations, volunteers serve in positions which require emotional fortitude and the ability to resist burn out.

My research is based on my experiences at AFH as a hotline volunteer, AIDS educator, library team leader and my role as ethnographer from the summer 1987 through January of 1990. I trained with other volunteers during the weekend of June 6-7, 1987 and began working a weekday afternoon shift on the hotline very shortly thereafter. My primary informants at that time were my fellow hotline volunteers, callers, and the many volunteers and staff who worked regularly in the AFH offices. I spent about six months towards the
end of my time at the Foundation working to organize their library and archives. Brown McDonald and later Executive Directors kindly welcomed me into the Foundation and provided me with access to AFH publications, some staff meetings, the AFH library, and gave me office space in which to work.

Ethnography at the AIDS Foundation could not be carried out in the usual fashion. Due to the importance of maintaining the privacy and anonymity of callers, AFH clients and other volunteers, it was not possible to tape record calls or conversations at the Foundation. It was my responsibility as both ethnographer and volunteer to protect informants from the real threat of exposure, discrimination, and even violence. I was forced to try alternate methods and sources for my research data. After taking the usual types of fieldnotes, I would carefully rewrite my notes to delete any identifying markers and then rewrite again. Then I would destroy my original notes. In addition to my carefully worded fieldnotes and journal, I used myself as an informant. How did I respond to training? What were my own reactions to events? What kind of stories did I tell about clients and fellow volunteers? I also used published accounts which closely paralleled my observations to illustrate certain aspects of AFH culture. There were stories very similar to those I heard daily at AFH readily available in print or video form. I relied most on works written by and about people with AIDS from the Houston area, videos used in the AFH training, and material published by the Foundation such as its newsletter. By relying on these unorthodox sources, I was able to piece together material which resonated with what I heard daily at AFH but which did not contravene my ethical responsibilities as either ethnographer or volunteer.
First Person Narrative: My Own Experience

One reason that I have chosen to research the way in which people speak about illness is because of personal experience. During my late twenties and early thirties, I began to have periodic bouts of illness. Doctors diagnosed the symptoms of fatigue, joint pain, fever and rashes as influenza or some kind of virus. On a few occasions, they (the doctors) suggested the repeated episodes might be due to stress or depression. Once, a doctor even told me that I was a hypochondriac. I was definitely under stress and depressed but mostly because I began to believe my unnamed disease was my own fault. I asked myself, did I lack the energy to get out of bed before noon because I was physically sick or because I was mentally ill? More and more, I began to believe that the illness episodes were somehow my own fault, an inherent mental or emotional weakness, a belief that my doctors seemed to encourage. Finally, I even managed to convince myself that the pain and weakness was all in my imagination. I undertook psychotherapy during two separate periods to try to overcome depression and a distrust of doctors.

Finally, after a lengthy period when I was in so much pain I couldn't sleep at night, I went to see one more doctor. I was more assertive and articulate about my symptoms than before and the doctor more thorough about taking a family history. The initial clue was a family history of arthritis. Blood tests came back positive. I was diagnosed with an autoimmune disease called Systemic Lupus Erythematosus. I almost couldn't believe that there really was something physically wrong, that it wasn't all in my head. I was relieved to find out that I had a “real” illness. It was so good to know that I wasn't lazy or a hypochondriac that I was relieved (even knowing that I had a potentially life-threatening, chronic illness).
A large part of my coming to terms with chronic illness was to rethink much of what I knew about medicine and anthropology. Why had the doctors I had gone to all those years been so set on seeing my mental and emotional state of being so completely separate from my physical body? That attitude is particularly problematic when thinking about autoimmune illnesses like lupus where emotional stress and depression are as likely to be caused by the physical effects of the disease process as they are to cause flare-ups in physical symptoms. The division of mind and body into separate entities is simply not workable in such circumstances. Rejection of biomedicine’s mind-body dualism was enormously helpful in coming to grips with living with lupus. This made me aware of the interdependence of emotional states and the lived-in body. My earlier pain at being judged a malingerer or hypochondriac eased when I realized that my sensations had been the result of a dialectic interplay of physical and emotional aspects of myself.

As part of this process of rethinking my illness, I read the medical and social literature on illnesses such as mine and found that there were consistent biases or misapprehensions. Some sources seemed to blame sick people for being ill, while others misrepresented the process of trying to live with chronic illness. These distortions were even more extreme in much material on AIDS. When I realized that I could no longer pursue my original plans to do research towards a dissertation in Indonesia, I decided to begin volunteering at the Houston AIDS Foundation. From the moment I entered the Foundation doors to begin my first training session, I was captivated by AFH's attempt to redress the inequities in the medical literature and the mass media. Here were people who took what was written about themselves seriously and attempted a concrete remedy (versus a public relations fix). As I began to
learn to speak and understand the Foundation ways, I also learned to appreciate the power of words.

**Organization of the Dissertation**

The focus of the first chapter is the hotline, where I spent most of my time at AFH, but is applicable to most types of volunteer positions in the organization. This introductory chapter attempts to evoke the process by which the Foundation teaches its neophyte volunteers a new way of thinking and talking about AIDS, one which provides tools to avoid burn out and create emotional support through solidarity. It goes on to describe the experience of working the hotline, addressing the kinds of calls received and the reactions of volunteers. The second chapter examines autobiographical representations by people with AIDS and discusses the theoretical aspects of self-portrayal for AIDS discourses. I draw upon autobiographies which have some special significance for Houston such as videos used in AFH training, an anonymous essay by a local Houston man, and several other sources. The books, essays, and films that I use demonstrate particular points I found in the self-presentation of persons with AIDS at the Foundation.

Chapter Three is devoted to exploring a series of biographical portrayals of person with AIDS. Each of these speaks to the worth of PWA's and expresses the tragedy inherent in their suffering and death. The chapter discusses works as diverse as the Christian-oriented allegories by Earl Shelp, Ronald Sunderland, and Peter Mansell, the secular story of anger and illness by George Whitmore, and the NAMES Project Quilt panels which memorialize the identity of those who have died of AIDS in more visual terms. Such work, along with autobiography, demonstrate the ordinary humanity of persons with AIDS and denies images which represent them as dangerous carriers of
contagion. Chapter Four looks at a somewhat different form of biography—articles profiling volunteers, persons with AIDS, and Executive Directors in the Foundation newsletter. Here the portrayal of persons with AIDS is more like the representations of chronically ill or disabled persons in other venues. As the official voice of AFH, the newsletter cannot afford to offend or alarm readers with the kind of passionate emotions displayed in the other (auto)biographies discussed. The Foundation needs the support of the broad spectrum of Houstonians. The Newsletter does prove to be one of the few external (though implicit) signs of conflict within AFH. The presentation of a new Executive Director in the newsletter was usually the culmination of a period of conflict among volunteers, staff, and Board members, most often over the distribution of resources. All in all, I have very positive things to say about the AIDS Foundation of Houston. The few criticisms that I do have are primarily related to their representation of volunteers and persons with AIDS in the newsletter, to the concealment of conflict within AFH or to the structural organization of the Foundation as a whole. None of these points should be taken as a rejection of the tremendous accomplishments of AFH or of the wonderful people that I met there. I was privileged to be able to work with such dedicated, caring people and will always treasure my memories of the time I spent there.
Chapter One

LEARNING TO BE A HOTLINE VOLUNTEER

Hotline Volunteers and AIDS Talk

Hotline volunteers talk to callers about almost anything: sex, family, fidelity, secrecy, death, sexual orientation, symptoms, the latest newspaper article, drugs (legal and illegal), testing, suicide, politics, food, money, government bureaucracy, and all the other myriad ways that AIDS or the fear of AIDS affects people's lives. Hotline workers must learn how to talk knowledgeably about and to be comfortable with topics that many people find distasteful, embarrassing, or immoral. This type of work requires not only training in medical and epidemiological areas related to HIV (human immunodeficiency virus) infection but also in techniques to become more at ease and nonjudgmental about the intimate details of callers' lives. Many physicians and other health care workers, who are presumably well informed on medical subjects, are often averse to or avoid talking to their patient's about sex, drug use, and emotions (Merrill, Laux, & Thornby 1987).

Hotline volunteers, like most AIDS Foundation Houston volunteers, begin their service with the weekend training session:

Early that Saturday morning, I arrived for the weekend training at the AIDS Foundation and the offices were quiet and mostly deserted. I searched briefly for someone to direct me and finally found the training room in the far corner. The building looks to have once been doctors' or dentists' offices. It is organized around the central core of maintenance rooms, a kitchen, and rest rooms with a square of

1 All volunteers except those involved in purely clerical, fund raising, or other office activities participate in the training weekend.
corridors and offices (varying in size) radiating outward. The training room [is] an unremarkable room, about 10 by 15 sq. ft., in the process of being remodeled and had stackable chairs arranged around the walls. A variety of rather sleepy people, mostly men, waited quietly for the seminar to begin. Soon we were woken up when a few newcomers began bustling about and preparing for the day long session. The three trainers were all men. I later learned that the usual AFH practice is to have one professional counselor, one gay man, and one long time volunteer teaching the seminar (Journal: June 6/7, 1987).

This 24 hours of training includes reviews of medical, epidemiological, and clinical facts, basic counseling techniques, the literature on death and dying, health education tactics, and introduces volunteers to the many problems that persons with AIDS are likely to confront in their daily lives.

There were fifteen potential volunteers, ten of whom were men and five, including myself, were women. We began by introducing ourselves and explaining why we were interested in volunteering. All of the men were gay, some knew that they themselves were HIV positive while others had friends or lovers who were HIV positive or had AIDS or ARC [AIDS Related Complex]. One man had been diagnosed with 
Pneumocystis carinii pneumonia and AIDS just two weeks before.

Almost all stated the need to do something productive and positive for their community and friends. Of the women participating in the session, two were lesbians and had friends who were ill, one straight woman had recently lost her brother (who had died of AIDS), another was a professional counselor and was going through the training as part of her job, and then there was me, token anthropologist (Journal: June 6/7, 1987).
The seminar also devotes a great deal of time helping each participant to explore their feelings, motivations, and fears. It is important for each to be prepared emotionally and intellectually for the difficulties he or she will encounter.

At first, the trainees were a little uncomfortable with each other but as the day wore on we began to know each other better and to trust each other a little more. During those two days, we saw training films produced by Shanti Project that include a taped interview with Gary Walsh\textsuperscript{2} called \textit{Facing Death and Dying} and another on the various manifestations of HIV infection called \textit{Care Beyond the Hospital}. We were given information about the Foundation's policies: on testing (voluntary, anonymous), AIDS education (tailored to the audience), relations between clients\textsuperscript{3} and volunteers (no sexual relationships [with clients]), and confidentiality of clients (never reveal the name or address of another volunteer or client). A Med Center physician, a longtime member of the AFH Board of Directors and internationally known expert on HIV infection, came and gave a lecture on the current medical knowledge of AIDS. A PWA [Person with AIDS] came to talk to us about what it is like to have AIDS.

We ate together, drank gallons of coffee, talked to the AFH teddy bear (a technique for helping one reveal the most painful parts of one's life), and laughed and cried with each other. We developed a tremendous sense of solidarity which transcended the group from the

\footnote{Walsh was one of the first persons with AIDS to come out publicly about his illness and be willing to appear on local and national television. You may be familiar with his appearance on a national talk show with Jerry Falwell.}

\footnote{Clients are persons with AIDS or ARC who have become members of the AIDS Foundation of Houston and are eligible for services and benefits.}
training weekend and included all the volunteers, staff and clients at the Foundation. When it came time for graduation and our official induction as AFH volunteers, all of us felt a real sense of accomplishment, a desire to do what we could, and pride that we had survived a sometimes emotionally wrenching process of self-learning (Journal: June 6/7, 1987).

Although everyone in this group passed the training, that is not always the case. Some are asked to either leave or to confine their volunteering to less difficult or sensitive areas. Those who showed strong negative reactions to gay men, refused to follow guidelines or were more interested in missionary activities than the goals of the Foundation are refused graduation to full-fledged volunteer.

The last activity of the training seminar is to choose and sign up for volunteer positions. There are a wide variety of options (see Table I). The hotline, like many of the other options, involves additional training. An introductory tour with the hotline coordinator\(^4\) shows volunteers how to use the hotline Macintosh computer, fill out client intake forms\(^5\) (so that PWA's or PWARC's, Persons with AIDS or ARC, can become eligible for AFH benefits and assistance), make appointments for clients with AFH advocates (volunteers who do the first interview with a client, see Table I), take requests for the speaker's bureau, and other hotline duties. Then the new hotline worker is assigned to work a shift with an experienced volunteer who can monitor their

\(^4\) This part of hotline training may be taken over by an experience hotline volunteer.

\(^5\) Client Intake forms record information such as name, address, phone numbers, name of physician and diagnosis (for state and federal requirements), and requested services. The intake is the basis for all interactions between the PWA and the Foundation until the time of the advocate's interview.
Table I

Volunteer Options

Social services

Advocate: Makes initial contact with new clients, determines type(s) of AFH assistance appropriate, assist clients with applications for disability and other types of assistance.

A-Team: Serve at the Foundation's residence for PWA's, McAdory House, on a regular (assigned shift).

Buddy: Make commitment to a one-on-one relationship with a client, offering friendship and emotional support by calling daily and visiting at least once a week.

Food Bank(Stone Soup): Staffing the AFH food pantry which supplies foodstuffs and household items to PWA/PWARC clients.

Hospital Team: Visit clients at hospitals and hospices, offering emotional support to clients, their families and significant others.

Pet Patrol: Assist clients in the care of their pets or find new homes for client's pets when necessary.

Phone Buddy: Monthly follow-up contact with clients of the Foundation.

Education

Education Committee: Oversee the educational arm of the Foundation (including Hotline, speakers bureau, conferences on AIDS and the various materials published on the Foundation)

Hotline: Answer the Foundation's information/referral telephone hotline (weekly shift).

Library: Coordination and maintenance of the Foundation's central library.

Speaker's Bureau: Present AIDS information to community and business organizations, schools and medical facilities.

Fund Raising

Fund Raising Committee(s): Working to generate donations to the Foundation.

Grant Writing: Identification of grant sources, preparation and submission of proposals.

---

6 This list of volunteer positions and descriptions is adapted from an AIDS Foundation Houston document prepared by the Director of Volunteers in 1989.
(Table I, Volunteer Services con't.)

**Volunteer Services**

Training Staff: Education of new volunteers for the Foundation.

Volunteer Committee: Oversee the volunteer programs, including recruitment, retraining and continued service of volunteers.

**Public Relations**

Public Relations Committee: Represent Foundation with community leaders, agencies, and news media.

Newsletter: Assist in publication of the Foundation's newsletter, called *Lifeline*.

**Office Administration**

Clerical: Assist with Mailings, typing, filing, switchboard, etc., at the Foundation offices.

Computer: Assist with programming and data entry.

Special Services: A pool of volunteers available to assist with special chores (moving heavy furniture, etc.).

first calls, be there to answer questions, and to assist with emergencies.

**Learning to Talk About AIDS**

The process of becoming an AFH volunteer is not only a matter of becoming familiar with facts about HIV infection but just as importantly learning to talk and think about AIDS in new ways. Descriptive terms such as AIDS victim or AIDS sufferer are not used; person(s), people with AIDS/ARC or PWA/PWARC are used. Promiscuity becomes multiple sexual partners. Drug abuse or addiction becomes drug use. Almost all such shifts in terminology are to relatively value-free equivalents. Each allows the speaker to suspend judgment or, at least, avoid discussing sectarian issues. The moral focus of Foundation discourse is on the goals of education and social services to people
with AIDS. Ideas about the rights of the individual to privacy, self-
determination, and equitable health care inform these activities. The basic
Foundation philosophy emphasizes teaching personal and sexual lifestyles that
prevent the HIV transmission without commenting on their other moral
qualities. Such attitudes conceal the wide variety of religious and ethical
beliefs among volunteers and staff as well as being the strategy which is most
likely to permit open discussion with those most in need of information and
counseling.

This approach has been criticized by some as promoting homosexuality
and drug use. One can promote homosexuality only if sexual orientation is
considered to be under conscious control or caused when older people convert
younger ones; neither supposition is supported by current models of human
sexuality (Adam 1986; Feldman 1984; Green 1980; Money 1980; Ruse 1988; etc.).
Additionally, AIDS risk reduction techniques such as needle exchange,
distribution of bleach for sterilizing needles, and instructing IV drug users
how to clean "works" are not associated with any reduction in the demands
for entry into drug treatment programs (Des Jarlais & Friedman 1988).

The neutral approach also marks services to persons with AIDS, no one
blames the sick client for his or her illness. Too many service providers

---

7 Explanation of the roots of human sexuality and homosexuality, in particular,
tend to cluster into two groups: genetic/biological (nature) vs.
social/psychological (nurture) causes (Feldman 1984). Neither type of
explanation agrees with the common American folk belief that homosexuality
is caused by childhood seduction or molestation (Klassen 1989; and see Green
idea that is somewhat similar to the folk belief of homosexual conversion is
that of situational or structural homosexuality where persons are denied
access to heterosexual partners or are required to engage in homosexual
contacts during rituals such as initiation rites (Adam 1986; Herdt, 1984; Money
1980).

8 The equipment used to prepare various substances for injection (e.g., heroin
or cocaine).
(volunteer and professional) have HIV infection to be overly critical of clients with AIDS. The exception is the person with HIV infection who continues practicing unsafe sex or sharing needles but even this disapproval is context sensitive. For example, there is an exemplary tale told by long time volunteers of a young, mentally retarded man who was diagnosed with AIDS and then left on the streets without enough money for food or shelter. He continued to solicit in order to survive. It is said that reporters from a local television station gave him money to proposition passers-by for the camera. This story is told with pity for the young man, resentment at the welfare system that neglected him, and anger at the media for exploiting the situation.9

There are a number of important elements in the AFH training that teach volunteers and others how to talk about AIDS in this relatively neutral fashion. The techniques and ideas taught come not only from people at the Foundation but are also borrowed from Crisis Hotline, Gay Men's Health Crisis, Shanti Project, and other similar groups. Borrowed ideas are then reinterpreted through the meanings and understandings of volunteers and staff who work at AFH. All of the resulting methods, ideas, and written materials emphasize the importance of the person with AIDS, the relationship of the volunteer with clients, and the work of volunteers as a protective bulwark against a society which discriminates against both.10 This is particularly clear in The Volunteer Handbook (Aids Foundation of Houston

9 The news story on Fabian Bridges concentrates on his criminal record (mostly petty theft) and on his continued solicitation (Houston Post, Oct 2, 1985). No mention is made in the news media of Bridges' financial situation or the efforts of gay activists to find him a place to live (Chad Gordon, personal communication, 1990).
10 Not only persons with AIDS or suspected of having AIDS experience discrimination. Volunteers and staff have found themselves evicted from apartments, lost jobs and friends, and other irrational responses to the fact of their association with AFH (ACLU AIDS Project 1990).
1986) which begins with a letter welcoming volunteers and granting them a central position in the workings of the Foundation: "the Foundation is its volunteers" (1986:1, emphasis in original). The Handbook goes on to stress the work obligations of volunteers: to work a specific number of hours, report absences and hours worked, and continue to update knowledge of HIV infection through available materials.

Volunteers frequently choose positions with great responsibility and some have even taken full time positions. The signing of the confidentiality statement reinforces the serious demands made on volunteers in many assignments. In positions where counseling, support or record keeping are part of the assigned duties, volunteers become privy to much sensitive or personal information. Foundation policies and guidelines repeatedly stress the importance of secrecy and protecting the client's privacy. The stories of clients and volunteers who have lost jobs, been evicted or denied health insurance are just as crucial as formal policies to creating an atmosphere where confidences are not broken. These tales are told mostly in informal or social settings. Almost all volunteers have their own stories to tell of how they themselves, clients or friends have met with discrimination because of AIDS. Stories such as these are different from the exemplary tale of the mentally retarded man mentioned above. Rather than the same story told over and over again by people not involved in the original event, these stories are everyday occurrences told by volunteers of their personal experiences. They help establish the importance of and reason for the existence of AFH by repeatedly demonstrating the need for an advocacy group. Volunteers first hear these

---

11 The letter is written by the then Director of Volunteers, Joe Lane.
12 During the first two years I was at the Foundation, funding was very tight and often volunteers took on positions such as Director of Volunteers.
stories (other than their own) during the course of training, coffee breaks, chats in the hall or team meetings. The stories articulate the purposes of the Foundation as well as problems to be solved. When volunteers complete training, they begin to collect their own accounts from clients. For example, the hotline receives a large number of calls about problems of discrimination and the callers are referred to individuals or organizations which can help persons with AIDS cope or seek redress. Volunteers tell these stories not only to seek help in solving problems but also to express the anger they feel to a sympathetic audience. Talking about clients' problems, especially the unsolvable ones, to other volunteers or to team counselors is a major strategy used by AFH to help volunteers avoid burn-out and lessen their frustration.

The style of these stories of discrimination is interesting because it is tailored to the requirements of confidentiality. Names of clients and the kinds of identifying tactics common in normal conversation are not used. Descriptive statements are used instead, so that people are referred to by HIV status (e.g., PWA or PWARC), ethnicity or race, age, sexual orientation, job type or their relationship to a person with AIDS. At other times, the subjects of stories are described in relationship to the volunteer: my buddy, phone buddy, someone I visited in the hospital or talked to on the hotline. In contrast, the events are related in detail and the difficulties of the person with AIDS take center stage. One story that I told myself follows this general pattern.

"I got a call from a young Mexican man worried about his father this afternoon. His father had come to Houston from Mexico for medical treatment but spoke little or no English. Their insurance had been paying his father's bills but for some reason had abruptly been canceled. The hospital immediately informed the son that he would have to move his father the same day. The father is so ill that he's
probably dying but doesn't seem to qualify for assistance and no other hospital will accept him. Ron [Director of Social Services] is trying to get him accepted at Omega House (a local nonprofit hospice). If they don't have room for him there, I don't know where the man is going to end up....

This story is typical in that it is focused on events leading up to a crisis. It avoids any identifying information but does give a fairly detailed account of the circumstances.

An organization which discriminates against clients or others with AIDS is named in stories if it is a local, large or well known company. Insurance companies tend to be treated as if they are all the same. It is unclear if this is because volunteers are not familiar with their names or simply lump all insurance companies together as prone to discriminate against people with AIDS. One characteristic of hotline tales, which is less common among stories told by other volunteers, is the lack of an ending to the story. Hotline workers refer callers to staff members or to other organizations but seldom hear how problems are resolved. All in all the stories told are remarkably discreet and carefully protect the identity of clients. Only if you have worked with the same client will you recognize the individuals involved. Volunteers are less concerned with keeping the identity of offending organizations secret. Instead, they are the focus of anger or the intention of "doing something about it". For example, when a local grocery store fired a gay man because management thought he might have AIDS, a boycott was started by a Houston gay rights organization. Information was spread among volunteers through word of mouth and by circulating a copy of a magazine article on the topic. In other situations, AFH has negotiated with some governmental agencies to change personnel and procedures to ease the way
for persons with AIDS. In official AFH actions, “doing something about it” is usually oriented towards a conciliatory, not confrontational solution.

**Foundation Etiquette**

The etiquette of speaking to persons with AIDS is learned early in the training process. Persons with AIDS are presented as experts in the experience of their condition and are people to be listened to carefully and with respect. During the training weekend, volunteers are introduced to a PWA speaker, view films by and about people with AIDS, and are taught AFH policies which are designed to protect and serve PWA’s. Fellow volunteers and training coordinators may also have AIDS. This early and intensive introduction helps volunteers to identify with clients and others with AIDS, and to overcome any fears or discomfort they may feel in the presence of someone with AIDS.

A Shanti Project training film used in training, *Facing Death and Dying*, serves as an exemplary model of what it means to have AIDS and the appropriate way to speak to a person with AIDS.\(^{13}\) The video is based on an interview by counselor Jim Geary with Gary Walsh, a person with AIDS, who was both on the Shanti Board of Directors and a client of Shanti. Walsh’s presentation of self and Geary’s respectful questions can be seen as constructing a reverse discourse which uses the categories supplied by society at large but resists the definition of person with AIDS as guilty victim (Foucault 1978; Macdonell 1986). Walsh tells of himself, of his life as a psychotherapist working with Gay couples, and the emotionally wrenching period after his diagnosis. The details of the life and personal perspective of a

\(^{13}\) *Facing Death and Dying* is a training film made by the Shanti Project in San Francisco (1983).
person with AIDS marks a kind of approach seldom found in the medical, epidemiological or psychological literature except within carefully guarded parameters as case studies or clinical examples. In the context of this film and its use in the training weekend, the person with AIDS is in many ways presented as the ultimate expert. This film and other examples of reverse discourse present the person with AIDS as the protagonist of his or her own story which is cast in an heroic mold. Walsh is not the passive victim but a spiritual adventurer who first actively seeks therapy and later explores the nature of life and death. In the end, death is transformed from the tragic ending to the beginning of new kind of existence.

By watching this film during the course of the training weekend, volunteers are introduced to this radically new definition of the person with AIDS. Here AIDS is not linked to victimization, criminality, promiscuity or addiction as is usually the case in the popular press and many other sources. Walsh's quietly heroic demeanor can neither be fit into any of the popular roles for a person with AIDS, nor does his evident lack of fear at the prospect of his imminent death allow him to be cast as a victim.\textsuperscript{14} This new construction is reinforced by the appearance of speakers who have AIDS during training, the respect shown to persons with AIDS among other volunteers and training coordinators, and AFH policies which are designed to guard the confidentiality of all those with AIDS associated with the Foundation. To a great degree, volunteers come to regard service to people with AIDS as the ultimate reason for the existence of the Foundation.

The filmed interaction between Walsh and Geary is instructive in that it gives volunteers a concrete model to follow. Walsh is visibly and audibly ill:

\begin{footnote}
\textsuperscript{14} Walsh died a few months after this film was made (Shilts 1987:426).
\end{footnote}
he is extremely thin, is very weak, and has trouble speaking. He responds to
questions slowly, with pauses and gaps between question and response, speaks
quietly, and often cries and laughs during the film. Geary, the interviewer,
carefully avoids pushing for faster answers, interrupting, speaking for Walsh,
or running over Walsh's responses. Geary makes a comment later which
reinforces the unspoken messages:

Geary: I'm reminded of, um, the time you were with Jerry Falwell on
television.
Walsh: Blood pressure just went up. (laughter)
Geary: And how you kept wanting to say more but he kept interrupting.
What always amazes me about people like Jerry Falwell that . . . that they
tell you that they love you. Um, but that doesn't seem to be the same
kind of love that you're talking about.
Walsh: No . . . I remember when that was happening and he was saying
how much [he] cared and loved me. And I'm sensitive and I didn't pick
up a bit of care or love. Um, not one bit. . . .

Respect and love are shown by letting persons with AIDS speak for themselves
without interruption or the presumption to speak for them.

This same etiquette is seen in everyday interactions between hotline
volunteers, clients, and other persons with AIDS. Usually the person with
AIDS' or ARC's first contact with AFH is with a hotline volunteer. They call the
hotline to complete a client intake form and make a first appointment with an
advocate (see Table I). Callers are often quite ill at that time: having just been
diagnosed, experiencing their first serious opportunistic infection and may

15 These quotations are from the film, Facing Death and Dying, 1983, made by
the Shanti Project. The emphasis is in the original. All transcriptions of
Facing Death and Dying are my own.
Table II
NEUROPSYCHIATRIC EFFECTS OF HIV INFECTION\textsuperscript{16}

<table>
<thead>
<tr>
<th>Chronic Stress Effects</th>
<th>Decreased Level of Concentration</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low Energy Levels</td>
</tr>
<tr>
<td></td>
<td>Lack of Restful Sleep</td>
</tr>
<tr>
<td>AIDS-Related Dementia</td>
<td></td>
</tr>
<tr>
<td>Cognitive</td>
<td>Poor Concentration</td>
</tr>
<tr>
<td></td>
<td>Slowed Mental Processing</td>
</tr>
<tr>
<td></td>
<td>Lack of Motivation</td>
</tr>
<tr>
<td></td>
<td>Forgetfulness</td>
</tr>
<tr>
<td>Motor</td>
<td>Slowed Movements of Eyes/Limbs</td>
</tr>
<tr>
<td></td>
<td>Ataxia (Abnormal Gait)</td>
</tr>
<tr>
<td></td>
<td>Abnormal Reflexes</td>
</tr>
<tr>
<td>Behavioral</td>
<td>Apathy</td>
</tr>
<tr>
<td></td>
<td>Social Withdrawal</td>
</tr>
<tr>
<td></td>
<td>Personality Changes</td>
</tr>
</tbody>
</table>

show signs of chronic stress or AIDS-related dementia (see Table II). The hotline worker must be responsive to the mental and emotional state of the caller so that correct information can be gathered for the intake form and their needs identified. Although eliciting correct information is not an explicit goal in teaching this way of interacting with clients, it none the less does have that effect. This is particularly important if the person with AIDS is in serious trouble (e.g. about to be evicted or is suicidal) and is requesting a priority intake (which are responded to immediately with an emergency advocate interview). This etiquette is not only important in maintaining good relations with the caller but is a necessity in such circumstances.

The pragmatic implications of the Foundation etiquette are crucial in the broader scheme of things as well. The frequency of AIDS-related

\textsuperscript{16} Adapted from Dilley and Boccellari 1989:140, 143.
psychological impairment is high enough that it effects most people (from 50% to 90%) at some point in time after their initial positive test result or diagnosis (Ostrow & Stryker 1990:34; Dilley & Bocellari 1989; Wolcott, 1986). For many this is due to the effects of chronic stress, depression or anxiety. For others it may be caused by an organic brain disorder such as AIDS-related dementia or one of the neurological opportunistic infections. The Foundation's way of speaking is flexible enough to compensate for the various psychic, physical and social problems that persons with AIDS are likely to experience. When volunteers are assisting clients, making referrals on the phone or working with volunteers who have AIDS, the most noticeable symptoms are cognitive. The person with AIDS answers questions slowly, takes longer to make a decision, may forget or scramble directions or take longer to learn a task. Foundation etiquette, by emphasizing that one does not interrupt, speak for or run over the speech of a person with AIDS, permits people to work together without compromising anyone's sense of self-worth or arbitrarily limiting the contribution of people with AIDS.

The strength of these injunctions was brought to the fore by a rather startling experience about one year after I went through the training weekend. An unorthodox counseling group, which had been highly recommended by a number of AFH clients, was to have a trial run of their style of therapy using the hotline volunteers as guinea pigs. The therapist in charge was a charismatic man who espoused a philosophy of "unconditional love." Volunteers seemed skeptical from the start. They kept asking, "How can you practice unconditional love while trying to change people's sexual and drug use activities?" Unconditional love seemed to imply no judgment and no criticism (not even on the relative riskiness of people's actions).
The therapist seemed to belie his own philosophy by the way he treated one of the volunteers. Patrick, a person with AIDS, was recovering from a bout of PCP (a type of pneumonia associated with AIDS). He was slow to respond but had some important questions to ask. The therapist tended to run over what Patrick had to say and kept interrupting him. The group got quieter and less sympathetic with each passing moment. Then the therapist really went too far when he told Patrick to be quiet. Surprising myself with the strength of my reaction, I angrily told the man I thought he was extremely rude. Another volunteer stated that his actions didn't square with his philosophy. Very shortly after that the experiment was brought to an end. The hotline team gathered together afterward to evaluate the session for the Foundation and all generally agreed on two points. The idea of unconditional love struck them as ridiculous. Instances of discrimination against people with AIDS or where people who are HIV positive but do not take precautions to avoid transmitting the virus were cited as times when criticisms must be made. Also, the group decided that the therapist's own behavior with Patrick made it very clear that he did not follow the philosophy with practice. That was unforgivable as far as the volunteers were concerned. The therapy group was not invited back to AFH again.

**Being a Hotline Volunteer**

Calling the hotline is designed to be as easy and low stress as possible. The phone number is partly mnemonic (524-AIDS) and all calls are anonymous unless the caller chooses to be mailed pamphlets or to become a client. What is stressful for the caller are the issues and fears surrounding AIDS. The

17 Patrick is a pseudonym.
situation for the volunteer is different. The job of the hotline volunteer is to solve problems and provide answers. There is great pressure to get things right the first time, whether it be information or detecting someone in deep emotional trouble, for there is usually no second chance. The majority of calls require fairly simple responses or referrals: the name of a doctor, what test results mean, where to report discrimination, how to find the local alternative clinic, where support groups meet, and so on. Referrals are easy enough since the information is available on the hotline computer, the bulletin board or in pamphlets but callers are often in highly charged emotional states. Sometimes, the callers themselves or a friend, lover, or family member have just been told they have a positive HIV antibody test, ARC or AIDS. Others are depressed because they have symptoms which may or may not be AIDS. Many are considering whether their lifestyles may have to be altered to avoid infection. Callers may be frightened, anxious, depressed, or simply curious.

The hotline volunteer must try to sort through the possibilities and to provide the information and support the caller needs.

The basic tasks of the hotline are relatively simple. Information is readily available both on the computer (which is updated periodically) and through articles and memos which are routed through the hotline office. The paper work is not demanding most of the time. When calls are few and responses simple, the volunteer can relax and read. The busier periods, particularly the morning and afternoon shifts during the week, can be far more demanding. The most stressful and difficult demands are emotional. When a significant proportion of callers are experiencing anxiety and discomfort, the volunteer must continually try to detect emotional states from the tone of voice or type of questions. Many callers believe either that they may have been exposed to HIV or that they are developing symptoms of AIDS.
or ARC and so are seeking a referral to a clinic or to ask, “What are the symptoms?” Others have just learned that they are HIV positive or recently have been diagnosed with AIDS or ARC. Most volunteers feel a need to offer what emotional support or assurance that they can; very few are so emotionally distant that they are unaffected.

Training helps volunteers to identify with people with AIDS and to lose their fear of people with AIDS. Sometimes, the cost is to overly empathize with callers. Volunteers are often emotionally and physically drained at the end of a busy shift. It becomes easy to overreact to small mistakes or expect too much from one's self as this excerpt from my journal demonstrates:

I think I screwed up once today. Somebody called having just found out they're HIV positive. I referred him to the Montrose Counseling Center but didn't catch on to how upset he was. He started crying just before he hung up. I felt so stupid. I should have caught on before that but it went right past me until the last moment. I went into the hotline just drained. I was overtired ... Its so hard to go into the hotline and just leave everything behind so that you can give it the energy it needs. I never realized before just how much it takes to really listen. You have to be able to detect all the little cues and have the desire to follow up on what you think is happening. I almost wish I could drop out of school or somehow give myself enough peace and quiet to be able to always give the hotline my very best. You never know how important the next call may be. It may just be someone wanting a simple question answered or it may be someone on the edge (Journal, Sept. 22, 1987).

Also, being in the AFH offices means that hotline volunteers are more often approached to extend their volunteer participation:
One thing about being involved at AFH is the self-imposed pressure to do everything or at least an ever expanding sphere of things. Sometimes it feels a little like a pressure cooker. I can't blame anyone else—I'm the one who keeps taking on more new things. In combination with work I sometimes feel like I'm going to go nuts. But I don't really want to cut back on AFH time because I get recharged there too, being there gives me a sense of purpose that I had lost last year. I don't know what my limits are now but I think I can push them a little harder and still maintain a reasonable level of productivity. It's a matter of motivation now. I really want to do these things (Journal, Sept. 16, 1987).

It can quickly become too much and volunteers "burn out." Others cope by regular vacations from volunteer work or other strategies to reduce stress but only a few manage to avoid burnout over the long run.

**Caller Stories: Transmission, Testing and Fear**

The majority of callers ask about transmission of HIV (Human Immunodeficiency Virus) while others ask about the most recent article in the newspapers. At various times, the questions have been about mosquito transmission (after the Belle Glade stories), claims for cures (e.g., hyperthermia treatment), or conflicting estimates of the expected rate of mortality of people infected with HIV. For many, there is a specific question, which when answered ends the conversation. Those with more complex concerns often require long discussions. The AFH hotline does not represent itself as anything more than an information and referral service but for many callers there is no one else with whom to talk. The anonymity of the telephone and the non-judgmental manner of hotline volunteers can often be
a key to open up the most sensitive aspects of caller's sexual and emotional lives.

A key issue for many callers is how HIV is sexually transmitted and whether they need to alter their sexual activities. When I first began to volunteer on the hotline, I had difficulty understanding the importance of sex, or of specific sexual activities, for many men. Most callers to the AFH hotline are men and many are concerned with the probability of exposure given their specific activities. For some men their lives revolve around their sexual contacts. Some are very forthright about the fact that they would rather take the risks involved than significantly change some crucial (to them) aspect of the lives. This excerpt from the journal I kept during my volunteer time illustrates:

Earlier in the day I had a call from a young Gay man who had just turned 21. He wants to partake of Gay night life, cruising the bars and having a good time, but is concerned about his future. He wants to be tested so that he will know where he stands at the beginning and to learn all he needs about safe sex. It says something about this young man's need to become part of the mainstream of Gay men's culture that he is not only willing to risk exposure but wants to inform and prepare himself as best as he possibly can. I don't know if he is afraid, he didn't seem to be, yet it's hard to imagine that he doesn't already know the possible consequences of an active sex life in that context. I personally have some difficulty understanding what drives men in those circumstances but I cannot deny the power of that need or desire (Journal, Oct. 27, 1987).

The power of this young man's needs were not strictly sexual. He also expressed the desire to belong to a community where his needs and feelings
would not need to be hidden or suppressed. Still, an important part of what the
caller was seeking was sexual intimacy and the emotional gratification he
hoped to find with similarly-oriented gay men.

The majority of callers are not gay but heterosexual. Their needs in
themselves are not very different from gay men but heterosexual men reside
in a culture that approves of or, at least, tolerates their sexual activities; even
those which are formally disapproved of such as sexual contacts outside of a
marital relationship or large numbers of partners. One common problem for
heterosexual men calling the AFH hotline is determining the riskiness of some
particular activity or partner. For example, one man in his early thirties
called inquiring about the risk to a man performing oral sex on a woman. He
was more than willing to discuss changing other aspects of his activities,
including the use of condoms during intercourse, but could neither envision
intimacy with a woman without cunnilingus nor did he wish to reduce the
number of his sexual partners. We talked for almost 45 minutes about the
different aspects of HIV transmission, about why oral sex might be dangerous
(vis-a-vis HIV transmission), and relative risk of various types of sexual
contact. In the end, he commented he just couldn't imagine giving it up or
using a barrier, that physical intimacy would be unfulfilling without oral sex.
Then the caller asked if he could endanger his partner if at some point he
became infected. I responded that it was unlikely that he could infect a woman
during oral sex, especially if he were following "safer" sex guidelines in other
ways (i.e., using a condom, avoiding rough play, etc.). In the end, he stated
that he would prefer to risk contracting the illness rather than change that
part of his life.

It is impossible from the context of a hotline call to do more than guess
at the more complex aspects of decision making or the unconscious processes
that lead callers to this kind of decision. It may be that for many callers AIDS
is not real or immediate enough for them to give up important aspects of their
sexual lives even knowing these activities may expose them to HIV. Sieber
notes that people may continue to engage in a certain “behavior precisely
because it has become their response to anxiety and their means of
temporarily reducing anxiety,” (1986:174). Sieber specifically points to
behaviors such as smoking, overeating, drug use and risky sexual behavior.
Whether straight or gay, using sex as a strategy for reducing anxiety or not,
there are a number of callers who simply could not or would not consider
changing their behavior at the time of the call (remember there is no
possibility of follow up on hotline calls). It is important to note that both of
these men were thoughtful and strove to be well informed on the subject of
HIV transmission, they were articulate in defense of the pursuit of their
desires, and both carefully calculated the relative risk of their actions for both
themselves and their partners. The young gay caller knew that he was
entering into a sexual and cultural life which would not be safe. He knew that
educating himself and following “safer” sex guidelines could substantially
reduce his probability of exposure. The caller also knew that he was likely to
be confronted with AIDS in his friends, lovers or himself one day. But he was
seeking out a life which he felt was the right one for him.

Not everyone who calls the hotline is as willing to discuss AIDS and
sexual matters as openly as the two men discussed above. For many, the issue is
so fraught with fear or other negative feelings that they can only deal with
the subject in small bits. One week on the hotline, I had the same man call two
or three times and during each call ask a small, limited question that could be
dealt with quickly. Can AIDS be transmitted through oral sex between a man
and a woman? Can one encounter with a prostitute transmit the virus? On
each occasion, the caller settled for the quickest answer and cut off any explanation or qualification. It is impossible to be certain but I suspect that this pattern of a series of short calls is common. These callers seem to be unable to deal with the discomfort of the conversation and explanations for any longer than a few moments. Spacing out the questions may help reduce the stress of any single call and allow people to slowly respond to the information they are collecting.

Some callers mention that they’ve called other AIDS hotlines or consulted other sources of information. They check and recheck information, trying to make sense of what they hear and be sure that there is consensus about the issues that most concern them. More assertive callers will confront the volunteer with contradictions and question the advice that you give them. Often these questions address points that are being contested within the medical or AIDS service communities. For example, there is at least one prominent, local doctor who argues that HIV cannot be (or is extremely unlikely to be) transmitted through oral sex. The controversy revolves around two issues: (1) Saliva is known to have an inhibiting effect on the ability of HIV to infect tissues; and (2) There have been very few recorded cases of oral transmission. AFH policy recommends that a barrier device (e.g., a condom) be used during oral sex. When callers hear both kinds of “information”—that oral sex is safe versus one should use a condom during oral sex—it is not surprising that they become confused. One way of helping people to make decisions in situations like this one is to tell about the background to such disagreements and leave the final decision to the caller. In the case of the oral sex controversy, telling callers the details of cases when HIV has been transmitted orally (associated with oral trauma or recent oral surgery), that saliva does inhibit HIV, and that even relatively minor cuts and scrapes in the mouth
might provide a pathway sufficient for transmission (although this isn't terribly likely). It isn't necessary to be a trained scientist to understand that this is a question of relative degrees of risk and not a simple case of misinformation. The authoritative answer of "no, it's not safe to have oral sex without using a barrier" is transformed into "these are the relative risks of certain activities and you must make your own final decision." Generally, the callers who are most assertive are those that respond best to such an approach but it must be remembered that many persons do not want this kind of information. Some callers want a response without equivocation or details. They want a simple, straightforward yes or no answer. The best response for them is the conservative one (a la Koop) which does not put them at risk: HIV can be transmitted by oral sex and so such contact is risky but if you do engage in oral sex an appropriate barrier will provide protection.

People who call the hotline repeatedly are not always simply pursuing a clarification of information. There are callers who may call again and again over the course of months. Hotline volunteers tend to lump such callers under the heading of repeat callers. Repeat callers at AFH have included a man who used the hotline for sexual excitement, assorted calls with rude comments or hang ups, and someone who used to leave messages to call the hotline number on people's beepers. Most repeat callers are "worried well," people who have either been exposed to HIV or believe that they may have been exposed to HIV. Sometimes they have recently discovered that an old lover has contracted AIDS, was bisexual or used IV drugs. They are deeply concerned

---

18 Use of the term worried well may vary regionally. One informant, who had come to Houston from the Eastern U.S., reported the term can also refer to people who are HIV positive (e.g., Acevedo 1986).
about the possibility of contracting AIDS and some may also seek help through support groups.

Most callers are simply worried or feeling a bit guilty over some self-perceived sin but a few people will become obsessive about the issue. The following is about a man who was particularly troubled about an instance of a sexual contact outside his formal relationship. He was troubled to the point of obsession:

One man, who has been calling for months, is berating himself because he cheated (one time) on his fiancée (who lives in another city). He has himself tested every 30 days. He constantly imagines new symptoms and no matter what you or his doctors say to him he is convinced he is coming down with AIDS. When you try to convince him to get counseling or go to the worried well support group, he says he tried that once (!) and it didn't help. We are doing him no service by continuing to talk to him—it just feeds his fantasy. Perhaps, if we could stop talking to him altogether he would get lonely enough to get help. The problem is identifying him. Sometimes, you don't realize who you're talking to until you've been on the phone for 10 minutes or more. I really get angry with him—especially when he starts trotting out fake suicide threats like “its too bad the government doesn't have euthanasia programs” or “I wish a burglar would shoot me.” At times like that I would/could shoot him. Especially if I've had [a] real suicide call earlier in the day! (Journal, Sept. 15, 1987).

This man's calls became notorious among hotline workers and whenever a newcomer would begin to tell his story (in the way the stories above were told) the others would chime in with the details. Discussions were held on several
occasions on how to deal with repeat callers and this man in particular. Neither the volunteers or the hotline team's psychologist felt it was helpful (for him or the volunteers) to continue supporting his preoccupation with AIDS. However, it is exceedingly difficult to detect and stop such calls.¹⁹

Dealing with repeat callers can be very stressful for hotline workers. It's very easy to become impatient with someone who calls and asks the same questions over and over again. Sometimes volunteers feel this is a sign of ineffectiveness on their part, at other times they feel resentment towards callers who don't have "real" problems. The difficulties of the callers are real enough but their problems are not with HIV infection. AIDS has become a substitute for the other concerns in their lives. The complexity of the hotline worker's dilemma can be seen in these contrasting journal entries:

It's easy to get impatient with the same questions being asked over and over again. I want someone to believe what I say the first time, not need to ask again, then again and again, what their chances are, what a negative test means, what 3 or 4 negative tests mean ... I have to keep reminding myself that the questions are too big for simple answers. People need to hear the answer—no, you aren't going to get AIDS—again and again in order to start believing it. That's why they go back for the test time after time or call the hotline daily for months on end. If I become impatient, it doesn't help anyone—especially not myself because then I feel guilty and like I've let someone down. It's almost easier to talk to someone who has AIDS—they know the worst has already happened and will usually be ready to start dealing with it. But the fact

¹⁹ Friends and informants who have worked on other sorts of hotline and crisis services say that similar repeat calls, although not usually AIDS-related, are a common occurrence.
remains that the vast majority of callers are and will continue to be the worried well (Journal Sept. 8, 1987).

But there is such a thing as being too easy going:
I'm starting to learn from listening to others. I can be too patient sometimes. The result is a few people, who don't necessarily need a lot of my time, end up taking great chunks of it. I also need to become less naive. Some people are on "using" trips—they call to get us to somehow reinforce some strange vision of the world or to get us to solve all their problems. Obviously, we can't do that and are doing people a disservice if we try. For example, there are a lot of people into heavy paranoia trips. They are not just scared, they are using AIDS and the hotline to construct self-flagellating gestalts where AIDS is the punishment for their sins (real or imagined) (Journal, Sept. 15, 1987).

AIDS is a large issue which the hotline workers must address in an immediate and small scale fashion—encountering difficulties that cannot be predicted from the outside:

Fortunately, [today] was a slow day with no real emergencies. Mostly just low-key guilt calls—the ones where someone has done something they feel badly about so they call to find out if they could have gotten AIDS that way. These calls require only a calm manner and a little rational thinking most of the time. Sometimes the guilt and fear become almost overwhelming and some people may almost cease to function. I don't understand why some are paralyzed and others not. I know that some of these callers must already have mental or emotional problems. For them, AIDS phobia is just one aspect of a more generalized dysfunction. What about the others who become disturbed just thinking

The volunteer's struggle to deal with such calls is particularly acute in the first few months. More experienced hotline workers learn to expect such problems and to deal with them in a matter-of-fact fashion. It is difficult to think of how the training could better prepare volunteers except in the most general way—that many calls are not merely requests for information but an expression of a desire for reassurance and safety.

Most calls are less emotionally difficult and can rely more heavily on Foundation policies, counseling guidelines, and information from the hotline computer. Talking to callers about HIV antibody testing is a case in point. Policies and issues on testing have changed over the past several years but AFH has continued to be concerned that positive antibody test results could be (and in many instances were) used as the basis of discrimination by employers, insurance companies, and others (ACLU AIDS Project 1990; Legislative Task Force on AIDS 1989). Until AZT began to be used as a treatment for people with positive test results but no symptoms, there were compelling reasons not to be tested. The Foundation policy emphasized six points:

1. Emphasizes personal choice: testing on a voluntary basis only;
2. Encourages people to carefully consider their reasons for being tested;
3. Recommends a setting that ensures anonymity such as a designated alternative testing site like the Montrose Clinic (not merely "confidentiality" which has been violated on a number of documented occasions);
4. An informed consent form designed for HIV testing should be available;
5. Test results should be communicated personally on a confidential basis (versus over the phone or in a letter);
6. Counseling should be available both before and after the test by qualified counselors.²⁰

Questions of testing are as much political and legal issues as they are issues of health and transmission.

For the hotline, testing is an issue that has crystallized many related, politically contested concerns. How does AFH work to halt discrimination against people who are HIV antibody positive or have AIDS? How can the Foundation counteract the image of AIDS as always deadly or a plague (in order to encourage people with AIDS not to simply give up on life)? What is the most effective way of convincing people to change their patterns of using drugs or sex contacts without destroying that which makes their lives meaningful or estranging them from family or friends? Is this possible? The Foundation's policy was designed to inform people of the personal and political risks of being tested. On the hotline, callers were (and still are) advised to avoid testing anywhere that does not follow a strict policy of anonymity except a diagnosis of AIDS or ARC is needed for social security applications or similar purposes.

Another important issue is that of pre- and post-test counseling. It is still not unusual for the hotline to receive calls from persons who have gotten the results of an HIV antibody test in a letter or over the phone. The results may be couched in language that they find confusing or unclear.

Terminology such as nonreactive (a negative result) is confusing to people, especially when the nature of antibody testing has not been explained carefully and they are already fearful. When the caller's test is positive, they are naturally concerned over the long term consequences. Volunteers usually emphasize that a positive test result is not a diagnosis of AIDS and that there is no absolute certainty that a person who has a positive antibody status will develop AIDS. Despair and thoughts of suicide are potentially as dangerous as HIV infection. For those reasons, callers who are considering testing are asked to think carefully about their choice and consider whether the detrimental effects may be greater than the possible benefits of early treatment.

AFH Discourse in the Larger Context

I have thus far described how AFH encourages volunteers and staff to use a common voice or, at least, to speak about AIDS in similar ways. The people at the Foundation are acting in the context of a public forum (in the press and popular culture) where many ways of talking and writing about AIDS exist and each of those ways has its own political and cultural ramifications. The Foundation has consciously worked to create a voice which will support its political goals and to counter views which they perceive as oppressive. These goals include encouraging increased AIDS funding and education, stopping discrimination against people with AIDS, and making all people aware of their potential vulnerability to HIV infection while discouraging unnecessary fears of casual contact. The discourse that they have created permits them to critique other forms of discourse in an implicit fashion—responding to expressions of political or religious beliefs without
recourse to overt criticism. Yet, the people who use this discourse are continually responding to (or in dialogue with) other cultural belief systems.

It is impossible to characterize the discourse of AFH or others on AIDS by simply describing beliefs on a few topics or separating competing positions into a typology of ideas and meanings. Instead, I will continue to evoke these multiple fields of discourse on AIDS as a series of simultaneous conversations where different yet overlapping, parallel or divergent fields of discourse exist. The AIDS Foundation often borrows whole or reinterprets the work of other organizations such as the Crisis Hotline or Gay Men's Health Crisis. AFH also extensively uses films by the Shanti Project and the San Francisco AIDS Foundation which concentrate on the particulars of the lives of PWA's in training weekends, to respond to the assertion that people with AIDS are dangerous or guilty victims. It is difficult to express blanket condemnations of PWA's once you have heard the story of someone like Gary Walsh. AFH extends that story into a general expression of compassion to anyone who is ill with AIDS. The exemplary story of the young mentally retarded prostitute is another case in point. Even though there are strong proscriptions at AFH against knowingly engaging in "unsafe" sex after diagnosis, the story told emphasizes the man's plight rather than condemning him for continuing to solicit.

The voices of the Foundation, as expressed in its newsletter, spoken on the hotline or various internal documents, are the subject of this exploration of AIDS discourses. The constraints of ethics and the circumstances of work at AFH have placed definite limits on what can be treated as data. I have no detailed transcripts of hotline conversations to present for such recording would have violated the basic purpose and intent of the Foundation: to provide a place where secrecy and silence permit frightening and painful revelation.
The Foundation must also protect its volunteers as they are as liable to be discriminated against as are people with AIDS.\textsuperscript{21} Instead, I have used myself and the documents produced by AFH as informants. When I do use notes on conversations or interviews with volunteers or AFH clients, I have very carefully removed all identifying information. The only times that I identify specific persons by name is after those persons have served in staff and Board positions or appeared in the Houston newspapers or on local television as representatives of AFH. This tactic both respects the requirements of hotline anonymity and forestalls fears of callers that their deepest secrets might accidentally be revealed to a hostile world. The bulk of what follows will be a textual analysis of my journal and fieldnotes, published sources of volunteers, persons with AIDS and others in similar circumstances, films by the Shanti Project, materials published by AFH and other AIDS-related organizations, and internally produced AFH handbooks and policies.

The focus of the analysis will be on areas where the Foundation (and many other AIDS organizations) has tried to counter condemnationary voices heard in the public press and television, on pulpits and the seats of government. In an important sense, every written and spoken AFH text is in competition or conversation with these many other sources of commentary. In this first chapter, the terrain of AFH has been mapped out and the form and content of the discursive fields has been sketched in using the hotline as the primary point of reference. Now the approach will shift to focus on several crucial, ongoing conversations about AIDS: (1) what it means to have AIDS;

\textsuperscript{21} The ACLU AIDS Project found that anyone associated with persons with AIDS, worked or volunteered in AIDS related organizations is vulnerable to the same harassment as people with AIDS (ACLU AIDS Project 1990).
(2) the language and experience of illness; (3) biography of people with AIDS; and (4) the re-writing of the experience of AIDS in the Foundation newsletter.
Chapter Two

ILLNESS NARRATIVE, PERSONAL EXPERIENCE, AND
THE CONSTRUCTION OF COUNTER-DISCOURSE

Public Conversations and AIDS Discourse

The ways in which people talk about AIDS seem to be fairly concrete and consistent until I started to take a close look. As I began to listen and read the overload of information, the various perspectives and beliefs began to overwhelm all the possible neat and tidy generalizations. The reasons for this multiplicity of discourses are almost as varied as are the discourses themselves. As I listened first to a gay rights activist, then to someone from the religious right or a social worker from a metropolitan hospital, I might easily have come to the conclusion that these people are talking about different things except for the repetition of the word AIDS. One immediately recognizable factor is that all these people are using AIDS as a marker for some crucial aspect of culture and morality; stretching AIDS far past a simple identification as a disease process.

There are a variety of different sets of tools that can be used to interpret these many and overlapping fields of discourse. These derive from cultural and literary criticism, from rhetoric, linguistics, folklore, and anthropology. Using such methods, modes of expression, selections of content and tropes, forms of understanding can be traced and teased apart. The patterns of association help the scholar to understand the importance of talking about AIDS to cultural understandings of AIDS. The idea of a conversation, actually many conversations with many points of view, is an instructive model for what all those people are doing. They are holding an ongoing, public conversation about AIDS, illness, sexuality, money, death, politics, religion,
morality, and other culturally related topics. People who have AIDS don't talk about AIDS in the same way as physicians, politicians and others talk about AIDS. However, doctors and persons with AIDS (PWA's) are busily conversing on the topic and they do at times overlap in what they are saying.

As in any conversation, not all the participants listen to each other. In fact, participants may interrupt, overrun or nay say one another. These conversations are constructed using some repeating elements, structures of understanding and style (as well as more idiosyncratic elements) that can be traced from one dialogue to another. People are answering to or conversing with participants in the public sphere. When AIDS organizations talk about the epidemic by referring to specific people with AIDS (a relative, friend or lover) they are responding to the depersonalized public images of those with AIDS as victim, criminal or pervert. When the head of the Houston police department's vice division referred to Fabian Bridges as a “threat to society,” he was trying to place Bridges outside the normal protections of society (see Chapter One, Houston Post Oct. 2, 1985). Bridges was not a sick man to be taken care of but a menace from whom society needed protection. Each speaker was participating in a dialogue, tailoring their discourse in response to others.

If the many fields of AIDS discourse are metaphorically described as conversation, then they must also be recognized as containing multiple voices and points of view. AIDS is a frequent subject of popular and everyday discourse. People tell jokes (whether in good taste or bad), mourn their losses, talk about who has AIDS, and argue whether homosexuality is a perversion. AIDS is a key issue for our times and just about everyone has something to say or not say (avoiding questions) on the subject. Gay political activists were correct in their assertion that by not addressing the issue of AIDS, Ronald Reagan was still taking a stand on the subject: AIDS is not important; or, AIDS
is a political hot potato; or, AIDS is not a topic to which Reagan wanted to respond. Peter Jennings, by hosting the AIDS Quarterly Report\(^1\) on PBS, was defining AIDS as important and people with AIDS as human (even if a blanket assumption of objectivity is made about news programs).

**Metaphor in AIDS Discourses**

Metaphors and figures of speech display other images, messages which are just below the surface in the stories of AIDS. Terminology often reveals important differences between points of view and judgments. Metaphors are found in the most formal of scientific literatures and the most relaxed accounts of self-experience (Sontag 1988). When the immune system is presented as an army defending the body from outside attackers, this is a figurative presentation of organs and cells, not soldiers and invaders (Martin 1990).\(^2\) Or, using a metaphor of contagion, HIV is transformed from a virus (a simple package of genetic material) into a creeping menace which strikes from bus seats or handshakes.

Words such as victim, person, menace, memorial, and patient carry meaning beyond the surface appearance and as such they also signal types and boundaries of discursive fields. The medical literature on AIDS abounds with words which indicate emotional distance: AIDS cases, patients, infectious persons or subjects. First person narratives of illness seldom use any of these terms. These words help to delineate normal and abnormal, active and passive, deviancy and hegemony, and human and not-human by associating the abnormal/non-hegemonic/not human with the emotionally distant and

---

\(^1\) Now called the Health Quarterly.

\(^2\) Martin also notes that white blood cells are engendered in immunological discourse. T-cells are "masculinized" since they kill by penetration while "feminine" phagocytes destroy by invagination (1990:416).
diseased scientific subject. The mass media, such as newspapers and television, use words which indicate helplessness: AIDS victim, AIDS sufferer, or dying of AIDS. People who work in hospitals or support a family member or lover with AIDS use metaphors of battle and struggle (Good et al. 1990). What may seem harmless (or merely descriptive) can dismiss one's experiences as marginal or anomalous. Thus, the implications of words and metaphors do signal important ideas about AIDS and can offer signposts through the complexity of AIDS discourses.

The importance of such attributes of AIDS discourses may seem obscure to social workers, volunteers, nurses, doctors, and others engaged in clinical or applied work. Why should the form and type of language be analyzed? After all, the important thing is the content, isn't it? My answer is that language can be a route to understanding as well as a powerful tool for redress. Why is it that some education, political action, and social services in AIDS-related areas have met with a number of notable failures? Some of these problems can be attributed to conflict, misunderstanding, and confusion resulting in part from the complexities of AIDS talk (Perrow & Guillén 1990). It is important to realize, along with Simon Watney, that

there is not in fact a single, unified "truth" about AIDS, available to be represented directly and universally . . . [AIDS] has been used by a wide variety of groups to articulate a host of issues and concerns, consciously and unconsciously (Watney 1989:9).

Additionally, standard terms used in the popular press and policy debates (e.g.,

---

3In a parallel situation, Joanna Russ describes how women's writing and experiences are suppressed and devalued through similar strategies: "She didn't write it. (But if it's clear she did the deed . . .) She wrote it, but she shouldn't have. (It's political, sexual, masculine, feminist.) . . . She wrote it, but she's an anomaly . . . (Russ 1983, from the paperback cover design).
AIDS virus, dying of AIDS, communicable disease) perpetuate confusion and aggravate political conflict (Gayle 1989). For example, the term AIDS virus makes HIV infection synonymous with terminal disease; leading people who are HIV positive\(^4\) to believe that their infection will inevitably lead to death (Sontag 1988). In actuality, those who are HIV positive may be free of serious opportunistic infection or rare cancers for decades.\(^5\) The metaphor communicable disease conjures up visions of passing HIV infection through casual contact like a cold or flu. Its not surprising such a term elicits fear and the desire to keep PWA's safely elsewhere. Solving communication difficulties will not resolve genuine political and social conflicts. There will remain people who condemn people with AIDS as guilty of sin or designate homosexuality and drug use as inherently evil. Others may simply ignore the situation as irrelevant to their lives.

The political competition for social services, research resources and health care funding taking place in state and national legislatures and other public forums is greatly influenced by the tacit assumptions and understandings of AIDS as expressed by the ways people talk about AIDS. The issue of what to call persons who have been diagnosed with AIDS is a case in point. The most common terminology used in the media are terms such as victim, sufferer or patient. It was at an early juncture in the AIDS epidemic that a group of people with AIDS chose to begin to contest the hegemonic usage of the word victim. At the 1983 AIDS Forum in Denver, a delegation of a new organization of those with AIDS presented a list of demands which included that they no longer be called victims, sufferers or patients (Altman

\(^4\) In other words, those who test positive on an HIV antibody test like the ELISA.

\(^5\) There is considerable disagreement over how long an HIV positive person may be symptom-free but long-term survivors are not rare.
1986). The Founding Statement of People with AIDS/ARC begins with:

We condemn attempts to label us as "victims," which implies defeat, and we are only occasionally "patients," which implies passivity, helplessness, and dependence upon the care of others. We are "people with AIDS" (PWA Coalition 1987:148).

This declaration accompanied the announcement of a political agenda to work towards more and better health care and research, and to strive to protect those with AIDS or suspected of having AIDS from discrimination. One purpose of the PWA Coalition was to construct another way of speaking or counter-discourse of AIDS. They also proposed more compassionate ways of interacting with persons with AIDS. All of these terms (patient, sufferer, victim, etc.) are negative in the sense that they imply passivity: one who is done to but does not do. This is a standard media practice when referring to anyone who has been diagnosed with or is experiencing any severe illness. People with AIDS are not the only ones who have to contend with oppressive stereotypes. Negative images are commonplace and often support a notion that people who are ill or disabled are incapable of "fully participating in everyday life" (Biklen 1978:35; also see Bogdan et al. 1982).6

Susan Sontag's work makes the importance of metaphor and figurative languages of disease as a political weapon quite clear (1978, 1988). She correctly asserts:

AIDS is a favorite concern of those who translate their political agenda into questions of group psychology: of national self-esteem and self-confidence. Although these specialists in ugly feelings insist that AIDS is a punishment for deviant sex, what moves them is not just, or even

---

6 The root of the word victim also implies passivity: the Latin word victima refers to an animal offered up for sacrifice.
principally, homophobia. Even more important is the utility of AIDS in
pursuing one of the main activities of the so-called neoconservatives . . .
A whole politics of "the will"—of intolerance, of paranoia, of fear of
political weakness—has fastened on this disease (Sontag 1988:63).
Sontag recognizes not only the political power of metaphor but also the
possibility of a redressive language.

Sontag's proposed counter-discourse is radically different from that which
I found at the AIDS Foundation of Houston; her's is a modern language of
disease stripped of all metaphor and "without meaning" in that sense (Sontag
1988:14, 94). This modern language would attempt to demythicize illness and
avoid the "fantasy of inescapable fatality" associated with AIDS and cancer
(Sontag 1978:84). She wishes to:

... calm the imagination, not to incite it. Not to confer meaning, which
is the traditional purpose of literary endeavor, but to deprive something
of meaning: to apply that quixotic, highly polemical strategy, "against
interpretation," to the real world this time. To the body (Sontag

I would argue that Sontag is attempting an impossible task. Metaphor is an
inescapable part of everyday and scientific language and thought (Geertz
and Johnson succinctly state:

... human thought processes are largely metaphorical. This is what we
mean when we say that the human conceptual system is metaphorically
structured and defined. Metaphors as linguistic expressions are possible
precisely because there are metaphors in a person's conceptual system
(1980:6).

Not only does Sontag reject metaphorical language but she also ignores the
(usually) narrative context in which metaphor is used. The counter-
discourses of the AIDS Foundation of Houston have been successful in large
part because they use new metaphors and narratives within empowering
contexts. The discussion of metaphor alone does not adequately address the
complexity of illness discourses. Participants in the public conversation of
AIDS use metaphor while telling stories, constructing argument, making jokes
or reporting new facts but not in isolation. It is necessary to discuss the
thematic and narrative context in which metaphor is employed.

**Theme, Motif and Narrative Structure**

Unlike metaphor, it is more difficult to separate theme, motif, and
narrative structure in discussing AIDS discourses. These aspects of discourse
are not discreet units as are specific metaphors. Certain themes are regularly
associated with particular narrative strategies and motifs. By theme, I am
referring to overarching concerns or issues that are the product of (self)
interpretation by the writer or speaker in the context of a discursive
community or culture of expression. Themes are returned to again and again.
Through reiteration, they help to shape autobiographical narrative structure
(along with experience, point of view, and culturally-specific narrative
conventions). In fact, specific narrative styles can be “symptomatic of the
presence of a theme” (Fowler 1987:249). Motifs are the local manifestations of
theme within a narrative moment; they are aspects of the story which are
dependent upon theme.

This conception of theme not only looks at “the construction of
significance backward in time” within a single work (Martin 1986:127) but
also across the multiple voices of AIDS discourse. Written or spoken
autobiography is in this sense a reply, one expression of a PWA’s participation
in the public conversation about AIDS. Gary Walsh is speaking to a varied audience in his video: volunteers in training, Jerry Falwell and the religious right or anyone else who might be shown this film. Walsh repeatedly comments on previous conversations and debates.

Walsh, along with other people with AIDS, uses a powerful set of discursive strategies which result from the central themes of his discussion. The most prominent theme in autobiographical accounts by persons with AIDS is what might be called "life on the edge of death" or "living with AIDS". This theme is part of what gives PWA stories their great emotional impact. We can all imagine the great courage that it takes to live well in the face of imminent pain, disfigurement, and death. Living with AIDS tends to incorporate compatible motifs such as "bargain making" or "knowing what is important in life" which are often subsumed under this general theme in American culture. Similar associations between theme, motif, and narrative structure can be found in stories by people with other life-threatening illnesses. Living with AIDS requires a narrative structure which is without formal resolution (i.e., death) or a true climax.7

AIDS narratives may contain shorter stories which do have a more structured format (vs. a series of complications without dénouement). These stories within a story are much like the American genre of personal experience narratives identified by Sandra Stahl (1983, 1989). These stories of personal experience combine nontraditional, secular subjects with traditional form, style, and function (1983:268). These narratives are not memorates or folk tales in the usual sense but do have much the same form. For Stahl, if memorates are about spiritual or sacred beliefs, then personal experience

7 Illness narratives are unlike other folk narratives in lacking this type of ending.
narratives are about values and attitudes (i.e., secular beliefs; 1989:19). She breaks down the narrative plots into several stages: initial situation, (one or more) complications, climax, crisis, and dénouement (1989:16-17). Personal experience stories have distinct beginnings and endings. Stahl's examples are relatively short stories centered around a discrete event or series of events. I discuss Stahl's idea of personal experience stories to show that the authors of illness narratives are not violating or ignoring American "rules" of storytelling but that they are following rules for a different kind of American story (Brody 1987, Kleinman 1988). Persons with AIDS use a different form of storytelling, illness narratives, which subsume personal experience narratives as episodes within a larger autobiographical matrix.

Gary Walsh's illness narrative in the Shanti video Facing Death and Dying contains one such personal experience narrative, a kind of story within a story (1983). It tells the story of Walsh's life at the time of his diagnosis:

Walsh: ... before the diagnosis, which was in January of eighty-three, I had just moved into a new office. I worked as a psychotherapist mostly with gay couples. Um, and we had, just a month or two before diagnosis, moved in, and ... it was one of the most exciting times of my life. To finally, own my own office, where I could practice what I love doing. Um, and it was also special because I was moving into the office with my friend Lu [Chalkin]. Who ... she's been a love for years now. Um, and I loved doing my work. I had just separated from a lover. It was a real stressful time. I had just moved into an apartment of my own. Um, and had been doing it [psychotherapy] a total ... total New York and San Francisco, for a total of about fifteen years. And the week I was diagnosed, I stopped ... doing it because for weeks I had been so tired. I assumed it was just stress. I would just come home and go to bed at seven
o'clock and then get up for work the next day. And, it was devastating to stop working. And, I had to tell thirty people, individually, in the first week of diagnosis, that I could no longer work with them, because I was the sick one now. And, um, it was incredible to see the therapist going to being kind of the one [being] taken care of by my clients. They would come over and hold me. And, we cried a lot together. And thirty times in that one week was enormously difficult but incredibly rich, There was such compassion and understanding for me. Um, the funny part was . . . Lu had her office right across from me, and each session I had that week was really very emotional. And clients were coming out of my office crying. And her clients, who were waiting kept saying to her, “we think we want to switch to Gary. He has such cathartic sessions.” [laughter] Um, but that was a difficult week. I've seen most of my clients since then as . . . as friends, as part of a support system.

This tale breaks down neatly into the fivefold parts suggested by Stahl:

1. Initial situation: Walsh sets up a new psychotherapy practice with his old friend Lu Chaikin.
2. Complication #1: Walsh has just separated from a lover and moved into a new apartment.
3. Complication #2: Walsh was so exhausted he was going to bed at 7 o'clock every night.
4. Climax: Walsh is diagnosed with AIDS and must close out his practice.
5. Crisis: When Walsh tells his clients of his illness, they leave his office crying. Lu Chaikin's clients want cathartic sessions, too.
6. Dénouement: Roles are reversed. Walsh's clients become his support group.

Walsh's personal experience is transformed into a highly structured
narrative. Although sections of AIDS narratives or stories within stories display this structure, their narratives as a whole do not. The illness narratives by persons with AIDS are open-ended and tend to be loosely organized. The fact that there are several different modes of expression complicates interpretation even though they all display a similar open-ended, episodic structure. Unlike the illness narrative as a whole, which requires an episodic narrative line without a true conclusion, there is nothing about this particular experience that demands this structure. In fact, if Walsh's tale is like those discussed by Stahl he probably made significant alterations to fit his story into this structure. It is interesting to compare Walsh's version of his story with the one Lu Chaikin tells in her interview with Lon Nungesser (Nungesser 1986:173-4, 194). Chaikin's version of the events are essentially the same as Walsh's but lack the narrative structure that Walsh imparted to his story.

Illness narrative has become an important topic of much ethnographic work and theorizing in medical anthropology over the last ten years or so. The key focus for most of this work is to explore the experiential nature of illness. What is it like to have cancer or lupus or AIDS? How do people with serious or chronic illness make sense of their lives and their illness? How do people live with chronic pain or disabilities? The foremost proponent of this type inquiry is Arthur Kleinman (1980, 1988, & 1992). His work forms the basis for much of what has been said, both positive and negative, about this approach to the study of illness narrative. In the best of such work, he and others follow the phenomenological threads of disrupted personhood; try to

---

tease apart the personal, cultural, social, political, and semiotic threads of the embodiment and experience of illness. Their work challenges the dismissal of the personal from the human sciences and underscores the fact that biomedicine is a culturally specific way of looking at human beings.

One difficulty with much of this literature is a tendency to see the experiential narrative as revealing the various components of power and symbolic in a self-evident fashion or to view the political nature of illness as merely one aspect of that experience. In more recent work, Kleinman explores some of the political aspects of illness, especially what he calls "resistance," and finds the idea lacking (1992). The difficulty is that Kleinman cannot let go of the dichotomy between psychosomatic (mind) and biogenic (matter) causes of illness. For Kleinman, if illness, in this case chronic pain, is a form of political resistance to oppression then it cannot have physical causation (1992:189 or see 1988:41). I would argue that the experience of most illness, especially chronic or life-threatening illness, is about relations of power. This is most clear with overtly stigmatizing illnesses like AIDS but is just as true of rheumatoid arthritis or diabetes. The physician and the insurance company have the power to name or not name a specific condition as illness. The family of the chronically ill person may view them as complainers or heroes. The culture defines them as malingering or justified in their pain. The life of a seriously ill person is walled in with questions of disclosure or secrecy—If I tell a friend/lover/family member about my illness will they still like/love me? In such a world of externally and internally imposed constraints, what chronically ill person can be said to be free of arbitrarily imposed restrictions specifically related to their illness? The experience of illness is a political one in all of its aspects, whether regarding cultural definitions of normality, related to microsocial or interpersonal
relations or the experience of the self and body during illness.

**Autobiography**

The many accounts of what it means to have AIDS can be broadly grouped as: (1) autobiographical and biographical narratives which tell the stories of people with AIDS, (2) objectivized expositions by medical researchers, social workers, psychotherapists, etc. cast as case studies, (3) accounts using people with AIDS as a cultural symbol or icon to amplify social dramas (Turner 1974) or to reinforce points of view within discursive fields on family, religion, freedom, and so forth. These groupings are very broad and overlapping but are associated with distinct patterns of expression. In this chapter, I will focus on narratives which speak about what it is like to have AIDS, how it influences self-interpretation, how it effects one's life, and how to be a person with AIDS. Gary Walsh tells his story in the training video, called *Facing Death and Dying*, as part of an interview with Jim Geary. Walsh was a white, gay psychotherapist who was very active in the Shanti Project and AIDS political organizing in San Francisco in the early 1980's. He died in the winter of 1984.9 “John” (a pseudonym) wrote a short autobiographical essay and his is the only first person account included in a collection of stories from Houston (Shelp, Sunderland, & Mansell 1986:89-98). Authors Shelp, Sunderland, and Mansell explain this exception with: “John is a competent scholar and an introspective, analytic person” (1986:88).10 Another

---

9 Except for well-known people like Walsh, it is impossible to know whether the persons with AIDS discussed in this book are still alive. I have chosen to speak in the present tense for the most part. These are people "living with AIDS."

10 This explanation doesn't really hold water as there are several other PWA/ARC's described in the book as articulate and well-educated. Was John the only one well enough or the only one who asked (or insisted?) to write his own story?
autobiography I will discuss is by Bobby Reynolds, a white gay man. He worked with Helen Shietinger to write the film, \textit{AIDS: Care Beyond the Hospital}, on the chronic nature of HIV infection for the San Francisco AIDS Foundation. Reynolds includes himself as the first of a series of case studies. Reynolds' case history will be supplemented by his published interview with Lon Nungesser (1986). This video, like Walsh's, was used as part of the AFH training weekend. The narratives by Walsh, John, and Reynolds all have (or had) some special significance in the Houston scene.

The above autobiographies form the basis for my interpretation but they do not address all the issues that I consider important. Thus, I have included several other narratives to supplement them in various ways. Fran Peavey's journal/autobiography is interesting because she describes her attitudes and feelings both before and after her diagnosis with HIV infection (1989). Peavey is a white, lesbian, socialist-feminist activist living in the San Francisco area. Her published journal provides a window on her changing beliefs and attitudes during her transformation to an HIV positive person. I also refer to Nancy Mairs' autobiographical essays (1990). Mairs is a feminist writer who has multiple sclerosis. Her work is pertinent because she has carefully considered the political implications of writing about the experience of illness. She writes to challenge the silences about disfigurement and disability in American culture.

All of the examples that will be discussed here speak about what it is like to have AIDS (or other serious illness), how it influences one's self perceptions, how it effects one's life, and how to be a person with AIDS. Most have had a special place in the Houston scene. The two videos were used as part of the AFH training weekend, and "John" is a Houston resident speaking in a popular book about AIDS in Houston. The other narratives are included
because they display characteristics of stories told to me when I worked at AFH. Stories told to me by persons with AIDS at the AIDS Foundation of Houston are not included here for several reasons. First, such stories were related in the strictest confidence or through the anonymity of the hot line. Second, the circumstances precluded the possibility of tape recordings or transcripts being made. Also, the personal narratives tended to be relayed in partial, incomplete or episodic fashion over the hot line, during the weekend training or in conversations with other AFH volunteers. It would have been impossible to acquire informed consent and been a violation of my responsibilities as a volunteer to record conversations without consent.

Autobiographies by persons with AIDS are culturally constructed texts as well as being intensely personal documents. The regularities of culturally specific forms take on meaning in a complex dialectic of private pain and public discourse. Illness narratives partake of what I will call cultural scripts. Such scripts are common stories and are found in television, movies, advertising, newspapers, and folk tales. They are American storytelling (in the broadest sense). Some scripts are explicit and often discussed such as the poor man who makes good through hard work and dedication (e.g., a la Horatio Alger). The Parsonian concept of the sick role parallels a cultural illness script which represents illness as having a beginning and an end. For Parsons, while engaged in the sick role, a person is exempt from normal social responsibilities, must seek out health care and make the effort to recover (Parsons 1951:436-7). But how can this model of illness fit the life of a person with AIDS or other chronic and life-threatening illness? This model of how to be sick is inappropriate and disheartening for those who cannot by definition ever be truly well.

Writers and speakers who depend on these culturally-specific forms of
narrative find many are not appropriate for the chronically ill. The usual family fantasy like "Father Knows Best" or the "Cosby Show" does not fit well with this experience. Nancy Mairs, a writer with multiple sclerosis, notes:

... [O]ur lives are stories we tell ourselves. And they tend to follow, as closely as we can make them, the conventions we have learned from reading (and nowadays watching television and films, too). We want them to contain all the features we've been told belong in a good story: a handsome prince or a beautiful princess, a scary monster who's not quite strong enough to withstand the handsome prince, an ending in which all the evil people are dead or at least in jail and all the good people live happily ever after... Stories of family life also follow predictable lines... In each episode, some member of the family develops a problem and, in no more than an hour's time, with the affectionate and good humored support of the other family members, resolves the problem to everyone's satisfaction (1990:122).

People with AIDS, or any serious or chronic illness, cannot follow this standard format. But they can and do find other cultural scripts which suit their needs.

In considering how best to explore narratives by persons with AIDS, I have found some of the perspectives in the literary study of autobiography to be pertinent. Literary critics primarily concern themselves with issues of theme, structure and the process of self-interpretation. Angrosino, in his review of the literature, sketches out some pertinent points made by literary criticism:11

1. The truth of a document recording someone's "life" is gauged by its

11 These three points are only some of issues discussed by Angrosino.
capacity to connect with the experiences of its intended audience, not by its conformity with established "fact."

2. The "Self" behind the "life story" is less important than the self that is created in the process of communication between writer and an audience.

3. The literary devices that communicate this "metaphor of self" are derived from, sanctioned by, and given meaning through the culture that the writer and the audience share (1989:12).

The first speaks to the goals of autobiographies by people with AIDS: they speak out for the purpose of connecting emotionally with their audience. Their truth is not the facticity of their story but in their ability to communicate their experiences. The second point refers to James Olney's ideas on the process of self-interpretation that occurs during the writing (or speaking) of autobiography. Olney argues the self in autobiography is metaphoric because:

one can give sufficient organization [to a wholly new sensational or emotional experience] by relating it to the already known, only by perceiving a relation between this experience and another experience already placed, ordered, and incorporated (1972:31).

One interprets the self by metaphorically associating the known and unknown (or self and other). However, this is not a totally idiosyncratic process but is based on culturally derived literary or narrative devices. The form and style of autobiographical narrative is something which the writer or speaker learns and which other members of the same culture will recognize. When I discuss Gary Walsh as an exemplary person with AIDS, I refer to his role as one way in which people learn to be and tell about being a person with AIDS.

What distinguishes an autobiography from biography is self-
interpretation (Starobinski 1980, Smith 1987) or self-characterization (Crapanzano 1987). Autobiography is a linguistic process and a dialogue between self and other. In this case, the "other" is an audience which ranges from other persons with AIDS to people who have never had AIDS touch their lives. Therefore, autobiographies of PWA's can be interpreted as a group which have this specific political goal in common and sharing this purpose they speak to one another. The American personal experience story, the gay coming out story, and the illness narrative are blended by persons with AIDS to construct a style and form of their own.

One aspect of autobiography that has tended to be left unexplored is its often political nature (e.g., Kleinman 1988). People who speak out in public or in written forms about their illness are not merely making some narcissistic comment on their bodies but are combating the discrimination associated with all chronic or life-threatening diseases. In fact, those who speak out without the protection of anonymity are probably more likely to face that kind of discrimination. Nancy Mairs, feminist writer and woman with multiple sclerosis, eloquently expresses that certain events and feelings related to her illness:

existed in the realm of the linguistically impermissible, I hadn't been able to speak them aloud and, in sharing them with others ease their weight. I thought that, by writing them and making them public, I could undermine their power to constrict my life and the lives of any others whose voices had been choked off by social taboos (1990:90-1).

Speaking out becomes work because it has (or is hoped to have) real social and

---

political consequences.\textsuperscript{13} Angrosino and many literary critics tend to ignore the political nature of autobiography. James Olney obliquely acknowledges this when he notes that some new academic fields (such as African American, women's, and African studies) have the autobiography as one of the primary subjects of study (1980). Additionally, many of the classic autobiographies are built around experiences with serious or chronic illness. While not identical experiences, illness, gender, sexuality, and race all produce stigmatized or damaged social identity (Goffman 1963).

It is always a struggle to construct a strong sense of self in a way that runs counter to societal pressures to conform or against social stigmatization. Autobiography provides a platform from which the author can speak to issues of color, sexuality, and illness by chronicling his or her own suffering. Perhaps, this is because autobiography tends to focus on some upheaval in one's life. As Starobinski notes:

\begin{quote}
...[O]ne would hardly have sufficient motive to write an autobiography had not some radical change occurred in his life—conversion, entry into a new life, the operation of Grace (1980:78).
\end{quote}

Autobiographies are tales which chronicle the upheaval of one's sense of self or the creation of a sense of identity in the face of suffering or societal disapproval (or approval). The stories of persons with AIDS qualify in several senses: AIDS itself is a sign of a damaged social self; lesbians and gay men must deal with society's disapproval of their sexual identity; and many heterosexuals with AIDS are people of color. A diagnosis of AIDS itself certainly qualifies as a radical alteration in both social and personal identity. The narratives of Gary Walsh, John, Fran Peavey, and others were chosen because they address this

\textsuperscript{13} See Nungesser's interview with Arthur Felson (1986:5).
issue directly and explain who their self is now that "I" have AIDS. Work by persons with AIDS has tended to focus on issues directly associated with the politics of AIDS and may refer only briefly to other, more personal areas. For example, callers to AFH often spoke of the difficulty they have in communicating with physicians and the stress of not having a final diagnosis. Of the handful of AIDS-related autobiographies discussed here, only John refers to this period in his life and then only very briefly. This time of uncertainty is extremely stressful and it is difficult for anyone to understand that a diagnosis of AIDS may actually come as a relief.

There must be a public face put on AIDS before public health efforts can be broadly successful (as in the more recent cases of Magic Johnson, Arthur Ashe, and Freddie Mercury). It is the personal statement that directly and concretely challenges the attribution of stigma and silencing of discussion in public life (Mairs 1990). It is the public statement of one's own story which can be the loudest, most important proclamation of all. Indeed, if it had not been for those willing to appear publicly as persons with AIDS, it is likely that the degree of stigma attached to AIDS would be as great now as it was in the early 1980's. But reducing stigma is not the only motivation for telling one's illness narrative.¹⁴

Inside/Outside

Clearly, the experience of illness cannot be understood and recounted by the outside observer as it is felt by a person with AIDS. Illness, pain, the loss of bodily integrity, and the imminent threat of death impact one's perspective of the world and oneself just as surely as do culture, class, gender or any other

¹⁴ Contrary to Weitz 1991 or Goffman 1963.
major aspect of identity. That is not to say that there are no meaningful statements and descriptions to be made by an observer but that the shift in perspective results in a shift in understanding and use of discourse. In other words, the chosen content, language, and interpretations of someone experiencing illness will be different from someone who observes whether that person is emotionally involved or distanced. This issue is particularly important if one wishes to respect the integrity of the narratives of persons with AIDS.

Fran Peavey is a white lesbian from California whose published diary, *A Shallow Pool of Time* (1989), shows this dramatic shift from those entries where she is an uninvolved observer of AIDS to the later entries when she has discovered herself to be HIV positive. In the early entries, Peavey discusses issues in ways that emphasize impairment, death, and newspaper stories which are tinged with fears of death and contagion. In 1986, she decides not to build a "community hot tub" in her backyard because she might have to invite the gay male couple from across the street (1989:8) and skips a testing appointment to find out if she might have been exposed to HIV (1989:4-5). Peavey is neither unsympathetic to people with AIDS nor does she express strong negative feelings against homosexual men or those who use drugs but she repeatedly demonstrates in those early pages what she herself later calls her "prejudice" against persons with AIDS (1989:XIV). For example, one evening she was having dinner with friends including Dennis, a person with AIDS:

> At one point, Carol's and Dennis' water glasses became confused. It was an awkward moment because of fear of drinking out of the "wrong"

---

15 Of special interest here are the standpoint theorists such as Hartsock (1987), Harding (1987), and Haraway (1991).
glass, and I was frozen with fear. Dennis ordered two fresh glasses. I thought he handled it elegantly (Peavey 1989:7).

Peavey was relatively well informed about HIV infection and, yet, was still afraid of the possibility of contracting HIV through casual contact. Her fear was of AIDS as a metaphor of contamination, as a metaphor of a creeping menace, not realistic caution.

After recovering from the initial shock of discovering she is HIV positive, Peavey begins to emphasize learning to live with uncertainty and the prospect of illness or death. She attends support groups where she hears how other men and women cope with HIV infection. She notes that issues which are only vague abstractions to other people are crucial in the lives of people with AIDS:

I have been in lots of intellectual discussions about the relationship of the individual to society, but never such vital discussions as these in our support group. Here alienation, ethics, and moral responsibility are not abstract concepts, but real day-to-day decisions (Peavey 1989:40-1).

Peavey goes on to comment on why that concern makes persons with HIV infection different than those who do not:

... I sensed one of the differences between HIV+16 people and those who do not know their status. Most of us HIV+ folks have somewhat come to terms with our responsibility to society. At least we think about this responsibility every day. But society has for the most part not come to grips with its responsibility to itself. Instead it wants to control those of us who are HIV+ rather than find out and implement the changes necessary to protect itself (1989:73).

---

16 HIV+ is short for HIV positive or testing positive on an HIV antibody test.
She is now personally involved with the possibility of legally required registration of person's with AIDS during the political fight over the Gann Initiative in 1988 in California. It is not merely a political issue. Fran works to maintain some kind of emotional and romantic life while trying to reconfigure her sexual activities in line with "safer" sex practices (the guidelines for women were far less elaborated than are those for men). Now, when she hears of the mistreatment of PWA's, Peavey can easily imagine herself in that position where before such stories concerned her but in a more distant fashion (1989:73-5).

Fran Peavey's journal is the story of the reconstruction of herself as a result of her HIV positive status. She becomes hypervigilant for the first possible signs of illness or appearance of symptoms of immune suppression:

I hate being obsessed with these physical worries. I have noticed this almost characteristic of HIV+ people—every little mark, every pain is a source of upset and preoccupation. This is natural, I guess. I realize that I need to know when to begin to fight with drugs—when I have gone from the latency stage to the stage when the virus is active. The earlier the treatment starts, the better the results. And so one is always nervous and on guard (1989:58).  

17

The shift that is demonstrated during the course of Peavey's journal is similar to the difference between autobiographical illness narratives and third person narratives. The stories from the observer's point of view elide certain aspects of chronic illness which are usually given a more central position in the first person narrative; especially those aspects which are most difficult to voice or to understand at a distance.

---

17 Peavey is writing in the summer of 1988 before the use of drugs such as AZT as an early prophylactic measure was common.
Alternative Discourse: An Exemplary Person With AIDS

Facing Death and Dying, the interview with Gary Walsh, is used by AFH to introduce volunteers to persons with AIDS during the training process. The AFH training weekend, described in chapter one, is carefully planned by training staff, the volunteer committee, and volunteer directors. The idea is to teach volunteers to use alternate form(s) of talking about and understanding AIDS. One intent is to produce effective, committed volunteers who are sophisticated about the political implications of speaking about AIDS. The story or autobiography of a person with AIDS teaches volunteers some of the implications of the way they speak about and understand AIDS. Some trainees have never met a person with AIDS and others have known only a close friend, lover or relative with AIDS. Their ideas about PWA's are as likely to be formed by the media as by any personal experience. They often have lingering fears of being around people with AIDS, fears that AFH tries to overcome through showing PWA's as ordinary people. Other trainees have more immediate experience with HIV infection. When I participated in a training weekend, some of the trainees revealed that they were HIV positive and one that he had AIDS. In effect, AFH was also teaching these folks how to be people with AIDS.

Gary Walsh, in Facing Death and Dying, articulates a different way of being a person with AIDS by not fitting any of the stereotypes. He is neither a dangerous carrier of contagion, demonstrated when interviewer Jim Geary holds his hand to show affection and support, nor the sort to knowingly infect

---

18 Training programs for other organizations such as Gay Men's Health Crisis, Shanti Project, and Crisis Hot line are similar to that at the AIDS Foundation of Houston both because training techniques are borrowed from such groups and because their parallel goals are articulated in the training process.
others which is clear from his caring attitude. By publicly presenting himself as a person with AIDS, Walsh is out to explode negative images in the media and popular culture. Walsh tries to replace those public stereotypes with an image that is both mundane and heroic: a normal life with aspirations and disappointments but in which an unforeseen event turns one's life upside-down and an ordinary person is forced to face an untimely death. Walsh's importance in Houston, far from his home in San Francisco, derives from the continuing use of the Shanti film in the AFH training weekends. He has become an exemplar or classic example of what it means to be a person with AIDS. His presence continues to be felt and used to deny the popular images.

Gary Walsh: Gay Man, Psychotherapist, Political Activist & PWA

The most noticeable thing about the film is the respect which the interviewer, Jim Geary, treats Walsh (see also Chapter One on Foundation etiquette). Geary makes it clear from the beginning that Walsh is an expert in several senses:

Geary: With me today is Gary Walsh. Gary is a member of our Board of Directors and he's also [a] person with AIDS. I'm Jim Geary, executive director of the Shanti Project. And Gary was going to be with us in, um, a support group today but because of the fact that his health is not too good and, um, the doctors have basically given up. Um, he only wanted to attend a shorter session so . . . Gary, its nice to have you here.

Walsh: Its nice to be with you and to feel like we're making a contribution.

19 As compared to the way Shilts talks about Patient Zero in his book, And the Band Played On... (Shilts 1987).
G: Well, I'm sorry you missed the support group. We had a really nice support group. But I'm glad you can be here with us now.

W: Me too.

G: It feels really good.

W: Yeah, it feels real... real important.

G: We had talked about how you wanted to feel like you could make a contribution to Shanti Project. Being a member of the Board of Directors and being a client as well, you've had a sort of long, intense history with Shanti...

Walsh also adds that he is a trained psychotherapist (working with gay couples) and is gay himself. Part of Walsh's impact is that his multiplex identity makes him and his story a bridge between volunteers, professional staff, and persons with AIDS. Walsh is not ashamed of being gay and makes this very clear:

Geary: How has having AIDS effected your feelings about being gay?

Walsh: Actually, it's made them stronger. My brothers and sisters are the people who are making life really worthwhile. And, the way the gay and lesbian community has pulled together. I don't know of another group that could do that. And... the amount of love that being expressed has just been overwhelming. Um, I don't feel... I think it's just increased my feelings. I feel so proud to be gay. I know all the stuff that was coming out and, you know, Falwell still preaches about the punishment from God. That's just bullshit. There's no reason why we'd ever be punished for being gay. I think we should be in ecstasy. I... and to see what may be the images, that maybe I bought along the way too, of some kind of butch, macho gay man... have some of the biggest hearts. Um... I think I feel much better. I feel much closer to [my] gay
brothers than I have probably ever.

Walsh reinforces the importance of his identity as a gay man with AIDS which both informs and is informed by his roles as psychotherapist and member of Shanti's Board of Directors. Walsh's story has far greater depth and resonance than any case study in the social work or medical literature could possibly have. The contrast bolsters his status as PWA expert: no matter how caring or knowledgeable the physician or therapist, only a person with AIDS can be the ultimate expert on having AIDS.

Geary directs the interview loosely, asking questions or making comments most often to show support (an example of the tenets of active listening and Foundation etiquette discussed in chapter one) and offers guidance when Walsh begins to run down or asks for direction. For example, while discussing how painful it is to die and leave the two people he cares about most, Walsh becomes distracted and loses the thread of his answer:

Walsh: . . . . Matthew who is my lover and Lu who has just been a love for years, are the two hardest people to leave in this life. I almost wish they could go with me. [Crying] . . . . Uh, I don't . . . . What was the question? [quiet laughter]

Geary: You answered it. It was very . . . . You've told, you've told both Matthew and Lu that you feel that you're . . . . that you're dying? And that the time is getting close.

Geary gently reassures Walsh, gives him time to recover from the emotion of the moment, and then points in a direction for Walsh to continue.

The questions asked by Geary structure the interview in a different way than if Walsh had been speaking purely off the cuff. During the course of the interview, Geary's questions and comments are of two types. In the first half, Geary asks about Walsh's history: "So you were diagnosed with K.S. [Kaposi's
Sarcoma] when . . . ?" or later, "And you've had pneumocystis [pneumonia] since that time as well . . . ?" Later, in the second half of the interview, Geary repeatedly directs the discussion to Walsh's feelings about his imminent death. Geary is not only asking questions but is also making his own comments about Walsh's experience:

Geary: You had talked about, um, about people in life and particularly nurses that you had extraordinary connections with . . . And how that made [you] aware that perhaps that type of connection is something that's possible all throughout life but that we often don't experience such intense, deep connections until maybe we are faced with a life-threatening illness.

Geary is actively encouraging Walsh to (re)construct his experiences into a coherent narrative by first concentrating on issues of historical time and then by expanding the resolution of the crisis of Walsh's story (i.e., his acceptance of death). 20

Perhaps one of the most important questions Walsh answers is are you the same person? Has AIDS changed the essential you? The diagnosis of AIDS—of any life threatening illness—seems to be the end of life or, at the very least, a radical transformation or disintegration of self. A common fear associated with chronic and life-threatening illness is of the loss or destruction of a sense of self. How can I be who I want to be or be the best I can be if I am sick or dying? Arthur Kleinman describes this cultural imperative as:

[an] injunction [which] prescribes a quest for authenticity in self-

20 Several theorists emphasize the importance of narrative to the process of psychotherapy. Spence notes: "Inside the hour [of the therapy session], we try to create continuity and coherence and make what sense we can from the emerging findings . . ." (1982:24). See also Paul Ricoeur's work on Freudianism.
identity and its expression (so-called self-actualization) that has been intensified in recent decades as the core moral requirement of the individual in American culture (1988:98).

This places a tremendous burden on the ill person, especially for the young and achievement-oriented. People with AIDS must deal with what seems to be a double loss: that of the potentially perfect self and the possibility of self-actualization. One of the first statements by Gary Walsh, is the denial of such a loss. Even though Walsh has had to stop practicing as a psychotherapist and leave a newly formed private practice, he still asserts that his real, authentic self has not only survived but thrived. Walsh counters that feeling from the point of view of one who has lived with AIDS for a long time:

Geary: ... Good. Gary, can you talk to me a little bit about ... about who you are, maybe who you are apart from AIDS, before your diagnosis with AIDS. And then, talk about when you were diagnosed.

Walsh: Before AIDS, I was pretty much like I am now, I think, in a lot of ways. I think that's a lot of what keeps me going is ... and made it tolerable, is not to have changed much in my life. To keep it as ordinary as possible....

Walsh is implicitly emphasizing that AIDS or the diagnosis of AIDS does not change one into a bad person or a saint, doesn't make one a guilty victim or a faceless source of contamination. Even the pain and emotional suffering of his illness has not changed the ordinary Gary Walsh into a sort of stranger. During the AFH training weekend, this statement is made explicit when training staff urge volunteers not to think that persons with AIDS will all be saints or even nice people; they are ordinary, everyday people. This helps to counter the innocent/guilty and victim/carrier stereotypes of persons with AIDS. It seems that AIDS would inevitably change the core of one's self
identity. Walsh is saying that yes AIDS shook up his life and changed much but the core of who he is is still who he is—a reassurance of stability in an extremely unstable world. Walsh's assertion of a unitary and somehow unchanging self is in contradiction to the many changes he describes later in the interview.

**Eureka? Or Things Suddenly Fall Apart**

John's autobiographical essay, discussed in this section, describes a somewhat different kind of experience than that of Gary Walsh but the two share a narrative strategy: they begin at the beginning. Illness narratives usually start by telling about diagnosis (Kleinman 1988; Brody 1987). The writer or speaker tells of an unusual, baffling bodily experience. The experiences may be spread over a period of time such as when Walsh tells of his profound exhaustion which forces him to bed by 7 o'clock every evening after work. Others, like John, suffer an acute episode of illness without prior signs of illness. A diagnosis is a kind of "eureka, it all makes sense now" feeling. Suddenly, all the information of bodily experience is reorganized and made sense of in a radically new fashion. Signs and symptoms are now interpreted in the light of this new knowledge. A simple cough or spot on the skin becomes cause for alarm. One can no longer dismiss such things as isolated, minor, everyday inconveniences. Now, they are signs which signify serious illness.

John's story begins with this break between normal, everyday life and the first signs of illness or pain. His narrative begins with a kind of "once upon a time" I was doing some perfectly normal thing and then suddenly I had trouble breathing. Suddenly and without warning, his life is overturned and the experience of his body is forever altered. No longer can normal function
be assumed and living taken for granted. Illness stories, whether told by persons with AIDS or with other life-threatening illnesses, often begin by marking the point of transition. John, a white Gay man in his early thirties living in Houston, begins his story with:

[O]ne afternoon in the spring of 1985 I donned my nylon running shorts and Niké shoes to run seven miles in my usual way. The next afternoon I went to do the same thing and had so much trouble breathing I had to stop after two miles. In two more days I was in a hospital bed. Thus, out of the blue, began the phase of my life I will tell here (in Shelp, Sunderland, & Mansell 1986:89).

John describes two further episodes of acute illness (a disseminated fungal infection and Pneumocystis carinii pneumonia) followed each time by more or less complete recovery from the infection but continuing immune suppression. There were a couple of months after his initial opportunistic infection when John was in limbo. His initial infection was not on the CDC list for diagnosis of AIDS and the tests for HIV antibodies were not yet available.21 The symptoms and signs were not yet symbolic of AIDS. As John puts his uncertainty into words:

young homosexual men who eat well, run fifty miles a week, lift several thousand pounds of weights per day, get sufficient rest, and so on—such as myself—just don't come down one day with disseminated disease ... 

unless they have AIDS. So I lived for several months in great fear of

21 Until 1992, the CDC recognized a diagnosis of AIDS through the presence of one of a list of opportunistic infections or rare forms of cancer that often accompany immune suppression. The ELISA test was not yet licensed at the time of John's first infection but became available in June 1985. The Montrose Clinic was designated as an alternative testing site to provide anonymous HIV testing at that time (See an open letter from the Clinic's Executive Director, Thomas Audette, dated July 13, 1987).
the truth before the CDC—mercifully—put a new word on their list of
inclusion criteria [for a diagnosis of AIDS] and I came to know the truth
Diagnosis, of even a life-threatening disease, can be a relief from the
uncertainty of disease without illness or social context. John had no name for
his condition, only an underlying sense that things weren't right and a body
displaying symptoms acute enough to land him in a hospital.

The transition from health to illness may also be marked by the rather
mysterious event of a positive ELISA or Western Blot (two commonly used tests
to detect the presence of anti-HIV antibodies). There may be neither external
symptoms of immune suppression and signs of AIDS, nor any certainty that
there ever will be. Callers to the AIDS Foundation hot line often describe this
state as being like carrying a time bomb in one's body, one which may never
go off or may explode tomorrow. Most young adults—remember most people
with HIV infection are young adults—have not yet had to face the true sense of
their own mortality. At some level everyone knows that human beings
eventually die but few have had to deal with the possibility of their own
imminent death or disability.

Living with Illness

Bobby Reynolds' brief story is more like that of Fran Peavey in that it
does not begin with an acute illness but with the appearance of seemingly
innocuous skin lesions. Before the use of HIV antibody testing, the diagnosis
of a Kaposi's Sarcoma lesion (KS) put people in a similar situation to those with
a positive HIV antibody test. Bobby Reynolds learned that the spots on his skin
were KS but that he was otherwise in reasonably good health. He tells his
reaction as part of a video by the San Francisco AIDS Foundation called AIDS:
My name is Bobby. When I was first diagnosed I had only a few lesions. I really felt fine but when they told me I had AIDS I went into shock. I was numb. I'd come home from work, kiss my lover, and head for the garden. I found that working with the plants was healing for me. . . As time passed though, I realized that AIDS would not go away. It was to stay a large part of my life.

Bobby's first response is to turn off his emotions and avoid thinking about his diagnosis. Eventually he begins to come to grips with his situation and find ways of coping:

I learned to devote more time to taking care of myself. I took a leave of absence from work which was a difficult decision. Besides gardening, I find other ways to reduce my stress and anxiety. I began to do visualization. I imagined armies of pacmen eating my lesions. A time came when I stopped looking in the mirror for more lesions. Now I try to keep a positive attitude, work on my projects, and take things a day at a time. I continue to do well and have learned how to live with AIDS. But when I see my friends get sicker and die, I wonder what lies in my future. Will I be disfigured? Will I be helpless? Will there be much pain? I don't have any answers.

Ultimately, Bobby Reynolds is left with big questions that can't be answered but he has found particular activities and attitudes which help him cope with the pain and uncertainty in his life. However, living with AIDS continues to be an ongoing struggle.

---

AIDS: Care Beyond the Hospital (San Francisco AIDS Foundation 1984) Bobby Reynolds was coauthor of the video and is the only one of the PWA's in the video telling his own story. The following quotes are from my transcriptions of the film.
Having AIDS has had a tremendous impact on John's sense of emotional well-being as well. In his autobiographical essay, he at first attempts to elide and skim over his anxiety and pain by launching into a discussion of the work of Kubler-Ross. Then, avoiding painful issues, John states: "I won't go into some of what I'm feeling now because a lot of it is very similar to what many people feel when they are faced with a big disappointment and loss" (In Shelp, Sunderland, & Mansell 1986:90). But the bulk of the rest of his story is devoted to describing his "compulsive anxiety," his need to pay close attention to his world, to be nice to people, and plan for the future, whatever it may hold, and to finish what he calls his AIDS vignette. What John skims over is the shock, depression, anger, and other distressing emotions but which he reveals implicitly in his narrative. He tends to concentrate on intellectual devices by which he is trying to cope with his situation. His attempts are not wholly successful for John repeatedly alludes to the emotional suffering that underlies his intellectual activities. For example:

I can't tell what's important anymore. Every goal, every ideal, every value I ever held is now jumbled . . . in a big heap (In Shelp, Sunderland, & Mansell 1986:90).

or

I wonder if much of my compulsiveness lately is out of insecurity. Perhaps I am afraid that my passing will not be adequately grieved (1986:92).

or

Death and life, black and white. I am caught up in a vortex somewhere in between (1986:93).

or

Sometimes, though, I don't even feel worthy even to think about having
a sexual interlude with anybody. I often feel dirty (1986:95).

John's pain seeps out of the cracks in the intellectual edifice he has
constructed in attempting to cope with his situation. Walsh is not alone in his
denial of the loss of a sense of self. John notes that even his mood swings and
somewhat compulsive behavior are not new:

I've always swung between idealistic and cynical extremes; my mental
life has been a tension between the role models of Mohandas K. Gandhi
and H. L. Mencken. At some time I have found myself balanced at almost
every intermediate point. AIDS has just made it harder for me to stay in
one place for any length of time (In Shelp, Sunderland, & Mansell
1986:90-1).

Neither man feels that their real or authentic self has changed. The physical
changes brought about by illness have not destroyed their desires to improve
themselves. In some ways, both men are even more themselves than they
were before diagnosis.

John has created an highly artificial theory and practice of self. He tries to notice everything: "Flowers, sunsets, crippled old people, [and] potholes in the street" (in Shelp, Sunderland, & Mansell 1986:91). And then he evaluates what he sees and experiences:

... [D]ata proceeds from the Noticer to the Evaluator. Many of these
evaluations are very elaborate, requiring much theoretical support.
[Then I] want to tell someone all about it, or write a letter to someone
(1986:91, emphasis in original).

This rather "compulsive" (John's word) process of noticing, evaluating, and
telling keeps John engaged with and working on his life. It gives him a
purpose which helps to override the depression and pain. It is not uncommon
for persons with AIDS to simply withdraw deep inside themselves but John
overcomes this by pursuing his work. Disengagement can be life-threatening to someone in John's position. Depression and suicidal thoughts occur in high frequency among men with AIDS (Saunders & Buckingham 1988). People forget medications, ignore symptoms or eat poorly (see also Kleinman (1988), page 150 for similar situation). John's rather intellectualized mode of adaptation may separate him from his feelings yet is not without utility. It provides him with ways of dealing with terrible uncertainty of his illness.

John makes efforts to be nice to people as a kind of return for the many people whose kindness has been important to him during his illness. It is not always easy though and John feels he is "siphoning a lot of energy into being nice" (in Shelp, Sunderland, & Mansell 1986:91) because "[e]ven common courtesy requires a small sacrifice" (1986:92). Sometimes, being nice even takes away from his work. John denies any sense of obligation to be good person but he contradicts himself when he says that he has things to set right: "I have lived most of my life in a way that was not very nice . . . I am now compelled to try to set it right myself—and in a hurry" (1986:92). John seems to have made certain bargains with himself wherein his earlier transgressions are offset by being nice now. Some HIV positive volunteers at the Foundation have expressed similar sorts of bargains. This is a defense against developing AIDS—nice, caring people don't get sick or die. The belief that bad things don't happen to good people reflects a larger cultural bias that serious illness is somehow deserved, even as John and others are trying to create a counter-discourse of AIDS.

Political Coming Out as Work

The motivations for the public (or private) telling of one's story are complex. For some it is the desire to directly combat the stigma of AIDS. In the
early eighties, Bobby Reynolds and Gary Walsh were willing to "come out" about having AIDS in order to state: I have AIDS but I am still a human being worthy of care. This may seem a spectacularly unambitious statement these days but one must remember that these two men were speaking out at a time when quarantining and tattooing of PWA's was being seriously discussed in the media. Such public statements were very risky. For example, Gary Walsh counters generic images of the person with AIDS with the specifics of his own life. This strategy was not unique to Walsh and Reynolds. Bobby Campbell, Michael Callen and others started going public about having AIDS as early as 1981 (Shilts 1987; Altman 1986). This strategy parallels the gay literature of coming out stories and illness narratives by people with other life threatening sicknesses.23

One thing shared by most people who go to the effort and trouble of publicly presenting their illness narrative is that they consider this activity important work in its' own right. John was the only one of the stories in Shelp, Sunderland and Mansell to write out his own story. He may be confused over his priorities and feel uncertain about his life yet he still calls writing his AIDS narrative his "work":

Even common courtesy requires a small sacrifice. I must take a little time away from my own thoughts and projects in order to do something as simple as holding a door open for someone. Thus, being compulsive about being nice can often be at odds with being compulsive about my own work. Shall I linger to chat with this acquaintance out of friendship, or shall I hustle back to the typewriter to finish my AIDS

23 Godwin posits a similar role for coming out stories and gay folklore in general (1989). No (or at least very few) gay men or lesbians grow up with a gay adult to socialize them into the gay subculture. Gay spoken culture helps to enculturate adult gays and lesbians.

Other persons with AIDS still express the same sense that doing something for others and emotional ties comprise much of what is really important. For example, Walsh's relationships to friends, lover, and his caretakers as well as his work for the Shanti Project and making his videotape are what is important. Although Walsh differs from John in that he has been ill for a longer period and seems far more comfortable about coming out about his sexuality, he still shares a similar sense of what is really important.24 Bobby Reynolds does not explicitly discuss his activities in his video but assisted in the writing and production of the film and is also described as a person with AIDS health-care advocate and a member of the executive committee of the Persons with AIDS—San Francisco Action Group by Lon Nungesser (1986:113). In the interview with Nungesser, Reynolds answers the question “What's the most important lesson that could be learned [about AIDS]”:

The first response that came to mind was that people are people. You know, we're not file cards and we're not labels and we're not stereotypes or statistics. We're people, and we breathe, and we hurt, and we bleed when we're cut, and we have fathers and mothers. We are people (In Nungesser 1986:129).

Reynolds communicates this message through his work of explaining what it is like to be a person with AIDS. Simply making a public statement about their illness is equally important to John and Walsh. So important that Walsh is willing to make the videotape even though he is obviously very ill and close to death. Fran Peavey's journal is different from Walsh's, John's, and Reynolds'

24 Walsh, unlike John, has never used a pseudonym or, evidently, hidden his illness. And although Walsh does not himself describe his involvement at Shanti Project or other more political activities, they are well known (see Shilts 1987).
work in a couple of respects. She began with the intent of being a chronicler of the AIDS epidemic (a woman's version of Defoe's A Journal of the Plague Year), an event that did not yet directly effect her. After testing HIV positive, Peavey's journal became a personal document for herself alone: "the journal became a confidant, a friend to share with, helping me pass through the myriad of shocking information and sort things out" (1989:95). She did not consider publishing until urged by friends. Fran Peavey had been politically active and involved in many types of social activism prior to her diagnosis but not in gay politics. The public speaking out on their illness has become work for all these people with HIV infection. It substitutes for the loss of the more usual avenues of achievement (paid employment, careers, etc.) and is framed as an even more authentic form of search for a sense of self.

Being closer to death gives the person with AIDS a special authority on what really is important. This is a special authority that Americans also give to soldiers on the battlefield and those who have had near-death experiences.25 The idea is that when death is near, superfluous and trivial problems are stripped away and leave only the true core of life. This is also true of illness narratives of people with other diseases besides AIDS. Almost all of the narratives that I have read have some component of this authoritative sense of the reevaluation of one's priorities. This theme is found in differing styles and degrees. John notes that things which were very important to him before his diagnosis now seem relatively trivial:

One day it occurred to me that the only reason to be overcautious about your finances is that someday in the future you may again need credit.

---

25 As I read my morning newspaper today (The Morning News Tribune, Jan. 11, 1992), the front page was dominated by a story made up of excerpts from the diary of a teenager who had recently died in a auto accident. When is a teen likely to be taken so seriously, except when he or she is dying or dead?
But when you have no future in which to need credit, you have less reason to be financially meticulous (In Shelp, Sunderland, & Mansell 1986:93, emphasis in original).

On the flip side, what was once down played as too serious, not fun or just taken for granted may suddenly become very important. Spiritual matters, stable interpersonal relationships, being a good person, or accomplishing something important become issues of looming concern. John has found "a wonderful man" with whom he can spend his life and they will "help each other grow as people" (1986:94). But John has not told his parents that he is gay or that he has AIDS. He states that his greatest fears include being abandoned by Gene, his lover, or his family. John's style of life has changed to accommodate this need for companionship which he might have rejected before his diagnosis.

Concluding Remarks

The people with AIDS whose stories have been discussed here are all involved in creating something new. They are constructing an alternate way of talking about and of having AIDS. After reading and listening to what they have to say about themselves, I can no longer characterize their situation as "dying of AIDS." John, Fran Peavey, and Bobby Reynolds are most emphatically "living with AIDS". Even Gary Walsh, knowing that his death is quickly approaching, is still living with AIDS. All four have learned to perceive the real possibility of their own deaths while continuing to work and strive to make sense of their situation. Persons with AIDS cannot use cultural scripts in which the participants know that in the end everything will be all right; it is clear that bad things do happen to good people. The theme "living with AIDS" offers an alternative through which people with AIDS can structure a new, powerful sense of self and purpose.
These narratives structure a way of living with AIDS by drawing upon and rewriting American forms of autobiography. The stories begin with the point when lives are turned upside down, things fall apart, and life falls into a jumbled heap because of a sudden acute bout of illness or diagnosis of AIDS. The narrative structure of the stories begins with these metaphors of chaos or disorder and then to recount the ways in which the speakers and writers coped through a series of introspective episodes. While paralleling other types of American personal narratives, AIDS autobiographies differ in lacking any true sense of ending. The facts of one's own death must be written by someone else. Thus, the stories are not about dying but about learning to live with the almost unbearable. Plots concentrate on the search for a new sense of self after extreme bodily and emotional changes. Am I still the same me after I've lost 100 lb., can no longer hold a job or walk to the bathroom without assistance?

In the process of elaborating this cultural script—living on the edge of death—persons with AIDS have contributed to a counter-discourse of AIDS. One in which people with AIDS are not passive but are working towards reconstructing the way in which AIDS is understood not just by them but in all of American culture. In that counter-discourse, persons with AIDS are as much the experts on what it means to have AIDS as therapists, doctors or scientists. They are active participants in the social and political processes which determine America's response to the epidemic. We listen to persons with AIDS because people close to death have a special authority in our culture. They know what is really important in life because they are close to losing it.
Chapter Three

TELLING TALES OF THE OTHER:
BIOGRAPHIES OF PEOPLE WITH AIDS

The central part of this chapter is a discussion of the stories or biographies of persons with AIDS or ARC. I have chosen three examples which talk about people from the Houston area but in distinctly different styles. The first is Shelp, Sunderland, and Mansell's AIDS: Personal Stories in Pastoral Perspective which is a combination of a series of biographical essays about PWA's and their caretakers, families, lovers, and friends, and a theological argument for the involvement of Christians in the care of people with AIDS (1986). The second example is a segment of Whitmore's book, Someone Was Here, which tells the story of Jim Sharp who was actively involved in the Houston AIDS scene in the late 1980's (1988b). Author Whitmore writes from the perspective of someone who has himself been diagnosed with AIDS. The third example is a series of panels from a Houston showing of the NAMES Project Quilt. The panels were made for or by people living in the greater Houston area by their friends, lovers, and families. While not strictly biographical in that they are not narrative, the NAMES panels are a form of storytelling with a primarily visual format and tell a great deal about local beliefs and representations of identity. Together these three examples offer a panoramic perspective on the public portrayal of people with AIDS, of who and what is considered important in their biographies.

When I began to attempt to characterize these stories, to try to re-tell them in such a way as to communicate both their power and weakness, I felt compelled to explore my part in their interpretation. I had great difficulty
reading the biographical stories in *AIDS: Personal Stories in Pastoral Perspective* when I first picked up a copy in the mid-1980's (Shelp, Sunderland, & Mansell 1986). I felt much more comfortable with Whitmore's *Someone Was Here* and the NAMES Project. Once, I tried to explain why I was so uncomfortable with Shelp, Sunderland and Mansell's book to a fellow AFH volunteer but only managed to sound contrary and overly critical. I was uncomfortable because all the narratives seemed somehow to be the same story, each seemed to have been remade by the authors.

It was only later that I began to understand what had been done—the short biographies in *AIDS: Personal Stories in Pastoral Perspective* had been re-structured to fit into the overall discursive structure of the book to support the argument being made by Shelp and his co-authors. My discomfort was because I, as a non-Christian, did not find their discourse compatible with my own view of the world. Whitmore's book and the NAMES Project were more in line with my own perspective on persons with AIDS. I felt more comfortable with their representations and did not immediately perceive them as changing or re-writing the "real" stories. Later, I realized that Whitmore and the makers of the panels in the NAMES Project Quilt were just as busy re-framing and re-writing the lives of PWA's as were Shelp, Sunderland, and Mansell.

Ironically enough, as I attempt to discuss these stories now, I find that I must do the same thing, re-frame the stories in order to fit them into my interpretation of biographical discourse. In this case, I am re-working the facts of their lives into the standpoint perspective that I find personally and theoretically compelling. Standpoint theorists argue that our gender, race, class, sexual orientation, and, in this case, HIV status are crucial components of our lives and influence our perspective on the world. I, too, become the biographer who retells the stories of people with AIDS to fit with my ideas of
how they should be told. I had great difficulty writing this section of the chapter but did not consciously realize why until after I had devised and discarded three different ways of describing the stories. I finally understood that I was uncomfortable with having to pick and choose which of the professed facts, characteristics, events, and feelings to write about and which to leave out. When I reached that point, I also came to understand that I had to pick and choose as it would have been impossible to include everything, and that I had to reorganize and interpret or I would simply be (re)copying the text. So I offer these choices and interpretations because I believe them to be valid and that I have something important to say.

**Strangers, Sojourners and the Search for Enlightenment**

In telling the tales of others, one goal an author or speaker often has is to make the story one which has meaning and truth. This is particularly true when the stories are written for the purpose of persuading the reader of the author's position about people with AIDS. The authors of *AIDS: Personal Stories in Pastoral Perspective* (Shelp, Sunderland, & Mansell 1986) state that their purpose in writing is to change the way in which their readers think about AIDS. They hope to make their readers aware of:

... the pain, suffering, satisfaction, and peace that people involved with AIDS have experienced and are experiencing (1986:vii).

Their ultimate goal is to alter the responses of churches, religious leaders, and American society from one of rejection and stigmatization to one of compassion and redemption. The authors argue that the power of the stories derives from their truth as realistic portraits representing the experience of persons with AIDS. Shelp, Sunderland, and Mansell assert the centrality of truth by beginning their book with:
The stories in the book are true. Names and minor details have been changed to obscure identities. The sequence of events and features of particular experiences have not been altered. We have endeavored to tell each person's story faithfully, using his or her language where appropriate and possible. We have refrained from interpreting or commenting about each story or class of subjects until the final chapter (1986:vii).

The stories, according to the authors, have power because they are true and that truth is largely what they hope will persuade their readers of the importance of their message.

My reason for choosing Shelp, Sunderland, and Mansell's book is that it is one of the few published works by and about the AIDS scene in Houston.¹ But it is also significant for its use of Christian allegory and metaphor in a way culturally in tune with one of the major discursive frameworks found in "Bible Belt" Houston. The authors of AIDS: Personal Stories in Pastoral Perspective (Shelp, Sunderland, & Mansell 1986) include Earl Shelp and Ronald Sunderland, both ministers with Houston's Institute of Religion. Shelp is well known in Houston as the founder of the Clergy Consultation on AIDS and, along with Ronald Sunderland, has been very active in ministering to persons with AIDS, and their friends, families, and lovers. Shelp has been criticized by some people in the church for his proactive stance on AIDS and his willingness to work with openly gay people with AIDS. He first became involved when a close friend and colleague, Jay Jones, was diagnosed with AIDS in 1985 (Houston Metropolitan February 1988). Shelp and Jones had, at

¹ Most but not all of the people with AIDS interviewed for the book by Shelp and his co-authors were living in Houston although several were moved to Houston as adults and one still lived in a nearby city.
that time, recently co-authored a book on societal attitudes toward handicapped infants. Shelp's involvement with Jones increased his awareness of the problems that persons with AIDS face and triggered his interests in ministering to persons with AIDS. Shelp felt particularly obligated to take on what he in lighter moments called the "TV pietists" including television evangelists like Jerry Falwell and Jimmy Swaggart (Houston Metropolitan February 1988:162). The book, AIDS: Personal Stories in Pastoral Perspective, was a part of his campaign to elicit a more compassionate response to AIDS from churches, clergy, and Christian communities.

Co-author Peter Mansell was at that time Medical Director of the Institute for Immunological Disorders and a professor at M.D. Anderson Hospital of the University of Texas Cancer Center. He was originally trained as an oncologist but became deeply involved in treating persons with AIDS while still at M. D. Anderson (Houston Post March 22, 1989). Mansell was well known as an "outspoken advocate for patients and critic of what he perceived to be government inaction" in regards to AIDS in Houston (Houston Post April 3, 1989). Then in December of 1987, the Institute for Immunological Disorders, a hospital devoted to the care of people with AIDS, was forced to close due to financial problems. Mansell returned to M. D. Anderson hospital but no longer wished to concentrate on treating cancer patients. When his efforts to find an appropriate position in order to treat people with AIDS, Mansell ended up leaving Houston for California.

AIDS: Personal Stories in Pastoral Perspective is organized around three sets of concerns (Shelp, Sunderland, & Mansell 1986). The first is a compelling set of arguments that Christians should involve themselves in ministering to persons with AIDS and gives a set of tools and recommendations on what shape this involvement should take. Second is a chapter which provides a detailed
(and somewhat overly technical) overview of the epidemiology, public health, transmission, and medical treatment of AIDS (presumably written by Peter Mansell). The third and fourth parts of the book are made up of the stories of people with AIDS and their families, lovers, volunteers, doctors and nurses. These parts are combined to try to persuade readers that AIDS is a problem with which all people of conscience should be actively concerned.

Shelp and his fellow authors address their writing to a specific segment of American society—those who consider themselves Christian and their leaders. They extensively cite both the old and new testaments, refuting on a point by point basis the arguments of those who would reject people with AIDS because of AIDS’ putative connection with homosexuality, drug use or sex outside of marriage and because of fears of the disease. Shelp, Sunderland and Mansell begin by describing the situation of persons with AIDS as enduring a tragedy whose story deserves to be told. This is in part because PWA’s are able to pull something positive from their experience:

It is something of a miracle . . . that in the face of such trauma there should be any redemptive experiences in the lives of those affected by AIDS. But in the midst of the tragedies, character has emerged, reconciliation has occurred between people who were estranged, and bitterness has given way to acceptance and peace (Shelp, Sunderland, & Mansell 1986:1)

It is in part the courage and spiritual strength of persons with AIDS that should be admired and convince Christians to help those ill with AIDS.

The authors endeavor to convince the reader that the primary thing causing most of the Christians who avoid people with AIDS is a problem with irrational fears. The authors call this fear “an almost unbreakable barrier to
rational discussion and the development of a humane, sensitive response” (Shelp, Sunderland, & Mansell 1986:7). Shelp and his co-authors address each of these types of fear in one or more sections of their book. They describe the first kind of fear that the average person has as a misplaced fear of infection and illness. The book states that being afraid of a life-threatening infectious disease is rational. However, since AIDS is transmitted in known ways which can be avoided by those who minister to people with AIDS there is no need to be concerned about transmission. The chapter on the medical aspects of AIDS goes on to reinforce their message: infection with HIV is easily avoided and not contracted through social or casual contact.

The other types of fear Shelp and his co-authors describe are less “rational” ones. The authors note that most people demand absolute certainty when it comes to AIDS but ignore the risks that they take in everyday life (like the possibility of an accident in a car or in the bathtub). What is unusual and not absolutely safe is feared while that which is familiar is not, even though the probability of injury or death may be higher. People also fear to be in the presence of death or the dying even when that presence holds absolutely no risk at all. It is this fear that Shelp and his fellow authors call the “most anxiety provoking of all” (Shelp, Sunderland, & Mansell 1986:6). Lastly, the authors point to a general fear of sexuality and a specific, culturally mediated fear of homosexuality which impedes a more humane response to AIDS. They characterize this reaction as a desire to clothe sexuality in mystery and to require that all “sexual contact should conform to archaic societal notions of right and wrong, normal and abnormal, natural and unnatural” (1986:6).

In part, Shelp, Sunderland and Mansell attempt to counter these irrational fears through rational argument. They discuss why absolute certainty cannot be given by medical researchers about the transmission of
AIDS in regards to unlikely possible routes of infection and the psychological reasons why people feel the need for certainty in the case of AIDS where they would not in more commonplace situations. The chapter on medical information on AIDS is structured in an historical view which begins with the initial findings about Kaposi's Sarcoma and *Pneumocystis carinii* pneumonia in young gay men. The authors then go on to describe the multiple discoveries of the virus that has come to be named HIV, its modes of transmission, the unlikelihood of any kind of casual transmission, and possibilities for treatments or vaccines.² The chapter is a kind of AIDS 101 which addresses the most commonly voiced concerns about HIV disease.

Shelp, Sunderland, and Mansell also work to counter fears by making an appeal based on Christian beliefs and theology. They point to the emphasis placed on caring for the stranger-outsider in both the Old and New Testaments. The Old Testament places the “alien in the midst” or the “stranger at the gate” under the full protection of Judaic Law (Shelp, Sunderland, & Mansell 1986:10). Widows, orphans, the poor, and strangers all have rights and privileges under these laws. In the New Testament, this list is expanded to include the hungry, thirsty, naked, sick, imprisoned, the outcast, and the dispossessed while enlarging the duties of Christians with injunctions to protect and befriend (1986: 10-11). Shelp and his co-authors argue that persons with AIDS and their lovers, friends and family all rightfully belong on this list. Good Christians must show “that perfect love which casts out fear” not only because it is the right thing to do but because it will help to determine the identity of the

---

² The authors tell an interesting tale, borrowed from a Discovery Magazine story, to illustrate the unlikelihood of HIV transmission in any circumstance. They compare the relative infectivity of HIV and hepatitis B virus by comparing what would happen if you put an eyedropper full these two viruses in a swimming pool and then injected a chimpanzee with the pool water (Shelp, Sunderland, & Mansell 1986:21).
Christian church. Shelp asks: "... [Is] the church a redemptive, loving
servant people serving a servant Lord?" (1986:178). For the authors, the
question is not about whether ministering to people with AIDS "condones"
homosexuality or drug use but whether the contemporary Christian church
conducts itself with "integrity and credibility" (1986: 178).

There are eleven stories included, one of which (John's story) is
autobiographical and was discussed in the previous chapter. The ten
biographical stories are generally representative of the distribution of AIDS
in the Houston area. Jim, Gary, Richard, Bryan, Kevin, and Paul have been
diagnosed with AIDS while Scott, Bob, Alan and Mary have been diagnosed with
ARC. Of these ten people, Jim, Scott, Gary, Richard, Bob, Alan, Bryan, and
Kevin are gay men. Jim also used intravenous drugs. They come from a
variety of social and economic backgrounds from poverty to the upper middle
class. Bob is evidently the only Black person in the group. Six out of the
eight gay men described are well educated with at least some college and most
have degrees of some sort. At least half were far enough past college to have
moved ahead in their careers and have good jobs at the time of their diagnosis,
although most have had to quit working due to illness. Few had insurance
coverage that would pay for their medical care and so most had to rely on some
sort of state or county-provided health care or on the support of lovers,
friends or family. Three of the eight, Jim, Scott, and Richard, died before or
during the writing of the book. There is one story about a heterosexual
woman, Mary, who contracted HIV after having a ruptured uterus and several
blood transfusions. Mary is a white, well-educated, divorced woman with a

3 See the figures in the AIDS Surveillance Report-Houston SMSA for either
October 6, 1986 or January 5, 1987.
4 Just about the only time race is mentioned is in Bob's story. "White" is the
unmarked category of race for the authors—race is a non-white characteristic.
good job until her illness forced her to stop working. The last story, Paul's, is about a middle class, white, heterosexual man with hemophilia. He has a large family and, unlike many of the others, is still in good financial condition.

Few of these people would have been considered outstanding in the normal run of things. Kevin is very active in national politics around the AIDS epidemic and Paul has been a key actor in the creation of AIDS policy for the National Hemophilia Foundation but the others are neither prominent in public life nor are they involved in volunteer or church work in their communities. Shelp, Sunderland and Mansell do admit that they biased their selection by choosing people "whose histories [the authors] considered interesting and instructive" (1986:vii). The stories are compelling because of what they tell us about living with and dying of HIV infection and, in the case of the gay men, what the emotional and personal costs are of growing up gay in America.

Metaphor, Theme, and Narrative Structure in AIDS: Personal Stories in Pastoral Perspective

Like the autobiographies of people with AIDS discussed in the previous chapter, Shelp and his co-authors avoid the use of terms like AIDS victim or patient (except in a medical context) and speak of persons or people with AIDS (or with ARC). In referring to the epidemic, they use the terms "the virus," HTLV-III or LAV (the name HIV had not been coined yet), ARC, and AIDS. In this fashion, they avoid some of the more negative stereotypes and analogies. They also avoid the use of war metaphors.⁵ American society is not "fighting a

⁵ There are a few exceptions to their avoidance of war metaphors. Most are in quotations from other people (see Shelp, Sunderland, & Mansell 1986:xi) but one notable exception is in their concluding remarks (see 1986:177). However,
war against AIDS" but is experiencing a tragedy or a crisis. The two dominant metaphors are that of life as a "journey of enlightenment" and the person with AIDS as the "stranger/outsider." In the latter, the person with AIDS is compared to the "stranger at the gate" whom Christians and Jews are bound by biblical teachings to treat with the same compassion they would expect for themselves. The journey is like that of the sojourner, we are all here on earth for a brief time and must pursue spiritual and intellectual enlightenment in our short lives. For people with AIDS, this injunction strikes a particular chord. They cannot know when the end will come and they must prepare for it now. As Gary notes, "I've been enlightened. But, unfortunately, its a terminal disease" (Shep, Sunderland, & Mansell 1986:45).

Several themes emerge from the stories which are repeated over and over again through the different accounts. These themes echo the metaphors of "stranger/outsider" and the "journey of enlightenment". The first is the emotional isolation of the people in most of the stories. For the gay men described, their isolation derives from their difference. The one real exception is the story of Paul, a heterosexual, who seems to have found support and love from his family, friends, co-workers, and fellow church members throughout his life. The others, including Mary, all had experienced profound emotional isolation during some part of their lives. The gay men kept their sexuality secret for most of their lives or have been rejected by part or all of their families when they revealed their sexual orientation or HIV status. All had a period of their lives when they lived a double existence (one

---

in their biographies of PWA's the authors do not use war metaphors except in one or two quotations of family members.

6 For a parallel discussion of the metaphor of love as a journey see Lakoff and Johnson (1980:44-45).

7 In fact, Paul's story is anomalous in a number of different ways which will be discussed later in the chapter.
gay, one straight) and some even married in an attempt to conform to their family's expectations of them. All loved their families and were pained by the secrecy and deceit of hiding who they were or by their rejection when they came out about their sexuality. A few came to some sort of reconciliation but all had suffered because of the difficulty of family relations.

Gary's story provides a good example of this process (Shelp, Sunderland, & Mansell 1986:38-46). His parents kept secret the fact that his father was really his stepfather until his sixteenth birthday. They had always wanted the perfect son and family but Gary had never really met their hopes and expectations. When he was still in high school, Gary's mother told him "she didn't want her son to be an actor, hairdresser, decorator or florist" (1986:39). Although Gary didn't make the connection between wanting to be an actor (an early ambition) and homosexuality, he was well aware that his mother disapproved of him in some fundamental fashion. Gary's parents would say that they wished to hear his problems but when he went to them, they would not listen. According to Gary, they were emotionally closed not only to him but to each other as well. His stepfather also cheated him out of an inheritance from his grandfather while he was still a boy. Later, after his diagnosis, Gary was too weak to work full-time so his parents allowed him to move back home. However, Gary was required to live in a garage room and to do most of the household chores even though his illness made this increasingly difficult. Finally, Gary decided he had to leave and moved into a residence for people with AIDS.8

A second prominent theme of the stories is the occurrence of grave personal problems and/or self-destructive behavior. Several of the stories

8 The only residence of the type described in the relevant time period (about 1986) was McAdory House, run by the AIDS Foundation of Houston.
mention serious drug or alcohol problems. Alan had a drinking problem before he attended Alcoholics Anonymous while Jim and Gary were unable to stop using drugs until their diagnosis of AIDS forced them to rethink their lives. Others mention an inability to form close emotional attachments with lovers or friends. Jim, Scott, and Richard were fortunate to form a strong attachment with one lover or friend about the time of their diagnosis but Gary, Alan, Bryan, Kevin, and Mary felt alone and isolated. Shelp and his co-authors also include frequent sexual encounters or anonymous contacts as self-destructive by definition. They overtly associate low self esteem, childhood abuse, and horrific venereal diseases with the “fast lane” style of life. The situation for gay men in regards to sexual activity is more complex than it might first appear. For example, in John’s autobiographical essay discussed in the last chapter he observed that: “Our society makes us hide this important part of ourselves and denies us open access to more conventional ego strokes. So we take to the sheets” (see previous chapter, in Shelp, Sunderland, & Mansell 1986:94). The need for secrecy that many gay men and people with AIDS feel is definitely a part of their isolation. In all of the stories of gay men, the authors note that being in the closet and keeping their sexuality a secret from family, friends and co-workers imposed emotional costs. The two heterosexual subjects, Mary and Paul suffered their own difficulties and sense of loss but did not show the same type of emotional scars.

For all of the people except one, spiritual beliefs become a major focus of their lives and way of coping with their grief and loss. The process of spiritual self discovery is closely related to the new found understanding of life. To quote Jim, “AIDS has made [me] a person [who is] able to separate the important from the trivial” (Shelp, Sunderland, & Mansell 1986:33). He no longer spends all of his time partying and hanging out with people who don't
really care for him. Now, Jim has created some “meaningful relationships” and found a sense of “spiritual awakening” (1986:33). In Alan’s story, the authors describe this feeling in greater detail:

... ARC has been an opportunity to reorder his life, to sort out priorities, to learn honesty and courage, to value time, people, and loving relationships, and to be liberated from the judgments of institutions and people that he is unworthy to love (1986:65).

Having to deal with HIV infection has created a situation where people re-think their lives and try to leave behind any feelings of self-doubt they may harbor. All of the people whose stories have been told by Shelp, Sunderland and Mansell have found something greater, something outside their usual concerns to turn to now that AIDS has changed their lives so completely. They have found true friends, who do not desert them when life gets tough, have discovered a new sense of the importance of the spiritual, have come to grips with their attitudes about homosexuality, and avoid blaming themselves for what has happened to them.⁹

There are several minor exceptions to the theme of gay men learning self-acceptance. Kevin has found a greater purpose through political activities rather than spiritual enlightenment. He also expresses greater anger than that found in any of the other stories. The authors describe him:

Kevin is angry about AIDS. He is angry that he has it. His anger is a complex mixture of grief over a lost future, impatience with interruptions related to his medical care, frustration about contradictory medical opinions regarding treatment, and anxiety about

---

⁹ Shelp and his co-authors note in the Preface that they avoided talking to people who were angry, at themselves or at gays in general.
not knowing what will happen to him next (Shelp, Sunderland, & Mansell 1986:71).

Kevin is still a positive role model in that he has put his anger to constructive use. Political activity allows him to be productive even though it takes a real psychological toll on Kevin. Neither of the two heterosexuals portrayed, Mary and Paul, are angry or blame anyone for their condition. As Mary states that her “experience with ARC has helped her to sympathize with all minorities, especially gay men” (1986:81). Paul comments that,

In a paradoxical way, AIDS shows us that we are one people. We all have and need blood to live ... We should recognize all people with AIDS as people in need of compassion and expressions of our brotherhood and sisterhood (1986:88).

For the authors, the spiritual quest lies not only in finding peace for oneself but also in learning not to blame anyone else. Neither the homophobia of some straight people nor the internalized homophobia of some gay people would be in keeping with the overall theme of spiritual awareness.

The stories of people with AIDS as told by Shelp, Sunderland, and Mansell are stories of redemption. The authors emphasize the seeking after spiritual values and the finding of inner peace. When Jim, Scott, and Richard died they did not “rage against the dying of the light,” rather they accepted and forgave the people and events which had caused them grief during their lives. Gary, Bob, Alan, Bryan, Mary, and Paul may be upset that their families or friends are not always as supportive as they might be and that government, churches and other major institutions in our society have not always responded well but they are not angry or resentful. The one real exception to the finding of peace is Kevin, but even he has redeemed his anger by putting it to constructive use through his political activities. But, for the most part,
this group of people with AIDS is no longer angry or blaming themselves or others for their situation although they may feel grief and loss. They have been set free from the concerns of their former lives. The gay men, along with the authors, do not consider their love of men sinful in itself and so they are freed of any self-hatred or internalized homophobia. Each has made a personal peace with God and with their lives. These are tales of redemption.

“Tending the Bones”: Whitmore's Tales of Being There

The next biography I want to discuss is the story of a Texan living in New York City, which makes up the first third of George Whitmore’s Someone Was There (1988b). This book does not make an attempt to tell the stories of many people with AIDS, rather it concentrates on a trio of stories: that of Jim Sharp, a person with AIDS, Manuella Rocha and her dying son, Mike, and the story of a place and the people who work there, Lincoln Hospital in the South Bronx. I have chosen to concentrate on Jim’s story because he is the only Texan in the book. He later returns to Houston and becomes involved at the AIDS Foundation of Houston. Whitmore's motivations for writing Someone Was Here (1988b) are very different from that of Shelp, Sunderland, and Mansell.

Whitmore, himself, was diagnosed with Kaposi's Sarcoma in 1985. He revealed in a later essay that he was “trying to bargain with AIDS: If I wrote about it, maybe I wouldn't get it” (Whitmore 1988a:14). Whitmore frankly admits a bargain that many people with life-threatening illnesses make (“if I do good things and am a good person, then I won't die”). In his honesty, Whitmore reminds the reader that his point of view is not so very different from his subject. And in the epilogue, he admits that his fear and anger were

---

represented by Jim Sharp. By writing Sharp's story, Whitmore was also writing his own story.

Whitmore explains what he has written in two different ways, with two distinctive metaphors. In the Author's Note at the beginning of his book, he argues that "things" are happening too quickly to give an exhaustive view of the epidemic but that he can provide "snapshots from a speeding train" (Whitmore 1988b).¹¹ He frankly admits that he is being overwhelmed by it all and it is almost more than he can deal with—yet, somehow he does deal with his experiences well enough to keep on writing. Whitmore's second metaphor for his work compares it to that of a picture he has of a monk in a isolated Greek monastery. The monk is displaying the bones of those who have died and been placed in the monastery's ossuary. Whitmore speculates on that the monk might have ambivalent feelings about the bones and about having his picture taken. But the author is revealing his own feelings about being the writer of Someone Was Here: the bones/dead/dying are disgusting, holy, revered and the monk feels shame, pride, humility (1988b). Even in his ambivalence about his role Whitmore feels that he has to be the one to write the story. As he states:

But someone, I thought, has to tend the bones. Someone has to arrange and rearrange the display. Someone has to take the box down off the shelf to show you (1988b:3).

Later, Whitmore even more explicitly reveals that he also feels ambivalent about the people he has written about and about AIDS. Although the reader learns little about Whitmore's personal history, he does reveal some intimate

¹¹ Quote comes from the unnumbered "Author's Note" page in the front of Someone Was Here.
aspects of himself through his use of metaphor. The tales he tells are his story as well.

Jim Sharp, who appears in the first third of Whitmore's book, is a transplanted Texan. He had already had a successful career in Houston but moved to New York City about a year before the opening of the book to pursue his career in advertising, feeling that it was time to take on "the citadel of business" (Whitmore 1988b:25). Whitmore describes Jim as churchgoing, monogamous, independent, a recovered alcoholic, and rather self-contained. He is described as very much the Texan:

[He] has this image of himself as a cowboy, a person who can pull himself together... He says he grew up to believe that "you get up in the morning and you pull your boots on by the straps" (1988b:27).

Jim's self-containment is expressed through a "bland, good ol' boy facade" that he presents in both personal and business relationships. This representation of Jim by Whitmore feels a bit like a caricature, the Northerner presenting a stereotype of a Texan. However, the independence and self-containment of the image are in keeping with Jim Sharp's presentation of self. Stereotype it may be but it seems to have some basis in Jim's overall character. Whitmore also notes that Sharp retains close ties to friends in Texas while living in New York. He makes regular calls to another person with AIDS in Texas. Eventually he returns to Houston and becomes "active in AIDS service as an advocate and voice for people with AIDS" (Montrose Voice April 13, 1990). Sharp served on the Board of the AIDS Foundation of Houston (Lifeline July 1987).

The story of Jim Sharp is also about two important people in his life: his buddy/crisis intervention worker from the GMHC (Gay Men's Health Crisis),

---

12 From looking at the publication dates of the first article on Jim Sharp by George Whitmore, I would estimate that this was sometime in the mid-eighties.
Edward Dunn, and Sharp's lover, Dennis. Edward Dunn's story is told in tandem with Jim Sharp's. Edward lost his lover, Robert, to AIDS and he had attended sessions with a grief counselor at GMHC. Later, he became a crisis counselor for the Gay Men's Health Crisis and Jim was his first assignment. Edward was matched with Jim because of their similar careers, both were in advertising. Jim had been chosen as needing a crisis counselor because of his refusal to deal with his illness. It was feared that his continued smoking, tendency to overwork, and reluctance to enter the hospital would put his survival at risk. Edward was there to be Jim's lifeline. Later, Jim describes him as his "ace in the hole" (Whitmore 1988a:41). For Jim it seems that no matter what happened, Edward would be there but that is not the way it worked out. Ironically, Edward Dunn died not too long after Jim moved back to Texas while Jim Sharp remained active in the Houston AIDS scene for several more years (Whitmore 1988a:54). 13 Jim met his lover, Dennis, on Labor Day weekend in 1983. When they moved in together, it seemed the natural thing to do, a "natural progression" (Whitmore 1988b:43). Dennis was the one who decorated their small apartment and brought home the paycheck when Jim became too ill to work anymore. But their relationship could not ultimately withstand the strain of Jim's illness and they eventually split up.

Whitmore is telling two parallel, combined stories in this first section of his book: how Jim Sharp learns to live with AIDS and how the relationship of Jim and his GMHC buddy, Edward Dunn, evolves. The author begins with a mundane morning scene as Dennis goes off to work and Jim stays home to finish his last project from his work at an advertising agency. Jim is terrified when he first becomes ill. At first, he refuses to alter his work habits or

---

change his life although his ill health forces him to work at home. He appears to take his diagnosis calmly but Jim is really so frightened he can’t really bring himself to talk about it. Jim is sure that if you have AIDS you’re a modern leper, everyone deserts you and you end up dying alone (Whitmore 1988b:26). Jim feels as if he has lost all control of his life and that terrifies him as much as the prospect of having a life-threatening disease. He identifies Edward with AIDS and keeps him at an emotional distance. As Whitmore puts it:

Edward saw he quite literally represented AIDS to Jim. And Jim was determined—maybe AIDS had its foot in the door, but he was damned if he would let it into the house (1988b:30).

Jim doesn’t want to face up to the fact that he is seriously ill. He keeps his interactions with Edward, his therapist, and his doctor strictly separate from the rest of his life. Jim’s refusal to deal with AIDS is not all a bad thing. Whitmore even calls denial a mitzvah, a godsend, as it allows Jim to protect himself from the immediate stress and strain of that fear (1988b:30).

The fear and anger that Jim feels is carefully bottled up inside at first but then these powerful emotions begin to leak out the edges of his life. He finally begins to open up to Edward and will tell him the truth when asked “how are you feeling today”? A stronger sign of this seepage (as recounted by Whitmore) is Jim’s reaction when Edward tells him that he is going to be reassigned to someone new since Jim seems to be doing well. Jim “wanted to rip off Edward’s face” but settled for asking him not to go away (Whitmore 1988b:41). Edward agrees, he will remain Jim’s buddy and refuse re-assignment. This slow process of increasing openness was difficult not only for Jim but also for Edward who at various points describes feeling
"stonewalled,"14 "frozen out," and that trying to help was like "hard-rock mining" (1988b:34-36). The final straw for Edward is when Jim goes into the hospital without letting Edward know where he is. Edward is furious and lets Jim know in no uncertain terms:

"I've been calling the damned switchboard all afternoon trying to find you," Edward shouted into the receiver. "I called your doctor and they couldn't find you, nobody could find you. Why didn't you call me, for god's sake?" (1988b:38).

Edward is sure that his relationship with Jim is over, after all, hasn't he just screamed at a sick man. What happens instead is that Jim finally figures out that Edward does care, cares enough to yell at him. Jim's diagnosis officially becomes AIDS during this time of adjustment but he still works whenever he can drag himself into work or get projects to work on at home.15 But his health continues to deteriorate and finally Jim's doctor warns him that he can keep working and die or quit working and take better care of himself. Jim finally gets the message. He manages to deal with some of this fear through humor. He and Edward make bad jokes about death and what will happen after Jim's death. This is the official end of the story but Jim, Dennis, and Edward show up again in the epilogue and in a later article that Whitmore wrote for The New York Times Magazine after the book was published (1988a). Jim and Dennis end their relationship and Jim moves back to Texas. Edward is diagnosed with AIDS and dies while, paradoxically, Jim continues to live and remain active in the Houston AIDS scene until his death several years later.

14 Evidently Whitmore did not intend a pun.
15 Although Jim contracted what was evidently Pneumocystis carinii pneumonia, he refused to have the lung biopsy which would have confirmed the diagnosis or enter the hospital for treatment. Instead, he was cared for and treated at home.
In part, Whitmore's goals are like Shelp, Sunderland, and Mansell: he is trying to put faces on the AIDS epidemic in order to encourage a more compassionate response. However, the book is as much about George Whitmore as it is about Jim Sharp, Dennis, and Edward Dunn. This first section of the book is really an expression of Whitmore's fears and anxiety. His form of expression is complex and articulates his ambivalence through a language of antithesis and metaphor. Whitmore's use of metaphor is particularly striking in his expression of emotional responses to AIDS, the sense of uncertainty, and the bodily experience of illness. For him, the simple saying of anger and fear alone, the knowledge of randomness, and the description of the physical changes caused by AIDS is clearly not enough. He amplifies and explicates by his use of figures of speech such as AIDS as a "crap shoot" (Whitmore 1988b:32), Jim feeling fear and rage which "pinwheeled in him" (1988b:36), and Jim having a drug therapy hit him "like a sledgehammer" (1988b:64). It is not that Whitmore can't or won't describe these events in less colorful terms, it is that the author cannot stop at "simple" explanation but must try to make the reader feel these events viscerally.

One of the most striking images is that of AIDS as a "piranha" which swims in a "medium charged with shame and guilt (Whitmore 1988b:16-7, 31, 36). This figure of speech combines the author's characterization of AIDS with his emotional response to AIDS and sense of uncertainty. Whitmore got his idea from a stuffed piranha that Dennis once gave to Jim as a joke and it is Whitmore's metaphor, not Jim's. He describes the piranha:

The fish is mounted as if poised for attack, bristling, jaws agape. Like AIDS, the piranha is at first glance shocking, repulsive. But on closer inspection, it doesn't look real. It looks like something whipped up out of latex and horsehair for some low budget horror movie. Thus
demystified, it can be dismissed—that is, until your eye happens to fall on it again. Then you wish it weren't in the same room with you (1988b:16).

This is an expression not only of emotion—fear and rage—but an interpretation of AIDS itself as uncertain, unpredictable, and brutal; combining emotion, uncertainty, and bodily experience.

The bulk of Whitmore's metaphoric language enunciates emotion: anger, love, fear, confusion, isolation, denial, disorientation, cruelty, illusion, helplessness, affection, vulnerability, mourning, humor, and acceptance (Whitmore 1988b). One repeating analogy likens AIDS to the arrival of an unwelcome visitor and, for Jim Sharp, Edward symbolizes AIDS at the beginning of their relationship. Jim resists becoming emotionally entangled with Edward because it would “bring AIDS into his home” (1988b:15), Edward is “on the outside and Jim wasn't going to let him in” (1988b:29-30), but AIDS had already “moved in” (1988b:30), and Jim lived “in a room with four doors... every once in a while he'd open one... [but] for the most part he remained alone... isolated (1988b:30). Health is Jim's home and AIDS is trying to break in, taking the form of his crisis counselor, Edward, but Jim has no choice because AIDS has already taken up residence in the house of his body.

A second set of metaphors that deal with the emotional toll of AIDS try to express both the sense of unreality and the difficulty of acceptance. Even Edward, the crisis counselor, has a hard time accepting what has and is happening when he thinks about Robert, his recently dead lover. All he wants to do is to grieve Robert and talk about his memory but to his friends “AIDS was like a dark, terrifying pit they didn't want to look into” (Whitmore 1988b:59). Since he could not talk to his friends he began to “feel very edgy” (1988b:59) and experience “shell shock” (1988b:50). Edward had to go to a
bereavement counselor to “babble incoherently every detail he had ever known about Robert” (1988b:60). But eventually the sharp edges of his grief start to blunt and Edward finds that there are “echoes...forming around memories [of Robert] that used to be crisp” (1988b:23). Jim’s grief and anger are still new and sharp, even at the end of the book. He must make jokes as a “safety valve” which “mask the fear and corrosive anger that are now as firmly rooted in Jim as the virus itself” (1988b:67).

A large part of Jim’s (and George Whitmore’s) fear and anger are the result of the uncertainty and randomness of AIDS. There is no knowing who will get ill, what course their illness will take, and how or when they will live or die. Whitmore uses the language of randomness and disaster to express this aspect of AIDS. New York City is at the “epicenter of the epidemic” (Whitmore 1988b:20), gay men are experiencing an “ego-leveling calamity” (1988b:30), are occasionally in the “eye of the storm” (1988b:30), and are “buffeted by waves of equivocal messages” (1988b:51). Randomness is portrayed through metaphors of games and war: it is being on the “front lines of the epidemic” (1988b:36), like “waiting for the Germans to attack at the Battle of the Bulge” (1988b:26), being in a “catch-22” situation (1988b:27), people with AIDS have gotten a “bad deal” (1988b:45), and become “odds maker[s]” (1988b:51). The emotional affect is like: “Sitting on a time bomb. Living under the gun. Waiting for the other shoe to drop” (1988b:50). The language of gaming and war is the only way to express the Whitmore’s notion of the fearful unpredictability and senselessness of what is happening all around and to him.

The physical effects of HIV disease are also expressed through metaphoric language. Edward notes that many of the volunteers that he trained with at GMHC talked about AIDS “as if it were a kind of gentle, Camille-
like wasting away . . . but Edward knew . . . AIDS is about shit and blood”
(Whitmore 1988b:24). The ugly reality of AIDS is too much for even those who
are preparing themselves to deal with it first hand. Jim learns this quickly for
“his own body [told] him” (1988b:29). When he must take medication for an
opportunistic infection, he feels “like someone had run [him] over” and as if
he had “been beaten to a pulp” (1988b:64). Later, even though Jim's
“numbers” remain good he “can feel the fires going out in his body”
(1988b:68). Jim's lover, Dennis, describes the changes he observes in Jim's
body and his own response when he likens his experience to anti-drunk
driving commercial on TV:

The skeleton hand would reach out and grasp the human hand and
there would be the sound of the crash in the background. When Jim
touched him, Dennis couldn't help it—Jim’s hand was like the skeleton
hand (1988b:45).

Every day there is a new sign of Jim's illness: “At least once a week we've
found, there's a little pin, a little thorn, a new added thing” as Jim’s condition
worsens (1988b:47). Dennis just wants the disease to be over and “has fantasies
of escaping with Jim” as if somehow they could runaway and leave AIDS
behind (1988b:48). In the end, Dennis and Jim's relationship ends and Dennis’
inability to cope is a large part of cause.

The narrative structure and organization of Someone Was Here, in each
of three sections, begins with an evocation of place: Greenwich Village, New
York City, Greeley, Colorado, and Lincoln Hospital, South Bronx (Whitmore
1988b). The geography, history, and culture are lovingly sketched and given
life . Whitmore paints a three-dimensional snapshot and then posits how AIDS
has changed everything. The effectiveness of his writing derives from its
straightforward prose, the juxtapositions between images of health and illness,
and the manner in which he reveals the affects of AIDS on his biographical characters. The narrative portions of the text are interspersed with AIDS 101 essays which directly relate to the subject of the story and then lead up to the next plot development or event. Whitmore is accomplishing more than one thing with his writing and using more than one form. By juxtaposing the "rational" essay format and an evocative narrative, he simultaneously combines two methods of persuasion.

The NAMES Project as Biography: The Houston Panels

No memorial is more complex, ephemeral, individualistic yet collective than the NAMES Project Quilt. Since 1987 when the Quilt was first displayed in Washington, D.C., it has mushroomed to thousands of panels. Each panel is uniquely created by those people who have loved and lost someone in the AIDS epidemic. Some panels are made by groups of family and friends working together at home or in a NAMES Project workshop (Ruskin, Herron, & Zemke 1988). Others are made by individuals or even by the person with AIDS for themselves. They are evidence that someone has lived and died. Has there ever been a memorial quite like it? The Quilt is a little like the Vietnam War Memorial in Washington, D.C. but unlike that black wall of names it is a personalized, more or less unplanned creation.16 One might draw parallels to the museums dedicated to the Holocaust which display the minutiae of clothing, jewelry, and belongings of the Jews, homosexuals, Gypsies, and political prisoners who died in the camps. But there is a beauty and hope in

---

16 The Names Project has only the most general requirements for the inclusion of a panel. It must be of a particular size (although this requirement is often waived for group quilts) and sturdy enough to withstand being moved and displayed (Names Project 1988 & 1990). Friends and family who visit the Vietnam War Memorial do bring personal belongings, flowers, etc. to personalize the memorial but these items are stored and displayed separately.
the NAMES Project that does not exist in the Holocaust memorials. The Quilt is an expression of American conceptions of identity, of self and “other,” and of grief and loss. In its’ complexity and power, the Quilt becomes something more than a memorial. So, what is the NAMES Project Quilt? Is it like the (auto)biographies of people with AIDS? What elements does the quilt have in common with biography?

The Quilt does the literal work of biography: it inscribes lives even though most panels are not narrative in the narrow sense. Panels, like biography, make available a sense of a person’s life through the use of metaphor, theme, and, in more elaborate panels, narrative. The Quilt itself is based on a metaphor of the “Quilt” and the “quilting bee.” Cindy Ruskin quotes Cleve Jones, who first promoted the idea of a quilt, as describing it as a:

... vision of a unifying quilt in memory of those who had died of AIDS. “Let’s take all of our individual experiences,” Cleve thought, “and stitch them together to make something that has strength and beauty” (In Ruskin, Herron, & Zemke 1988:9).

The Quilt is the stitching together of lives, of the representations of lives. Although shown in a collective setting the panels are constructions of American individualistic expressions of identity. The hundreds of panels on display form a kind of mosaic of people, names, and identities, each distinct and yet sharing common cultural themes.

In a discussion of the artistic merits of the NAMES Quilt, E. G. Crichton calls the Quilt a “visual metaphor for the tragedy of AIDS that transcends individual grieving to communicate beauty and hope” (1988:6) and later comments that “there is an amazing and unplanned repetition of imagery” (1988:8). These statements are both true and not true. The Quilt itself is metaphor and metaphor is used in all of its panels; its metaphors are visual as
well as textual. It also combines and transcends its many parts to become a single whole even as those parts change and panels are added. But the Quilt is not symbolic of "the tragedy of AIDS." It commemorates thousands of individual losses, not a single, faceless loss. Crichton confuses collective expression with the quilt's tremendous collective impact. The same types of metaphors, visual images, and themes appear again and again because they are cultural themes as well as personal expressions, not because the quilt is a collective expression. Thus, the quilts can be explored for what they have to say about what Americans think are important ingredients of identity.

I will concentrate on quilts displayed at the 1990 display of the Quilt in Houston. On this occasion, the Quilt had grown large enough to be displayed simultaneously in five sites around the country: Atlanta, Chicago, Houston, Los Angeles, and Washington, D.C. Some of the panels discussed here were displayed for the first time in 1990 and had not yet been sewn into the quilt itself. They memorialize several people who were active at the AIDS Foundation of Houston, people from other local organizations, friends and relatives of people who were at AFH, and other Houstonians with AIDS. When the quilt visited Houston in 1990, I saw panels for many people who had been active at the AIDS Foundation of Houston. Gary Beauregard, whose name used to be the password on the hot line computer, has a panel there. Michael McAdory's name, after whom McAdory House was named, is found on another panel. Panels for Jay Muckey and Tim Gonzalez were there (both were active at AFH). Lee Marcum's panel was there. His parents were one of the first married couples to volunteer at AFH.

As a group, the Houston panels are somewhat different from those from other parts of the country. They repeatedly use imagery and metaphor(s) which are distinctly Texan but, in other ways, these panels share much in
common with panels from other parts of the U.S. Like other panels, the large majority of Houston quilts focus on naming. This would not be surprising given the name of the Quilt except for the silence that surrounds a death due to AIDS. Very few obituaries in the mass media mention AIDS as a cause of death and many family members fear the consequences of exposure. People with AIDS and their families often go to great lengths to keep a diagnosis of AIDS secret, trying to avoid stigma and discrimination. But in the Quilt, names are almost always at the center of panels even when it only includes a first name, a first name or a relationship “name” (like brother, sister, father, mother). The dates of birth and death usually come next on the panel. This can be the most shocking and emotionally charged part of a panel because so many are so young. It is difficult to generalize after this point because the panels are much more diverse in their inclusion of place, personal characteristics, memberships, political activity, favorite things, and expressions of love. However, all of these things create and signify aspects of identity that the makers thought important.

Panels in the Quilt range from elaborate and complex to the very simple. Some are merely the inscription of a name while others are skillfully decorated. The methods range from traditional styles of quilting and appliqué to oil painting on canvas. The materials are diverse and include plain cloth, flannel, canvas, leather, lamé, various whole pieces of clothing, logos and designs cut from t-shirts, “t-shirt” paint, spray paint, toys, and photographs. In Houston, the newest panels were hung in the lobby of the George R. Brown Convention Hall while the older panels were laid down as part of the Quilt on the floor of auditorium. People entered the Center, rode up a series of escalators, and saw a brightly colored pathway through the hanging quilts.
Once having gone through the hanging panels, those in attendance then walked down on the main floor along the canvas pathways between the large sections of 36 panels (see Plate I). The quilt transforms the gymnasium layout of the convention center into something like a church. I felt touches of awe and sadness as if I were entering a graveyard or cathedral. Everywhere are people quietly walking, standing or kneeling down next to panels. Many place flowers or keepsakes next to the panels of those they knew and loved. You can hear the quiet sobbing of someone grieving, hushed movement of people down the aisles, and others speaking softly. There are no loud noises or conversations, even the children are quiet. The people in attendance come in all ages, colors and speaking many languages. There are families clustered around panels or walking down the aisles. All in all the atmosphere is one of restrained grief and almost no one reaches the end of their visit without tears in their eyes.

The Quilt has such a tremendous impact because it evokes a generalized sense of loss even in those who haven't experienced a personal loss due to AIDS. The panels do what all the statistics in the world cannot do: make the loss real and concrete, demonstrate that persons with AIDS leave behind people who love them, and show the youth of most people who die of AIDS. To accomplish this, the quilts do not have to be elaborate, complex or technically beautiful. For example, there was a whole section of panels which were simply the scrawled names of men. When I saw them, I imagined they were the product of some lone, sick survivor of a circle of friends and my sadness had nothing to do with their artistic merits or lack thereof. A slightly more elaborate example is Robert Allen Martin's panel which has his name

---

17 All photos by the author.
inscribed across the top of the quilt (see Plate II). Under the name are listed the dates of his birth and death, his city (Houston), and the inscription “My darling Robby, Our Love Will Live Forever” with a red flower on either side which look to have been pre-printed. The letters are in a block style in dark green appliqué on a white quilted background. Martin’s panel shows the emphasis placed on names and dates and the personal touches of the maker. Martin is somehow made more a concrete person by the evidence of the panel. I believe this is due to the combination of the “factual” evidence of name and dates, and the loving inscription of the maker. It makes clear that a person, Robert Allen Martin or “Robbie,” has died and that he was real, was loved and will be missed. Other panels convey the same sort of impact, a memory of someone, of a person, not a simple statistic. Like (auto)biography, the Quilt panels resist the victimization, the making faceless of people with AIDS.

The Quilt panels reveal the ways in which Americans explore and define identity. The panels each are a statement of who has died much more than of how they died. AIDS is seldom mentioned except in the context of more political statements of gayness, of memberships in social or political organizations, or in the commemoration of “anonymous” people who have died of AIDS (see Ruskin, Herron, & Zemke 1988:77,80). Panels use a variety of strategies to demarcate “who” has died such as names, photographs, regional cultures, ethnicity, clothing, favorite things, group memberships, and statements of relatedness (i.e., friend, lover, or family member). Photographs are often used to supplement partial names as in the case of “Hal H.’s” panel (see Plate III). The panel was apparently made by Hal’s gay friend or lover whose expression in the panel was evidently circumscribed by a need for secrecy. With a large yellow flower on the left side of the quilt, the years of birth and death, a letter from Hal that begins “To Those I Love and Those Who
Love Me," the name Hal H. in large off-white block letters, the words "Love is Forever" in cursive below the name, and a photograph of two men, their arms around one another and their backs to the camera. This panel speaks of conflicting desires to both announce and conceal the identity of the person who died. The photo with the two men facing away from the viewer proves the existence of Hal and his lover without breaking silence. Photographs in the Quilt more usually show the subject facing the camera. Sometimes there may be one formal photo and other times there are three or four which show the person being commemorated in different settings. None of the quilts I have seen show the person actually dying; there is a need to remember the person as they were before illness took a heavy toll.

Regional identity is a frequently expressed aspect of identity in the NAMES Project panels from Texas. Texas flags, cowboy boots and hats, bluebonnets (the state flower), the name "Houston," various city places and organizations, and outline maps of Texas, all signal an identity as Houstonian and Texan on panels. One panel, for example, shows the name "Randall" in large, brown block letters above a cowboy hat, spurs, and boots on a field of bluebonnets. The identity of Texan is prominently expressed on many Houston panels and seems to be a prominent ingredient in descriptions of persons with AIDS. Part of this may be due to the popularity of country and western music and dance in the gay culture. It also seems to be a statement of masculinity, a contradiction of the prevalent image of gay men as effeminate. How can a cowboy with spurs and boots be effeminate? Western style dress is also a kind of "drag" in the gay community. Many quilts use clothing, ranging from gold lamé dresses to t-shirts and jeans, as indicators of identity.

Expressions of ethnicity and race are less commonly seen as part of the language of identity in the Houston quilts. There is one double panel entitled
"Aves de Houston 1990" with the outline of human figure with arms raised in front of a setting sun at the bottom center of the quilt (see Plate IV). Above the figure are thirteen white birds flying upward, each with a name of an Hispanic person who has died of AIDS. In this case, the use of Spanish and the names signal identity but it is one of the few Houston panels which visibly portray ethnicity. In the book, *The Quilt: Stories From the NAMES Project*, some panels use the race or ethnicity of the subject to construct identity or are in some way ethnic-identified (Ruskin, Herron, & Zemke 1988:17, 67). There are panels which use a drawing or photograph of the person as black or Hispanic (1988:14, 48, 156), cultural or religious artifacts to signify Filipino nationality (1988:129) or maps or flags to show Mexican or Dutch nationality (1988:17, 118).

The dearth of racially or ethnically identified panels in the Houston exhibit could have one of several possible sources. The first is that many ethnic and racial communities have expressed reluctance to deal openly with the issue of AIDS. Some community leaders are concerned that AIDS will be conflated or lumped together with racial or ethnic identity or are reluctant to confront these issues because of conflicts with religious beliefs. Another possible contributing factor may be the timing of the exhibition. At that time in Houston, only a relatively small proportion of all the people ever diagnosed with AIDS in Houston were black, Hispanic or Asian. The large majority of PWA’s were still white gay men although this has changed in the intervening years. However, the problem with this explanation is that many of the people I saw at the 1990 Quilt exhibition in Houston were Hispanic or black. One final possibility is that gay identity or other personal ways of structuring identity takes precedence for Texans who make panels.
Another important way in which identity is constructed in the Quilt is through the representation of “favorite things.” Special clothing, toys, and other activities are represented through t-shirts or patches, musical notes and so on were all used to represent the person as well as the activity. An excellent example of this is the Goedken family quilt. This panel has representations of each of the four members of the Goedken family who have died of AIDS: Dennis, Carl, Ernest, and the baby, Clayton. The panel is divided into four equal sections and each is devoted to one family member with the name, “Goedken,” along the center, horizontal axis and the word, “Yahweh,” on the lower perpendicular axis.¹⁸ A quarter of the panel is devoted to each person with their names, dates of birth and death, and a symbol of their favorite things (or vocation): Dennis' section has a large block “H,” Carl's has pair of scissors (the symbol of a barber or hairdresser), Ernest's has a treble clef and musical notes, and Clayton's section has a puppy and a bib. These things help to define who the people were, what they cared about or worked at in life, and how the family and friends would like to remember them. Sometimes a combination of regional identity(s) and favorite things are combined to accomplish something similar. Don Barnhart's panel declares him affiliated with Paris, Milano, Houston, and New York. His quilt displays a cowboy hat, boot, a gold record and the statement “Born to Dance,” emphasizing a jet set and exciting life.

Many other panels do the same things, take some part of the person's life and use it as a visual sign of who they were as well as of what they accomplished in life. For some, names of their memberships and workplace

¹⁸ There is another symbol on the upper portion of the perpendicular axis but it is illegible in my photograph.
Plate I: The NAMES Quilt at the George R. Brown Convention Hall

Plate II: Robert Allen Martin's Panel
Plates III and IV

Plate III: Hal H.'s Panel

Plate IV: Aves de Houston 1990
Plates V and VI

Plate V: Michael McAdory's Panel

Plate VI: Greg Moorhead's Panel
serve much the same purpose. On Charles Lewis' panel, he is portrayed not only through the use of a photograph and a letter but also through a list of his memberships and job: EPAH, MSC, LWMBC, LAMBDA, KΣ, and Texaco.¹⁹ Michael McAdory’s panel has a similar list of memberships and mentions his role in the creation of the AIDS Foundation of Houston and that McAdory House, a residence for people with AIDS, is named after him (see Plate V). In the language of the quilt, person is what they love, what organizations they are members of, and the work that they do as well as their names and dates of birth and death.

The panels in the Quilt express more than just identity and personhood; they also describe a variety of ideas about life, death, and afterlife. Seldom is death explicitly referred to but rather is expressed through metaphor and image. Death as a journey is most prevalent among the Houston quilts. Bruce, the maker of John Day and Ramon Flores’ combined panel, says good-bye “until or whenever our paths meet . . . again.” Greg Moorhead’s panel shows a rocket leaving earth and headed off to the stars (see Plate VI). This conception of life and death presents death as a stage of life’s journey, an adventure, not something to feared. Similar ideas about death appear in Gary Walsh’s discussion of death (see Chapter Two) and parallel Shelp, Mansell, and Sunderland’s metaphor of people with AIDS as sojourners. This image is prevalent in both popular and theological notions of life, death and the afterlife. The setting (or rising) sun and rainbows in one form or another are also found in many panels. Ray Morris’ panel shows a rainbow over an outline map of Texas while Nicholas P. McCauley’s displays his name over the setting sun. Sometimes the metaphor of life as a journey is combined on

¹⁹ This list includes volunteer, gay political, and social organizations.
panels with other representations of life and death. Roger Dempsey's panel shows a setting sun and the words "Left for a Better place." Journeys, the setting (or rising) sun, and rainbows displace the raw saying of death, allowing instead a re-imagining of death as not an end but as a transformation of self.

Sometimes the metaphor of life and death as a journey is elaborated into a true narrative. Terry Lee Caffey's remarkable panel has an elaborate combination of imagery, story and metaphor. The overall impression is of a picnic on the beach. There are sand dunes, fork, knife and spoon, flowers, and a cloth. Across the top are the words "And He Came & Went in the spring" and on the bottom are Caffey's name and dates of birth and death. Across the picnic cloth is written the following:

The eternal bond

We met at the beginning of time
We formed an eternal bond of friendship
We chose our own paths of learning, vowing to be with each other from time to time, to check on each other's progress, and to help each other in our quest!
We have been both husband-wife, brother-sister, mother-father, friends and lovers, in past lifetimes.

When it is time again to separate, we will still be with each other through the strength that is the eternal bond.
One in flesh, the other in spirit.

You may choose to wait,
till I also return to spirit,
Guiding me as I go,
till my cycle is complete.
I pray that should the opportunity arise,
that you continue in your quest.
I will follow suit—and after an appointed time
I will again—seek you out—for we are eternal,
and, we are one—and always shall be.

Terry L. Caffey
1987

The maker incorporates Terry Caffey's own writing into the panel; creating both epitaph and story. The panel combines the story of life and death as a journey while also expressing that this journey is cyclical. This journey travels the same path over and over again, Terry is forever linked with his friend and lover. The expressed conviction that lovers, friends and family will somehow, somewhere meet again, is found in many quilts. On Hal H.'s panel it declares "Love is Forever" and on Robert Allen Martin's "My Darling Robbie, Our Love Will Live Forever." These expressions of life and love describe love as never-ending and overcoming all obstacles, even that of death. These portrayals combine identity, love, memory, death and grief into a montage, proclaiming identity and faith.
The Discursive Work of PWA Biography

The NAMES Project, Whitmore's *Someone Was Here* (1988b), and Shelp, Sunderland, and Mansell's *AIDS: Personal Stories in Pastoral Perspective* (1986) are all attempts to portray or tell the stories of people with AIDS. Each of these examples does this through distinctly different discursive strategies and methods although doing similar work. The portrayals return identity which is stolen when people with AIDS are made into victims and statistics. The stories work to counter negative representations, to overcome the alienation and secrecy which is imposed upon people with AIDS. However, each has its' own distinct agenda in addition to these parallels: Shelp and his co-authors work to persuade fellow Christians of the relevance of the AIDS epidemic to the contemporary church and its' similarities to situations in both the Old and New Testaments of the Bible; Whitmore admits that he is both trying to discover what his own future might be as well as stave off suffering and death by doing “good work;” and the (mostly) anonymous makers of the NAMES Project panels are retrieving the identity of their loved ones while creating a memorial which expresses and preserves their memory.

The stories of persons with AIDS told in *AIDS: Personal Stories in Pastoral Perspective* (1986) are much more patterned and repetitive than is Whitmore's biography of Jim Sharp. Each follows a tale of a journey through life which illustrates and elaborates the overall structure of the book. Shelp and his co-authors followed a vision of life as an overcoming of obstacles and pain to find peace and beauty within and with God in the end. The form is that of “life as a sojourn,” wherein life is a temporary journey on which we all travel and which people with AIDS are traveling “strangers.” As sojourners, persons with AIDS are mistreated and suffer but true Christians are
Table III
METAPHOR AND CORRESPONDENCE

<table>
<thead>
<tr>
<th>Christian Ideal</th>
<th>Person with AIDS</th>
<th>“General Public”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compassion</td>
<td>Suffering</td>
<td>Hysteria</td>
</tr>
<tr>
<td>Information</td>
<td>Pain</td>
<td>Misinformation</td>
</tr>
<tr>
<td>Rational</td>
<td>Tragedy</td>
<td>Irrational</td>
</tr>
<tr>
<td>Education</td>
<td>Redemption</td>
<td>Ignorance</td>
</tr>
<tr>
<td>Service</td>
<td>Death</td>
<td>Fear</td>
</tr>
</tbody>
</table>

commended to care for the stranger/outsider with compassion and kindness. The biographical essays are part of this overall argument and the form in which the stories are presented serves this strategy. The authors did not choose anyone whose story could not be fit into this narrative structure and avoided the anger which is so prevalent in Whitmore’s book and the focus on memorializing the person which is the focus of the NAMES Project.

The structure and order of the arguments presented by Shelp, Sunderland and Mansell can be understood more clearly by discussing the series of metaphors and ideas which represent their concerns. Each of these terms represent their subject by a single characteristic (synecdoche) but are placed within a complex structure of correspondence (see Table III). By presenting the suffering, pain, tragedy, redemption and death of people with AIDS through their biographical stories, the authors hope to counter hysteria, misinformation, irrationality, ignorance and fear and to substitute Christian compassion, scientific information, rationality and education, and Christian service to the stranger/outsider. Thus the stories of people with AIDS become persuasive allegory and part of Shelp, Sunderland, and Mansell’s overall argument.

Whitmore’s story of Jim Sharp is less highly structured and more dependent on metaphor than on allegory. For this author, writing the story of
a person with AIDS is telling his own story as much as it is telling the biography of another. Dealing with his own anger, bitterness, and fear plays as great a part in *Someone Was Here* as that of Whitmore's biographical subject (1988b). Whitmore uses the relationships that form and change between Sharp, his buddy, and his lover to explore the emotional consequences of a diagnosis of AIDS for himself as well as for Sharp. He combines this intimately emotional portrait of a person with AIDS with a series of essays on the characteristics of HIV disease, transmission, "safer" sex, and treatment. In this, he parallels the argument structure of Shelp and his co-authors. Whitmore is trying to persuade his reader of the worthwhile nature of his subject and the importance of the AIDS epidemic.

The NAMES Project Quilt is more visually than textually oriented. It is a collection of symbolic fields which are manipulated by panel makers into unique combinations and contents. It is interesting that although panel makers are trying to construct unique identities for the person who has died of AIDS they use a relatively limited number of possible aspects of their lives and personalities. Like biographers, they have a culturally learned set of ideas about what constitutes a person and how that person should be represented. A number of possible ways of referring to or describing a person are not used.20 Sins, bad behavior, and faults are never indicated; never do they speak ill of the dead. Whereas biography, like those discussed above, has more leeway in discussing complexity of human character in both its' bad and good aspects. The Quilt presents only the best of a person's life, character, and

---

20 Imagine what a memorial might look like in another culture. There might be houses built for the dead spirit to dwell in, individual identity might be considered irrelevant and the only thing mentioned might be the religious, clan or tribal affiliation of the dead person, or the person might be physically represented without names or dates.
personality. In that sense, panels re-write the life of person who has died of AIDS (just as did Whitmore or Shelp, Sunderland, and Mansell) by leaving out the "bad." The NAMES Project is a memorial in the sense of being a way of reminding and telling that here was a person who lived, who died of AIDS, and who is worth being remembered.

Each of the above forms of telling the tales of people with AIDS have accomplished a variety of kinds of discursive work simultaneously. All have worked to persuade an intended audience that people with AIDS are worthwhile and that their suffering is tragic. They are part of the complex of counter-discourses constructed in the 1980's to counteract the negative images of PWA's in the mass media, the medical literature, and churches and other religious communities. Like the autobiographies discussed in the previous chapter, these "biographies" contradicted those portrayals with the details of real people's lives. However, unlike the autobiography, biographical discourses found in AIDS: Personal Stories in Pastoral Perspective (1986) and the NAMES Project tend to emphasize the positive and to almost ignore the less positive aspects of people's lives. Whitmore's work is an exception because it is really a combination of biography and autobiography. Whitmore is telling his own anger and fear as much as he tells about Jim Sharp's. It is probably inevitable that an author with AIDS will write himself into his subject. What all of the works discussed in both this and the previous chapter have in common is a concern for the reclaiming of and making a public statement about the worth of the person with AIDS.
Chapter Four

THE FACE TURNED OUTWARD1

I lit a candle in the dark.
A friend came by; I shared the spark.
Another passed; again I gave
My tiny light to one so brave.

These two friends, they passed it on
To two more each, and on and on.
The dark it changed into a haze
As more and more passed on the blaze.

Clouds and winds, they came along,
But still our candles’ light grew strong.
Everyone held high their light
And suddenly, the world grew bright.

The darkness and despair were gone. . .

Michael Wilson2

The AIDS Foundation of Houston creates another type of discourse about people with AIDS in their newsletter, Lifeline. Although the newsletter creates a discourse on AIDS and on persons with AIDS, it is significantly different from the oral discourse described in the first chapter. Lifeline is the “official” publication of the Foundation and lacks much of the emotional punch that volunteer’s stories deliver. The AIDS Foundation of Houston uses the newsletter as a necessary public “face” to encourage donations and assist in soliciting volunteers. As the face that AFH shows to people outside the gay community, Lifeline tends toward a calm, conciliatory tone.3 The newsletter is

1 This chapter is dedicated to Bill Napoli whose kindness and concern made my time at AFH more meaningful and enjoyable.
2 Printed in Lifeline (February/March 1988:5).
3AFH has often been accused of being a “gay” organization and needed some way of presenting itself as a general purpose humanitarian organization to avoid stigmatization.
aimed at those who donate money to AFH as much as it is written for staff, volunteers, and clients. It avoids the painful and emotional aspects of AIDS and presents a slick, almost commercial face to the world. Here there is no overt anger or grief and little mention of issues around sexuality. For example, during this period of time Lifeline published only one obituary. It was for Michael Wilson who was one of the founders and an important motivating force of AFH in the years between 1981 and 1987. The newsletter conceals the emotional turmoil, burnout, and conflicts that frequently affected volunteers and staff at the Foundation. Lifeline could be the public face of almost any nonprofit organization of the same general type. There are few of the special qualities of AIDS counter-discourse found in Lifeline which characterize both the oral discourse of AIDS at the Foundation and the exemplary written discourse discussed in previous chapters.

Of course, the activities of the Foundation include much more than the creation of written and oral discourse such as their newsletter. Their service and educational activities were as much apart of their impact on the gay community and the city as a whole as did their participation in the public discussion of AIDS. In the early days of the epidemic, AFH was just about the only local group, either governmental or nonprofit, which offered services specifically for people with AIDS (see Table IV). It is these efforts that are the focus of volunteer activities and provide the forum around which their discourses grew. It was the Foundation and the volunteer's and staff's scramble to create, find or encourage someone else to offer the services desperately needed by clients that led to much of their interactions with other

---

4 The following discussion concentrates on the services to clients rather than on educational activities because I have the most information on those activities, not because the educational activities where not important.
Table IV  
AFH Client Services\textsuperscript{5}  

<table>
<thead>
<tr>
<th>Service Description</th>
<th>1987</th>
<th>1989</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Client Intake: Specially trained volunteers assist PWA's &amp; PWARC's in filling the necessary paperwork to become AFH clients (necessary to qualify for governmentally funded programs serviced by AFH)</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>2. Case Management: Staff assists clients in finding and applying for services and funding including AFH emergency assistance and social security disability.</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>3. Buddy System: A volunteer is assigned to act as psychosocial &amp; emotional support by maintaining regular contact with the client and act as liaison with AFH.</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>4. Phone Buddies: Volunteers (under the code name Pat Benton) call clients regularly, checking on their well-being &amp; relaying information on events &amp; services.</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>5. Counseling &amp; Referral: AFH provides initial counseling &amp; referral to other therapists or organizations.</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>6. Helper Assistance Program: Volunteers provide housekeeping, cooking &amp; related services to PWA's unable to do so themselves</td>
<td>Yes\textsuperscript{6}</td>
<td>No</td>
</tr>
<tr>
<td>7. Transportation Vouchers: AFH distributes vouchers for taxi and metro (bus) rides.\textsuperscript{7}</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>8. AFH Food Pantry (Stone Soup): Provides supplemental or emergency source of groceries &amp; other necessities to clients on a weekly basis.</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>9. AFH Residence: McAdory House offers temporary emergency shelter for PWA's.\textsuperscript{8}</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>10. AFH Housing Referrals: AFH acts as a clearing house for roommate and apartment referrals.</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

\textsuperscript{5} Table IV is based primarily on the AFH Social Services Handbook (1987, 1989), issues of Lifeline, The Volunteer Handbook (1986) and my notes. It lists approximate dates when these services were available.
\textsuperscript{6} The Helper Team was dissolved by mid-1987.
\textsuperscript{7} Metro vouchers were not available in 1987.
\textsuperscript{8} AFH also purchased two apartment houses in 1989 to be renovated and used as housing for persons with AIDS (Lifeline July/August 1989).
AFH Client Services (Con't.)

<table>
<thead>
<tr>
<th>Service Description</th>
<th>1987</th>
<th>1989</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. AFH Legal Services: A group of attorneys volunteered to provide legal services to clients free or at minimal charge.</td>
<td>Yes</td>
<td>No⁹</td>
</tr>
<tr>
<td>12. AFH Financial Assistance Program: AFH supplies small emergency grants to clients to pay rent &amp; utilities.</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>13. Physician &amp; Nursing Care Referral Lists: AFH maintains a list of local doctors and nursing services who care for PWA's, with information on their willingness to take Medicare/Medicaid patients, HMO's, &amp; so on.</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>14. AFH Wakeup Calls for AZT Patients: Arranges for two calls a night to awaken PWA's to take their AZT.</td>
<td>Yes</td>
<td>[No]¹⁰</td>
</tr>
<tr>
<td>15. AFH Blood Bank Life Plan: Assists PWA's who need blood transfusions or blood products.</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>16. Hospital Teams: Groups of volunteers who regularly visit &amp; support patients with AIDS in four local hospitals.</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>17. Community Resale Center Vouchers: AFH provides vouchers to clients which are good for clothing, household goods, &amp; furniture.</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>18. Pet Patrol Organization: A group affiliated with AFH which provides assistance for PWA's with pets.</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>19. AFH Social Service Handbook: Contains referral lists for locally provided support services as well as detailed information on how to apply for SSI/SSD, Harris County Dept. of Social Services Benefits to the Disabled, local medical district benefits, various utility assistance programs, and so on.</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

⁹ By 1989, several local organizations provided free legal assistance to all AFH clients (including the Houston Young Lawyers Association and the Houston Bar Association) but AFH no longer had its own volunteer attorneys.

¹⁰ I have conflicting information on this point and so wakeup calls may still have been offered at that time.
organizations in the Houston area. Also, disagreements about the differential allocation of funds were important points of conflict within the Foundation. By the end of 1989, AFH offered a wide variety of services to clients. There were also increases in services city-wide through new offerings by existing nonprofit agencies and the creation of new AIDS-related organizations. As will be discussed below, some of the new, small groups were founded by former Foundation volunteers or staff.

Lifeline: The AIDS Foundation Houston Newsletter

This chapter will be focused on the issues of Lifeline from February 1987 to November 1989 when I was most intensively involved at AFH. In the newsletter for this period, there are articles on a variety of topics including the activities of AFH and other local AIDS organizations in the Houston area,\footnote{Those organizations which are mentioned in Lifeline do not include all local organizations and some organizations appear or disappear through time. I know that in some cases AFH (i.e., the executive director, board of directors, etc.) would clash with other groups and their names would disappear from Lifeline.} fundraising drives, hiring or election of new staff, Board members, and Directors, and occasional articles with medical or treatment information. Lifeline always carries some sort of introduction to new Executive Directors as they begin their tenure\footnote{Generally, executive directors of AFH stayed in that position about a year (sometimes a little less, sometimes a little longer). The job was extremely stressful and placed the holder in a position of trying to reconcile the demands of the many groups with differing interests and perspectives (i.e., Volunteers, Board of Trustees, etc.).} and occasional articles called "From the Executive Director," which resemble editorials in a newspaper. The publication also regularly presents profiles of volunteers, called "People Making a Difference," and other articles which focus on particular persons. The
Newsletter, during this period, was written and edited by a changing group of volunteers, some with professional experience, and by various staff members. Lifeline has been published about every other month or so since 1986. It is printed on glossy paper with a professional appearing layout and style in four or six pages. The newsletter is published somewhat erratically at times, sometimes every month and sometimes every other month but occasionally three months or more will elapse between issues. Much of the printing and materials are donated so that the cost is about ten percent of what it would cost to publish professionally. There have been major changes in format and visual presentation at several times, including in the April of 1988 issue. The latter change consists primarily of going from two vertical columns per page to three and changing the logo on the front page. A change to smaller print size and three column format allows the newsletter to go from six pages to four without losing much of the space available. Some other alterations include a change to unjustified margins (i.e., not all the lines were the same length) and fewer formal headings, all of which increases the effective space of the newsletter. The logo used in the earlier newsletter plays on the metaphor of a “heart” as a life line, using a red tracing of an electrocardiogram with the title, Lifeline, superimposed. A new logo appears after the format change, a heart shape traced over a shading of red below the title. The new logo uses the same metaphor but is smaller and takes up about half of the space of the original.

The structure and organization of Lifeline goes through a more gradual change over the year and a half period under consideration. The newsletter

---

13 The Newsletter has changed formats again since that time. It is no longer published on glossy paper, has gone back to a two column format but is still only four pages and is using a smaller print size and denser presentation.
was originally published in several distinct sections with each devoted to some area of AFH activities or subject matter. For example, the February/March 1988 issue (last of the earlier format) had segments entitled: “In Focus” (longer articles on the front page), “Medical,” “Legislature,” “For Your Information” (on events), “Social Services,” “A Tribute” (Michael Wilson’s memorial), and “Volunteers.” Most of these sections were included in each issue of the earlier format. In later issues, the newsletter became less formal and had fewer articles. The “For Your Information” section became less detailed and was renamed “Calendar Highlights.” Many subjects that earlier might have gotten full articles were included in another new section called “In Brief.”14 Most of the these changes had the effect of making Lifeline less expensive and time consuming to publish. The attribution of authorship is sketchy throughout the newsletter although overall the number of signed articles did increase after the change in format in April 1988.

Portraits of People: Poster Boys and Valiant Volunteers

I want to begin by discussing a series of profiles of volunteers published in Lifeline during the 1987-1989 period. The profiles, called “People Making a Difference,” make up of a series of fifteen short articles. This series is the part of Lifeline which is most similar, at least in subject matter, to what I have discussed in earlier chapters. While I have limited information about how specific interviews were conducted or articles were written, I do know that interviews could be conducted either in person (sometimes during a

14 This sections was even called “Briefs” for one month, presumably before someone realized the pun looked a little silly.
volunteer’s shift at AFH) or over the telephone. More than half of the articles are published anonymously but six are attributed to authors Bob Scanlon, Richard Laub, or Julie Finch. All of the “Making a Difference” columns published after June 1989 are attributed.

Volunteers in the articles are chosen for various reasons but often profiles are accompanied by or follow closely on a request for additional volunteers in a particular area. For example, the October 1989 interview with hotline volunteer and information coordinator, Kelly Martine, follows a September 1989 plea for more people to work the hotline. I was present on several occasions when the choice of that month’s subject of “People Making a Difference” was made. The decision at those times was based on the need to recruit volunteers for particular activities. It is not that the people chosen do not deserve the recognition but that the Foundation has a wealth of dedicated volunteers almost any of whom would make good subjects for an article. The request for volunteers is not always made overtly in the “Making a Difference” articles, although often a call for volunteers would go out in a previous month’s newsletter. Only in four profiles is a call for volunteers explicitly stated. In one case, there is a call for new people for the hospital team at Jefferson Davis Hospital (Lifeline June 1989) and there is a request for help in the AFH library (Lifeline July 1988). In other instances, Arthur urges

---

15 I was present at a couple of the on-the-job interviews and was interviewed myself on the telephone.
16 All of those volunteers who were profiled in the “Making a Difference” articles gave their permission to be interviewed by AFH. However, it is unlikely that I would be able to track down these individuals to get permission to use their full names here. Due to the sensitive nature of volunteering for AFH, I have decided to use last names only for those volunteers who were publicly affiliated with AFH by being on the Board of Trustees, appearing as speakers for AFH, and so on. I will use only first names for all other volunteers discussed.
volunteers who have "drifted away" to return as they are "needed desperately" (Lifeline November 1989:4) and Brad, PWARC volunteer, encourages other clients of AFH to volunteer if they are able (Lifeline April 1988).

The structure and organization of the profiles varies according to several traits of the volunteers. Most volunteer interviews are very short, running about 250 to 300 words but there are two longer articles profiling married, heterosexual couples. In these articles, both spouse's volunteer activities are discussed in equal detail. However, none of the articles on "couples" are of gay or lesbian partners, an interesting omission given the nature of the Foundation. Each of the articles is written in a "journalistic interview" style, by which I mean that descriptions are interspersed with quotes organized in an attractive and attention-getting fashion. The profiles become more professional and smoothly written over the two and half year period in question. This change seems to be associated with the increasing number of attributed articles.

Volunteer profiles begin with an "attention-getter," some item or quote which quickly grabs the eye and interests the reader enough to continue reading. For example, they often mention an unusual characteristic of the volunteer(s) such as: "One of the only two married couples who are AIDS Foundation volunteers . . ." (Lifeline August 1987:5) or "Mitchell Katine is a man with exuberant energy" (Lifeline June 1989:1). Sometimes this evidence of being in some fashion special is skipped and the lead-in begins with a statement of how the person came to volunteer at AFH. The most common reason given is some sort of personal tragedy or loss. For example, the married couple, Katie and Gene Marcum (mentioned in Chapter Three):
... lost one family member after another: Gene's father, Katie's mother and sister—and their 22-year-old son... [they] lost another son in a drowning accident in 1981... (Lifeline August 1987:5).

Gene and Katie lost another son to AIDS. Four other volunteers are described as having had friends and relatives diagnosed with or die of AIDS. There are also three volunteers who have been diagnosed with AIDS or ARC themselves.

Others volunteer even though they have had no personal involvement with AIDS before their association with the Foundation. One woman simply states that "I had decided that I wanted to do something about this disease" (Lifeline September 1987:2). Another volunteer is described as having "seen a news story about an AIDS Foundation Houston grant application and knew at once where she was needed" (Lifeline December/January 1989:3). One man, Bruce, sees being involved as both a political and philanthropic activity: "[H]e decided to stay in Houston... because "the city needs screamers" in the fight against AIDS "and I have a loud voice" (Lifeline July 1987:5). Bruce's line about screamers is after a line from Larry Kramer, nationally known AIDS and gay activist. Using this quotation is a coded way for Bruce to indicate that he is gay.

A variety of such code words and phrases are used to specify the sexual orientation of a volunteer. Bill, whose story is discussed below, talks about "escap[ing] from an ex-wife" and refers to having participated in a study of hepatitis B among gay men in 1981 (Lifeline September/October 1987:5).17 References are made to various gay organizations or publications. George

17 This study is one which is well known among AIDS researchers and activists for its usefulness in tracking the early history of HIV infection as it involved storing blood samples from a large number of gay men just at the beginning of the AIDS epidemic.
mentions that he learned about the need for volunteers at the Foundation in the *TWT* (short for *This Week in Texas*) a statewide gay publication (*Lifeline* February/March 1988). Harry Livesay, in an article introducing him as a new case manager, indicates his identity by talking about serving on the Board of Directors of a local gay organization, the Houston Gay and Lesbian Political Caucus (*Lifeline* May 1989). In oral discourse at AFH, words and phrases from American gay slang or argot may be mentioned (for examples see Chesebro & Klenk 1981 or Hayes 1981). Neither the volunteers or the writers are usually explicit about being gay or lesbian in print but this aspect of volunteer identity and reason for volunteering can be signaled through such codes.

Even old chestnuts, like saying one is “a friend of Dorothy” or swishing just a little, are occasionally used to advertise one’s sexuality. At the Foundation, such usage is not usually an attempt to pick somebody up (or “cruise”) but rather statements about the identity of the speaker.18 Like Gary Walsh, most volunteers are proud of their community and its ability to respond to the epidemic.

In *Lifeline*, the volunteers are shown as having compassion and strong feelings about the people at the Foundation and their work but they are not shown as having emotional, romantic or sexual relationships. The few cases where personal relationships are referred to are almost exclusively in the context of marital or traditional family relationships. I noted above that none of the couples presented in these interviews are gay couples. Wives, husbands,

---

18 I'm not pretending that romantic or sexual relationships have not occurred among volunteers or staff but that is not the focus of what is being talked about. There is little gossip about who is dating or sleeping with whom. Stories are about clients or what is going on with the organization. One place where a little discreet matchmaking did take place was at the special socials for PWA's, everyone wants a little happiness for clients.
sons, daughters, nieces, and nephews are mentioned but gay lovers are not. Occasionally, the articles refer to “friends,” in a plural, non-sexual sense. Usually, this phrasing appears when stating that a volunteer has “lost” friends to AIDS.

Volunteers, both those with AIDS and those who not ill, are denatured. They are divorced from social and sexual relationships outside the Foundation if those relationships are not traditional ones. This makes them less threatening to Houstonians who either disapprove of or are uncomfortable with the idea of gay sexuality (and gay relationships are almost always viewed in a purely sexual light). Here, volunteers are represented as untainted by virtue of their apparent isolation from the stigma of gay sexuality and an emphasis on their traditional family relationships. They are sons and daughters, husbands and wives, or uncles and aunts. They are not lovers, boyfriends, girlfriends, “long time companions” or even survivors. The nonsexual portrayal of persons with AIDS coincides with the general view of ill or disabled people as asexual or incapable of having a loving relationship (Biklen & Bogdan 1978, Bogdan et al. 1982). This helps make PWA’s seem less threatening and more deserving of assistance.

Biklen and Bogdan suggest that there are a limited number of stereotyped ways in which people who are disabled or ill are portrayed in the vast bulk of the American media (1978). Persons who are disabled are presented as pathetic or dangerous but never as ordinary. They are the monsters or villains in horror, gangster, and adventure films (Bogdan et al. 1982). The bad guy is a violent, one-armed man in The Fugitive and a sinister, scarred man in The Phantom of the Opera. The disabled person may have super abilities like Ironside's deductive skills or the Joker’s talent for mayhem
(in Batman) or be a pitiable burden as in countless movies made for television (like the recent David's Mother). Persons who are disabled are seldom portrayed in loving relationships (except perhaps with their mothers) and very seldom in romantic or sexual relationships. As often as not, the disabled person is presented as their own worst enemy—if they just coddled themselves a little less, were less restricted in mobility or tried hard enough they could somehow overcome any obstacle. In other words, if all disabled or seriously ill people could be "poster boys" like the PWA volunteers presented in Lifeline then all would be well. The Foundation etiquette counters these types of representations by making room for people with AIDS to be as active as they wish to be (or can be) and to speak about AIDS as experts but doesn't trap them into being "super-crips." The newsletter is designed to appeal to an audience which does not commonly associate with PWA's and who expect a more usual type of representation of persons with serious illness.

Other people are represented as volunteering because they have a special skill. One volunteer has a background as an hospital administrator. Others are ill themselves and, therefore, have a special perspective on AIDS to offer. Loren Allen, who installed energy conserving electrical systems at the AFH offices, made a seemingly unrelated skill useful to the Foundation (Lifeline February 1989). Kimberly tried to work at other nonprofit organizations and found that her energies were not being fully utilized (Lifeline December/January 1989). She came to AFH looking for a position which would effectively make use of her skills. She feels that the Foundation not only gives her worthwhile work but has changed her life goals. Now, she plans to pursue a degree in social work. Several other people also mention that their feelings about AIDS are the thing that finally pushes them into
working at AFH. Arthur describes himself as once “so phobic about AIDS he refused to let it even be mentioned in his presence ... [later he] simply realized that [he] couldn’t stay in denial any longer” (Lifeline November 1989:4). Jim states “What we can change, we change. What we can’t, we learn to accept and live with” (Lifeline July/August 1989:2). Volunteering with AFH allows him to change what he can. Another volunteer describes being prompted to volunteer “by guilt, paranoia and the decision to get off my ass” (Lifeline July 1987:5).

The articles usually go on to identify the volunteer’s place of origin and/or how long they have resided in the Houston area, their paid occupation, what sort of activities at AFH the volunteer has been involved in, and their feelings about these activities. The volunteers include several native Texans and some are transplants from the East Coast or the Midwest but even the newer Texans have been in the state for years. Their professions are as varied as their backgrounds and include attorneys, small business owners, managers in large companies, teachers, and students but most seem well-educated. Almost all describe their volunteer activities as being rewarding in some fashion. One man finds his work “ultra-rewarding” (Lifeline July/August 1989:3), Bruce states “I enjoy feeling that I’m the one who’s spurring this [project] on” (Lifeline July 1987:5), and for Alice, a hospital team leader, “it’s like coming home” (Lifeline September 1989:2). Several state that they like the people that they work with, enjoy volunteering or it just makes them feel good. Volunteering is portrayed as something everyone can and should do. But there are occasional hints that volunteering can be difficult, demanding and lead to burn-out. Katie, an “A Team” volunteer (made up of those who work at McAdory House), describes her experience as “exhausting both
physically and, when she loses her new friend, emotionally” (Lifeline August 1987:5). There are costs and burdens involved in volunteering at AFH that the articles almost always elide and conceal, only rarely mentioning them explicitly. The articles usually close with a general appeal to become involved in the community although not always a direct exhortation to a specific activity. How many people would volunteer if they knew just how difficult the work can become?

Of the fifteen “People Making a Difference” articles written from 1987 through 1989, three were about volunteers who had some form of diagnosed HIV disease (either ARC or AIDS). The profiles of Bill, Brad and Tim were organized and written differently than any other writings by or about people with AIDS I have discussed elsewhere and the other “Making a Difference” articles as well. The difference is primarily in content and theme while the narrative structure of the articles is similar for both PWA/PWARC volunteers and those not self-identified as having AIDS or ARC. There are hints in several other profiles that some of the other volunteers described may have some form of HIV infection. For example, one food bank volunteer states that “it's my chance to do something first, before I have to ask for help” (Lifeline July 1987:5; emphasis in original). The most obvious difference is in the use of humor. The profiles of PWA/PWARC volunteers use humor prominently although there is little or no humor in other articles. In an article on a former coordinator of the AFH buddy program, “bowling used to be Bill's only hobby... [n]ow working for the AIDS Foundation is” (Lifeline September/October 1987:5). Another jokes that his diagnosis of ARC in April of 1987 “was Brad's... April Fool’s joke” (Lifeline April 1988:2). While Tim is described in the following way:
Guts has been defined as “grace under pressure.” Tim ... is an AFH volunteer who truly has guts (Lifeline May 1989:2, emphasis in original).

No mention is made of the emotional difficulties and fears associated with the diagnosis of a life-threatening illness and increasing disability. While joking and humor is used by PWAs in their autobiographies or in the biographies discussed in chapter three, it is not used without placing it in a real context of the stresses and strains of a diagnosis of AIDS or ARC. One reason for the lack of context is probably the short length of profiles.

There is oblique mention of physical problems, such as Bill needing more sleep than usual, having to take leave or quit a regular job or Tim needing a wheelchair to get around but no discussion of the real physical difficulties involved in an serious illness like AIDS. Instead, the emphasis is on how these three can act as role models and exemplars. The emotional action of putting aside fear and self-absorption is emphasized in each of the articles. In a combination of quotation and description of Bill, it is described as a matter of just doing it, of just carrying on:

"The work needs to be done, and it's very satisfying. There's no need to sit around your house and depress yourself," especially when keeping active and maintaining a positive attitude can be like a tonic to PWAs (Lifeline September/October 1987:5).

In similar statements, Brad argues that “It's important that PWA's take the time to volunteer and not just sit at home and feel sorry for themselves" (Lifeline April 1988:4) and Tim posits that “... volunteering at AFH would help him put aside his fear ...” (Lifeline May 1989:2). Bill, Brad and Tim are models of how to be a “good person with AIDS,” poster boys for AFH. They are brave,
don't draw uncomfortable attention to their illness, and can make jokes about their situation. They are comfortable to be around and don't display unseemly emotion.

These three men are exemplars to people outside the Foundation as well. Tim, for example, acts as a speaker and appears with his father to talk about how AIDS has affected him and his family. He has a powerful impact on his audience because: "he has no prepared notes, but he never fumbles, no matter how large the audience. He speaks from his heart, telling people what AIDS is all about" (Lifeline May 1989:2). Brad talks about the need to be a living example that people with AIDS or ARC can regain some of their health:

Recently, a client's worried parents came to the Foundation and spoke with [Brad] about their son's situation. "They saw me take my AZT and couldn't believe I was ill," he said. "Seeing that their son's health could return like mine, they hugged me when they left" (Lifeline April 1988:2-3).

People like Brad can give clients and their families hope that there might still be a future. As I mentioned in an earlier chapter, convincing people that AIDS does not mean instant death is always one of the most difficult tasks on the hotline. Seeing someone like Brad can make those statements more of a reality. PWA's who work as volunteers also act as goads to the conscience. Bill argues that: "...total amnesia would have to set in for Bill ... to forget his responsibility to his fellow PWA's ..." (Lifeline September/October 1987:5). If someone who is seriously ill talks about fulfilling his responsibilities, how can someone who is healthy do any less.

The newsletter is not a place were people with AIDS and volunteers are encouraged to display their fear or pain. Only rarely are any emotionally
charged subjects raised in *Lifeline* and then they tend to be addressed obliquely or implicitly. The mourning and grief of clients, volunteers, and staff are kept hidden from readers. For example, only one obituary appears in *Lifeline* during the period from summer of 1987 through the winter of 1989. The one exception is the obituary of Michael Wilson, one of the founders and early Executive Director of AFH. During that period of time, hundreds of AFH clients and volunteers died or suffered serious losses and yet only this one death is directly mentioned. Only upbeat and pleasant emotions are displayed in the newsletter. Pain and other strong emotions that might offend are kept well distanced from the reader. Any sign of the difficulties of volunteers are hidden but the courage and strength of AFH volunteers is displayed as signs of worthiness—see what good people we are and how we continue despite the difficulties of our situation. It says that “we are the kind of people that you should donate your time and money to, despite anything you may have read in the papers or heard people say.”

The hiding of the difficulties of being ill with AIDS also feeds into the common image of ill or disabled persons as having certain extraordinary abilities. Biklen and Bogdan describe the stereotype as the “super crip,” using the television character Ironsides as an exemplar of this sort of stereotype (1978:34). In this image, ill people are portrayed as having abilities and stamina beyond that of normal folk. They can resist great pain, continue to function regardless of their physical deterioration, and never, never display the signs of illness in a way that would make other people uncomfortable. This is true of the three PWA volunteers profiled in the newsletter. No one talks about chronic diarrhea or displays unsightly Kaposi’s Sarcoma lesions. Bill makes jokes about feeling more tired than usual. The fact that Tim is confined
to a wheelchair is mentioned only in passing. His advancing illness is referred to as something to be overcome and not as a true barrier to his activities. Brad shows his illness only by taking his medication. He is a symbol to visitors of how a person with AIDS can be well again.

What kind of purpose can be served by this concealment? And what can the occasional glimpses of painful emotion tell us? By hiding the pain that is associated with experience the of volunteers and clients, AFH avoids scaring anyone off or discouraging people from volunteering or donating money. These stories all emphasize the ability of persons with AIDS to remain useful even after suffering serious illness. In part, this portrayal helps to counteract the tendency to see AIDS as an immediate death sentence and supports PWA's active involvement at AFH. As I discussed in the first chapter, one of the most important things to communicate to newly diagnosed people with AIDS is that AIDS does not mean immediate death. But these articles take that type of message much further than do the autobiographies by persons with AIDS; AIDS becomes transparent and readily overcome.

How are these images created for Lifeline? It is unlikely that there was or is any sort of censor telling volunteers and newsletter writers to delete any mention of the unpleasantnesses of AIDS or to make persons seem safer by making them asexual. However, I know from my own experience that chronically ill people learn very quickly what is acceptable to say to listeners and what is not. After becoming ill, we learn to censor ourselves and to shape our stories in ways which will make us acceptable to people around us. As members of our own culture, we know what images of sick people are regarded as pleasing and which are not. The interviewers act as a second type of screening. They pick and choose the themes, story lines, and images which
will create the most acceptable story for their readers. The results are stories of volunteers, especially those with AIDS or ARC, which are neither threatening nor unpleasant for the audience to read.

The Official Face of AFH: The Executive Directors

There are two types of articles in Lifeline related to the various Executive Directors during the period in question. There is a series of interviews which introduces each new AFH Executive Director when they begin their tenure and other, editorial-like articles written by the directors themselves. Together these make up seven articles. There are three interviews of new appointees: Brown McDonald, Ed Mayo, and Evelyn Cox. There are four editorials written by Executive Directors themselves: one by Curtis Dickson and three by Brown McDonald.19 Later Executive Directors, Mayo and Cox, do not explicitly use Lifeline as a political or personal forum. There are similarities in theme, content, style, and emphasis in the "From the Executive Director" editorials and the interviews which introduced new Executive Directors over the period of time in question. The editorial style "From the Executive Director" articles are most often devoted to a specific topic such a newly received grant or pertinent happenings in Houston at large.

Each Executive Director has a distinct style, emphasis, and manner in which they use (or do not use) Lifeline as a forum. Interviews concentrate on the background of the new directors, their history of education and service, and their priorities for AFH. There were four Executive Directors from February 1987 to November 1989. Curtis Dickson was just ending his tenure at AFH in the

Spring of 1987. Dickson was followed by Brown McDonald, who served from the summer of 1987 through early summer of 1988. Ed Mayo became Executive Director in mid-summer of 1988 and served through the early Fall of 1989. He was followed by Evelyn Cox who began her term at AFH in November of the same year.

The basic division between those at the Foundation who would emphasize educational efforts and those involved in services to people with AIDS is diplomatically laid out by Curtis Dickson is his editorial “From the Executive Director—Education or Social Services?” (*Lifeline* February 1987:1). Dickson outlines the conflict that arose from the changing demands being made on the Foundation during the mid-1980’s as a debate over “AFH’s primary mission . . . as [either] education and prevention, or the delivery of needed social services” (1987:1). Dickson is the first and only Executive Director to publicly identify this conflict rather than simply appealing for the support of AFH volunteers and staff. His editorial also argues that the root of the problem is the distinction between current priorities and the Foundation’s long term mission. The realities of limited funding and resources lead to a basic conflict between the ideals of prevention and service. Dickson, like those who follow him as Executive Director, argues that the long term mission of the Foundation is the two-fold goals of education and service. He ties the debate to the changes in the demands on AFH with the increasing number of people with AIDS in the Houston area. Early in 1980’s, AFH concentrated on getting the word out about AIDS. During the mid-1980’s, the increasing number of AFH clients meant greater need to provide services, including everything from buddies to direct financial aid. These demands came at a time of economic recession in Houston and greater difficulty in getting needed funding. Dickson ends his editorial
with a plea for understanding and patience from volunteers; he is trying to be a peacemaker. His subsequent resignation and the hiring of the next Executive Director demonstrate that Dickson was not very successful. The next three Executive Directors would face the same problems and conflicts.

The interviews of incoming executive directors are visible signs of these conflicts and are accompanied by attempts to overcome disagreements and splintering within the organization. Brown McDonald is introduced to subscribers of Lifeline with journalistic flair and the attention grabbing comment; “Everyone tells me AIDS is complex. I see it as simple ... ” (Lifeline August 1987:1). McDonald’s view of AIDS as a simple issue elides and covers up the basic schism which led to the exit of his predecessor. He is portrayed as coming from an AIDS activist background at the Cascade AIDS Project in Portland and a fundraising background from having operated a theater there as well. McDonald is an attractive and charming white, gay man in his thirties with an air of competence. Although he was hired as a kind of peacemaker, McDonald was often secretive about his own activities and tended to be more politically oriented than the Board of Trustees would have liked.\(^\text{20}\) He, like all the Executive Directors during this period of time, eventually came into direct conflict with the Board of Directors and left AFH.

The brief article introducing McDonald is followed by his statement that his immediate priority for AFH is fundraising for programs for both AIDS education efforts and social services for people with AIDS. He implies that the conflict will be resolved when there is adequate funding for the goals of both

\(^{20}\) For example, McDonald would periodically ask volunteers to secretly engage in activities that contravened AFH official policy or went against Board’s wishes. See also below for a discussion on McDonald’s editorials published in Lifeline.
education and service. This is followed by an endorsement by the chairman of the Foundation Board of Trustees, Joe Tumlinson, who comments that McDonald "has the organizational skills needed by the Foundation and the fundraising experience needed . . ." (Lifeline August 1987:1). The article goes on to review McDonald's experience with the Cascade AIDS Project and the hope that he could accomplish in Houston what he did in Portland by "bringing the community together" (1987:1) The interview ends on a note of optimism from Tumlinson, "If anyone can [bring the community together] in Texas, Brown McDonald can" (1987:1). Tumlinson ignores the Board's conflicts with the previous Executive Director and is trying to avoid any problems that might arise by bringing in an outsider to head up AFH.

The introduction is followed by a brief autobiographical essay written under the title "From the Executive Director" (Lifeline August 1987:1). In it, McDonald expresses a kinship with things Texan and admiration for what AFH has been able to accomplish with little or no governmental or private financial support. He also appeals to volunteers and staff with "we [at AFH] need your support now more than ever" (1987:1). In both of these articles, McDonald is representing the conflict within the Foundation as one born from too little funding and not a basic disagreement over the mission of the organization. He downplays any doubts about the fundamental nature of AFH by holding out the hope that sufficient funding will be made available to accomplish all the goals of volunteers, staff, and Board members. Unlike Dickson's editorial, McDonald makes no explicit reference to conflict within the organization, referring to it obliquely by urging solidarity and community among volunteers.
Lifeline published two more editorials by Brown McDonald during his
tenure. 21 McDonald used these editorials as a way of communicating his own views to members of AFH. In the September/October 1987 issue of the newsletter, McDonald discussed Houston's search for a new Director of Health and Human Services. The former Director of Houston's Health and Human Services, James G. Haughton, was often criticized by local AIDS activists for his refusal to make AIDS a priority for his department. McDonald urges that Haughton's replacement be someone who will make AIDS the department's number one priority, a common feeling among AFH volunteers and staff. In the February/March 1988 issue, McDonald announces a large grant from the Texas Department of Health for social services and case management. This grant helped to ease tensions between factions within AFH for a time because it allowed for greater resources to be devoted to service purposes. McDonald is using newsletter as a podium from which to rally the support of volunteers, staff, and donors for his positions. Executive Directors were often in conflict with the Board of Trustees and this was one way of maneuvering for power within the organization.

Although later issues of Lifeline cease to publish editorials the practice of printing introductory articles about Executive Directors continues. The articles change in style and structure with the advent of new format in the Spring of 1988. These later pieces are unsigned but show signs that they may have been written by or under the direction of the incoming Executive Directors. For the first time, photos of the incumbent and details of their careers are included. The style and organization of these interviews are

21 After the change in the format of the newsletter in the spring of 1988, Lifeline ceased publishing such editorials.
distinct from other types of articles published in *Lifeline* and matches with the personal style of each of incumbents. Another change was that the two later Executive Directors, Ed Mayo and Evelyn Cox, were hired from within the Foundation. Mayo had served on the Board of Trustees of AFH since 1987 and held the position of Vice President of Social Services. He had a very low key personal and managerial style and avoided the politicking which characterized other Executive Directors. Cox, Mayo's successor, was Director of Education for a year before being named executive director. Their experience as AFH insiders may have given them greater working knowledge of *Lifeline* and more direct input but did not significantly extend the length of their tenures.

Ed Mayo's tenure was a sign of the beginning of a sea change in the concerns and clientele of AFH. Mayo was a black man with a quiet, self-effacing manner and who conveyed an impression of integrity and personal strength. In the late 1980's, there was a slow but definite increase in the proportion of black and Hispanic, and IV drug users among persons with AIDS in the Houston area.\(^{22}\) As Mayo argues that the Foundation needs "new and innovative programs . . . outreach efforts to . . . blacks, Hispanics [sic], and also IV drug users. . ." (*Lifeline* July 1988:2). While not as large an increase as occurred in other parts of the U.S., a trend toward more cases of AIDS related to IV drug use was beginning in Houston. Ed Mayo was the first black man to hold a key staff position at AFH. He came to AFH from Cenikor, a drug treatment non-profit organization. He had worked as a clinical supervisor and

\(^{22}\) See issues of the AIDS Surveillance Update—Houston SMSA (Houston Department of Health and Human Services) for the period from 1986 to 1989.
psychologist rather than coming from an AIDS activism or political background as did McDonald and Cox.

Although black men and women have always been active at the Foundation, the majority of clients, volunteers and staff were at that time still white, gay men. Mayo's photo is the only tangible sign of his race which is not explicitly mentioned elsewhere in the interview. Race is referred to obliquely by using a quotation emphasizing minority outreach and IV drug use programs. The article on Mayo itself is without the kind of attention grabbing quotation that begins McDonald's and without the statement of personal career philosophy which characterizes Cox's later introductory piece. It also more directly refers to the previous executive director, Brown McDonald. Neither McDonald's or Cox's introductory pieces even mention the name of the previous holder of the position.23

The introductory interview of Evelyn Cox is longer and somewhat more elaborate than that of either McDonald and Mayo (Lifeline November 1989). This is partially due to the fact that Cox was first announced in August as acting Executive Director after Mayo's resignation. Later, when Cox was formally named Executive Director, a longer article introduced her to readers of Lifeline. Cox is a small statured, white woman who tended to dress more formally than previous Executive Directors. She gave an impression of a kind of aggressive competence and of being very politically savvy. She came from a career first as a teacher of speech and debate, had owned her own speech communication firm, and, later, served in city and local politics as a speech writer and advisor for Mayor Kathy Whitmire. Her interview is accompanied

23 There is a short note that was published in Lifeline's In Brief section when Cox was named acting executive which does include mention of Ed Mayo's resignation (Lifeline July/August 1989:4).
by a large photo of Cox and begins with two rather strange paragraphs which sound as if they come from Cox's speech writing background:

It's true that a strong professional background and an impressive set of education credentials can prime the right person for a successful career and future. But to succeed as executive director one of the country's largest and most progressive AIDS organizations, that person has to have more. And Evelyn Cox has more (1989:1).

These paragraphs have the sound and feel of having been prepared for oral rather than written presentation. Cox, the professional speech writer and politician, has left her mark on her own introductory article.

In the article introducing Cox, she is quoted as delineating various goals for her tenure at the Foundation (Lifeline November 1989). She states her primary goal is stabilizing Foundation finances which tended to fluctuate significantly due to the predominance of short term (one or two year) grants and one time donations. From her previous experience with the Foundation, Cox recognized that much of the internal conflict between goals of AIDS education and services to people with AIDS had been due to limitations in funding. A second goal named by Cox is increasing communication within the Foundation. While she initially phrases this as a kind of open door policy, it later became more of a method for controlling what went on in AFH. Cox emphasized regular meetings of the various directors and strove to be as informed as possible on the activities of the staff. Her style was significantly more formal and her control more extensive than previous Executive Directors.

These interviews of incoming Executive Directors are interesting because they are one of the few external signs of the conflict within AFH
which inevitably accompanied the resignation of one and the installation of a new Executive Director. During the period when I was at AFH, there were repeated schisms and conflicts around the relative importance of AIDS education on the one hand and non-medical services to people with AIDS on the other. From 1987 through 1989, a whole series of confrontations occurred between volunteers, staff, and the Board of Trustees which were caused by disagreements on this issue. Most often the volunteers and staff were concerned that inadequate resources were being devoted to services to PWA's and were in conflict with the Board over how funding should be divided among the various AFH Programs. Only on those occasions when the disputing parties left the Foundation, did anyone publicly discuss these disputes. A number of splinter groups devoted to serving people with AIDS were formed by volunteers who left AFH. While there was some gossip about these conflicts among volunteers and staff (and probably the Board as well), any public hint of conflict was carefully suppressed by the Foundation. Only those joining the splinter groups spoke publicly about conflicts but they had little access to any public forum.

Two associated issues complicate this problem further. First, there was little government or private sector funding available to supplement AFH's own fundraising for PWA services during the late eighties. Most large grants received during this period by AFH were specifically for education activities. Many volunteers saw the lack of funds for client services as the result of prejudice against gay people. Many felt the Board of Directors was not working hard enough in pursuing service grants although they were aware of the difficulties in acquiring funds for these purposes. Unlike the Board, volunteers and staff had to confront the difficulties of PWA's due to AFH's lack
of funds on a daily basis and keenly felt the inadequacy of their ability to satisfy client needs. Such conflicts are exacerbated by the organizational structure of AFH itself. The AFH Board of Trustees is divorced from the everyday activities of the Foundation and only a minority of Board members are involved in service to persons with AIDS. They lack the urgency and pain experienced by volunteers in their work with AFH clients.

The resignation and replacement of each Executive Director during the late eighties was the culmination of a period of heightening tensions and a series of confrontations between the various groups within AFH. The primary power volunteers and staff could wield in these situations was to threaten to leave the Foundation. Often volunteers contributed vital services to the Foundation. A volunteer might be the only person who thoroughly understands the computer system or fills a full time staff position on volunteer basis. Their threats to leave could give them a certain power but was a two-edged sword. Often vocal volunteers were branded as trouble-makers. The result was that each period of conflict was marked by the departure of a group of volunteers, who often later joined or founded other AIDS service organizations. If one was judging solely by the newsletter, it would seem that the Foundation had few if any internal conflicts. These periods of upheaval are marked only by the hiring of a new Executive Director, while exodus of core groups of volunteers and the resignation of former Executive Directors goes unremarked.24

The hiring of a new Executive Director is also a signal of ideas about what the Board of Trustees thought that the Foundation needed at any point in time. The position of Executive Director was responsible for several functions

24 The resignation of an Executive Director is mentioned only once in Lifeline.
which were fulfilled in different ways by the various appointees. Executive Directors were the primary mediator between volunteers, staff, the Board of Trustees, and the various community(s) and factions in Houston. They are the face of the Foundation at fund-raisers or society functions, and act as spokesman(persons) for AFH to the media. Whenever the Foundation sends out a press release or responds to some issue in a local venue, more often than not it is the Executive Director that is quoted or mentioned as a source. Executive Directors have had to do much of the work involved in managing or administering the AFH offices at times as well.²⁵ The Board of Trustees hired people who they believe will be able to fill these roles and present a good image for the Foundation itself. People were chosen as much for their political connections as they were for their qualifications.

Each of the Executive Directors has had various political and social characteristics and contacts which made them seem a good choice. The traits desirable to the Board changed through time, showing definite trends which correspond to changing circumstances at the Foundation and in the City. In the mid to late eighties, when the supporters AFH were primarily white, gay men, the Board hired white, gay men like Curtis Dickson and Brown McDonald. When AIDS started to be a problem among those who had used drugs or were of a minority group, Ed Mayo was hired, a black, heterosexual man who came to AFH from Cenikor. As city politics and funding from public sources became of greater importance, Evelyn Cox was appointed, a white, heterosexual woman with extensive connections to city hall. I do not argue that these people did not have other important qualifications and experience but their hirings were

²⁵ The amount of office administration done by Executive Directors has varied according to whether or not AFH has had an office manager on staff.
also political decisions by the Board of Trustees. Indeed, such decisions have to
be political decisions in any organization which relies as heavily on public
and community support in order to do its work.

-hidden Emotion and Concealed Grief-

The AFH newsletter creates a different type of written discourse than
that found in either texts by persons with AIDS or the oral discourse of
volunteers and staff. It is a cooler, less emotionally charged language which
avoids displaying either the suffering caused by AIDS or the periods of
internal conflict. *Lifeline* accomplishes this through image and metaphor as
well as through its textual presentation of the organization. The logo and title,
based on the symbol of a heart, on the front page of the newsletter reinforces
the idea of compassionate caring. The title, *Lifeline*, represents the
Foundation as a vital service to the community and creates a parallel of AFH to
the basic necessities of life. The heart logos, in the various versions, do the
same thing. The earlier logo, appearing from 1987 through the first half of
1988, consists of the tracing of an electrocardiogram to tie the Foundation to
the beating of a human heart. Just as a human being cannot survive without a
healthy heart, Houston cannot survive without the services of the Foundation.
With both visual and title metaphors, these symbols create a sense of urgency
and of being crucial to the work of AFH. Indeed, this was the primary basis of
the early Foundation's appeal to people outside the gay community. AFH, like
other AIDS organizations, argued that AIDS was and is not a problem just for
the gay men but is a problem for the entire city. By appealing to the civic
pride and sense of responsibility of readers, the newsletter implicitly supports
the importance of the Foundation and its services.
The logo was changed when the newsletter format was changed in 1988 to a heart-shaped tracing. The new symbol changes the emphasis of the image although still based on the American notion of "heart." The heart-shaped tracing moves from the focus on the necessity of the Foundation to an appeal to the compassion of the reader. The heart has (at least) two meanings in this context.\textsuperscript{26} First, Americans say that someone "has heart" when they mean that a person continues on in the face of great obstacles and difficulties. Such a person is deserves respect for their determination and ability to stick to a difficult task as do the volunteers and staff at the Foundation. This is proven through the volunteer profiles and the various grants received by AFH reported in \textit{Lifeline}. Foundation volunteers are described as persevering in extremely trying and painful circumstances and deserve to be admired for their activities. A second meaning of the heart relevant here is that of equating of the heart with compassion. In American culture, one says "have a heart" to elicit a sympathetic response. The goal of the newsletter is nothing if not an attempt to encourage a more caring and compassionate response from Houston residents. The heart-shaped logo symbolically and visually reinforces the explicit message of newsletter articles.

AFH continually reports on itself and its activities as a way to further demonstrate itself worthy of support. \textit{Lifeline} presents an image of distanced but compassionate caring, much like that based in Christian beliefs (see the discussion of Shelp, Sunderland, & Mansell in Chapter Three). The newsletter also conceals any signs of conflict within the organization. The Foundation is

\footnote{26 I do not intend to imply that there are only two interpretations of the heart shape in American culture. Any symbol used so extensively and for so long has multiple and shifting meanings. I discuss only those which seem most pertinent to the context.}
portrayed as made up of a group of people who work cooperatively without confrontation or disagreement. The newsletter also demonstrates the Foundation as deserving by presenting a wide variety of proofs. The stories of volunteers and persons with AIDS show them as good people who honorably struggle to meet difficult challenges. The proof is also in the reports on their various activities ranging from the Speakers Bureau to the food bank. AFH is also demonstrated as worthwhile through the evidence of the various grants and large donations received from governmental and private sources. All such donations are regularly reported in Lifeline. Readers are encouraged to contribute time and money in a cause that is proven deserving. This is in part to counter the accusations and stigma of being considered a "gay" organization. It communicates that the suffering of PWA's and the activities of AFH are a positive benefit to the community rather than the being a danger to the city through their dangerous sexuality.

The Interactions of Sympathetic Discourses

There are a variety of nonprofit and AIDS-related organizations other than AFH around Houston. There are several organizations in Houston which have been involved in AIDS-related activities as long as the Foundation. The Montrose Counseling Center and the Montrose Clinic both served the Montrose area, considered the "gay part of town," prior to the AIDS epidemic. Beginning in the early to mid-eighties the Counseling Center and the Clinic, began offering AIDS-related services. The Montrose Clinic was the first to offer AIDS antibody testing in Houston while the Montrose Counseling Center was one of the first to offer extensive counseling and support groups for persons with AIDS. AFH cooperated with and regularly worked with both of
these agencies. Together the three nonprofits regularly submitted grant
applications for state and federal funding, were the recipients of private fund-
raisers and events such as showings of the NAMES Project Quilt, referred
clients to one another, and jointly organized workshops and other educational
events such as the annual "Living with AIDS in Houston" symposium.

Not all interactions between the Foundation and other Houston
nonprofits is amicable. Occasionally, relations between AFH and other groups
become rancorous. Such conflicts may occur because of disagreements
between individuals and be resolved when those persons are no longer
associated with the Foundation or another group. There were recurring
disputes between AFH and the Houston Department of Health and Human
Services over grant applications and the disbursement of funds channeled
through the city.\(^\text{27}\) The Foundation and other nonprofits found themselves
first left out of grant applications, then found Health and Human Services slow
on providing the necessary information to the federal government, and, at the
end of 1988, found necessary confirmation of a grant withheld so that the
grant could be announced through the offices of a local congressman.

Sometimes the only sign of conflict might be the disappearance of the
name of a group from the newsletter's scheduling information or the referral
lists. AFH is very careful to avoid giving space to groups which have a dubious
reputation. The simple act of listing of an organization is a kind of
endorsement and AFH has to be very careful to whom they give their approval.
There have been a number of groups in Houston which used dangerous

\(^{27}\) See articles in the *Houston Chronicle* dated Sept. 8, 1988, Nov. 1, 1988, and
Dec. 31, 1988 and see the *Houston Post* Dec. 6, 1988. Also, in a similar conflict
over funding the following year, see the *Houston Post* dated Sept. 11, 1989.
therapies or offered problematic services to persons with AIDS. The listing of another organization's events, fund-raisers or workshops in Lifeline, on the AFH bulletin boards, on referral lists or in photocopied flyers is a courtesy that can not be extended equally to all local groups. Also, there is a kind of hierarchy of who is given what kind of space according to scarcity, cost of including an announcement in Lifeline, and the importance of the service offered. Most nonprofit groups can easily get their announcements posted on one of the bulletin boards. Only an event that a Director, Board members or an influential volunteer or client thinks is particularly worthwhile or an organization that has a long-standing relationship with AFH can be given limited, valuable space in Lifeline. AFH is especially careful about listing for-profit organizations; many do not make it to the bulletin board. Businesses, such as testing clinics, hospitals, and private physicians, are only found in the referral lists if they provide necessary services or actively support AFH or other AIDS-related causes.

The AIDS Foundation also has had close relations to a number of other local organizations through the members of the Board of Trustees. Members of the Board are commonly drawn from other local groups, are Houston activists, or are local health care professionals. For example, Bernice Moncrief, president of Houston Hospice, Solomon Brownstein, of Jewish Family Services, Bill Napoli, president of the Houston PWA Coalition, and Eleanor Munger, founder of Omega House, have all served on the AFH Board of Trustees (Lifeline July 1987 & May 1989; Houston Metropolitan April, 1991). Board members also include local physicians and researchers such as Miguel da

---

28 See Barth's article, "Getting Rich off AIDS" (Houston Metropolitan April, 1991).
Cunha, who is on the faculty of the University of Texas Health Science Center's School of Nursing, Adan Rios, who was a researcher at the ill-fated Institute for Immunological Disorders and more recently is in private practice. Other local physicians who have served on the Board of Trustees include Joseph C. Gathe, Jr., Indira Lanig, and John O'Donnell. The Board has also included many local businessmen and women, who have been particularly helpful in supporting AFH fundraising efforts.

A number of people volunteer at more than one organization or leave the Foundation for other AIDS-related groups around Houston. Volunteers who have AIDS will often be active in the PWA Coalition. Counselors and therapists who volunteer their services for AFH usually work in related organizations around town, such as Executive Director Ed Mayo who worked with Cenikor before coming to the Foundation. There have also been a number of Board members, volunteers, and staff who are active in local, state, and national politics. Evelyn Cox, a speech writer to a former Houston mayor, served as AFH Executive Director and well-known feminist, Sissy Farenthold, served on the Board of Trustees. The overlapping memberships, volunteer activities, work, and service positions imply a great deal of admixture of personnel, ideas, and language. People learn AIDS discourses in more than one organization and transfer this language with them as they move about. Combined with the practice of borrowing and adapting training materials from other organizations (see Chapter 1), there is tremendous degree of overlap and blending of AIDS discourses.

29 See Lifeline May/June 1988 & June 1989; Houston Metropolitan April, 1991; & AFH referral lists on the hotline computer.
In addition, the spread of AFH's style of AIDS discourse can be traced through relationships formed through training, much like academics trace their background through who their teachers were. The Foundation provided a variety of regularly held workshops for health care professionals, leaders in the minority communities, civic groups, police, businesses, and governmental groups. A few of the groups who were trained by the Foundation in the two and half years that I was at AFH include the Harris County Sheriffs Department, Hispanos Unidos of Houston, incoming students at Texas Southern University, and the United Way hotline. The intensity and length of the workshops varied but the majority were approximately one to two and a half hours long, although some types were as long twenty four hours over days or weeks. This is just a few of the over 30,000 Houstonians who attended AFH training sessions, safer sex workshops and educational presentations during that time period (Lifeline June 1989). Those who attended these sessions weren't a large proportion of Houston's population but included those who were in influential positions in Houston's civic, political, business, and medical life.

The Foundation also spread their way of understanding AIDS through a variety of events, television presentations, and workshops co-organized or cooperatively sponsored with other local organizations. The following list will provide an idea of the range of educational activities pursued by AFH. Members of AFH participated in the annual "Living with AIDS in Houston" Symposium held at the University of Houston (Lifeline August 1987 & September 1989). In conjunction with the PWA Coalition, they sponsored

---

30 This information is drawn from Lifeline issues for February 1987, September/October 1987, April 1988, June 1989, September 1989 and from my notes.
workshops for persons with AIDS called "Life after Diagnosis" (Lifeline April 1988). AFH was featured in the local segment of the PBS special "America in the Age of AIDS" (Lifeline March 1989). The Foundation also produced their own documentary on AIDS in the Black community and their own play called "AIDS: Just Say Know" (Lifeline July/August 1989). Hundreds of people called the AFH AIDS hotline every month (see Chapter One) and many more saw the billboards advertising the hotline along major streets and freeways around town. Newspaper articles on AIDS in Houston in local papers often quoted one or more members of the Foundation, especially Executive Directors and several particularly active Board members such as Miguel da Cunha and John Paul Barnich.

Final Note

In this chapter, I have been critical of certain aspects of the newsletter and the organizational structure of the Foundation. I argued that Lifeline articles tend to downplay how difficult volunteering can be and portrayed PWA and PWARC volunteers in a stereotyped fashion. AFH is not the only nonprofit group that feels it necessary to downplay the difficulty, conflict, and pain associated with their work. Similar discursive strategies are used by other nonprofit groups which depend on the donations of money and time by their members and community. It may well be a necessary survival strategy. The organizational structure which separates the Board of Trustees from staff and volunteers is like that found in the majority of American nonprofits (see Douglas, 1987; DiMaggio, 1990). It is intended to protect the organization from the domination by a single individual or clique. It performs this function well but at the cost of disenfranchising volunteers, who end up with little direct
input into the goals of the nonprofit. No organization can be perfect and no

group of volunteers without flaws but AFH has performed admirably in an

often hostile environment. I fully support their efforts. The Foundation's

successes and strengths far outweigh any problems the organization may

have.
Chapter Five

CONCLUSION: SPEAKING IN VOICES, LEARNING TO TALK

Writing and talking about AIDS discourses implies talking about talking, telling stories about telling stories, and using metaphors about using metaphors. It is a circular sort of exercise but not a futile one. When I first began working at the AIDS Foundation of Houston, I encountered people who were determined to make a difference in how AIDS was discussed in the Houston public forum and, as a result, how persons with AIDS would be treated. The Foundation, along with many other organizations and individuals, was able to initiate enormous changes. People with AIDS in Houston now have a wide variety of support services available. The situation is far from optimal but it is light years away from what it was in the early and mid-eighties. Citizens may not be overjoyed to know that there are residences and hospices for PWA's in their neighborhoods but no longer are there real threats of violence. Funding for AIDS education may still be limited but at least it exists. Telling stories and providing new ways of talking about AIDS helped AFH significantly change the way Houstonians think about and understand AIDS. In retrospect, creating a counter-discourse of AIDS seems a very tentative weapon but it has been a more effective one than I would ever have realized in 1987.

Controversial ideas and issues, like AIDS or sexuality, are regions of culture which are inevitably contested in public arenas. What issues are seen as controversial depends on the beliefs and points of strain within that particular culture. AIDS inevitably became such a controversy because it is situated at a cross point between concepts of Christian compassion and cultural
prohibitions against homosexuality and drug use. American culture sees such activities as simply desires, not needs and, as such, irresponsible, dangerous or self-seeking. When homosexuality and drug use are combined with the transmission of a serious disease, it is inevitable that many will view that illness as deserved and threatening to a more traditional style of life. If a person cannot control their animal or base tendencies, then they will be divinely punished by AIDS, syphilis or some other deadly disease.

Persons who engage in use of illegal drugs or homosexual activities are often defined a source of danger for the “general population.” In this context, general population refers to all those people who do not (or at least say they do not) engage in such activities. As Sander Gilman has noted when examining the similarities between Western notions about syphilis and AIDS, there is prevalent tendency to represent people with either syphilis or AIDS as potential sources of corruption for those seen as innocent (1988). Without some kind of additional motivation, disdain or a simple lack of compassion for people with AIDS would not have resulted in the kind of violent reactions that occurred. It was the fear of contamination which caused people in small towns and large cities to have such extreme reactions to persons with AIDS. Such responses meant that acts of discrimination against PWA’s were wide spread and relatively few people were willing to protest such deeds. There were very few legal safeguards in place and most persons with AIDS were too terrified to make their illness public. In such a climate of fear, getting funding for programs like sexually-explicit AIDS education or providing services for persons with AIDS was almost impossible. Organizations like AFH were forced to rely primarily on private donations from the gay community even though there were many gays who didn’t want to even think about a disease like AIDS much less want to support the Foundation’s activities. In the early eighties,
there were only a handful of organizations around, such as AIDS Foundation of
Houston, San Francisco AIDS Foundation, and Gay Men's Health Crisis in New
York, which were actively working to change these attitudes. They realized
that their lobbying and public relation activities would not be successful until
they were able to change the way in which Americans understood AIDS and in
order to accomplish that they needed to change the way Americans talked
about AIDS.

Learning to Talk the Talk

By the time I joined the Foundation, they had a very effective way of
teaching incoming volunteers, staff, and Board members¹ their own brand of
AIDS discourse. In the early and mid-eighties, organizations like AFH shared
with and borrowed ideas from other AIDS organizations around the country
for their training programs. The Foundation's intensive weekend training
sessions and subsequent training for specific volunteer positions articulate a
moral stance which leads participants away from thinking about PWA's as
victims and teaches them the Foundation etiquette for interacting with
persons with AIDS. Another goal of the training is to help prepare people to
deal with the emotional and intellectual demands of volunteering and to try to
reduce burn out. The training is only partially successful in this goal. Most
volunteers eventually experience burn out but the training does equip them
with a clearer understanding of their own fears and doubts. The training is
most successful in teaching participants the Foundation way of talking about
and understanding AIDS. The curriculum includes talks by a prominent local
medical expert, a person with AIDS, and other volunteers who are active in

¹ Not all members of the Board of Trustees participated in the training sessions
but those who intended to be actively involved with AFH did attend.
AIDS education. Once they have completed this demanding weekend, volunteers can speak knowledgeably about symptoms of HIV infection, epidemiology, transmission and a variety of related topics.

When I attended, one important component of the training was the film of PWA Gary Walsh made by the Shanti Project in San Francisco. This video shows Walsh as an exemplary person with AIDS. He is shown in such way as to demonstrate how people can learn to deal with the difficulties posed by a life-threatening illness like AIDS. When he speaks about how AIDS has affected him, Walsh asserts that he is essentially the same person as he was before his diagnosis. Like most seriously ill people, Walsh wants to establish the authenticity of his sense of self. Americans with chronic or life-threatening illnesses fear that their value and possibility for self-fulfillment is stolen by their illness. It is that sense of loss which makes Walsh so insistent that nothing has changed. Walsh is also shown as an expert on AIDS by virtue of his illness and, by extension, so are all persons with AIDS. The interviewer, Jim Geary, listens without interrupting, does not try to rush Walsh when he speaks slowly, and offers emotional support when Walsh chokes on his feelings. Because Walsh is gay, a trained therapist, and a volunteer at Shanti, he can speak not only to people with AIDS but also to volunteers, staff, and professionals. He has something to say to everyone. In these ways, the video shows trainees how they can support clients in a positive but empowering fashion. The film was supplemented by hand outs of written material, role playing, and an appearance by an AFH client but the Shanti film is a kind of standard of behavior for trainees. It clearly demonstrates all the points important in helping volunteers understand how to support a person with AIDS while making clear the terrible physical cost that AIDS can take. Since the making of this film in the early eighties, many more (good and not so
good) representations of people with AIDS have appeared in written and film versions. However, all the autobiographies and biographies that follow owe something to the people with AIDS who were willing to speak out in the early days of the epidemic.

The Foundation's way of speaking about AIDS takes a kind of neutral or (ostensibly) "value-free" moral stance. It avoids an explicitly Christian outlook although it relies on a Christian ideal of compassion at its core. This is a counter-discourse which speaks directly to lay and religious voices who argue that people with AIDS are not worthy of help. These portrayals of people with AIDS refute all the stereotypes of persons with AIDS or gays as dangerous, amoral or not worthy through the telling the tales of their lives. The stories demonstrate the courage, concerned attitudes, and responsible conduct of PWA's as well as showing them as ordinary people who have the same kind of lives as anyone. These gay people are completely unlike the negatively stereotyped images that have been presented of persons with AIDS in the mass media during the mid-eighties. These are people who are not only worthy of compassion but are heroes who demonstrate a quiet courage in the face of pain, disability and loss. However, by also showing the ordinariness of their lives they also avoid the kind of "super-crip" representation that can characterize American cultural notions about ill or disabled people (Biklen & Bogdan 1978). Such "super" representations show people with disabilities as having some extra ability. The Foundation portrays persons with AIDS in a romanticized but lesser light.

By following the Foundation etiquette, volunteers learn to show respect for persons with AIDS and to allow for their full participation in AFH. As both clients and volunteers, PWA's are active participants and greatly influence the "feel" of the Foundation. Volunteers become committed to serving and
protecting persons with AIDS. They learn to tell tales of their experiences in ways which will not jeopardize the confidentiality of either clients or volunteers. Stories are stripped of normal identifying markers and names. Instead, volunteers refer to clients and other participants through references to age, race, HIV status, or need. Volunteers feel compelled to tell these stories in order to share and make sense of their experiences. Their problems and happenings are shared in order to collectively discuss obstacles and how to overcome them. For example, repeat callers to the hotline are often an obstacle for callers who really need help. A repeat caller may call daily or even hourly and want to discuss the same problem over and over again. They usually need therapy, not referrals or a brief discussion of an immediate problem. Often the issues they perceive as life-threatening are illusions or displaced feelings of self-hatred. One such repeat caller, a heterosexual man, was convinced he had AIDS although he had not had sex in years and had experienced no other possible modes of transmission. Volunteers are neither equipped to deal with such deep-seated emotional problems or provide long term therapy. Telling stories of the characteristics of repeat callers and how to identify them assists hotline volunteers to weed out problem calls quickly.

Another reason why volunteers have so much difficulty feeling any real sympathy for repeat callers is that volunteers are in a frame of mind to solve problems as well as to listen to callers. In retrospect, I am astonished that I felt so much antipathy to repeat callers but would probably feel the same way if I were ever in the same situation again. The catch is that volunteers cannot even begin to address the emotional problems of repeat callers. Volunteers are trained to give out information, make referrals, make appointments or support a caller in making a decision. Even when a person newly diagnosed with AIDS calls the hotline, the volunteer knows that their
pain and anguish is the beginning of their coming to terms with life-threatening illness, not an end in itself. For repeat callers, the phone conversation and the rehashing of their story is in itself the goal. The volunteers come to feel a great deal of frustration and anger when faced with the same person and the same insoluble problem over and over again.

Volunteers come to identify with their clients, feeling the injustices they observe deeply. They try to protect clients and solve problems that are often nigh insoluble. Volunteers come to see themselves as a protective bulwark between people with AIDS and a world that treats them unjustly. The family members of PWA’s may reject them, employers fire them or landlords evict them but volunteers try to be the resource that is always there. Often they are caught in no-win situations where there is little or nothing that they can do to remedy a problem. This situation creates tremendous strains on volunteers. They can take some of the stress off themselves by talking to one another and telling stories of the injustices they observe. Volunteers can also support each other when they experience the grief of losing a client. AFH also offers support groups with a professional therapist for volunteers but these sessions are held infrequently (at least for the hotline volunteers). Generally, this is one area that the Foundation support for volunteers was less than successful. Support groups were held sporadically and it was rare that the Foundation would publicize memorial services. Unless the volunteer was in regular contact with a client or happened to learn about such things independently, they would not find out about a death until days or weeks later. I experienced an ongoing, almost continual feeling of loss without the release of a ritual event such as a funeral. In such an emotionally demanding situation, burn out becomes almost inevitable.
The Foundation etiquette that volunteers learn is one which counters or reverses the image of people with AIDS. This counter-discourse romanticizes PWA’s somewhat (as spiritual adventurers and quiet heroes) but effectively invalidates the discourse which would cast people with AIDS as dangerous sources of contamination. It encourages persons with AIDS to speak for themselves. They are experts on AIDS from their own experience and actively involved in the work of Foundation. This etiquette is not the only voice in the public conversation about AIDS at the Foundation. It is supplemented by medical, political and public relations fields of discourse which make up the official communications of the Foundation. And, although there are many AFH styles, they share a common use of theme and metaphor. Those diagnosed with AIDS are called persons with AIDS, PWA’s or clients but not AIDS victims. This is true in either the newsletter or Foundation etiquette. Gay identity is not usually actively displayed in either oral or written discourse but neither is it actively hidden. Being gay is usually assumed or communicated through gay language or coding such as mentioning membership in a gay organization or using turns of speech which will be recognized as part of the gay community (e.g., being a “screamer” just like Larry Kramer).

The Foundation newsletter, Lifeline, is different in that it does not tell the same sorts of stories that are common in volunteer oral discourse although there is overlap in the other areas. The emotional pain displayed in the stories of volunteers and persons with AIDS does not appear in Lifeline. Instead, the reader is distanced from the emotional costs of AIDS and presented only with success stories: the volunteer who fills a full time position without pay or the PWA who manages to continue to volunteer even though he or she is so weak they cannot walk unaided. In AFH etiquette, there is no prohibition against conflict when the volunteer is guarding the interests of a client but such
strife is never displayed in the newsletter. All disagreements and confrontations are carefully hidden from the reader of the newsletter.

*Lifeline* courts its readers, urging them to volunteer or donate money. The newsletter's purpose is not to document the real qualities of the clients' or volunteers' experiences. It is intended to appeal to a wide variety of people. Evidently the editors and authors believe (probably correctly) that too much truth would make many readers uncomfortable and drive them away. AFH also presents itself as objective and as somewhat distanced from the gay community in Houston. Although it does not deny that most of its clients and volunteers are gay men, it does not emphasize that point either. The Foundation has often been labeled as a "gay" organization and as partisan in gay politics. This reputation has made it very difficult for AFH to get the funding it needs from both public and non-gay private sources. By presenting itself as a service organization for all of Houston's citizens, it attempts to invalidate such characterizations. The Foundation slants many of its public voices, such as releases to local newspapers, in the same fashion. AFH makes no attempt to silence the voices of clients or volunteers who would speak more explicitly but does not include them in *Lifeline*. However, persons with AIDS associated with AFH do talk more frankly about their experiences when acting as speakers (like Tim) for local groups or on television.\(^2\) The official type of voice in the newsletter is concerned but nonpartisan. It supports the Foundation's struggle to compete with other nonprofit groups and to gain access to alternative types of funding (such as the United Way).

\(^2\) In the late eighties, PWA's associated with the Foundation appeared in television specials on both local public television and cable access stations.
Discourse as a Public Conversation

There is an ongoing conversation about AIDS, sexuality, and drug use in public arenas. AIDS is a marker for several aspects of American culture which are changing or threatening to change. AIDS and gay sexuality are associated with cultural themes such as contamination, the military, male fears of sexual assault, and blood as emblem of both purity and disease. Uncertainty about these and a variety of other key issues disturb and frighten many Americans. Many people believe their way of life under attack and see increasingly open gay communities as one cause of their uncertainty. Therefore, many different sorts of people within American culture feel compelled to participate in the conversation on AIDS and present their point of view. Gay activists and Christian ministers, right wing political groups and liberal civil rights organizations, and blue and white collar workers—all talk about the points of contention surrounding AIDS. People make jokes at work and write editorials in local newspapers. They speak up in churches and synagogues or in bars and singles clubs. The citizens of Houston and the rest of country are involved in trying to figure out culturally appropriate ways of responding to AIDS by participating in these public conversations.

Like any conversation, participants in this society-wide discussion may or may not listen to, interrupt, ignore, agree with or even be honest with each other. The conversation has a variety of repeating elements and structures of understanding. Many of these have been borrowed from earlier debates on infectious illnesses (such as syphilis), drug use, gender, sexuality, law, and Christianity. The same arguments and statements of belief are used over and over again. Some Christians contend that homosexuality itself is a mortal sin and, therefore, AIDS is a punishment brought on gay men by their own
actions (e.g., Jerry Falwell as discussed in Chapters One & Three). Others who participate in the conversation assert that homosexuality is dangerous, that gay men "recruit" new homosexuals by seducing young boys, and, therefore, people with AIDS deserve to be ill. Christians of different beliefs argue that their religion counsels compassion for the outsider or "sojourner" and that Christians have an obligation to care for persons with AIDS as they would any other person in need (e.g., Shelp, Sunderland, & Mansell 1986). Many gay people argue that they were born gay, and, since God would not cause someone to be born with a characteristic which would automatically condemn them, their sexuality in itself cannot be a sin. From this point of view, AIDS is not a punishment but simply a tragedy.

These same arguments are heard over and over again in the conversation on AIDS. The Foundation has had to find its own voice and articulate a point of view which would support their efforts to get funding. What the Foundation has done is to change the rules of some parts of the conversation in order to challenge those segments of American society which would condemn people with AIDS as not worth helping and reject explicit AIDS education as immoral. AFH pulls on several well rooted beliefs such as compassion for the ill, tolerance for people different from ourselves, and the rationalization of the treatment of disease but wraps them in a package of narrative, metaphors and themes which serve to reinforce their message. Instead of representing those who have been diagnosed with HIV infection as helpless victims and patients, AFH and many Houstonian people with AIDS have loudly and repeatedly denied this attribution. They have named

---

3 This interpretation of the beliefs of some Americans is supported by the findings of the Kinsey Institute study of attitudes in regards to sexuality in the U.S. (Klassen, Williams, and Levitt 1989).
themselves persons with AIDS (or ARC) or PWA’s rather than victims. They claim the right to actively involve themselves in determining the nature of the American response to the AIDS epidemic, to participate in the research process (even running some research projects themselves), and reworking the image of people with AIDS as portrayed in the mass media.

**People with AIDS Speak Out**

Many people with HIV Infection have presented their written or oral autobiographies in the public sphere. Gary Walsh, John, and the others discussed earlier are only a tiny fraction of the many around the country who have come forth in one way or another to tell their stories since 1981. These stories are not of helpless, passive victims waiting for death but of active people fighting to stay alive and change the stereotypes. Their stories are of struggle and battle, and of working to change indifference or hatred to support or, at least, tolerance. Their many voices are an effective way for persons with AIDS and organizations like the Foundation to challenge the way AIDS is understood. Instead of simply trying to counter argument with argument or logic with logic, the stories of people with AIDS undermine the equation of “AIDS victim” as identical with abnormal, passive, deviant, and not human. People with AIDS alter such perceptions by demonstrating themselves as real people with everyday lives who are neither better or worse than are other Americans. When combined with other Foundation ways of talking, these stories form a powerful new discourse on AIDS.

Autobiographical narratives common in Foundation oral discourse and the various printed sources share a common theme. These stories are about “living with AIDS” rather than about “dying of AIDS.” The people who portray themselves do not focus on the possibility of death in the near future
so much as on how they will live their lives. People with AIDS talk about how to deal with the emotional, financial, and physical problems they face after HIV infection. Their questions revolve around issues like: should I tell my family I have AIDS, how do I pay this month’s rent after being forced to quit working or which of the available treatments would be best for me? Their stories (and their lives) do not freeze into immobility with the advent of an AIDS diagnosis. A person with AIDS, like any other seriously ill person, has to come to terms with their situation. They probably spend time angry, frustrated, and depressed about their situation but those who tell their stories have resisted becoming passive or immobilized. Writing about one’s illness is an important action in itself and wouldn’t be undertaken by a passive “AIDS victim.”

The stories told by people with AIDS have a number of special characteristics which arise from the complex intersection of culturally accepted forms and their own experiences. First of all, the stories persons with AIDS tell are constituted much like any autobiography. Such oral or written narratives are a process of creating “self” through a dialogue with the “other.” The writers of autobiography are writing a truth, not of facts of their lives, but of the creation of self. Autobiography is written in a process of self-examination. “I” write to explicate who the “I” really is. A unitary self does not exist prior to this but is born through the process of inscription. The writer must pick and choose what to tell of him/herself. John does not tell the details of what having pneumonia was like. Instead, he tells what the possibility of having AIDS means for him, the cost of this uncertainty in his life. He talks of upheaval and change, and how this has changed his life. John chooses what of himself he will tell to the reader and what is not spoken.
Writers of autobiography must choose which aspects of their experience to present in order to communicate a sense of their lives to the reader. This self-portrayal has validity if the writer is able to connect with and create a positive sense of empathy in the reader. The PWA's discussed here have all been able to make the leap across the boundaries between writer/speaker and reader, between "self" and "other," between you and me. These authors have overcome the reader's resistance to identifying with a "damaged" person, to someone who has AIDS and is gay. Making this connection is made somewhat easier because even though people with AIDS are problematic for Americans, PWA's have the authority that Americans give to the dying or dead. In our culture, people who are dying are seen to have a special understanding of what is really important in life. Being close to death strips away the unimportant and inessential parts of everyday life and leaves only what is real and significant. This authority gives what is said by persons with AIDS a special aura of authenticity. Thus, someone who might be ignored or ridiculed in the normal course of things will be listened to much more intently when they are perceived as dying. When an autobiography by a person with AIDS speaks on spiritual or emotional issues, Americans take what is said to heart.

This challenge of metaphors of victimization and passivity by people with AIDS and the Foundation etiquette contradicts Susan Sontag's argument against the use of metaphor in language about illnesses like AIDS or cancer (1978, 1988). She states that the only way to redress inequities is to remove metaphor from language about illness. Her position is based on an assumption that all such metaphor is based on cultural prejudices, fears, and anger. Sontag does not account for the possibility of metaphoric language which would originate with those who are ill and be aimed at resisting hegemonic
discourses. She also ignores the importance of (auto)biographical narrative in changing peoples understanding of an illness like AIDS. The counter-discourse used at the Foundation by clients, volunteers, and staff challenges negative discourse and has made enduring changes in the way Houstonians and other Americans think about AIDS. Even if it were possible to remove the metaphor from language, such a denatured language would lack the emotional power that is possessed by the stories of PWA's. Much of the appeal of any of the prevalent points of view on AIDS is an emotional one. This is true of any issue which occupies such a central position in the American cultural landscape. Any point of such intense contention is tied as much, if not more, to sentiment than it is to any rational argument. The discourses used at the Foundation, which effectively combine narrative with metaphor to make certain points, are able to tap emotion as well present reasonable arguments in support of their ideas.

These stories are also illness narratives—stories which tell about being sick. Normally, illness narratives tell how one becomes ill, diligently seeks treatment, and then recovers. For persons with AIDS, like others who have chronic illnesses, there is no happy ending of health and well-being. The autobiography of a person with AIDS has no real ending in that sense. Who can write their own death? Only in biography or memorial is the death of a person with AIDS inscribed. The autobiographies of PWA's like John, Fran Peavey, Gary Walsh or Bobby Reynolds are stories of living with illness, not of dying. This is a large part of their appeal to readers. There is hope and struggle but not the ultimate defeat of death. The reader glimpses the viewpoint of the dying without experiencing the tragedy of death. Autobiographies of people with chronic illness break the cultural rules by not ending with a cure and return to normal life. They speak about suffering,
something that is not supposed to happen to good people. People with AIDS who write the stories of their lives are creating a new kind of theme for an illness narrative, that of “living with AIDS” or “living on the edge of death.” This gives PWA’s the greater authority of the dying but does not position them as passively waiting to die.

People with AIDS deny the equation of suffering without cure to being a bad person. They demonstrate their worth through the details of their everyday lives and deny negative attributions made of people with AIDS. For PWA’s who speak out (or write), the telling of their lives becomes work that has real political and personal consequences. They do not tell their lives merely to reduce the stigma of their illness but in an attempt to have a real impact on attitudes. People with AIDS have been particularly vocal and successful in changing the dominant discourses on AIDS. In part, this is because they have combined illness narrative with the discourse of gay politics. There is a tradition of speaking one’s life in “coming out stories” as a political statement in the gay (sub)culture. Persons with AIDS do not merely tell their stories to the sympathetic but take on adversaries (like Falwell) head to head in public debates and in the mass media. This was especially dangerous in the early years of the epidemic but even now persons with AIDS who “come out” invite rejection by family members, co-workers, and friends. Even in the nineties, conservative political groups in Texas continue to call for the quarantine of people with AIDS. The risk of telling the story of AIDS also removes the taint of self-pity or self-involvement which Americans tend to attribute to anyone who talks about being ill. It is serious work which takes courage.
Biography As Counter-Discourse

People with AIDS are not the only ones telling stories about what it is like to have AIDS. Biographies by ministers, doctors, family members, friends, and activists have been published in the last ten years. In addition, the quilts of the NAMES Project made by friends, lovers, family members, and fans of the famous memorialize those who have died of AIDS in ways which are much like biography. These books, essays, and other types of portrayals have much the same sort of effect on the public conversation on AIDS as do autobiographies, establishing PWA's as real people with real lives. Such works document that people with AIDS are loved by their partners and mothers, respected by their friends, and honored by their peers. Biographies are part of the public conversation on AIDS, written to counter the images of persons with AIDS as isolated from normal social connections.

The primary thing that separates biography from autobiography is point of view. This may seem an overly obvious point but it leads to an enormous difference in the slant and emphasis of the story of a person's life. The biographer is not constructing the "self" but reconstructing the "other." The substance of the story is the interpretation of someone else, the molding of memories into an allegory of a real life. For example, Shelp and his co-authors reshaped the stories of people with AIDS into Christian tales of redemption (1986). George Whitmore wrote Jim Sharp's life into an exemplary story of the fears, anger, and pain of persons with AIDS (1988b). The creators of NAMES Project quilts put together culturally defined collages of identity and inscribe brief reminiscences of lives. The biographer must imagine the interior life of the person from their own point of view. Since the writer can only know what they have seen or been told, there is an element of fiction in
biography, of extrapolation. It forces the writer or speaker to recast the story of the life in figurative terms. Each of the examples discussed tell the reader something more than the life of a single person, they are cultural inscriptions of personhood and identity. Biography tells the reader as much about the culture and author as the life it purports to describe.

There are difficulties with talking about biography as distinct from autobiography. The line between the two genres often becomes blurred. Authors incorporate bits of interviews, letters, quotations and poems by the person they write about as well as reminiscences by friends, lovers, and family into the author’s text. Shelp and his co-authors intermix quotation, description, and narrative into their stories of persons with AIDS as do Whitmore and the creators of quilt panels.4 The inclusion of such material establishes the authenticity of their portrayal. However, biographers are not willing to include the less pleasant sides of the lives of their subjects. Writers of biography tend to put a pleasing polish on the lives of their loved ones. As in all kinds of memorials, people tend to be remembered only for the good things that they have done. John, for example, is willing to describe himself as not a very nice person before he was diagnosed with AIDS. And, although PWA’s don’t represent themselves as bad people, they are detailing their lives, not memorializing their deaths.

Authors of stories about persons with AIDS write for a purpose. Some, like Shelp, Sunderland and Mansell (1986) or Whitmore (1988b), write in large

---

part to try to convince the reader of the worth of PWA's and to counter negative perspectives on people with AIDS. Shelp and his co-authors address their book to Christians while Whitmore speaks to a more secular audience. The makers of NAMES Project quilts memorialize and identify people who have been made nameless. The fear of stigma and rejection keeps the majority of people with AIDS and their families from discussing their diagnosis. The NAMES Project is about naming and remembering the creator's relationship with the person now dead. While obituaries and regular funeral services may conceal large parts of a gay person's life, the quilt can be more open about showing who this person was and what was important to him or her. It rescues the memory of friends and lovers who may have no other way of expressing their losses. Another type of cultural work performed by the quilt is to express spiritual beliefs. Quilt creators portray death in various ways: as a journey, a cycle of death and rebirth or as a place where lovers will meet again. The panels express hopes for an afterlife that will be better than this life and deny that persons with AIDS will be punished for what they were in this life. All of these reasons for inscribing a life can be attributed more to the author than to the person with AIDS. Biographers write for themselves and have their own motivations.

It is clear that all of the biographies and autobiographies discussed here are concerned with making a public statement about the worth of the person with AIDS as a way of changing the way in which people with AIDS are portrayed in the public conversation on AIDS. The question is whether all of this effort had any results and whether anyone was willing to listen. There is one striking change that occurred in the local media in the late eighties that seems most directly linked to the representation of people with AIDS. Beginning about 1987, a new type of article about AIDS begins to appear about
persons with AIDS in local newspapers. Unlike the reports about Fabian Bridges in 1985, these stories talk about persons with AIDS in a more sympathetic fashion. Articles were written about the lives of AFH activists Michael Wilson, Michael MacAdory, Joe Varvaro, and Jim Sharp. These articles, published in 1987 and 1988, talk about the difficulties of their lives and portray them as people with friends, lovers, and family. They are still called “AIDS patients” and “AIDS victims” but they are also called people with HIV infection or AIDS. Their illness is not a deserved punishment but a bad thing that has happened to a good person. Michael Wilson attributed with leaving “legacy of hope” and Michael MacAdory is called a “hero.” Both are shown as valiant men who struggled against overwhelming odds to establish the AIDS Foundation and services for people with AIDS. These articles are more than a little melodramatic but are a much improved representation when compared to the pieces on Fabian Bridges.

The ways in which AFH talked about and understood AIDS was easily accessible in Houston and familiar to many Houstonians through the training programs, documentaries, hotline, coverage in local newspapers and magazines, symposia, special events, and the public figures and shared personnel who worked at the Foundation. I would argue that these discourses have made real changes in the way that AIDS is perceived in Houston. The difficulty is how to demonstrate the concreteness of this change and its specific cause. The Foundation and its volunteers, staff and clients have not

5 Bridges was the young mentally retarded man discussed in Chapter One (see Houston Post Oct. 2, 1985).
6 This is the same Jim Sharp who is portrayed in Whitmore’s book.
acted alone but in concert (sometimes in conflict) with many other AIDS-related organizations and AIDS activists. The impact of AFH discourses cannot be separated from these many other influences. The complexity of the situation is increased by the ephemerality and changeability of AIDS discourses. There are indications that AFH helped to create change in the way Houstonians think about AIDS but none these can be specifically associated with changes in public opinion. In fact, I am not certain that direct cause and effect relationships could be established in any relationship between a counter-discourse and change in content of the public debate or actions on an issue.

A large part of the difficulty is that there is always variation and change in beliefs across a cultural group or through time. How can anyone trace changes in beliefs to specific challenges in the public conversation on AIDS? Cultural beliefs are like a bowl full of soft gelatin cubes—you can gently separate out one colorful bit if you are very careful but usually they form a solid, constantly shifting mass, bleeding one into another. It is nearly impossible to keep all the different cubes neatly separated but it is much easier to look for patterns and fields of color in such a mess. That is what discourse analysis does; it looks for patterns and trends in the messy bowl of culture rather than trying to pin down and delineate absolutes. The counter-discourse used at the Foundation forms a pattern which can be traced through AFH educational efforts, seen in other discourses such as the mass media, and in the increase in the number of programs9 devoted to serving people with AIDS. It is clear that Houston area organizations shared training, funding sources,

9 One indication of the overall increase in AIDS-related organizations and programs is the size of the AFH Social Service Handbook (1987, 1989). It increased by about 50% in overall size and sheer number of listings over the two and a half years I was a volunteer.
personnel, and overall goals in their work with persons with AIDS and AIDS education. The final and most compelling argument is the mere presence of AFH as they actively took part in Houston’s debate on AIDS. By simply offering an alternate perspective, the Foundation ensured that those who portrayed PWA’s as dangerous and opposed services would no speak unopposed. While these various reasons does not constitute anything like final proof, they do support my contention that AFH discourses have had real impact on Houstonian’s understanding of and response to issues around AIDS and sexuality.

Conclusion

The counter-discourse used by persons with AIDS, volunteers, and staff at the Foundation competes with other discourses in the public conversation. This discourse provides radically different ways of thinking and talking about AIDS and PWA’s. When AIDS is not understood as a punishment or the deserved outcome of deviant behavior, then people are far more sympathetic. They are more willing to fund service programs either through the public or private sector and less likely to tolerate discrimination against people with AIDS. I don’t mean to argue that there are no longer people who have negative feelings about persons with AIDS but that there are more people willing to express sympathy and a greater willingness to support anti-discrimination laws or similar measures. Language, as used in the counter-discourse of the AIDS Foundation of Houston and other such nonprofit groups, has become a powerful tool for redress. The PWA Coalition was correct in its assertion that changing the language of AIDS was an important first step in initiating change.
LIST OF REFERENCES

Newspapers and Magazines

AIDS Surveillance Report-Houston SMSA (Houston Department of Health & Human Services)

HIV/AIDS Surveillance Report (Centers for Disease Control, U.S. Dept. of Health & Human Services)

Houston Chronicle

Houston Metropolitan

Houston Post

Lifeline (AIDS Foundation of Houston)

Montrose Voice

The Morning News Tribune

The New York Times

Out/Look

This Week in Texas (TWT)

Video and Film

1984   AIDS: Care Beyond the Hospital [with Bobby Reynolds & Helen Shietinger]. San Francisco: San Francisco AIDS Foundation.


Books, Articles, and Manuscripts

Acevedo, John R.
ACLU AIDS Project

Adam, Barry D.

AIDS Foundation of Houston


Altman, Dennis

Angrosino, Michael V.

Anspach, Renee R.

Barth, Linda

Biklen, Douglas and Robert Bogdan
Bogdan, Robert, Douglas Biklen, Arthur Shapiro and David Spelkoman

Brody, Howard

Burns, Irene
1988 "We Were There." In The AIDS Epidemic: Private Rights and the

Bury, Michael
1982 "Chronic Illness as Biographical Disruption." Sociology of Health and
Illness 4:167-182.

Charmaz, Kathy
1991 Good Days, Bad Days: The Self in Chronic Illness and Time. New
Brunswick, NJ: Rutgers University.

Chesebro, James W. and Kenneth L. Klenk
1981 "Gay Masculinity in the Gay Disco." In Gayspeak: Gay Male and

Crapanzano, Vincent
1987 "On Self-Characterization." Unpublished manuscript in the author's
possession.

Crichton, E. G.

Des Jarlais, Don C. and Samuel Friedman
1988 "The Psychology of Preventing AIDS Among Intravenous Drug Users:
A Social Learning Conceptualization." American Psychologist 43(11):865-
870.

Defoe, Daniel

Dilley, James W. and Alicia Boccellari
1989 "Neuropsychiatric Complications of HIV Infection." In Face to Face: A
Guide to AIDS Counseling. James W. Dilley, Cheri Fles and Michael Helquist,

DiMaggio, Paul J. and Helmut K. Anheier
1990 "The Sociology of Nonprofit Organizations and Sectors." Annual
Review of Sociology 16:137-159.

Douglas, James
1987 "Political Theories of Nonprofit Organization." In The Nonprofit
Yale University Press.
Eakin, Paul John

Feldman, Philip

Fischer, Michael M. J.
1989  "Autobiographical Voices (1,2,3) and Mosaic Memory: Experimental Sondages in the Postmodern." Unpublished manuscript in author's possession.

Fowler, Roger

Gayle, Jacob A.

Geertz, Clifford

Gilman, Sander L.
1988  Disease and Representation: Images of Illness from Madness to AIDS. Ithaca: Cornell University.

Godwin, Joseph P.
1989  More Man Than You'll Ever Be: Gay Folklore and Acculturation in Middle America. Bloomington: Indiana University.

Goffman, Erving

Good, Mary-Jo DelVecchio, Byron J. Good, Arthur Kleinman and Paul E. Brodwin


Green, Richard
Haraway, Donna J.
1991  
Simians, Cyborgs, and Women: The Reinvention of Nature.  
New York: Routledge.

Harding, Sandra
1987  
Feminism and Methodology: Social Science Issues.  
Bloomington, IN: Indiana University.

Hartsock, Nancy C. M.
1987  
"The Feminist Standpoint: Developing the Ground for a Specifically Feminist Historical Materialism." In Feminism and Methodology: Social Science Issues. Sandra Harding, ed.  

Hayes, Joseph J.
1981  
"Gayspeak." In Gayspeak: Gay Male and Lesbian Communication.  

Herdt, Gilbert
1984  
"Fetish and Fantasy in Sambia Initiation." In Ritualized Homosexuality in Melanesia. Gilbert Herdt, ed.  

Herzlich, Claudine and Janine Pierret
1987  
Illness and Self in Society.  
Baltimore: John Hopkins University.

Houston Dept. of Health and Human Services
1986  
Houston: Houston Dept. of Health and Human Services.

Klassen, Albert D., Colin J. Williams and Eugene E. Levitt
1989  
Sex and Morality in the U. S. Hubert J. O'Gorman, ed.  
Middletown, CT: Wesleyan University.

Kleinman, Arthur
1980  
Patients and Healers in the Context of Culture.  
Berkeley: University of California.

1988  
New York: Basic.

1992  

Lakoff, George
1987  
Women, Fire, and Dangerous Things: What Categories Reveal About the Mind.  
Chicago: University of Chicago.
Lakoff, George and Mark Johnson
1980  *Metaphors We Live By.* Chicago: University of Chicago.

Legislative Task Force on AIDS
1989  *AIDS in Texas: Facing the Crisis.* Report to the Seventy-First
Legislature (Texas). Austin: State of Texas

Macdonell, Diane

Mairs, Nancy

Martin, Emily
1990  “Toward an Anthropology of Immunology: The Body as Nation State.”

Martin, Wallace
1986  *Recent Theories of Narrative.* Ithaca: Cornell University.

Merrill, Joseph M., Lila Laux and John I. Thornby
1987  “Troublesome Aspects of the Patient-Physician Relationship: A Study
of Human Factors.”  *Southern Medical Journal* 80(10):1211-1215.

Money, John
1980  “Genetic and Chromosomal Aspects of Homosexual Etiology.” In
New York: Basic.

NAMES Project
1988  *National Tour 1988 [List of Names and Guide to Quilt].* San Francisco:
The NAMES Project.

1990  *AIDS Memorial Quilt: List of Names 1990-1991.* San Francisco: The
Names Project.

Nungesser, Lon G.

Olney, James
1972  *Metaphors of Self: the Meaning of Autobiography.* Princeton:
Princeton University.

1980  “Autobiography and the Cultural Moment: A Thematic, Historical, and
Bibliographical Introduction.” In *Autobiography: Essays Theoretical and

Ostrow, David G. and Jeff Stryker
1990  “Neuropsychiatric Aspects of HIV Disease.” In *AIDS and the Health
Care System.* Lawrence O. Gostin, ed. Pp. 32-44. New Haven: Yale
University.
Parsons, Talcott

Pearson, Carol Lynn

Peavey, Fran
1989 A Shallow Pool of Time: One Woman Grapples with the AIDS Epidemic.
San Francisco: Crabgrass Press.

Perrow, Charles and Mauro F. Guillén
New Haven: Yale University.

Personal Narratives Group
Bloomington: Indiana University.

Phillips, Marilynn J.


PWA Coalition

Register, Cheri

Richardson, Ann and Dietmar Bolle

Robinson, Ian

Rosenblatt, Roger

Ruse, Michael
Ruskin, Cindy, Matt Herron and Deborah Zemke

Russ, Joanna
1983 How to Suppress Women's Writing. Austin: University of Texas.

Saillant, Francine

Saunders, Judith M. and Stephen L. Buckingham
1988 "When the Depression Turns Deadly." Nursing 88 [July]:59-64.

Shands, Nancy

Shelp, Earl E., Ronald H. Sunderland and Peter W. A. Mansell

Shilts, Randy

Sieber, J.

Smith, Sidonie

Sontag, Susan

Spence, Donald P.

Stahl, Sandra Dolby
Starobinski, Jean

Traweek, Sharon

Turner, Victor

Tyler, Stephen A.

Watney, Simon

Weitz, Rose


West, Richard

Whitmore, George

1988b  Someone Was Here: Profiles in the AIDS Epidemic. New York: NAL.

Wolcott, Dean L.