MAKING SENSE OF THE EXPERIENCES OF PEOPLE LIVING WITH HIV/AIDS: AN APPLICATION OF GOFFMAN'S FRAME ANALYSIS

By

REGINA M. STEPHENS

Bachelor of Arts
Arkansas Tech University
Russellville, Arkansas
1994

Master of Science
University of Central Arkansas
Conway, Arkansas
1995

Submitted to the faculty of the
Graduate College of the
Oklahoma State University
in partial fulfillment of
the requirements for
the Degree of
DOCTOR OF PHILOSOPHY
December, 2000

MAKING SENSE OF THE EXPERIENCES OF PEOPLE LIVING WITH HIV/AIDS: AN APPLICATION OF GOFFMAN'S FRAME ANALYSIS

Thesis Approved:

Thesis Advisor

Dean of the Graduate College

ACKNOWLEDGMENTS

I wish to express appreciation to Chuck Edgley, my committee chair, for his supervision, guidance, and friendship. I would also like to extend recognition to my other committee members; J. David Knottnerus, Jean VanDelinder, and Thomas Shriver, whose encouragement, constructive guidance, and friendship have been invaluable throughout this process. I would also like to thank Doren Recker in the Department of Philosophy for his support as an outside committee member.

In addition, I would also like to thank the many people living with HIV/AIDS that volunteered to participate in this study. I would especially like to thank the members of the Long Term Survivors Group for giving me the opportunity to become a member of their group during my research process. I am greatly indebted to these individuals.

I would also like to extend a sincere appreciation to my mother, Rita Beam, for her long hours doing verbatim transcription. If it had not been for her long hours typing these extensive interviews, I would not have finished this project in such a timely manner.

I am very thankful and appreciative of the support of my family while I have pursued my academic career. My husband, Jim, has been especially supportive as I have moved him to many states and places he would rather not have been. My husband has been very encouraging and understanding throughout this process. I would also like to thank my friends and colleagues for listening to me and giving me advice about academic matters.

In conclusion, I would like to thank the Department of Sociology at Oklahoma State University. I have had a very positive experience at this university and with this sociology program. I feel as though I received a better education and more encouragement in this sociology program than any other that I could have attended. The faculty have provided me with a foundation to pursue an academic career. I especially appreciate the opportunity to teach at OSU. Thank you for allowing me the opportunity to spend three years in this department at OSU.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER ONE

THE RESEARCH ISSUE

This project has taken several transformations since its development. I began working on this project in 1997 as I increasingly became interested in people living with HIV/AIDS. In 1997 I was working with Joan G. Turner at the University of Alabama at Birmingham in the School of Nursing. She and I were working on a project entitled "HIV Symptoms, Engagement, Adherence, and Quality of Life." We had received a grant to conduct this study and I was the person responsible for collecting the data. I made contacts throughout Birmingham to different organizations that served people living with HIV/AIDS. These places were either medically oriented or support oriented. The data that we were collecting was part of a multinational sample of 1200 HIV infected persons and Birmingham had been chosen as one of the 12 international sites from which to collect the data.

The data was collected in survey form and the participants were given a ten dollar grocery voucher if they participated. My responsibility was to visit the sites where the data were to be collected (Cooper Green Hospital, the 1917 Clinic, and Birmingham AIDS Outreach) and recruit interested HIV infected persons to complete the very lengthy questionnaires.

There were several aspects to this project that I now take for granted. The first is that I had very easy access to this population. Working with Joan allowed me to play on her name which was helpful in gaining easy access to these facilities and their HIV infected clientele. The second aspect is the reflections that I would have, personally, when working with this population. I remember the first time that I walked in a room where there sat a support group of HIV infected persons. I had never thought about my reactions to this situation or these people prior to that. I left the Birmingham AIDS Outreach that night around 9:00 P.M. and one of my first thoughts, as I was driving the hour commute home, was that I had just spent the evening with a group of people that had HIV/AIDS and I did not feel any sense of distance from them whatsoever. What I felt was a sense of compassion and sadness for each of them.

I continued to harbor an interest in this topic and pursued it during a qualitative research methods course at Oklahoma State University. I knew that my focus would have to be more sociological than the project in Alabama. I decided to conduct an exploratory needs assessment of people living with HIV/AIDS in rural areas that focused on health care, medical therapies, and social support. There was not much literature on this topic and I thought it would be a good start to a future dissertation project.

I began making some contacts throughout the state to the HIV/AIDS organizations including the recently dissolved HIV/AIDS organization in Stillwater, the Community AIDS Network. A volunteer that was managing the organization at the time was very helpful in locating and contacting some of his clients for me. He would contact the people in the area that had HIV/AIDS and ask them if it would be OK if I were to contact them about my project. He located several local people that I later interviewed. I had no luck at all with the larger state organizations, which had rural outreach programs and could have been very helpful to me had I been able to "get in" with these organizations. I was perplexed by this 'access' dilemma, I had not before encountered such resistance. I was aware of the possibility that these organizations were busy and I was not a priority for them, but this resistance made me realize that maybe their clients were not a priority either since they were not given the opportunity or the choice to decide for themselves whether they would want to participate in my project or not. I utilized HIV/AIDS organizations in other states so that I could complete my project with an ample amount of interviews.

The resistance of the organizations in Oklahoma became a focal point in my project in that qualitative methods course. I was determined to get access to the HIV/AIDS population in Oklahoma regardless. I knew from experience that the majority of people that make up the HIV/AIDS population feel somewhat isolated by this disease. I also knew that many of them had experiences that they would love to share and have heard. What I did not understand was why organizations that were designed to help this population would make decisions for them regarding different avenues for which they may vent their experiences and even frustrations.

As I have pursued this topic my focus has changed tremendously as well as my ability to gain access to this population. During the evolution of the current project, I have taken several routes from which I have had an overall success at gaining access to the HIV/AIDS population in the State of Oklahoma. I placed an advertisement in the Gayly Oklahoman, a gay oriented newspaper published in Oklahoma City, that ran four times in two months (2 issues per month). I later sent flyers to state wide HIV/AIDS organizations and made contact with support groups and community food banks so that I could get to a diverse group of people. I visited a group called the Long Term Survivors Groups that met once monthly and I visited the HIV/AIDS food bank in Oklahoma City.

My theoretical framework has shifted from stigma, inequality, social support, and rural residence to the experiences of people living with HIV/AIDS framing them in the context of hegemony. I decided to make Erving Goffman's *Frame Analysis* (1974) the central theoretical focus of this project because it seemed relevant to understanding hegemony and its relationship to the experiences of people living with this disease. I was having a very difficult time confining this project to experiences with health care and social support because this disease encompasses so much more and impacts many other experiences that those living with HIV/AIDS encounter on a daily basis.

Because I was initially interested in the impact of rurality on the experiences of people living with HIV/AIDS and did not want to alter the focus of this project too drastically, I decided to concentrate on other sources of constraint placed upon the HIV/AIDS population. The source of constraint that I will focus on in this project is that of hegemony. Hegemony is the exertion of powerful and controlling ideologies that prevail in a society (Gramsci 1971). Hegemonic ideologies, especially those prevalent in medicine, impede people living with HIV/AIDS with regard to health care, treatment modalities, social support and stigma. I have framed hegemony to encompass these issues because they are relevant when discussing this disease.

The theoretical framework that I have utilized in this study to examine hegemony was Erving Goffman's (1974) *Frame Analysis*. This framework was used to conceptualize hegemony as well as to provide a context with which to analyze the diverse experiences of people living with HIV/AIDS.

The research issue has really become a very personal topic not only because I am interested in the social consequences of HIV/AIDS, but because the social consequences of this disease have produced very different experiences among those living with HIV/AIDS today. The evolution of my interest in the social consequences of HIV/AIDS and the people affected by it, are directly related to my focus in this project. Had it not been for my numerous encounters with HIV/AIDS affected persons in various states, trying to gain access to this population in the mid-south, and having been exposed to the professional structure of disease bureaucracy, my project would not have evolved into what it is today.

The research issue in this project is to understand the lives and experiences of people living with HIV/AIDS as they are framed in the ideology of hegemony. The experiences of those living with HIV/AIDS are framed within this context to provide a meaningful and insightful interpretation.

The following chapter discusses the demographics of AIDS in the United States and the social and medical construction of this disease. These are important components in understanding the production of medical knowledge as a dominant authority of information in contemporary American society. Because medical authority is held in high esteem in this culture, society has and continues to associate HIV/AIDS with deviant behavior. This is largely due to the professional manner in which epidemiological profiles of this disease have been disclosed. Providing an epidemiological and historical overview of HIV/AIDS creates the foundation from which to proceed with framing experiences of people living with this disease in the context of hegemony.

CHAPTER TWO

HIV/AIDS HISTORY

Introduction

In the United States HIV/AIDS has increasingly become a health and medical concern over the last twenty years. The epidemiology of HIV/AIDS suggests that this disease is a social, as well as an economic and medical problem (Centers for Disease Control 1998; Rushing 1995; Herdt and Lindenbaum 1992; Heyward and Curran 1988). HIV/AIDS, when discussed, must be understood from an historical perspective to fully comprehend its implications in a social, political, economic, and medical context. When looking at the historical progression of HIV/AIDS there are several components that must be mentioned in order to fully comprehend the evolution of this disease.

The first burgeoning component of this disease is the discovery and naming of HIV. The naming of HIV/AIDS has created the foundation from which people, including the infected, the affected (those that know or are close to someone with the disease), and the uninfected (the population not infected or affected by the disease) can frame their experiences and attitudes. To understand the experiences of those living with HIV/AIDS one must begin the analysis with the naming of this disease.

The process of naming HIV/AIDS allows one to logically frame the many experiences enveloped by this disease among those affected by it (Epstein 1995). The naming of the disease has been directly related to the groups/persons infected with HIV/AIDS, thus resulting in a stigma associated with HIV/AIDS infected persons. The relationship between the naming of this disease and the stigma associated with it would suggest that negative impressions of HIV/AIDS exists, due to the group(s) that are associated with it as well as the deviant nature of the disease transmission (Quam 1990; Plummer 1975; Sandstrom 1990). The primary source of disease transmission to date, both globally and nationally, is sexual (CDC 1999). Because of its connection with sexual acts, persons who contract it are considered deviant as well as ill (McCoy and Inciardi 1995; Foucault 1978; John 1995).

The next section discusses medical construction of HIV/AIDS. HIV/AIDS was medically constructed by health professionals as the disease was documented in the early 1980's. The medical construction of HIV/AIDS had a relational effect on the demographic profile of this disease in the United States (CDC 1981a; CDC 1982a; CDC 1982b; CDC 1982c).

Often the first analysis of a disease or illness is brought about by the medical community. Medical constructions of a disease or illness are important when attempting to understand a particular disease or illness and frame the experiences of those affected by it (Epstein 1995; Crystal and Jackson 1992; Rosenberg 1988; Sontag 1989).

When medical constructions create the hegemony of a disease or illness; there is always the potential to create damaging inferences about a disease or a population it strikes. This hegemonic interpretation occurs as the medical community constructs the epidemiological profile of an illness by looking at factors such as: 1) those affected by the illness, 2) the symptomologies the illness produces, and often, the 3) geographic location of reported disease cases (DeNoon 1999; Kearns 1996). Each of these components of disease construction have implications for how an illness and those affected by it are interpreted (Crystal and Jackson 1992).

The hegemony of HIV/AIDS has and continues to be controlled by the medical community (Schiller 1992; Haas and Coe 1998). The influence of medical hegemony on both the general population and those that are affected by HIV/AIDS create and maintain powerful and potentially damaging inferences about this disease and those living with it. Such damaging inferences were created when this disease was initially recognized as a 'gay disease' or a 'disease of outcasts' (Wang 1997).

In the next section I provide a discussion of AIDS demographics in the United States. I have provided only a discussion of AIDS because HIV is not consistently reported across the United States. Not all states report HIV incidence to the Centers for Disease Control. A profile of AIDS incidence for the United States is provided to show the significant changes that have taken place both in terms of the groups that are effected and to what degree. Appendix G shows both HIV and AIDS incidence for the State of Oklahoma.

AIDS in the United States

This section will focus on the demographics of AIDS in the United States. There continues to be an increase of people living with AIDS (PLWA's) because of significant pharmacological advances (CDC 1997). The CDC reports that AIDS incidence showed a decrease for the first time in 1996 and the decline continued into 1997 (CDC 1999).

The presented data represents adult AIDS cases in the United States. Adult AIDS cases are the only data that is reported consistently by the CDC. HIV cases are not used in this section because not all states are required to report cases of HIV. It would be very difficult, confusing, and possibly inaccurate to report and compare adult cases of HIV and AIDS since not all states are required to provide this information to the CDC. Therefore, only AIDS data will be reported in this section. Also, not all states are required to provide estimates on pediatric cases of AIDS (that is, children less than 13 years old). All states, however, report estimated adult cases of AIDS. In order to maintain consistency throughout this section, only estimated reports of adults AIDS cases will be mentioned (except where indicated).

The focus of this section is not to provide a comprehensive demographic profile of this disease in the United States, but to give an overview of the groups that are most affected by it. Only reporting AIDS incidence (as opposed to both HIV and AIDS) is unlikely to hinder comprehending a basic understanding of this disease, the groups that have been affected by it, or the influence on the medical construction of this disease.

AIDS Demographics

AIDS in the United States has affected many groups. HIV/AIDS has affected all age groups, racial/ethnic groups, and both males and females. This section indicates which groups have been most affected by AIDS.

Table I shows the incidence of AIDS on sex and race/ethnicity in the United States as of September 1998. This table indicates that males represent 84% of persons infected with AIDS while females represent only 14% of AIDS cases. Therefore, males continue to be the category most affected by AIDS. Table I also shows that white, non-Hispanic PLWA's make up 45% of all AIDS cases, black, non-Hispanics PLWA's make up 36% of all AIDS cases, and Hispanics PLWA's make up 18% of all AIDS cases.

Table I. Cumulative AIDS cases for all ages by sex and race/ethnic category

Race/Ethnic Category	**Males**	**% of male cases**	**Females**	**% of female cases**	**% of race/ethnicity**
White, non-Hispanic	272,345	49%	24,089	22%	45%
Black, non-Hispanic	179,929	32%	60,998	56%	36%
Hispanic	98,578	18%	21,906	20%	18%
Asian/Pacific Islander	4,225	1%	561	>1%	>1%
American Indian/Alaskan Native	1,541	>1%	307	>1%	>1%
Total	**557,324**		**108,031**		
% of Total (665,355)	**84%**	**100%**	**16%**	**100%**	**100%**

Source: Centers for Disease Control, *HIV/AIDS Surveillance Reports*, 1998.

Table II represents the cumulative reported number of AIDS cases by sex, race/ethnicity, and exposure category. It is interesting to note that the only exposure category where females out number males is in the heterosexual contact category.

In table II the group most affected by AIDS is the group of men who have sex with men exposure category. In the heterosexual exposure category females have the most reported AIDS cases and are therefore the group that represents the majority in this exposure category.

The total cumulative cases of AIDS heterosexual contact among females is 40,706. Black, non-Hispanic females make up 52.5% of the total AIDS cases contracted through heterosexual contact. Whereas, white, non-Hispanic females make up 23% and Hispanic females make up 24% of the total adult AIDS cases reported for heterosexual contact.

The reported number of AIDS cases for females in the heterosexual exposure almost doubles that of males in this exposure category.

Also in table II the estimated number of AIDS cases for the IV drug use exposure category clearly indicates that there is a significantly larger number of infected males in his exposure category than females. Females make up only 27% of all the AIDS cases in this exposure category.

Table II. Cumulative AIDS cases by sex, race/ethnicity and exposure category.

HETEROSEXUAL CONTACT	**MALES**	**% of SUBTOTAL**	**FEMALES**	**% of SUBTOTAL**
White, non-Hispanic	4,387	20%	9,250	23%
Black, non-Hispanic	12,309	56%	21,372	53%
Hispanic	4,972	23%	9,723	24%
Asian/Pacific Islander	126	>1%	253	>1%
American Indian/Alaskan Native	39	>1%	108	>1%
Subtotal	**21,833**		**40,706**	
IV DRUG USE		**% of SUBTOTAL**		**% of SUBTOTAL**
White, non-Hispanic	24,609	20%	9,993	22%
Black, non-Hispanic	62,372	51%	26,096	58%
Hispanic	35,362	29%	8,710	19%
Asian/Pacific Islander	220	>1%	93	>1%
American Indian/Alaskan Native	234	>1%	134	>1%
Subtotal	122,797		45,026	
MEN WHO HAVE SEX WITH MEN		**% of SUBTOTAL**		
White, non-Hispanic	204,339	64%		
Black, non-Hispanic	67,346	21%		
Hispanic	41,862	13%		
Asian/Pacific Islander	3,114	1%		
American Indian/Alaskan Native	884	>1%		
Subtotal	317,545			

Source: Centers for Disease Control, *HIV/AIDS Surveillance Reports*, 1998.

There is also a higher incidence of AIDS cases for black, non-Hispanic males in this exposure category than for Hispanic males, and white, non-Hispanic males. White, non-Hispanic males represent the lowest numbers of AIDS cases in this exposure category (IV drug use) than black, non-Hispanic males, and Hispanic males. The same goes for the females, black, non-Hispanic females represent more cases of AIDS in this exposure category than white, non-Hispanic females, or Hispanic females.

Black, non-Hispanics make up 53% of all AIDS cases in this exposure category. Black, non-Hispanic females make up 58% of the total number of AIDS cases among females in this exposure category. So, black, non-Hispanics make up the majority of AIDS cases (53%) in both the IV drug use and heterosexual exposure categories.

The last exposure category in table II represents men who have sex with men. The CDC labels this category 'men who have sex with men' as opposed to homosexuals. The significance of this label may indicate that there are some men who do not identify with a homosexual lifestyle, but do engage in sexual relations with other men. The table indicates that the percentage of males who represent estimated AIDS cases in this exposure category is dominated by white, non-Hispanic males. White, non-Hispanic males represent 65% of the estimated cases of AIDS in this exposure category. While black, non-Hispanic and Hispanic males represent only 21% and 13%, respectively, of the cumulative AIDS cases in this exposure category.

Table III represents AIDS incidence (people diagnosed with AIDS) by race/ethnicity and year. It is interesting to note that there was a decrease in AIDS incidence from 1996 to 1997. The CDC reports that the decrease in AIDS incidence may be attributed to the introduction of drug combination therapies ("the cocktail").

Table III. AIDS incidence by year and race/ethnicity.

RACE/ETHNICITY	1996	1997	% DECREASE
White, non-Hispanic	**21,157**	**16,164**	**14%**
Black, non-Hispanic	**26,754**	**24,478**	**5%**
Hispanic	**12,004**	**10,590**	**6%**
Asian/Pacific Islander	**535**	**381**	**16%**
American Indian/Alaskan Native	**194**	**165**	**8%**

Source: Centers for Disease Control, *HIV/AIDS Surveillance Reports*, 1998.

The drug combination therapies that are combined are protease inhibitors and reverse transcriptase inhibitors. These are used to interact with the bodies RNA and DNA to reduce the level of HIV infection in the body. If a persons HIV infection does not reach levels that produce an AIDS diagnosis they will continue to have HIV and not advance to the next disease level, which would be AIDS (Frumkin and Leonard 1997).

The CDC indicates that the drop in AIDS incidence in 1997 may have been affected by the introduction of the combination therapies in early 1996. By looking at table III, it is interesting to note that black, non-Hispanics had a higher rate of AIDS incidence than did white, non-Hispanics in 1996 and 1997. This is interesting since the majority of PLWA's in the United States are white, non-Hispanics. This may imply that public health efforts to educate certain populations are working, and the incidence among those populations are decreasing due to public health efforts or because these groups have been targeted by the health care community to get tested for the disease as soon as they think they may have been exposed. Each of which would result in a decrease in reported AIDS incidence among certain race/ethnic groups.

It has been suggested that the black, non-Hispanic population who are at increased risk for contracting HIV/AIDS are just now being targeted to seek health care (Eriksen 1999; Thomas and Quinn 1994). The reported AIDS incidence may be revealing this information with regard to certain race/ethnic groups. Because reported AIDS incidence has much to do with one receiving adequate health care and medical therapies when given an HIV diagnosis, there will be some groups that do not have access or receive health care which could be revealed in the reporting of AIDS incidence among certain populations.

If black, non-Hispanics were receiving adequate health care and had access to available medical therapies, when initially diagnosed with HIV, their AIDS incidence would probably look more similar to that of white, non-Hispanics, as opposed to only a 5% decrease in AIDS incidence from 1996 to 1997.

Table IV represents the estimated number of deaths of male and female PWA's by exposure category and year of death, and race/ethnicity and year of death. Table IV shows that the mortality rate among PWA's is highest in the men who have sex with men category. This figure presents a logical portrayal of AIDS mortality within this exposure category given the estimated percentage of males (65%) that claim to have acquired AIDS in this manner.

Table IV. Estimated AIDS deaths by exposure category, sex, race/ethnicity, and year of death.

MALES	1992	1993	1994	1995	1996	1997	TOTAL
Men who have sex with men	22,785	23,666	24,936	24,483	16,695	8,527	121,092
IV drug use	8,077	9,188	10,221	10,661	8,457	5,388	51,992
Heterosexual contact	1,181	1,540	1,933	2,297	2,050	1,425	10,426
FEMALES							
IV drug use	2,720	3,098	3,652	3,764	3,252	2,185	18,671
Heterosexual contact	1,970	2,597	3,423	3,909	3,421	2,347	17,667
RACE/ETHNICITY							
White, non-Hispanic	20,369	21,422	22,195	21,611	14,359	7,098	107,054
Black, non-Hispanic	13,333	15,296	17,704	18,822	15,863	10,401	91,419
Hispanic	7,098	7,668	8,740	8,969	6,887	4,174	134,955
Asian/Pacific Islander	270	306	401	355	280	152	136,719
American Indian/Alaskan Native	76	133	147	186	116	70	728

Source: Centers for Disease Control, *HIV/AIDS Surveillance Reports*, 1998.

Table IV represents the estimated number of deaths for males by exposure category. The exposure category, men who have sex with men, represents 66% of the total mortalities between 1992 and 1997. The mortality pattern of this exposure category indicates that over time (from 1992 to 1995) the mortality rate among this exposure category was high or at least significantly higher than the other exposure categories. In 1996 and 1997 the estimated number of deaths decreased substantially. Again, this could be the result of the introduction of the drug combination therapies. Among males, the exposure category with the highest decrease in number of deaths was the category, men who have sex with men.

As Table IV indicates, each of the exposure categories, among females with AIDS, do not show a significant decrease in the number of deaths. Again, the decrease in AIDS deaths, in both exposure categories, from 1995 to 1996 and 1996 to 1997 may be a result of the availability of drug combination therapies.

Table IV also represents the estimated number of deaths among PWA's according to race/ethnicity. The percent decrease in deaths was figured for years 1995 to 1996 and 1996 to 1997. The data presented in table 5 reveals interesting results in terms of race/ethnicity and poor health care. For example, AIDS mortality decreased across all categories of race/ethnicity. However, years 1996 and 1997 reveal a substantial decrease in AIDS mortality for white, non-Hispanics. From 1995 to 1996 the estimated number of deaths among white, non-Hispanics decreased by 51%. From 1996 to 1997 AIDS mortality decreased 101% among white, non-Hispanics. For black, non-Hispanics, AIDS mortality did not show a decrease quite as substantial to that of white, non-Hispanics.

Table V. Decreases in estimated deaths of PWA's by race/ethnicity and year of death.

RACE/ETHNICITY	**1995**	**1996**	**% decrease 1995-96**	**1997**	**% decrease 1996-97**
White, non-Hispanic	21,611	14,359	**51%**	7,098	**101%**
Black, non-Hispanic	18,822	15,863	**17%**	10,401	**53%**
Hispanic	8,969	6,887	**30%**	4,174	**65%**
Asian/Pacific Islander	355	280		152	
American Indian/Alaskan Native	186	116		70	
TOTAL	49,985	37,525	**33%**	21,909	**71%**

Source: Centers for Disease Control, *HIV/AIDS Surveillance Reports*, 1998.

From table V it is apparent that AIDS mortality only decreased by 17% among black non-Hispanic PWA's from 1995 to 1996. From 1996 to 1997 the decrease in AIDS mortality was better with a decrease of 53%. However, the decreases in AIDS mortality when comparing white, non-Hispanics to black non-Hispanics is astonishing. These numbers, if only estimations of AIDS mortality, clearly speak racial/ethnic segregation. There were obviously more white, non-Hispanics dying of AIDS prior to 1996 than black, non-Hispanics. However, the year, 1996, clearly shows a decrease among AIDS mortality among white, non-Hispanics. Again, it is interesting that 1996 was the year combination drug therapies were introduced. Such therapies are very expensive to consume. The data presented in table V may indicate that black, non-Hispanics and Hispanics with AIDS are not receiving the same level of health care that white, non-Hispanics with AIDS may be receiving. These data suggest an interesting interpretation for understanding health care and medical therapy access within this population.

The states that are the most highly populated with PLWA's are along the coastline. One will notice, however, that the southern region of the United States is the most highly populated area for PLWA's. This is also indicated in table VI, which represents the estimated number of PLWA's by region of residence.The southern region of the United

States, as indicated in table VI, has the highest proportion of PLWA's and has continued to have the highest proportion since 1992. Table VI represents the actual estimated numbers of PLWA's by region of residence and year.

The states that are included in each of the regions, as specified by the CDC, are as follows. The **Northeast includes**: Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Vermont; in the **Midwest**: Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, and Wisconsin; in the **South**: Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia; in the **West**: Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, Wyoming, Guam, Puerto Rico, the U.S. Pacific Islands, and the U.S. Virgin Islands (CDC 1998).

Table VI. Estimated number of PLWA's by region of residence and year.

REGION	**1992**	**1993**	**1994**	**1995**	**1996**	**1997**
Northeast	39,586	51,660	59,254	66,053	73,575	82,482
Midwest	15,132	18,391	20,316	21,714	23,404	25,965
South	47,161	59,533	69,121	76,738	86,753	99,312
West	33,382	39,234	42,771	45,855	49,866	55,373

Source: Centers for Disease Control, *HIV/AIDS Surveillance Reports*, 1998.

The number of deaths of PWA's by region of residence and year of death show similar results as Table VI. The southern region of the United States has the highest estimated rate of AIDS mortality than any other region in the United States. Although, AIDS mortality decreased substantially in all regions from 1995 to 1997, the southern region continued to have the highest AIDS mortality rate. It is logical, however, that the region with the highest number of estimated PLWA's would have the highest AIDS mortality rate. AIDS mortality was similar for the northeast and the south from 1992 through 1994 and for the western region AIDS deaths remained roughly the same from 1992 through 1995. However, beginning in 1996 and continuing into 1997, there is a significant change in AIDS deaths in the northeast and western regions of the United States. A dramatic decrease in AIDS deaths occurred in these two regions, although in the southern region the decrease in AIDS deaths was not as dramatic.

AIDS demographic data for the United States has been presented. The data should reveal that there are many groups of people affected by AIDS. The data should also reveal that there are some groups, when diagnosed with HIV/AIDS, that receive better health care, have better access to advanced medical therapies, and may live longer as a result of these interventions. The presentation of demographic AIDS data is important in this paper because it contributes to the understanding of this disease. It is also important to compare regions of the United States with regard to AIDS mortality because the focus of this paper rests on the experiences of persons living with HIV/AIDS in the mid-south region of the United States. For one to fully comprehend this disease and the experiences of those living with it, this information must be presented.

A demographic profile has been presented on AIDS in the United States. The purpose of the demographic profile was to provide the necessary information to make assumptions about the social construction of this disease. The groups affected by HIV/AIDS have changed since the initial onset of this disease. Men who have sex with men are no longer the only group affected. However they continue to be the group with the largest number of reported AIDS cases.

Creating an epidemiological profile on a disease such as HIV/AIDS has the potential to establish negative responses among the public. Once the public situates a disease like HIV/AIDS with specific groups it becomes difficult to alter those initial apprehensions. The medical and social construction of a disease like HIV/AIDS becomes an important entity in the experiences of people living with it. In the next section of this chapter I will discuss the importance of the social construction of HIV/AIDS.

The Medical Construction of HIV/AIDS in a Historical Context

~~The medical construction of HIV/AIDS began with the~~ recognition of this disease in the early 1980's. Although, the first reported cases of HIV/AIDS did not occur until that time there is medical literature which suggests that there were symptoms of HIV infection as early as the 1960's (Huminer, Rosenfeld, and Pitlick 1987). Medical researchers have examined frozen tissue and serum samples taken from a 15 year old black male who was hospitalized in St. Louis in 1968 and later died of, what was eventually identified as, Kaposi's Sarcoma. The frozen serum sample showed up as having HIV antibodies (Garry, Witte, and Gottlieb 1988).

When HIV was first recognized, it was interpreted as a gay plague because of its association with gay males. The name *gay-related immunodeficiency syndrome* (GRID) was adopted because of the association of this new plague with gay males. The first public report of the disease appeared in the June 1981 issue of the *Morbidity and Mortality*

Weekly Report, which revealed that five gay men in Los Angeles had a rare form of pneumonia (Pneumocystis Carinii Pneumonia - PCP) (CDC 1981a). This lead to other rare and fatal illnesses being reported in gay men. Another observation a few weeks later was reported in New York and San Francisco that 26 homosexual males had been diagnosed with Kaposi's Sarcoma of which, four were also reported as having PCP (CDC 1981b). Similar illnesses were also being reported among IV drug users. This name was later replaced because it was reported that other people were having similar symptomologies that did not identify with a gay lifestyle (CDC 1982a; CDC 1982b; CDC 1982c).

In late 1981, there were more than 100 cases of AIDS reported to the CDC. By 1989, more than 100,000 had been reported and by 1991 more than 200,000 cumulative cases of AIDS had been reported to the CDC. As of June 30, 1998 there were an estimated 89,170 adults reported to be living with HIV and an estimated 258,135 adults reported to be living with AIDS in the United States (CDC 1999). In September 1982, the Centers for Disease Control (CDC) published a definition of what is now referred to as AIDS -*Acquired Immune Deficiency Syndrome* (CDC 1982d).

The HIV hypothesis derived from Robert Gallo, that HIV is the cause of AIDS, is the most dominant theory of this disease today (Gallo, Salahuddin, and Popovic 1984). There have been scientists that have formulated other hypotheses of HIV/AIDS (Duesberg 1995). However, they have been largely discredited and rejected by Gallo and his colleagues (Treichler 1992).

The medical construction of HIV/AIDS has continued to change since its inception in the early 1980's. In 1983 Robert Gallo, during a press conference, announced the discovery of the AIDS virus. The AIDS virus was given the name - *human T-cell leukemia virus, type III (HTLV-III).* At the same time Gallo had discovered this virus, Francois-Barre Sinousi at the Luc Montaignier laboratory at the Pasteur institute in France also had given this virus a name *LAV - lymphadenopathy associated virus* (Barre-Sinoussi, Chermann, and Rey 1983). Gallo, who developed the theory that HIV is the cause of AIDS, has been known to change the wording of a manuscripts under review to conform with his own hypothesis or to discredit other hypotheses all together if they did not fit his own theory (Nichols 1986; Treichler 1992; Duesberg 1995).

The contradictory medical construction of HIV by Francois-Barre Sinousi and the French (Pasteur Institute) and Robert Gallo's along with the NIH (National Institute of Health) endorsement, forced the scientific and medical communities to settle on a name for this virus. The virus was given the name, *HIV - Human Immunodeficiency Virus,* in 1987 because of the dispute between the NIH and the Pasteur Institute (Nichols 1992; Treichler 1992; Juengst 1989).

Naming helps establish an existence for the public as both socially significant and conceptually real. The discourse of this virus can be constructed by the name in which it was given or by the scientific understanding and interpretation of it (Taylor 1990; Becker 1973).

In their attempts to find a cure the medical and scientific communities have altered the face of HIV/AIDS, so that, it is seen as a controllable chronic disease and not a life threatening plague. There have been extensive public announcements made and much literature distributed about the causes and consequences of this disease. Today, HIV/AIDS is medically constructed as a controllable chronic disease to which new medications are sustaining the lives of people living with this disease (Parmet and Jackson 1997; Stephens 1998; Treichler 1992).

Because HIV/AIDS was initially named and identified as a disease that was affecting the homosexual population (GRID) the public responded negatively. There was fear, stigma, abandonment, lack of adequate health care and social support when this disease was discovered (John 1995).

It has been almost twenty years since the onset, detection, and initial naming of this disease, but there are many people still having negative experiences because they are either infected or affected by HIV/AIDS. Because it has been nearly twenty years since the discovery of HIV/AIDS, it is logical to think that knowledge about this disease has increased and attitudes toward those affected by it have improved. However, there are still many people today experiencing things that those affected early by this disease would have experienced. People affected by HIV/AIDS today are still experiencing stigma, both in the professional community and in the general public (Bunting 1996; Bor and Elford 1998; Crandall, Glor, and Britt 1997). And many people infected with HIV/AIDS are feared by others because of contagion concerns (Wang 1997).

The medical construction of HIV/AIDS has impacted how people affected by this disease experience it. This disease would be a very different disease today had it been initially associated with non-deviant groups, namely heterosexuals. Consequently, the level of stigma and negative connotations attached to being infected with HIV/AIDS, would not be as vast (John 1995).

Understanding the medical construction of HIV/AIDS is important when looking at the experiences of people living with this disease. The influence of professional communities in this culture, specifically medicine, has the capacity to create realities that foster impartiality already present in society (Schiller 1992; Epstein 1995; Berger and Luckman 1966). One group that is considered deviant by societal standards is homosexuals (Herrell 1996; Reinig 1990; Kayal 1993). As Hills (1980) points out:

> "Homosexuality is one of the most vile blasphemies against God...... It is not society that is sick, it is those whose life-styles debase the sacred purpose of the sex act. Homosexuality is not part of the 'total human experience' which a healthy, well-balanced human being can ever accept. The practice of homosexuality is an abomination of the natural order.....It is not love; it is undisciplined lust, drawing man down to the level of animals" (p.9)

The inception of HIV/AIDS was initially associated with one of the most deviant groups in society. When the medical and scientific communities named the disease *Gay Related Immunodeficiency Syndrome* (GRID), it set the precedence for negative actions toward people affected by HIV/AIDS. The authority granted to the medical and scientific communities by society cultivate dominance. This results in extraordinarily powerful groups that tend to control and dominate medical knowledge that gets disseminated throughout society. Information generated by compelling groups that have large credulous audiences manifest immense power and exert hegemonic capabilities (Schiller 1992; Brown 1990).

The implications of professional hegemony are embedded in the epidemiological information that contributes to the construction of HIV/AIDS knowledge. There is a connection between what people living with HIV/AIDS are experiencing today and the social construction of this disease (Schiller 1992).

The focus of this thesis rests in understanding the experiences of people living with HIV/AIDS according to the idea of hegemony. In the next chapter I will explore hegemony both conceptually and theoretically. I will discuss the theoretical framework, Frame analysis, as well as the existing literature on this topic.

CHAPTER THREE

THEORETICAL FRAMEWORK

Introduction

In this chapter I will discuss the theoretical foundation of Goffman's *Frame Analysis* (1974) as a framework for understanding the experiences of people living with HIV/AIDS. The aspects of this disease that will be covered in this chapter as they relate specifically to the organization of experience include professional hegemony and cultural hegemony, health care and medical therapies, social support, and stigma.

Frame Analysis has been used in many areas of sociological study. It has been used in the media to examine the framing of violent and nonviolent television programs (Hubbard 1994; Davis and Abelman 1983). It has also been used to look at various interaction contexts including sexuality and framing sex talk (Adelman 1991). The use of frame analysis has also been used to look at interaction during gynecological exams (Cullum-Swan 1992); and framing the idea of virginity 'as a gift' (Carpenter 1998). Frame analysis has also been used to examine the relationship between virtual and real reality (Chayko 1993) and as a framework for understanding identity (Krinsky 1997; Saleebey and Hunter 1980). In addition, Frame Analysis has been used in framing social movements and (Snow, Rochford, Worden, and Benford 1986; Carroll and Ratner 1996; McInerney 2000; Pellow 1999; Ashley and Olsen 1998; Shemtov 1999).

Frame analysis, as it applies to this project, has been used in connection with stigma (Willems 1998; Levy 1993) but not as it relates specifically to HIV/AIDS and hegemony. The other concepts that will be utilized in this study, health care and medical therapies, and social support have not been used with frame analysis, although some have been used in conjunction with hegemony (Waitzkin 1989; Eaton and Webb 1979; Elling 1981; Frankenberg 1988; Kearns 1996; Barnhart 1994) .

I begin the presentation of the theoretical framework with an introduction to Frame Analysis. I then discuss the concept's primary, social, and natural frameworks. Lastly, I discuss the topics that will be included in the presentation of hegemony; professional hegemony which includes physicians, pharmacists, and HIV/AIDS organizations and cultural hegemony which includes rural ideologies. These will be discussed within the context of health care, medical therapies, social support, and stigma.

Discussion of Frame Analysis

Erving Goffman took the idea of 'frame' from Gregory Bateson's "Steps to an Ecology of the Mind" (1972). Bateson indicated that, in order for people to interact and communicate appropriately in a given situation, they must be able to 'frame' the experiences in order to make meaning out of them. Bateson (1972) said that:

> "Every meta-communicative....message defines, either explicitly or implicitly, the set of messages about which it communicates, i.e. every meta-communicative message is or defines a psychological frame" (pg. 161).

The messages that one receives from a communication, therefore, suggests a certain frame from which one might comprehend the situation. Given the frame one chooses, the interpretation of an action is determined by that specific frame. The experiences one has encountered will either limit or increase the number of frames one has to evaluate situations. So that, "the frame is involved in the evaluation of the messages which it contains" (Bateson 1972:160). The more exposure one has to social situations and cultural interpretations, the more one is able to effectively frame their experiences.

In Goffman's (1959) *The Presentation of Self in Everyday Life* the 'stage', is a frame. The stage must be understood as a 'frame' in order to comprehend what is happening on the stage and to place it within a non-reality context. To understand a phenomena, one must 'frame' the experience of the phenomena. The more experience one gains with regard to social phenomenon, the better one can 'frame' or understand his or her experiences.

Meaning gets constructed when experiences are framed within a given context. HIV/AIDS has been constructed within the context of deviance (Frank 1979; Goffman 1974; Snow et al. 1986; Kayal 1993). Because HIV/AIDS is transmitted through the exchange of bodily fluids primarily during sexual contact and when IV drug users are sharing used needles, people have framed this disease with groups that engage in these deviant activities. However, homosexual males, not only because they are the group initially associated with this disease, but because homosexuality (or men who have sex with men) is framed as a very deviant activity in our culture, are what constitutes the negative framing of this disease (Altman 1986). Consequently, people that are affected by this disease are treated differently by professional communities as well as the public (Lee 1990; Johnson 1995).

Goffman (1974) uses Bateson's (1972) work as a foundation for his interpretation and elaboration of the term 'frame.' Goffman develops a theoretical framework grounded in reality construction based on the elemental ideas of Gregory Bateson. In *Frame*

Analysis, Goffman continues to use the term 'frame' in the same context as Bateson. Goffman (1974) states that:

> "I assume that definitions of a situation are built up in accordance with principles of organization which govern events, at least social ones, and our subjective involvement in them; frame is the word I use to refer to such of these basic elements as I am able to identify......my phrase 'frame analysis' is a slogan to refer to the examination in these terms of the organization of experience" (pg. 10-11).

Persons affected by HIV/AIDS are forced to experience their disease based on the convictions and negative associations that others have attached to this disease. Because this disease has been framed within the context of deviance, the prevailing ideologies confine people to negative and often degrading experiences (Johnson 1995; Kayal 1993). The structure of ideologies outlined by the medical and scientific communities are enforced by the professional public which, in turn, perpetuates negative experiences that people affected by HIV/AIDS often encounter (Epstein 1995).

In *Frame Analysis,* Goffman is dealing with the structure of experience that individuals have at any moment in their lives ('frame in use') as opposed to the structure of ideologies ('frame as structure') that are present within society. He isn't necessarily trying to bridge the gap between agency and structure, however this theoretical construct is present (Manning 1992; Giddens 1984). What Goffman offers in Frame Analysis, however, is more closely linked to the work of Husserl, Schutz, and William James. Goffman provides the foundation from which to understand institutions as well as social interaction (Burns 1982). However, his main concern is still on the organization and interpretation of experience. Goffman indicates this by stating:

> "I make no claim to be talking about the core matters of sociology, social organization and social structure, ...I am not addressing the structure of social life but the structure of experience individuals have at any moment of their social lives. I personally hold society to be first in every way and any individuals current involvements to be second" (1974:13).

Professional communities create the structure of ideologies that are present within our culture. People that are affected by HIV/AIDS are exposed to the structure of ideologies created by the medical and scientific communities that are maintained by society and must, therefore experience and interpret their disease consistent with these prevailing ideologies (Gramsci 1971). Waitzkin (1989) reiterates this by stating "structures of society help generate the specific social context in which patients and doctors find themselves" (p 221).

The structure of ideologies in our society is a very important component when framing and understanding experiences. In order to understand social experiences, one must understand the structure of ideologies that are present within society. The ideologies within a society create a frame from which people interpret experiences. The frame that is employed to interpret experiences is called the primary framework. The primary framework that is explored in this thesis is hegemony. In the following section, I discuss the concept of primary framework as well as natural and social frameworks. In addition, I provide a discussion applying natural and social frameworks within the context of the primary framework, hegemony.

Primary Frameworks

Primary frameworks provide a foundation from which to explore social phenomenon and the experiences that occur within that particular phenomenon. They are said to be really, actually, or literally occurring if actions are framed entirely within them (Goffman 1974). If experiences are framed entirely within the context of the primary framework, a claim may be made so as to frame 'real' events. 'The sense of reality' is accounted for in the primary framework (Crook and Taylor 1980). This means that the subjective interpretation of an experience must be framed within some context in order for a sense of reality to emerge (Goffman 1974).

A Primary Framework, according to Goffman (1974):

> "is one that is seen as rendering what would otherwise be a meaningless aspect of the scene into something that is meaningful...it allows its user to locate, perceive, identify, and label a seemingly infinite number of concrete occurrences defined in its terms" (pg. 21).

Framing events or experiences within the primary framework allows for a division of realms in which the world is experienced. Experiences are sorted according to the frames in which those experiences fit and make sense. In order for meaning to emerge from experiences one must create a frame and understand what is really going on (Goffman 1974; Burns 1992). A person would then be able to react according to the 'real events' that they have observed and framed. Thus the interpretation of 'real events' allows one to adopt a 'sense of reality' or a frame with which to create meaning and to organize experiences (Crook and Taylor 1980; Johnson and Weigert 1980).

There are two types of frameworks that augment the primary framework. The kind of primary framework that is used depends upon the context within which the framework is utilized. The two types of primary frameworks are natural and social and are employed according to the phenomenon being investigated. The primary framework in this study is hegemony and will be explored in a social context, however I will discuss both types of primary frameworks.

Types of Primary Frameworks (Natural and Social)

The primary frameworks, natural and social, offer different approaches to exploring social experiences and how one might frame those experiences. The Primary framework offers a way to make sense of what might be considered meaningless events if it weren't for its application. In other words, establishing a primary framework from which to organize social experiences allows us to take, what might otherwise be meaningless experiences, and turn them into something meaningful. Natural and Social Frameworks are a part of the Primary Framework in that they allow us to further comprehend the social phenomenon.

There are two types of Primary Frameworks that Goffman discusses. They are "natural" frameworks and "social" frameworks. A natural framework is considered to be "purely physical" and due to "natural determinants" (Goffman 1974:22). Natural Frameworks are seen as "undirected, unoriented, unanimated, and unguided" they are from start to finish, based on "natural determinants" (Goffman 1974:22). Natural frameworks are used when something that is naturally occurring lacks a frame. The weather, for example, is a natural phenomenon and would be framed within a natural framework. A hurricane on the coast of Florida would be a natural phenomenon and it had better be framed and understood within a 'real' natural framework. However, the experience of reconstruction and first-aid aftermath of the hurricane, when individuals work together and help one another, would be understood from a social framework (Johnson and Weigert 1980; Manning 1992; Burns 1992).

Social frameworks, on the other hand, provide interpretations for "understanding events that incorporate the will, aim, and controlling effort of an intelligence, a live agency, the chief one being the human being" (Goffman 1974:22). Social Frameworks provide a guide for standards of "honesty, efficiency, economy, safety, elegance, tactfulness, good taste, and so forth" (Goffman 1974:22). Social frameworks allow us to construct meaning, of others' motives and intentions, according to some background understanding. They are the mental contexts in which happenings are interpreted (Burns 1992).

~~Social frameworks allow us to interpret events in which humans are chiefly~~ responsible. Understanding human motives requires a specific social framework from which to apply honesty, elegance, tactfulness, and so forth. People that have suffered losses from a hurricane might interpret the reconstruction and help from others in a caring, compassionate framework. If others are helping to restore what was destroyed as opposed to either raiding homes or causing further structural damage. Framing events as either raiding and stealing or helping put the pieces of a home back together, are social frameworks.

The primary frameworks have been integrated to form, what Goffman calls a 'framework of frameworks' because the combination of the natural and social frameworks provide a foundation from which to organize perceptions and experiences. If persons had not experienced a hurricane, having others help in house construction may be anomalous. However, the natural framework, in this case, the hurricane, lays the foundation from which social frameworks, the helping and or stealing of others in these circumstances, may be interpreted.

In the next section I provide a discussion of applying natural and social frameworks to understanding and interpreting HIV/AIDS. Both frameworks are important when attempting to understand this disease.

Application of Natural and Social Frameworks to HIV/AIDS

The concepts 'Natural' and 'Social' Framework are important in understanding the primary framework, hegemony, and HIV/AIDS (specifically with regard to health care, medical therapies, social support, and stigma). They are all intrinsically related and embedded within each another. Natural frameworks are important in relation to HIV/AIDS because this disease is a biological phenomenon. The etiology of this disease suggests that it invades the body, takes over the immune system, and in many cases results in death in a relatively short period of time (Frumkin and Leonard 1997). However, the primary means by which this disease is transmitted might be considered social given the sexual nature of HIV/AIDS. People do not just 'get' or 'pass on' HIV/AIDS without having first engaged in activities where bodily fluids are transmitted (Kayal 1993). Therefore, HIV/AIDS although a biological phenomenon, is often overshadowed by social frameworks imposed upon this disease. Namely, the association of this disease with deviant activities (John 1995).

Natural frameworks may be more useful when interpreting the biological or etiological consequences of HIV/AIDS. However, a social framework is most appropriate when looking at the ways in which this disease has been framed from the medical and scientific communities and the resulting consequences from which people affected by this disease must interpret and understand their everyday experiences with HIV/AIDS (Epstein 1995). Because HIV/AIDS has both natural and social consequences, and while both are significant especially to the person living with this disease, I am most concerned about understanding the social frameworks.

Social frameworks are significantly important when understanding the lives and experiences of people living with HIV/AIDS. The social construction and the etiology or causes of HIV/AIDS are what create a 'frame as structure' approach to discerning the meaning that becomes attached to this disease (Gramsci 1971; Hoare and Smith 1971).

The predominant social framework from which HIV/AIDS is understood has displayed hegemonic influences within the medical community and throughout the public (Lee 1990; Wang 1997). These influences include the initial onset, discovery, and naming of HIV/AIDS which was centered around homosexual males (or men who have sex with men), the framing of HIV/AIDS to particular deviant groups which created an understanding or interpretation that continues to be maintained by public, that HIV/AIDS is associated with deviant sexual activities and deviant groups (Kayal 1993).

Homosexuality in this culture is seen as deviant. This ideology largely prevails due to the association with biblical convictions (Herrell 1996). Biblical references taken from The King James Version of the Bible have been interpreted to suggest that homosexuality is a sin. The verses that make these suggestions are:

In Romans Chapter 1 verses 26-29.

> "For this cause God gave them up unto vile affections: for even their women did change the natural use into that which is against nature. And likewise also the men, leaving the natural use of the woman, burned in their lust one toward another; men with men working that which is unseemly, and receiving in themselves that recompense of their error which was meet. And even as they did not like to retain God in their knowledge, God gave them over to a reprobate mind, to do those things which are not convenient; Being filled with all unrighteousness, fornication, wickedness, covetousness, maliciousness; full of envy, murder, debate, deceit, malignity; whisperers."

In 1 Corinthians chapter 6 verses 9-11:

> "Know ye not that the unrighteous shall not inherit the kingdom of God? Be not deceived: neither fornicators, nor idolaters, nor adulterers, nor effeminate, nor abusers of themselves with mankind, Nor thieves, nor covetous, nor drunkards, nor revilers, nor extortioners, shall inherit the kingdom of God. And such were some of you: but ye are washed, but ye are sanctified, but ye are justified in the name of the Lord Jesus, and by the Spirit of our God."

In Deuteronomy chapter 23 verse 17:

> "There shall be no whore of the daughters of Israel, nor a sodomite of the sons of Israel."

In Genesis chapter 13 verse 13:

> "But the men of Sodom were wicked and sinners before the LORD exceedingly."

Romans Chapter 1 verses 27 through 32:

> "And likewise also the men, leaving the natural use of the woman, burned in their lust one toward another; men with men working that which is unseemly, and receiving in themselves that recompense of their error which was meet. And even as they did not like to retain God in their knowledge, God gave them over to a reprobate mind, to do those things which are not convenient. Being filled with all unrighteousness, fornication, wickedness, covetousness, maliciousness; full of envy, murder, debate, deceit, malignity; whisperers, Backbiters, haters of God, despiteful, proud, boasters, inventors of evil things, disobedient to parents, Without understanding, covenant breakers, without natural affection, implacable, unmerciful: Who knowing the judgment of God, that they which commit such things are worthy of death, not only do the same, but have pleasure in them that do them."

These biblical scriptures suggest that the only sexuality that should be practiced in our society is that of legally committed heterosexuals. There are no references made to engaging in sexual activities for pleasure, only for reasons of procreation. Homosexuality is condemned by people in our culture largely because of the relationship between biblical statements and the sinfulness attached to this activity (Reinig 1990; Herrell 1996). Because homosexual acts are not able to yield the fruitful consequences of fertile heterosexuals, they should not engage in sexual relations. Foucault (1978) even makes a reference to this, he states that society promotes a "sexuality that is economically useful and politically conservative (p37)." Homosexual activity is considered deviant because people interpret these biblical statements literally.

The religious influence throughout this culture is very prevalent. When religious influences and beliefs are coupled with the authority of the medical and scientific communities, the likelihood of persons creating a negative understanding of diseases such as HIV/AIDS are tremendous. The medical and scientific communities exert a significant amount of influence on the maintenance of disease constructions in a society, such as this one, that heavily relies on medicine (Epstein 1995; Gramsci 1971; Schiller 1992; Waitzkin 1989).

There have been other diseases and illnesses throughout history that have been viewed negatively because of religious influences. Cancer and Tuberculosis, for example, were once seen as a diseases of lust (Sontag 1978). Lust is considered sinful and there are several biblical references that denote this:

In Galatians chapter 5 versus 16 through 26:

> "This I say then, Walk in the Spirit, and ye shall not fulfil the lust of the flesh. For the flesh lusteth against the Spirit, and the Spirit against the flesh: and these are contrary the one to the other: so that ye cannot do the things that ye would. But if ye be led of the Spirit, ye are not under the law. Now the works of the flesh are manifest, which are these; Adultery, fornication, uncleanness, lasciviousness, idolatry, witchcraft, hatred, variance, emulations, wrath, strife, seditions, heresies, envyings, murders, drunkenness, revellings, and such like: of the which I tell you before, as I have also told you in time past, that they which do such things shall not inherit the kingdom of God. But the fruit of the Spirit is love, joy, peace, longsuffering, gentleness, goodness, faith, meekness, temperance: against such there is no law. And they that are Christ's have crucified the flesh with the affections and lusts. If we live in the Spirit, let us also walk in the Spirit. Let us not be desirous of vain glory, provoking one another, envying one another."

In 1 John chapter 2 versus 16 and 17:

> "For all that is in the world, the lust of the flesh, and the lust of the eyes, and the pride of life, is not of the Father, but is of the world. And the world passeth away, and the lust thereof: but he that doeth the will of God abideth for ever."

There appears to be a significant relationship between societie's interpretation of a disease or illness and how they are medically constructed. Cancer was thought to be a disease associated with lust primarily because it was associated with activities that are (or have been in the past) considered deviant such as smoking (lung cancer) and sex (ovarian cancer) (Fife and Wright 1999, 2000; Sontag 1978; Foucault 1984). The consequences of these activities could result in cancer, however, participating in these activities will not necessarily lead to acquiring cancer. If persons were unable to control lustful activities such as these they may be held responsible for having acquired a disease such as cancer.

Responsibility is something that must be considered when discussing either cancer or HIV/AIDS. The stigma associated with HIV/AIDS in the present and cancer in the past, have required people to be accountable for their actions by making them aware that there are stigmas to having either disease (Leiker, Taub, and Gast 1995; Schulte 1999).

Presently, HIV/AIDS has taken some of the stigma away from people living with cancer, because of the sexual nature of the HIV/AIDS, however both diseases have some degree of stigma attached to them (Walkey Taylor and Green 1990; Goffman 1963; Fife and Wright 2000).

The hegemonic influences of professional communities in our culture reinforce the social framework that HIV/AIDS is a deviant disease because it is primarily contracted through deviant and sexual means (Altman 1986). Consequently, the frames that are created about people living with this disease are negative. People affected by HIV/AIDS are treated differently because the public assumes and reinforces the negative frames when interacting with them (Johnson 1995). There is a sense of shame confined upon people that are affected by this disease and they suffer the consequences by being stigmatized (Sontag 1989; Bunting 1996; Crandall, Glor, and Britt 1997; Fife and Wright 2000).

The social frameworks from which people living with HIV/AIDS will interpret their experiences with health care and medical therapies, social support, and stigma are inherent in the understanding of the hegemonic influences of the medical community, the professional community, and society. These understandings should rest on the assumption that those infected with HIV/AIDS are responsible for having acquired it because of their engagement in deviant behaviors (Leiker, Taub, and Gast 1995). Any act that one chooses to engage in is seen as a 'guided doing' (Goffman 1974:22). A guided doing 'subjects the doer to standards,' therefore enforcing the standards that are embedded in society. A societal standard that is present in this culture would include not engaging in deviant activities such as injecting drugs and homosexuality.

Because HIV/AIDS has been associated with deviant groups since its initial discovery and these deviant groups are fervently condemned throughout society on religious grounds, behavioral standards can be enforced within many realms and institutions throughout our culture (Sigal 1998; Herrell 1996; Reinig 1990). When these standards are reinforced throughout the institutions of medicine, politics, organizations, family, and religion, people living with this disease suffer, especially those that are responsible for having acquired HIV/AIDS through sexual contact or IV drug use. This creates the precedence for negative experiences among people affected by this disease.

Comments from political figures such as Trent Lott, the Mississippi Republican, who in 1998 publicly remarked that "homosexuality is a sin," reinforces the ideologies already present within this culture. This comment was later reinforced when House Majority Leader, Dick Armey, pulled out the bible to suggest what Lott had said was true. Statements made by political figures influence the institutions that are funded to provide services for people living with HIV/AIDS.

If social frameworks provide a guide for standards of "honesty, efficiency, economy, safety, elegance, tactfulness, good taste, and so forth" (Goffman 1974:22), one can easily see how the influence of societal standards and ideologies would be imposed on those that have acquired HIV/AIDS (Leiker, Taub, and Gast 1995; Anderson 1992). I would argue that these ideologies brought about and maintained by the social structure are even imposed upon those that have acquired HIV/AIDS through non-deviant means (blood transfusions and during birth) (Crandall, Glor, and Britt 1997; Bunting 1996; Blendon and Donelan 1988). Because the label of HIV/AIDS has been attributed to deviant social acts, one must ask the infected person how they acquired this disease in order to know the degree to which societal ideologies will be imposed on them. The infected person will still be judged based on the enforcement of the social framework that regulates ideologies with regard to the moral standards that have been created about HIV/AIDS (Kayal 1993; Altman 1986; Sigal 1998).

To look only at HIV/AIDS through a 'natural framework' would not yield the rich exploration and interpretation of this disease, not to mention that it would lack sociological significance. A Social framework, on the other hand, is more appropriate when looking at HIV/AIDS. Although HIV/AIDS certainly has natural consequences it may be more appropriate to approach the understanding of this disease as well as those affected by it through a 'social framework'. A sociological analysis of institutional hegemonic influences on the organization of experiences among people living with HIV/AIDS will provide an understanding of the encounters one affected by this disease must manage. People affected by HIV/AIDS must interact with the medical community, social organizations that provide monies and social support, and families and religious affiliations that may not understand the disease or their lifestyle if the person is gay. A person affected by HIV/AIDS is likely to encounter interactions from any one or all of these institutions.

In this thesis I examine the concept of hegemony in a professional context as well as a cultural context within the realm of the organization of experiences among people living with HIV/AIDS. My discussion of professional hegemony will include the medical community (physicians and pharmacists) and HIV/AIDS organizations (Ryan White funded). I will provide a discussion of cultural hegemony that will include an examination of rural ideologies within the context of HIV/AIDS. I will also discuss experiences within the contexts of health care and medical therapies, social support, and stigma, which are elements that a person affected by HIV/AIDS might encounter.

In the following section I will discuss the primary framework utilized in this thesis, hegemony. That discussion will be followed by a presentation of professional and cultural hegemony. I will then look at the literature on health care and medical therapies, social support, and stigma within the context of professional and cultural hegemony.

Hegemony

Hegemony is the dominant influence or authority over others. It refers to the subordination of an individual or group over others who become deprived of their individuality, power, and autonomy (Urbinati 1998; Gramsci 1971). The concept of hegemony can be linked to ideologies present within a culture (Elling 1981). When ideologies are influential within a society, weaker individuals or those whose ideologies do not fit into the mainstream are dominated and deprived of their self-reliance as persons as well as citizens.

While ideologies are a set of ideas or principles that create a distinct perspective of a social group, hegemonic ideologies make available the authority by which to persuade a particular group (Waitzkin 1989). Although ideologies may be considered as imaginary on one level they become very real and powerful on another. Particularly when they are continually reinforced by groups in society that create havoc for disadvantaged groups who do not buy into those dominant ideologies (Urbinati 1998). Gramsci (1971) suggests that hegemonic influences create a reality or ideology that becomes diffused throughout society.

Antonio Gramsci (1971) introduced the concept of ideologic hegemony, which is an important mechanism of institutional control. Institutions such as the family, religion, and medicine indoctrinate a system of values, beliefs, attitudes, and morality among those that dominate them (Waitzkin 1989). Disadvantaged groups suffer consequences because of the ideologies brought about by this collection of hegemonic influences. Gramsci asserts that ideologic hegemony creates a significant amount of power within society.

The hegemonic ideology of Gramsci is inherent in Marxist thought. Antonio Gramsci's theory of hegemony rests on the assumption of subordination in which individuals or groups are deprived of their individuality and power. An individual is deprived of their self-reliance and denied full participation in society (Hoare and Smith 1971; Femia 1987; Urbinati 1998).

Foucault (1972; 1973; 1977) also discusses the concept of power with regard to institutions. Although his definition of power was not clearly presented until after *Discipline and Punish: The Birth of the Prison* (1977), he made reference to the idea in previous works. The notion behind power is that it is not assumed from the top down, from a dominant to a dominated class, rather power is diffused throughout society on all levels. Foucault indicates that knowledge can not be separated from power at any level of society. He also suggests that because science and ideology are forms of knowledge, they are embedded in power relations. What Foucault is signifying is that there is a connection between knowledge and power, whether knowledge is derived from science or ideology, that shape relations and interactions in society (Lemert and Gillan 1982). The questions that Foucault tries to answer are 1) how is power exercised and by what means, and 2) what are the effects of exercising power (Smart 1985).

Institutional social control mechanisms that are present within our culture include medicine, the family, organizations, and religion (Gramsci 1971; Foucault 1973). Each of these institutions are purposeful when considering how and to what extent ideologies get constructed and maintained in society. Each of these institutions convey ideological beliefs about desirable behaviors. The medical community conveys ideas about maintaining good health, while also promoting and rewarding positive health behaviors. Organizations, particularly those that are classified as non-profit, convey a sense of financial support should a person need to access assistance. The family convey a sense of support while laying the moral groundwork from which one should abide. Religious affiliations convey a sense of support on moral grounds which provides a foundation of values and beliefs. In addition, each of these institutions can influence one another as well as the media, education systems, and the general public.

Ideologic hegemony is very powerful when considering how closely these institutions function. There ability to influence one another as well as other arenas only adds to their already dominating authority. People living with HIV/AIDS encounter these institutions and because they are already a disadvantaged group are likely to be deprived of autonomy and participation as a full citizen in society. This group is considered marginal by societies standards or they would not encounter the stigma that they do (Goffman 1963; Bunting 1996; Weitz 1989).

Althusser (1971) takes Gramsci's thoughts and further elaborates on the idea of hegemony. Althusser includes two types of institutions to reflect upon hegemony. The two types of institutions include 1) repressive state apparatuses (RSA's), which include institutions with government influence that maintain hegemony through repression and coercion, these include medicine, and organizations; and 2) ideologic state apparatuses (ISA's), which refer to institutions that instill dominant ideologies in the population, including the family, politics, the media, and cultural systems.

The combination of ideas provided by Gramsci and Althusser provide a fruitful way in which to look at professional and cultural hegemony, especially in relation to HIV/AIDS. The RSA's and ISA's work together to legitimate one another. The conception that HIV/AIDS is a stigmatizing disease is an ideologic notion that functions to legitimate the treatment of people living with it. People in medicine or organizations may use force or coercion when managing those living with HIV/AIDS (RSA's) because of their marginal stigmatizing status in society (ISA's). There is a stronger influence, Althusser (1971) suggests, among the ISA's in society because they have the capability of influencing class frameworks throughout the culture.

Hegemony is important when discussing HIV/AIDS because people affected by it are a marginal group and are likely to reap the consequences from the medical community, organizations, families, and religious affiliations. In the next section I will discuss professional hegemony which includes the medical community and organizations.

Professional Hegemony

Professional hegemony occurs when professional communities exert a powerful influence or control over a particular group (Annandale 1989). This can take place in the form of coercion and legality (Gramsci 1971). An example of professional hegemony through the use of coercion would occur when professionals threaten to revoke health care or access to therapeutic modalities because a patient or client refuses to proceed with treatment because they are physically unable to take medications. This is also what Althusser (1971) refers to as RSA's, repressive state apparatuses.

Professional hegemony, in the context of HIV/AIDS, cooperatively includes the medical community and HIV/AIDS non-profit organizations. Hegemony of this type becomes an important component to people living with this disease because they must obtain health care and social support services in order to sustain their health (Connors 1995; Mouton 1997).

Medical hegemony is inherent in ideology and social control (Zola 1972;Waitzkin 1989; Charles, Whelan and Gafni 1999). Medicine exercises a vast amount of social control because practitioners have the ability to control their own institution as well as the capability to regulate other groups or individuals (Sherwood 1992). Today, medicine is an institution of authority in this culture. However, physicians have not always been an influential group within society.

It was not uncommon for early medical practitioners to have included in their duties such jobs as wig maker, food merchant, and cloth manufacturer (Starr 1982). Most medical care, for example during the 1700's, was delivered by apothecaries who provided drugs and gave medical advice on dressing wounds and performing amputations (Ford 1965).

The first effort to organize medicine came in 1766, when New Jersey became the first state to have a state medical society. In 1847 the medical community became established as an authoritative profession when 250 physicians met in Philadelphia to establish the national medical society known as the American Medical Association. This organization was created for ideological and economic reasons. Physicians were seeking more esteem while also condemning the alternative practice of homeopathic healers (Starr 1982; King 1984). The motivation to create the AMA was largely to establish visible standards for medical practice and to gain confidence from the general public (King 1984).

Paul Starr (1982) has described the rise of medical authority in America as a transformation from a weak and poorly regarded occupation to a powerful, prestigious, and sovereign profession. He suggests that professions develop authority in order to maintain their position in society. The level of respect a profession receives is embedded in the "awe and respect from the general public and legislators" which produces the cultural authority of medicine (Anderson 1983:1243). Starr reiterates this idea by stating:

> "The triumph of the regular profession depended on belief rather than force, on its growing cultural authority rather than sheer power, on the success of its claims to competence and understanding rather than the strong arm of the police. To see the rise of the profession as coercive is to underestimate how deeply its authority penetrated the beliefs of ordinary people and how firmly it had seized the imagination even of its rivals" (p 229).

The authority of medicine is prevalent in our culture. The medical profession consists of physicians, nurses, and pharmacists who seek to control medical knowledge and information. Each of these professions encompass the hegemonic ideology that comprises medical authority.

Physicians are the group who dominate the hegemony of medicine. They are the group who listens, diagnoses, and prescribes medical regimens. Nurses too must listen, and they may assist physicians in diagnosing and prescribing medication, however, the physician still maintains authority. Pharmacists, on the other hand, may have to listen to patients, however their primary function in the medical scheme is to interpret prescriptions and dispense medications. Each of these medical authorities comprise the hegemony of the medical profession (Starr 1982; Anderson 1983).

Each of these positions in the medical hierarchy are significant to the practice of medicine when working with HIV/AIDS patients. However, HIV/AIDS patients are most likely to deal with physicians and pharmacists, rather than nurses. Most HIV/AIDS patients seek medical care and in many cases are seen by disease specialists (Sherer and Goldberg 1994). However, when there is an inadequate amount of trained specialists, patients seek care from infectious disease and primary care physicians who may have little or no additional HIV/AIDS training (Zuger and Sharp 1997; Cunningham, Mosen, Hays, Andersen, and Shapiro 1996; Heckman, Somlai, Kelly, Stevenson, and Galdabini 1996).

Many people affected by HIV/AIDS are very knowledgeable about the disease, including treatment modalities and side effects. This level of knowledge among laypersons, especially persons who are considered deviant by societal standards, may not be well received among the medical community. Professionals, in general, do not enjoy being informed about their area of expertise, specifically when the knowledge is accurate and is presented by a layperson. Many physicians would especially loathe this type of conduct (Browner and Press 1996; Miller 1989; Eddy 1990; Young 1983).

Medical encounters between physicians and patients with illnesses like HIV/AIDS should provide a basis for making partnership treatment decisions. The dominant mode of medical decision making is paternalistic, where the patient is passive in medical decisions and the physician functions as the authority on treatment (Mouton, Teno, Mor, and Piette 1997). However, with many HIV/AIDS patients, practicing this type of medicine is nearly impossible given that so many of these patients understand their treatment modalities and what works best for them (Charles, Whelan, and Gafni 1999). Medical encounters where both patient and physician share in the decision making, are more likely to be characterized by the level of education, race/ethnicity, and sex/gender of the patient (Mouton, Teno, Mor, and Piette 1997; Mouton 1997; Malterud 1999).

One factor that hinders shared decision making and doctor-patient communication is patient compliance (Roberts and Volberding 1999). The dominant ideology indicates that an ill person must seek medical treatment from licensed and trained professionals if their goal is to obtain knowledge and medication. In addition, they must also obey the authority of medical professionals if they want to continue receiving care. Each of these signify that the degree of hegemonic influence is ubiquitous in this culture (Rueschemeyer 1987; Haas and Coe 1997).

Patient compliancy is a significant element in medical hegemony (Roberts and Volberding 1999). There are several reasons why many patients do not comply with medical authorities. One explanation for noncompliance is lack of communication or rapport between the medical authority and the patient (Catz et al. 2000; Mouton et al. 1997; Gewirtz and Gossart-Walker 2000). The second explanation for noncompliance occurs when medical regimens or treatments are not considered by the patient to be effective for eliminating or aiding the health problem (Ungvarski, Wainberg, Friedland 1998; Proctor, Tesfa, and Tompkins 1999; Hunt, Jordan, Irwin, and Browner 1989).

These two explanations provide deviant justifications for noncompliance on behalf of medical authorities. Peter Conrad (1987) suggests that these two types of noncompliance should be viewed as a matter of patient autonomy rather than an opposition to medical authority. Rather than seeing this type of noncompliant behavior as deviant, medical authorities should see it as a matter of patients tailoring their medical regimens to concur with their lives.

Compliance is especially important among people living with HIV/AIDS. The degree of medical hegemony imposed upon them is great due to the level of non-compliance within that population (Mouton 1997; Mouton et al. 1997; Chesney, Morin, and Sherr 2000; Schiller 1992; Catz et al. 2000). Although, the majority of people living with HIV/AIDS adhere to treatment regimens because they are life sustaining, there are some who cannot take the newly introduced combination therapies (This group would rather not take the medication than suffer the side effects that cause additional problems) (Catz et al. 2000). On the other hand, there are some people who do not comply with treatment regimens because they are expensive and are unable to afford them (Gelone and Kostman 1998).

Pharmacists are often key players in patient compliance. They must contend with issues of compliance with regard to drug side effects and drug interactions, and offer advice about new drugs and combination therapies. Because HIV/AIDS drug regimens are complicated, pharmacists are available to provide assistance (McCann 1997). In larger cities, there are some pharmacists who call their clients that have filled prescriptions for protease inhibitors and make sure that they are complying (McCann 1997; Gelone and Kostman 1998). Other pharmaceutical chains have provided education programs on HIV/AIDS for their pharmacists (Slezak 1998). Although, HIV/AIDS patients' interactions with pharmacists are unlikely to override the importance of the physician encounter, they are nonetheless important and serve a function of hegemony with the community of medicine. Namely, that of creating and understanding new HIV/AIDS treatment modalities (Hansen, Ranelli, and Ried 1995).

The hegemony of medicine and its impact on the daily lives of people living with HIV/AIDS are inherent in the perceptions about this disease. HIV/AIDS is currently a terminal illness, although there are many people living long lives due to therapeutic modalities. And HIV/AIDS is predominantly transmitted through deviant means.

These two rudiments provide authorities that comprise the medical community with power and influence that are capable of constructing ideologies throughout the medical community and the general public (Bruder 1998). Because the medical community deals with HIV/AIDS patients, that are technically terminally ill, it is likely that ideologies about death and dying could dominate what people come to believe about this disease and those living with it (Browner and Press 1996; Holstein 1997). In much the same manner that stigma prevails because of the association of this disease with deviant groups. The ideologies constructed about terminal illness and death lead to further stigmatizing this group and eventually to negative interactions among people living with HIV/AIDS, the medical community, and the public.

Although medical hegemony is ever-present within society, powerful influences are also exerted by non-profit organizations that deal with HIV/AIDS clients. These service organizations are funded by the federal government using Ryan White monies to offer assistance to economically disadvantaged persons living with HIV/AIDS (Buchanan and Chakravorty 1999; Montoya, Trevino, and Kreitz 1999). These service organizations are vital to people living with this disease and are also indicative of hegemonic practices.

HIV/AIDS Service Organizations are an important component to the arrangement of medical and social support assistance provided to people living with HIV/AIDS. Monies are regulated through a network that often begins on the state level with the Department of Health. Monies are then distributed to HIV/AIDS service organizations throughout the state.

The Ryan White Care (Comprehensive AIDS Resources Emergency) Act is the public law (101-38, 1990; 104-146, 1996) that distributes funds throughout the United States. There are four titles that regulate the dispersion of monies. Title I grant monies provide emergency assistance to income qualified individuals. A city must demonstrate eligibility for Title I funds based on critical need. Since 1991, there have been more than 3 billion dollars allocated for Title I funding in the U.S (http://www.hivdent.org/funding/rwcactoer.htm).

Title II monies are available to improve the quality, accessibility, and organization of health care and support for people living with HIV/AIDS. Services that are provided include, health care, support, home and community-based care, assistance in continuing coverage of private health insurance, and assistance with obtaining medications through ADAP (AIDS drug assistance program). Since 1991, there have been more than 2.7 billion dollars allocated to Title II funds, with 965 million being consumed by ADAP (http://www.hivdent.org/funding/rwcactoer.htm).

When granted Title II funding under the CARE Act, states must establish a consortium of people in public and nonprofit health care, support service (HIV/AIDS) organizations, and the community. The consortium serves to plan, develop, and deliver services for people living with HIV/AIDS. The consortium, along with people living with HIV/AIDS, convenes to discuss the needs of this population within the state (http://www.hivdent.org/funding/rwcactoer.htm). In the state where the research for this thesis was conducted, a consortium is in place and consists of physicians, service organizations, the state department of health, and health care consumers.

Title III monies provide comprehensive care for people living with HIV/AIDS and at-risk populations, including females, the homeless, and substance users. These monies are also used for education, counseling, and testing interventions. From 1991 until 1998, 539 million dollars have been allocated for Title III funding in the U.S (http://www.hivdent.org/funding/rwcactoer.htm).

Title IV monies are used for grants proposed to research children, youth, and families. Organizations must have the capability of providing access to clinical trials or have links with organizations or health care providers that do. Since 1994, 199 million dollars have been allocated for Title IV funding, including 55 organizations in 23 U.S. states (http://www.hivdent.org/funding/rwcactoer.htm).

The data for this thesis were gathered in an area appropriated by Ryan White Title II funds. The funds are used for prescription drug assistance, case management, nutritional supplements and counseling, and transportation to and from medical appointments. They also provide housing opportunities through HOPWA (Housing opportunities for Persons with AIDS), which is funded through HUD (the Housing and Urban Development). These funds are allocated only to persons who are homeless or at risk for homelessness. Title II monies that are provided to the state are primarily allocated to the two largest HIV/AIDS organizations in the state CarePoint, Inc. (in Oklahoma City), which serves 54 counties and HIVRC (in Tulsa), which serves 23 counties (http://www.health.state.ok.us/program/hivstd/ryanw/index.html).

Monies that are accessed by the income eligible HIV/AIDS population are provided for health care services, drug assistance programs, mental and nutritional health counseling, employment service counseling, case management, limited dental assistance, and transportation. Health care providers and other agencies that offer these services to income eligible HIV/ AIDS infected persons that are accessing services through the large HIV/AIDS organization that controls the money, must go through the large social service HIV/AIDS organization to be reimbursed for providing services (Rundall et al. 1999). When one overarching social service organization in an area controls monies that are allocated for specific services, they create another facet of professional hegemony (Buchanan and Chakravorty 1999; Cain 1997; Robinson 1998; Bayer 1997; Frans 1994).

The increase in hegemony among HIV/AIDS service organizations is inherent in attitudes about people living with HIV/AIDS in general (Shilts 1987). The government and social services organizations have responded slowly to the HIV/AIDS crisis. The ideology that, services to people with HIV/AIDS should be provided through public welfare agencies, personal funds, and Medicare or Medicaid, suggests that persons infected with HIV/AIDS can be linked to how people with HIV/AIDS are viewed by the medical community, the government, and the public. This suggests that because HIV/AIDS is a deviant disease, persons infected with it should not be allocated proper and comprehensive health care or social support (Cain 1997; Frans 1994; Buchanan and Chakravorty 1999; Sundwall and Bailey 1988; Altman 1986).

Non-profit organizations have historically acted against these ideologies to provide people living with HIV/AIDS at least a minimal continuum of care (Silverman 1988; Kayal 1993; Bailey 1991). However, this was not done without some resistance from the public and the government. The government eventually mandated the Ryan White Care Act when a young man (Ryan White) from Indiana died at the age of 19. He struggled with HIV/AIDS and the discrimination that often goes along with it. In 1999 the government allocated $1.4 billion to this act. These funds are allocated to provide services to people living with HIV/AIDS and have been deemed inadequate for providing basic ambulatory care and social support (Rundall et al. 1999; Aday et al. 1994; Fleishman, Mor and Piette 1991).

With the dominant appropriation of Ryan White monies being distributed from large, social service HIV/AIDS organizations, the likelihood exists for political influences from the general public, the government, and the medical community. Controlling physical and mental health care as well as social support increases hegemony among large HIV/AIDS service organizations. In addition, the relationship between health care and HIV/AIDS service providers increases professional hegemony. As services and monies continue to be allocated in the manner that they are currently; with the government distributing funds to the state, the state distributing funds to social service organizations, and social service organizations distributing funds to health care and service providers, there will only be an increase in professional hegemony among the providers of HIV/AIDS services. And because these services are so vital to persons living with this disease, they have very little control over the utilization of health care social support services, especially the low income HIV/AIDS infected population that rely on these services.

Professional hegemony is ubiquitous in this culture. However, when coupled with a disease like HIV/AIDS, professional hegemony emerges to embrace a wealth of authority. Both the authority of medicine and social service organizations influence and are, in turn, influenced by ideologies present in society.

The medical community is influenced by the prevailing ideology that, HIV/AIDS is associated with deviant groups because of how the disease was medically and culturally constructed (Schiller 1992; Epstein 1995). The medical community has sequentially influenced perceptions about this disease and people living with it because they have socially constructed it to represent deviancy. And because social service organizations are more readily a group that would identify with the public, this ideology is perpetuated among those that provide services to the HIV/AIDS population to the general public.

HIV/AIDS organizations function as both the liaison between the infected HIV/AIDS population and the medical community and the liaison between the affected HIV/AIDS community and the general public. The HIV/AIDS service organizations offer a compelling approach to professional hegemony when looking at this disease. The HIV/AIDS service organizations emerge as a very influential hegemonic institution.

Despite the fact that knowledge about the disease is widespread, a fear of HIV/AIDS and those living with it exists among the professional community and the general public (Wang 1997; Robinson 1998; Lee 1990). The prevailing attitudes toward this disease and people affected by it breed negative attitudes about HIV/AIDS, which result in the hurtful treatment of people affected by HIV/AIDS in many situations. Because prevailing negative ideologies are likely to be perpetuated by professional hegemony that are comprised by the medical community and HIV/AIDS service organizations, persons affected by HIV/AIDS are likely to encounter attitudes when dealing with these professional communities, families, friends, employers, churches, and less significant others in the general population.

The situations that people living with HIV/AIDS are likely to encounter with regard to negative attitudes are derived from the culture in which they find themselves. Professional hegemony is not the only element that contributes toward ideologies about this disease. The other important element that plays a role in creating and maintaining those ideologies rests upon cultural influences. Therefore, cultural hegemony, in addition to professional hegemony, plays a crucial and unique role in how people affected by HIV/AIDS experience their disease.

In the next section I will discuss cultural hegemony in the context of rural ideologies. People impacted by rural ideologies are likely to encounter negative experiences due to the affects of HIV/AIDS. Cultural hegemony will allow for an additional way in which to frame and organize experiences among people living with HIV/AIDS.

Cultural Hegemony

A supplementary approach to professional hegemony is cultural hegemony. Cultural hegemony provides a complementary approach to professional hegemony when looking at the organization of experiences among people living with HIV/AIDS. The experiences of people affected by this disease are not only influenced by professional hegemonic ideologies present within medicine and social organizations but also by the culture in which one is situated. Cultural influences are often positioned according to geography and encourage the perpetuation of dominant ideologies that are present within those locations. In consequence, prevailing ideologies in a geographical location become encouraged by hegemonic interests of dominant groups within the culture.

Cultural hegemony then, is the process by which the interests of a dominant political/social/economic order are supported and maintained through the implicit acceptance of dominant ideologies. The ideologies that are prevalent within a culture are transmitted by groups with the most power, it is often a societies 'bourgeois' that controls and conveys those messages (Frankenberg 1988; Gramsci 1971). Hegemony occurs when the dominant social influences or messages within a population become institutionalized and perceived as normative. The dominant social influences eventually create realities that are reflective of the ideologies present within a given culture (Gramsci 1971; Wilson 1995). Persons can then frame their experiences within the reality created and maintained by the culture in which they are situated.

Cultural hegemony can only persist if the dominant ideologies are framed successfully within the prevailing sociocultural context. Dominant ideologies are often accentuated through sociocultural meanings, values, and beliefs (Stein and Hill 1993). One characteristic of sociocultural ideologies can be situated in geography (Semmes 1992; McGovern 1997; Maggard 1983).

Geographical locations influence the ideologies that are present in a given locality (Fischer and Friedman 1993; Myntti 1988). There is one constituent that supports sociocultural ideologies with regard to geography, rurality. Rurality is the degree to which rural ideologies shape and are shaped by the culture where a person is geographically and/or socioculturally situated (Willits and Ke 1995; Edmonson and Fontanez 1995). Such things as religion, values, and beliefs can shape rural sociocultural ideologies (Gramsci 1971; Hoare and Smith 1971). Being situated in a rural or urban culture will bring about ideologies that represent the prevailing values and beliefs within it (Leach 1997; Whatmore 1993).

Although geography is not the only factor that influences sociocultural ideologies and produces hegemony, the geographical location where persons reside can influence values and beliefs and hence, construct realities. Realities that are influenced by geographical location and the ideologies present within a particular region provide a framework from which to interpret experiences. Interpreting experiences based on hegemonic ideologies present within society can provide a fruitful approach to understanding cultural hegemony. However, a comprehensive conception of cultural hegemony may be difficult to grasp when coupled with geographical region (Stein and Hill 1993; Hurt 1981).

Gramsci has suggested that geography can bring about a paradoxical conception of hegemony because of the fluid, rather than static, nature of culture and location (Urbinati 1998). Gramsci attempted to create rural classification but suggested such a classification complicated itself. However, he did indicate that there were cultural variations inherent in ruralism (Gramsci 1957; MacLaughlin 1993; Leontidou 1996).

Variations of ruralism fluctuate according to space (density), geography, and ideologies (Berry et al. 2000; Whatmore 1993; Leach 1997; Edmonson and Fontanez 1995). What is considered rural varies according to space, geography, and ideologies because ruralism or rurality is conceptually fluid rather than static, especially here in the United States. There are certainly places in this country that would be considered rural because they are not densely populated, or remote, however they may maintain a progressive ideology (Edmonson and Fontanez 1995). On the other hand, there are densely populated areas that adopt or adhere to conservative ideologies that are inherent in rurality (Willits, Bealer, and Timbers 1990; Mitchell 1999; Berry et al. 2000). Rurality then must be considered with regard to density and space, geography, and ideology;

because rurality cannot be described or understood in the context of one alone (Stein and Hill 1993).

In the remainder of this section I will discuss the concept of rurality within the context of cultural hegemony. I will focus on the historical development and significance of rurality. In addition, I will provide a discussion of rurality in the context of HIV/AIDS.

Rurality

Rurality is an important concept with regard to cultural hegemony because it can influence how people experience the social world (Fischer 1993; Wilson 1995). Cultural hegemony, with regard to rurality, can be influenced by space or density, geography, or ideology. In this section, cultural hegemony and rurality will be examined in the context of geography and ideology.

There are several ways in which the terms rural or rurality have been conceptualized in order to understand their meaning. The term has been construed as an ecological or geographical construct, an occupational construct, and a sociocultural construct. This section focuses on the geographical and the sociocultural construction of the term but each will be defined and discussed (Bealer, Willits, and Kuvlesky 1965; (Berry et al. 2000; Edmonson and Fontanez 1995). The ecological/geographical and the sociocultural conceptions of rurality are the only two of the three concepts being described because they are the most relevant to this thesis. The sociocultural conception of rurality will be explored in detail because it is the most abstract of the two concepts being explored in this section.

The meaning of the term rural or rurality within the context of an ecological construct, refers to low density or how people are distributed with regard to space (Bealer et al. 1965). The United States Bureau of the Census defines rural, in an ecological sense, as a resident population of less then 50,000 in a metropolitan statistical area (US Bureau of the Census 1999).

The meaning of the term rural or rurality with regard to an occupational construct refers to an employment category. The focus within this context is on agriculture and/or farming (Bealer et al. 1965; Whatmore 1993; Willits, Bealer, and Timbers 1990). The occupational construction of the term, rural, provides an alternative approach to understanding rurality. However, rurality defined within a sociocultural context allows more freedom with regard to sociological phenomenon and explanations of those phenomenon.

The sociocultural construction of rurality refers to the structure and functioning of a society with regard to both an interaction or social component and a cultural component. Rurality, in an ideologic or 'sociocultural' context, is used to refer to the many aspects of a society's structure (Bealer, Willits, and Kuvlesky 1965; Leach 1997; Willits, Bealer, and Timbers 1990; Mitchell 1999).

Culture is used in this context in the same way it is used throughout sociology. Culture denotes 'guided actions' by which means and outcomes are directed in a society. Culture is guided by the prevailing norms, values, beliefs, mores, folkways, and shared ideals of society (Sumner 1906). A rural culture is depicted as traditional, conservative, slow to make changes, homogenous, 'provincial' and 'fatalistic' (Bealer et al. 1965:264;

Rogers 1960; Willits, Bealer, and Timbers 1990; Guizzardi 1976). Such values can serve as a barrier to new ideas within this culture (Hurt 1981; Rogers 1960). Therefore, ideas about the rural culture should be inherent in these described characteristics (Larson 1978).

Throughout the rest of this project, the meaning of rurality will be conceptualized with regard to the ideas and characteristics based on a geographical and a sociocultural understanding of the term. Geography and sociocultural ideology are both important components to understanding and offer a unique perspective on cultural hegemony in the framework of rurality with regard to HIV/AIDS.

Cultural hegemony can be reflected in both facets of rurality when looking at this disease (Smyth 1998). Hegemony can be reflected in rural geography when a person living with HIV/AIDS is not able to receive adequate health care. This can occur when the health care community refuses to medically treat a person who has HIV/AIDS (Gesler 1992; Willard 2000).

Hegemony can also occur because of physicians/patient ratios in an area. This occurs when the ratio of patients per physician is exceedingly high. Physicians practicing in geographically rural areas are likely to encounter an out-weighted patient to physician ratio due to the low number of practicing physicians in those areas (Willard 2000).

Hegemony will result where rural ideologies prevail because there are fewer practicing physicians who will dominate and produce existing medical knowledge about HIV/AIDS. Persons living with HIV/AIDS will be influenced by the hegemonic influences in this culture by not receiving proper ambulatory health care and the proper medical regimens.

Density, however, may not be the only factor that influences hegemony. Hegemony, with regard to rurality, can also be affected by ideologies that are present within the culture. An area can be densely populated but at the same time be impacted by the ideologies that are prevalent within it. The sociocultural ideologies that are present within an area can create hegemony when they are foremost and prevailing. When the prevailing ideologies become superlative in an area, it creates a dominant framework from which people can interpret their experiences.

There are ideologies that are inherent in rurality. Rural ideologies are embedded within culture and are influenced by religion, conservatism, tradition, and geographical region (Tevis 1999; Swierenga 1997; Mookherjee 1995; Seligmann 1995; Grasmick et al. 1990; Hobson 2000; Davidson, Pyle, and Reyes 1995). Sociolocultural ideologies are pervasive with regard to cultural hegemony because of its ubiquitous relationship with rurality. Ideological influences that are prevalent within the cultural contexts of rurality produce a great degree of hegemony (Grasmick et al. 1990; Hobson 2000; Guizzardi 1976; Brock 1996; Shibley 1991; Torres 1992).

Sociocultural ideologies embrace rurality and thus, affect experiences of people encountering that culture. Persons affected by HIV/AIDS that inhabit areas where rural sociocultural ideologies are present are likely to experience their disease within the context of prevailing beliefs (Kearns 1996). In consequence, if ideologies that are present within the rural culture rest on religion, conservatism, and tradition, persons with HIV/AIDS will be seen in a negative and deviant context; because of the relationship between deviant activities and acquiring this disease. Therefore, people that are affected by HIV/AIDS will experience this disease according to the ideologies present within the culture (Thomas and Thomas 1999; Guizzardi 1976).

When sociocultural ideologies are insidious, a cultural hegemony develops that encourages others to sustain the prevailing belief system. If HIV/AIDS is seen as a deviant disease, persons affected by it will be deemed deviant as well. Consequently, the experiences of people affected by HIV/AIDS will be reflective of the dominant system of beliefs about this disease. When this occurs cultural hegemony is created.

Cultural hegemony in the context of rurality, frame the experiences of people affected by HIV/AIDS into something meaningful. There are underlying dimensions relevant to everyone infected or affected by this disease that are embraced by rurality, because this disease is deemed deviant. The experiences that people living with HIV/AIDS must encounter when in a rural sociocultural context are embedded within the ideologies of that society or culture. Persons affected by HIV/AIDS are more likely to be aware of the prevailing cultural ideologies when engaging in social encounters than someone not affected by this disease.

Framing the experiences of the HIV/AIDS infected population, with regard to a rural context, provides a unique way in which to approach this disease particularly how those living with it experience health care, medical therapies, social support and stigma within that culture. Framing the experiences of those living with this disease in a rural sociocultural context forces a hegemonic frame from which those living with this disease must function. The ideologies that are mandated within a rural context have the potential to influence how this disease is experienced by those living with it.

Rurality and Living with HIV/AIDS

This section will address how rurality can pose barriers regarding access to and affordability of health care, adherence to and availability of needed medications, and social support. Such barriers can be life threatening to people infected with HIV/AIDS who are affeccted by ruralism (Brownlee et all 1997; Henderson 1997; McKinney 1998).

There is evidence (McGinn 1996) to suggest that people infected with HIV/AIDS are migrating from metropolitan areas to non-metropolitan areas to contend with their illness. One of the main reasons for the migration is to be with parents or other family members that can offer financial, emotional, or medical support (Buehler, Frey, and Chu 1995). Patterns of migration among people infected with HIV pose many problems especially when the migration is to a rural or non-metropolitan setting (Fordyce, Thomas, and Shum 1997; Cohn, Klein, Mohr, Horst, and Weber 1994).

The problems faced by ruralism when encountered with HIV/AIDS infected persons include fear of contagion, stigma, inadequate social services, inadequate health care services, and inadequate access to available and life-sustaining treatments (Heckman et al 1996; Bunting 1996; Voelker 1998; Brownlee et al 1997). Each of these potential problems place a great strain on HIV/AIDS infected persons and can become more difficult to cope with (Cohn et al. 1994).

The needs of people living with HIV/AIDS are overwhelming to patients and caregivers. The needs of HIV/AIDS infected individuals are multidimensional including, social and emotional support, knowledgeable health care personnel, and adequate therapies. Social and emotional support are necessary therapeutic coping strategies when living with HIV/AIDS (Friedland, Renwick and McColl 1996). Health care personnel need to have adequate knowledge of HIV/AIDS in order to provide the patient with a holistic approach to treatment. A holistic approach to treatment would involve understanding the extensive medical, social, cultural, and psychological problems that one living with HIV/AIDS continuously encounters (Eriksen 1999; Heckman et al 1996; Voelker 1998).

People living with HIV/AIDS have specific treatment regimens such as drug combination therapies which are sometimes difficult to administer in urban areas, rurality only complicates an already difficult and complex treatment regimen. Barriers to adequate care for people living with HIV/AIDS include the inability to meet any one or several of these needs. Barriers such as rural living can hinder the needs of people living with HIV/AIDS (Eskovitz and Birdwell 1996; Goicoechea-Balbona 1997; Lockman-Samkowiak 1994).

Health Care and Medical Therapies

A specific health care consumption is necessary and life sustaining to people living with HIV/AIDS. The availability of adequate health care with respect to rurality can pose barriers to those infected with HIV/AIDS (Cunningham, Mosen, Hays, Andersen, and Shapiro 1996; Frumkin and Leonard 1997; Voelker 1998; Henderson 1997). For example, physicians must be knowledgeable and understand the possible physical problems people living with HIV/AIDS may encounter. People living with HIV/AIDS require access to a type of medical care that is specific to their illness (Cunningham et al 1996; Stone, Seage, Hertz, and Epstein 1992). Often, people infected with HIV/AIDS living in areas characteristic of rurality have to rely on emergency medical treatments that are not adequate to the level of care they need in order to sustain their health when more appropriate care is not available (Henderson 1997; Himmelstein 1999; Antonovsky 1967).

Though chronic, HIV/AIDS has become an illness that is a controllable health condition, since the initial introduction of the epidemic in the early 1980's. However, the proper therapies and medical care must be obtainable. In order to control the chronic nature of HIV/AIDS, one must have access to proper medical care and drug regimens (Beaudin and Chambre 1996; Weitz 1991).

Often, it is not just the limited knowledge about HIV/AIDS among general practitioners within the rural context that is problematic. Patients that have been diagnosed with HIV/AIDS and are seeking treatment or those that have not been officially diagnosed, may not seek care within the rural context due to the stigma that is associated with this disease and the fear regarding breaches in confidentiality. The rural context poses barriers to those that are infected and need to be treated for this disease because the fear of this disease and those living with it is greater in those areas (Heckman et al. 1996).

The cost of care for a patient with HIV per year in 1992 was $10,000, for an AIDS patient it was $38,000, or a lifetime cost of approximately $100,000 (Frumkin and Leonard 1997; Hellinger 1983). The cost of care for an HIV/AIDS patient today is likely to have risen since then, given the invention of combination therapies and other new medicinal treatments which are very costly.

The cost of adequately treating people living with HIV/AIDS is very high. If the patient is not regularly receiving adequate ambulatory health care or does not have adequate health insurance, the cost of health care becomes inflated (Nykamp, Barnett, Lago, Parham, Fernandez 1997). Living within the rural context where one may not have access to less costly means for getting their needed medications, must purchase their medications at pharmacies that are not equipped to fill such prescriptions(Williams and Collins 1999). It is often costly to the pharmacist and even more so to their clientele (Katz, Draugalis, and Lai 1995). The HIV/AIDS patient must also deal with the stigma of getting prescriptions filled in pharmacies where rural ideologies are present.

Those living with HIV/AIDS must not only contend with the difficulties of their disease but the bureaucratic structure of getting treatment for their disease as well. Accessing the systems in areas that are not equipped to deal with the nature of this disease can cause additional stress for those that are living with this disease who must utilize these systems if they are to survive.

There is also a limited number of physicians trained to treat people that are living with HIV/AIDS, especially in the rural context. The area where this study was conducted has a clinic that specializes in treating people that are living with HIV/AIDS. However, there are still a limited number of physicians that are specifically trained to treat this disease. Many of those that are treating people living with HIV/AIDS are doing so because the need has continued to rise within the area, but not because it is their area of expertise.

Many areas are already burdened by a dearth of physicians in general, let alone specialists (Schroeder and Beachler 1995). Rural living, where such a shortage of health care practitioners is likely to occur, particularly specialists, poses a burden on such an area in terms of adequate and affordable health care for people living with HIV/AIDS (Voelker 1998; Fuchs 1997; White 1994; Ferguson 1994). People living with HIV/AIDS add to this burden by residing in places where there are few practicing physicians that are specifically trained to treat HIV/AIDS (Sherer and Goldberg 1994; Voelker 1998).

Understanding the aggregate value of health care required by people living with HIV/AIDS with regard to rurality may aid the medical community in adopting an education practice for general practitioners or those in family practice and emergency medicine to understand and address the needs of people infected with HIV/AIDS (Willard 2000; Andrulis 1998; Goicoechea 1997). An increased attempt among general practitioners to understand this disease may aid in people that are living with it to access proper health care (Vladeck 1983).

People living with HIV/AIDS in rural areas are often limited in the kind of health care decisions they can make, due to inadequate, unavailable, or conservative services. Since there are fewer physicians in areas embraced by rurality who are specialized in treating HIV/AIDS, there are many potential health problems that may arise for someone infected with HIV/AIDS if the physician is unaware of the medical conditions associated with this disease (Shreffler 1996; Carwein, Sabo, and Berry 1993). Although, this disease is manageable if HIV/AIDS patients are allowed adequate treatments, see a physician regularly, and obtain proper diagnoses, rural areas may have to adopt alternative approaches to encouraging patients to seek and maintain health care services, as well as to encourage physicians to increase their knowledge about HIV/AIDS and to maintain it (Pristave, Becker, and McCarthy 1995; Berry and Seavey 1994).

The relationship between an HIV/AIDS patient and their physician is an important dynamic in health care quality. It is reported that a shift is occurring in the doctor/patient paradigm among patients in general. Physicians have become less paternalistic and are allowing patients to become active in their health care decisions (Cockerham 1993; Catalan, Brener, Andrews, Day, Cullum, Hooker, and Gazzard 1994). These are important issues when discussing rurality as it relates to health care.

The health care setting in which rural ideologies are present, where physicians are more likely to practice medicine using the outmoded traditional paternalistic method, does not allow the physician/patient medical encounter to become a setting in which there is a holistic approach to medical treatment (Lindenbaum 1992). Patients with HIV/AIDS need to be involved in their medical treatment and health care decisions because they have unique needs that require a more holistic approach to treatment (Catalan et al 1994; Christensen and Bender 1994; Ervin, Walcott-McQuigg, Chen, and Upshaw 1992; Stein 1998). Often, people that are living with this disease become very knowledgeable about their health and current medical treatments available in order to treat it. If physicians are utilizing a traditional medical model when interacting with their patients, it becomes difficult for the HIV/AIDS patient to actively participate in their health care decisions. The ability to actively facilitate health care decisions, regarding therapies or providing knowledge, can stimulate one's quality of life when living with HIV/AIDS, but at the same time can also cause problems between the physician and the patient (Burgess and Catalan 1991).

In contrast, living in rural areas may be beneficial to the HIV/AIDS infected person. Patient load may be smaller in rural areas, especially the load of patients infected with HIV/AIDS. This could have positive benefits for the psychological well-being and overall health of the patient (Voelker 1998). The ability to communicate and sustain a positive relationship with one's physician can enhance the health care quality of one's life. Such benefits may not be available in metropolitan areas where physicians are seeing only patients infected with HIV/AIDS, and have an increased patient load.

The HIV/AIDS infected person living in a rural area, if able to see a physician locally, may benefit both psychologically and physically by having a healthy relationship with his or her physician. This may be an important shift in urban to rural migration of people living with HIV/AIDS (McGinn 1996).

Social Support

Social support may be defined simply as resources provided by social interactions with people. House (1981) has defined social support as "an interpersonal transaction involving socioemotional or instrumental aid in the following ways: 1) emotional concern (liking, love, empathy), 2) instrumental aid (goods and services), 3) information (about the environment), or 4) appraisal (information relevant to self evaluation)" (p. 39). One's system of social support can include either or both socioemotional aid or instrumental aid (Thoits 1982).

People who provide resources particularly in terms of HIV/AIDS may be health care personnel, the community, organizations, family members, care takers, religious affiliations, support groups and friends. These people provide resources, emotional and social support, and expressions of empathy and acceptance (Johnston, Stall, and Smith 1998; Jankowski, Videka-Sherman, and Laquidara-Dickinson 1996). Some social support networks may be more professional and others more intimate (Abbey, Abramis, and Caplan 1985). However, both types of social support are necessary for the person living with HIV/AIDS.

For instance, people living with this disease must interact with organizations and health care providers that are equipped in dealing with HIV/AIDS. In order for many people living with this disease, especially those that do not have insurance and/or have limited incomes, to receive health care, they must participate or interact with organizations that provide (Ryan White) funding for needs such as health care, medical therapies, psychological well-being, dental care, transportation, etc. This type of professional support is necessary if one is to receive Ryan White monies for any of these needs.

Social support may also available in the form of support groups. This type of support may be beneficial to the person infected or affected by HIV/AIDS that need to share information or receive additional information regarding this disease.

For people infected with HIV/AIDS that reside in a rural context, both types of social support may not be present. If there is a lack of one form of social support, the physical and mental health of the HIV/AIDS infected individual may suffer as well as their health care and therapy needs (Sherbourne et al. 2000; Bor and Elford 1998; Jankowski et al. 1996; Ganster and Victor 1988; Cassel 1974). Rurality may worsen the absence of social support provided to people living with HIV/AIDS (Goicoechea-Balbona 1997; Turner, Pearlin, and Mullan 1998).

Social support within the rural context, that may not be familiar with the needs of people living with HIV/AIDS or may not be aware that the need exists, is often inadequate when dealing with individuals infected with this disease (Mancoske 1997: Kadushin 1996). Community social support networks are often inadequate in dealing with issues surrounding HIV/AIDS because of a lack of psychosocial and health care resources and the social stigma associated with living with HIV/AIDS in such areas. These issues cultivate a lack of community support as well as decrease the likelihood of obtaining adequate health care and psychosocial resources for those living with HIV/AIDS in rural areas (McGinn 1996; Sherbourne et al. 2000).

Social stigma with regard to HIV/AIDS is often the result of negative associations with deviant behavior, such as, homosexuality and IV drug use, fear of contagion, and fear of death and dying (Hays et al. 1998; Kadushin 1996; Blendon and Donelan 1988; Coates et al. 1990; Kegeles et al. 1989). People living with HIV/AIDS as well as their families may have no community resources on which they can rely within the rural context. If there were more support in the rural context, people living with this disease may find it easier to access and utilize the resources that are available through HIV/AIDS funding organizations.

In addition, providing more resources for the general population about this disease as well as those who are living with it, may allow for a better understanding of HIV/AIDS, thus potentially reducing the stigma associated with it. In areas where negative ideologies prevail about diseases like HIV/AIDS they are more apt to breed hegemonic influences when providing social support services.

Responses such as these may decrease the psychological well-being and, in turn, hinder the health of persons living with HIV/AIDS that must also deal with issues of rurality (Jankowski et al. 1996; Grant and Ostrow 1995; Hays et al. 1998; Gangster and Victor 1988). The HIV/AIDS patient may be compelled to not get their prescriptions filled in a local area but drive to another area where they are not known, etc.

Since there are fewer people infected with HIV/AIDS residing in rural areas, as opposed to large metropolitan areas, support groups are not likely to be present or not likely to be well advocated due to fear of exposure and stigmatization. People living with HIV/AIDS need support services whether they are proposed by community organizations, health care personnel, by individuals living with HIV/AIDS, or by families involved in HIV/AIDS care taking. Making areas characterized by rural ideologies aware of HIV/AIDS related issues could foster support networks for those living with this illness. However, hegemonic influences are more likely to perpetuate negative images about this disease and those affected by it than to promote the positive implementation of social support networks (Sowell and Christensen 1996; Fordyce 1997; Kearns 1996; Thomas and Thomas 1999).

Community support may also be the only network for some people infected with HIV/AIDS. In some cases, family members of people infected with HIV/AIDS may be ashamed or embarrassed by other family members' HIV status. This could pose additional problems and burdens on the HIV/AIDS infected person. If the family of an HIV/AIDS infected person neglects them, the only support network available to them is often through community resources. Persons infected with HIV/AIDS may be reluctant to seek those support services, after having had their family turn them away.

Also, the person infected with HIV/AIDS may not inform family members of his or her HIV status thus having to rely solely on other forms of social support to cope with their illness. This happens quite often given the stigma associated with this disease, especially if the infected person has acquired HIV/AIDS through deviant means, such as sexual transmission or drug use.

Social and emotional support are important components to quality of life among people living with HIV/AIDS. Quality of life can be stimulated by the availability of social and emotional support networks. These networks can be made up of family, friends, community outreach programs, and health care personnel (Friedland et al 1996). In order to understand HIV/AIDS coupled with the issues and problems of rurality and hegemony that people affected by this disease must contend, the population living with HIV/AIDS must be approached if community support is to be secured.

Living in an area that embraces rurality makes it very difficult for people with HIV/AIDS to fully integrate into society because the rural culture may lack the knowledge about the disease as well as what those living with it experience. Cultural hegemony is present when the people affected by HIV/AIDS alter their lives and behavior when they encounter others. Those that are affected by HIV/AIDS must suffer because of the prevailing cultural ideologies present within society.

The stigma associated with HIV/AIDS is likely to be present regardless of geographical location (Quam 1990). However, it appears to be stronger in the areas that have smaller populations, those that are geographically isolated, or those that adhere to sociocultural ideologies (which again, may have very little to do with population size). The area where most of the interviews for this thesis were conducted would be considered a densely populated area, however people affected by HIV/AIDS residing in that area have experienced hegemonic influences dominated by the local sociocultural ideologies. The population of the county where the data were collected is approximately 636,539. The population of the largest city in that county is approximately 472,221 (U.S. Bureau of the Census 2000). Despite the fact that the area is densely populated, the 'rural ideology' prevails.

The issues regarding health care, medical therapies, and social support have been presented and applied to the context of rurality and hegemony. Empirically understanding these problems and the degree to which persons infected with HIV/AIDS encounter and deal with them has the potential to enhance many facets from which to comprehend this disease and those living with it, as well as to suggest future modalities of treatment. These issues, however, can not be fully comprehended without some understanding of the stigma associated with HIV/AIDS.

Stigma is a very important component when attempting to grasp the abstraction of hegemony. Hegemonic influences are perpetuated by the stigma that is associated with this disease and the people affected by it. In the next section I will thoroughly address the concept of stigma to show how it relates specifically to HIV/AIDS and encourages both professional and cultural hegemony.

Stigma

Stigma, is referred to by the Greeks as, a bodily sign designed to expose something unusual and bad about the moral status of the signifier. This suggests that stigma results from the morality of an individual or his acts (Goffman 1963). Stigma is also defined as "a moral or physical blemish" or "a mental or physical characteristic that serves to identify a disease or a condition" (Mosby's Medical, Nursing, and Allied Health Dictionary, 1998). If a person engages in an act that society deems as immoral, the act itself or a result of such an act may lead society to negatively sanction the person or the act.

Stigma is a characteristic of a person that, according to the social structure, has deviated from normality and will not reach the full status of a normal member within the social structure. Goffman's work on Stigma refers to the framing of identity of a stigmatized person as a result of a person being stigmatized by others and the ability and strategies used by the stigmatized person utilizes to deal with those situations (Goffman 1963; Munch 1994). Goffman discusses three perspective's from which one may achieve a spoiled or stigmatized identity.

<u>Conceptualization of Stigma</u>

There are many different ways in which stigma has been conceptualized. Erving Goffman must be accredited for each of them. The ways in which stigma has been defined are:

> 1) "A stigma, then, is really a special kind of relationship between attribute and stereotype....which is not quite human" (Goffman 1963:4-5).

> 2) "In brief and in theory, stigma denotes one's morally spoiled identity, one's social undesirability" (Pfuhl 1980:202).
>
> 3) [As related to stigma], "we are discussing the entire field of people who are regarded negatively, some for having violated...rules, others just for being the sort of people they are or having traits that are not highly valued" (Birenbaum and Sagarin 1976:33).
>
> 4) [Stigma]......"conjures up images of blemished and discredited bodily or moral attributes that automatically exclude the bearer from the competitive game by assigning labels of inferiority" (Davis 1980:207).
>
> 5) [Stigmatized] "individuals.....have attributes that do not accord with the prevailing standards of the normal and good. They are often denigrated and avoided - openly in the case of known criminals and other transgressors, or covertly and even consciously...when the disdained person is an innocent victim of misfortune" (Katz 1981:1).

These definitions suggest that an inequality exists between those who are stigmatized and those who are not. Stigma is construed as an ideology to explain inferiority and account for the danger one represents that is rooted in inferiority (Goffman 1963). Stigmatization can occur on the basis of sex/gender, race, income, age, or sexual orientation. Goffman (1963) equates stigma with "undesirable differentness", such as 1) physical deformities; 2) blemishes of individual character; and 3) tribal stigmas of race, religion, etc. (pg. 4-5). Specifically with regard to HIV/AIDS, most people having acquired the disease are stigmatized based on their 1) being carriers of it; 2) how they contracted it; and 3) their race and sex/gender.

Goffman does not specify a stigma that relates to disease. Although he does focus on the physical deformities as a result of disease. Susan Sontag (1989), however, does focus on the historical context of stigma with regard to specific illnesses. In order to understand how stigma relates specifically to diseases, one must look historically at the association of stigma to disease.

Sontag (1989) says that "it seems that societies need to have one illness which becomes identified with evil, and attaches blame to its 'victims', but it is hard to be obsessed with more than one" (pg.104). The 'Blaming the victim' approach is very prevalent when reflecting on the carriers of HIV/AIDS.

According to Sontag (1989) tuberculosis and cancer were once illnesses that were associated with evil and that stigmatized disease carriers. These diseases were thought to be contagious and people feared others who were unfortunate enough to have acquired them. Even today cancer is a feared word, but not as feared as HIV/AIDS. There is no known cure or "magic bullet" for cancer, nor for HIV/AIDS, both have the future potential to result in death, probably at about the same rate (given the invention of cocktail therapies for persons with HIV/AIDS). The prognosis for both diseases depends upon the degree of invasion inside the body. Of course, one can prescribe to treatment regimens that aid in diminishing the amount of disease progression in the body, but there is something significant in the understanding of the diagnosis - stigma.

What was once thought of as "diseases of passion," TB and cancer, have been replaced by HIV/AIDS. The stigma of a disease itself is rooted in the social construction of its contagion. TB was once thought to stem from too much passion, while cancer was thought to stem from insufficient or repressed passion (Sontag 1978; Fife and Wright 1999). The discovery of HIV/AIDS has historically been associated with homosexuality and white males, with intravenous drug use and black males and females, and with heterosexual promiscuity and white and black females (Anderson 1992, Stine 1993, Frumkin and Leonard 1997).

Sontag (1989) suggests that identifying a disease with certain at risk groups implies deviance by blaming the victim for their chosen lifestyle. The behaviors that result in HIV/AIDS are more than just weakness, they are indulgence and delinquency. Therefore, HIV/AIDS is the most harshly judged of all diseases in contemporary society because of its perversity. This disease is seen as a punishment for engaging in deviant activities (Quam 1990).

The association of HIV/AIDS with deviant sexual activity, excessive unprotected sexual activity, and illicit IV drug use, creates a multi-dimensional aspect of stigma from which to analyze this disease. Acquiring HIV/AIDS through any of these deviant means requires more blame than having contracted the disease as an ‘innocent victim’ (blood transfusion, having a promiscuous partner/spouse, or during birth) (Crandall, Glor, and Britt 1997; Leiker, Taub, and Gast 1995). If this is the case, it would seem logical that the ‘innocent victims’ of HIV/AIDS might experience the disease much differently, particularly with regard to the role of stigma.

As discussed earlier, stigma is largely related to group inferiority and inequality. So those that identify or belong to certain groups, and have a particular status within society, have access to different benefits or luxuries that society deems significant. If a person or group is stigmatized within a society, that person or group would have less access to the benefits or luxuries based on the status of the group that deems themselves as superior.

Goffman's Three Stigmatizing Identities

Stigmatized persons have more trouble establishing identities than the person who is considered normal by society. Persons who are stigmatized are considered marginal members of society. Therefore, they experience stigma according to the marginal identity that society has assigned them. There are three aspects of identity upon which Goffman (1963) enumerates. They are the social identity, the personal identity, and the ego identity. Each is reflective in understanding stigma particularly with regard to those affected by HIV/AIDS.

Social Identity

Social identity is the foundation from which persons augment stigmatization (Goffman 1963). There are two types of social identity, including *virtual* and *actual* social identity. *Virtual social identity* is how a person should be according to prescribed social categories. In this case, a person should not be a carrier of feared chronic diseases, one should not engage in homosexual relations or in sexual relations with more than one partner, and one should not inject drugs for euphoric inducing pleasures. Instead, one should ideologically adopt religious values, be middle-class, maintain traditional family values, be heterosexual, and maintain good health (Goffman 1963; Tevis 1999; Mookherjee 1995; Grasmick 1990).

Actual social identity is the degree to which one is seen as conforming or deviating from the expectations based on one's virtual social identity. So if one is not like one should be, then one's actual social identity would be jeopardized. Anyone who has HIV/AIDS, who is homosexual, or who uses IV drugs, etc. would be violating the expectations brought about by society's virtual social identity. The actual social identity one occupies is placed in reference to the societies' virtual social identity and if one does not meet the expectations of society then one is stigmatized (Goffman 1963; Munch 1994).

A person is stigmatized if they are not seen as a fully functioning person in society. Even when the stigma is not known or can be hidden (such as HIV/AIDS) the infected person(s) still carry with them an imperil that might at any point be discredited because of the stigma of having HIV/AIDS. One must be able to manage their stigma (or HIV/AIDS status) so that they are not revealed and can, to some degree, participate as a fully responsible person with a normal life. This degree of concealment creates a great burden for the stigmatized individual as well as those with which the individual must interact.

The social aspect of stigmatized identities are embedded within the culture of society. Persons are considered marginal characters in this culture when they are economically disadvantaged, diseased, or deviant because of the stigma attached to these identities. Most people would view the individual with HIV/AIDS as very different from the prescribed virtual identity that the social structure deems as important.

A person infected with HIV/AIDS, when met with the challenge of a society's 'virtual social identity', are likely to deviate substantially from that, since they are carrying a disease that most of society fears was likely contracted through deviant means. For those infected persons who did not contract the disease through deviant means they are still likely to suffer, although maybe not to the same degree, from having a spoiled identity when society compares them to the 'virtual social identity' present within the culture.

Personal identity does not become challenged until viable information is leaked with regard to a person's HIV/AIDS status. When this occurs, the infected person may do whatever they can to keep from any further revelation of their disease status. Goffman's (1963) second aspect of stigmatized identities is the personal identity.

Personal Identity

Personal identity involves the degree to which a potentially stigmatized person may become stigmatized due to revealing something about his or her own personal biography. For example, a person who is infected with HIV/AIDS that looks healthy and does not have to see a physician but twice a year, might easily conceal his or her status because others would not be suspicious of the person concealing a chronic disease. The person might have to give an account for visiting a physician, but if the visits are six months apart, suspicion should not arise and the person could continue to conceal their status. In other words, the less visible or apparent the stigma, the less likely one will be stigmatized and can lead as normal of a life as is possible. The person could establish a positive personal identity (Goffman 1963; Munch 1994).

However, the amount of energy consumed in concealing one's HIV/AIDS status might cause a person to have ongoing personal conflicts. Managing a stigma, such as HIV/AIDS, can be a burden. The infected person has to constantly be concerned about perceptions others have of their physician visits, or the amount of medication they are taking. If an infected person is working, concealing this disease can become very difficult, because they must take time from work to see their physician. Also, co-workers might concern themselves with the infected persons business during office hours, especially if the infected person is taking several prescription medications throughout the work day. Work relations are one of many concerns about personal stigmatizing identities that the HIV/AIDS infected person must manage. Goffman (1963) describes the third aspect of stigmatizing identities as the ego identity.

Ego Identity

The stigmatized person is always concerned with how to see himself or herself. Coping with a stigma can have a significant impact on the way one sees himself or herself. If the social structure is more accepting of a given stigma it is likely that the person who carries the stigma will have a more positive perception of himself or herself than a stigma that society chooses to overlook because the stigma carries such negative connotations (Goffman 1963; Munch 1994).

HIV/AIDS is probably the most stigmatizing condition of any, given the level of understanding throughout our culture. There are no commercials, flyers, or advertisements in mainstream society that promote a positive outlook for HIV/AIDS infected persons. The media, during AIDS awareness week, might promote being tested for the disease, which is about the extent to which society would allow any positive promotion of HIV/AIDS. The degree to which one who is infected with HIV/AIDS participates in 'in-group', (associating with those that share positive statuses), activities may benefit by becoming more accepting of the stigmatized self (Goffman 1963).

Information control, which Goffman describes as the most basic element of managing stigma, is also the most crucial if one is to maintain perceptions of a virtual social identity. Because the virtual social identity is what is supported by society, a person must manage their stigma so it is not revealed and their identity spoiled. Being infected with HIV/AIDS requires an ability to control information, if not with everyone, at least with those that are not worthy of obtaining one's HIV/AIDS status.

Chapter Summary

In this thesis, the focus is on the professional and cultural hegemonic influences as they are experienced by HIV/AIDS infected persons. These are addressed in the context of the medical community, HIV/AIDS support organizations, and rural sociocultural ideologies. Each of these contexts helps frame the experiences of people living with HIV/AIDS with regard to health care, medical therapies, social support, and stigma. HIV/AIDS infected persons would be deemed as socially inept, given the virtual social identity of rural ideology, and they would thus be stigmatized because of their inability to meet the conservatively prescribed virtual social identity present within this culture. The HIV/AIDS infected person(s) residing in a context characterized by rural ideologies would be stigmatized because of their inferior minority status in the community (regardless of how they contracted the disease). If an infected person contracted the disease through deviant means (and the community had access to that information or assumed they did) the person would be further stigmatized. Together, the multi-dimensional aspect of stigma with regard to HIV/AIDS in the rural sociocultural context has the capacity to 1) hinder one from seeking health care (due to fear of exposure and ridicule), thus jeopardizing that person's life and health; 2) create a hegemonic atmosphere between the medical community, HIV/AIDS funding organizations and the community; 3) create a fear of contagion within the community; and 4) lessen the number of social support networks to which one may have access. All of these affect the experiences of people living with HIV/AIDS and may thus, discourage them from seeking health care, social support services, which perpetuates their marginal identity status.

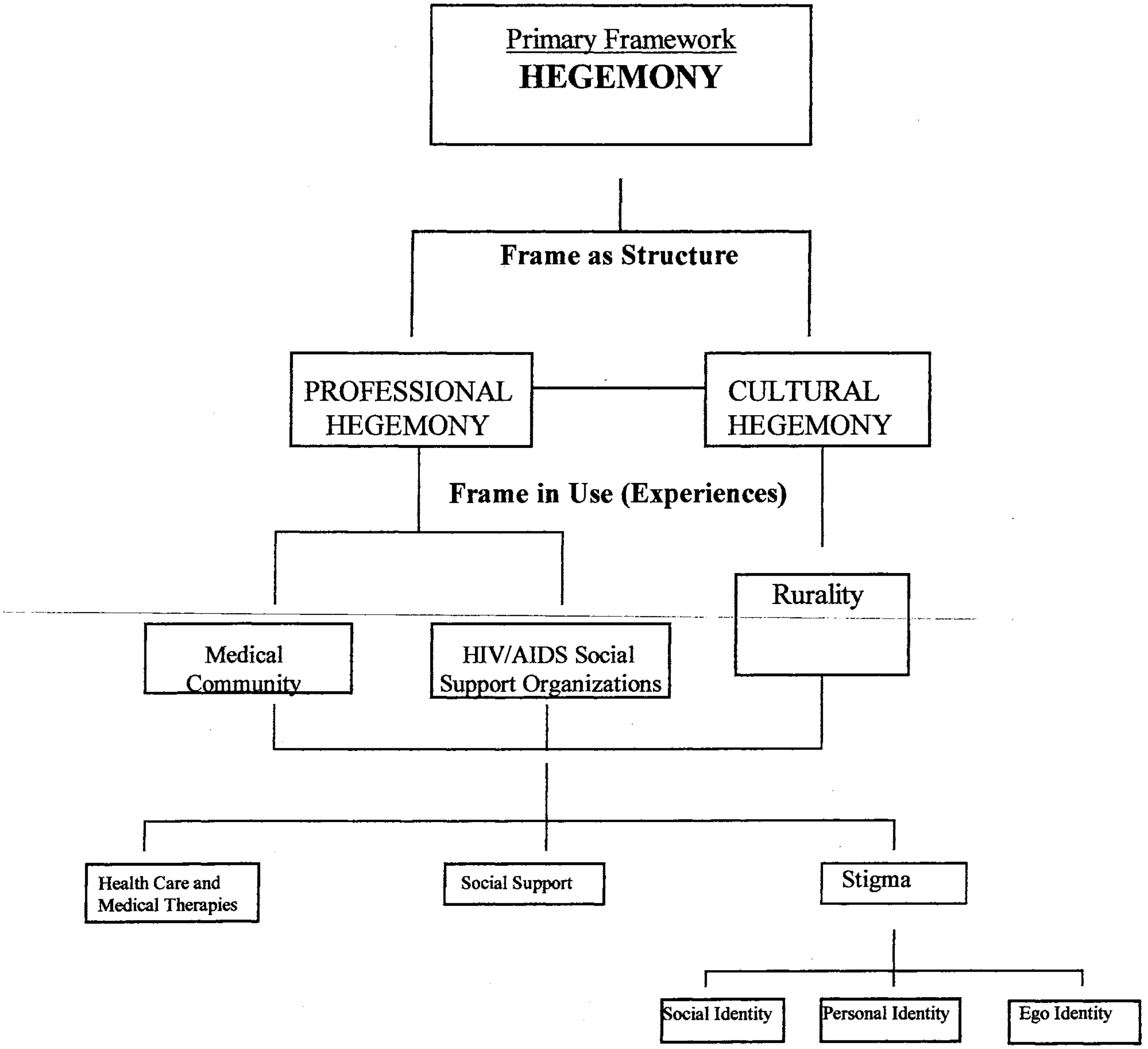
Hegemony is a significant framework from which to approach and understand the issues relevant to those living with HIV/AIDS. Health care, medical therapies, social support, and stigma are critical issues with regard to someone living with HIV/AIDS. People with HIV/AIDS will encounter distinctive experiences with these issues when professional and cultural hegemonic influences prevail in a society. This project was conducted for the purpose of exploring the lives and experiences of people living with HIV/AIDS using hegemony as a primary framework from which to interpret those experiences.

A discussion of hegemony in the context of culture is important, and provided in addition to professional hegemony, so that a supplemental understanding about the enforcement of sociocultural ideologies that dominate in society are tacitly followed. Both types of hegemony are important components to comprehending the experiences of people living with HIV/AIDS.

Understanding this population, particularly the impact of hegemony on their needs, should be addressed from a sociological perspective. There is currently no sociological literature that looks specifically at professional and cultural hegemony and people living with HIV/AIDS. It is evident, by reading this chapter, that the experiences of people infected with HIV/AIDS are impacted by hegemonic influences from the medical community, social support organizations, and the culture where they reside. Framing the experiences of people living with HIV/AIDS in the context of professional and cultural hegemony offers a prolific interpretation of their social encounters.

The research questions that are being addressed in this study are: 1) what experiences do individuals infected with HIV/AIDS encounter within the context of professional and cultural hegemony; 2) How does the framing of these experiences impact their understanding of these hegemonic influences; 3) Is professional or cultural hegemony more important to understanding the experiences a person infected with HIV/AIDS encounters; and 4) Are experiences with health care, medical therapies, social support, and stigma adequate when framed within the context of professional and cultural hegemony. A conceptual model is provided on the following page that summarizes this chapter.

FIGURE I. Conceptual Framework Model



CHAPTER FOUR

RESEARCH METHODOLOGY

Introduction

This research project attempts to understand the lives and experiences of people living with HIV/AIDS in a mid-south region of the United States. These experiences are framed within the context of hegemony. This thesis is an attempt to expand the literature on this concept specifically as it applies to professional and cultural influences in order to expose some of the issues related to the experiences of people infected with HIV/AIDS.

This research project is a qualitative study based on the lives and experiences of people living with HIV/AIDS. The primary data came from interviews with HIV/AIDS infected individuals. Semi-structured, in-depth interviews were conducted with 27 respondents. The interviews were tape recorded and transcribed. The following will be discussed in this chapter 1) qualitative methods, 2) in-depth interviews, 3) participant observation, 4) ethical issues, and 5) gaining access to the population.

Qualitative Methodology

The methodologies used in this project are embedded in symbolic interactionism. Denzin (1970) indicates that society contributes to reflections of interactions through the symbols learned and communicated through the socialization process and in settings where behavior occurs. In order to understand what people experience in the social world, we must understand the symbols that are communicated within the social world that prompts what people experience. The best way to do that is to study and analyze the world in its natural settings. Using an interactionist perspective to analyze the social world, allows the researcher to view how man is able to guide his own activities within it. For one to study the social world and the persons that occupy and create it, one must be able to understand that the interaction process is an emergent event. If the researcher is able to explain the emergent occurrences within the social world, through these methods, they have been successful (Blumer 1969; Greer 1969; Glaser 1978).

Qualitative methods were used in this study due to the type of research questions that were asked. When the research question(s) in a study involves understanding a phenomenon, and not just, simply, testing it, qualitative methods are the most appropriate (Douglas 1976; Lincoln and Guba 1985). Since all people living with HIV/AIDS do not have the same experiences, qualitative methodologies were the ideal mode of inquiry to use in this study.

Lincoln and Guba (1985) suggest that:

> "realities are wholes that can not be understood in isolation from their contexts, nor can they be fragmented for separate study of the parts, because of the belief that the very act of observation influences what is seen, and so the research interaction should take place with the entity-in-context for fullest understanding; because of the belief that context is crucial in deciding whether or not a finding may have meaning in some other context as well; and because of the belief in complex mutual shaping rather than linear causation" (pg. 39).

Using qualitative methods and conducting research on a topic such as HIV/AIDS, the researcher will likely get more information than he or she needs when interviewing respondents. Consequently, it allows the researcher to gain a multifaceted view about a phenomenon. Utilizing qualitative methods to study people living with HIV/AIDS thus allows the researcher to formulate a multi-dimensional representation of the abundant experiences that are encountered when living with this disease.

Qualitative methodologies are practiced in the social sciences to gain thick, rich, or detailed insight into social phenomenon (Geertz 1973, 1979). In many instances, the only way a researcher might obtain data about a particular phenomenon is through qualitative inquiry.

There are several strengths and limitations to using qualitative methods. One strength to using qualitative methods is that they are adaptable and flexible. The flexibility of interview schedules allows the researcher to adapt to the subject being interviewed or to the issues that need to be addressed (Hammersley and Atkinson 1983; Becker and Geer 1957; Blumer 1969; Denzin 1970).

Validity is another strength of qualitative methods. Providing 'thick descriptions' about a phenomenon being studied allows the researcher to give detailed illustrations based on accounts given by the respondent(s). Accounts given by respondents in a study offer comprehensive meanings about the phenomenon being studied. This type of depth is not available when using quantitative methods, which often only attempts to define concepts rather than giving in depth explanations about them (Tittle and Hill 1967; Blumer 1969; Geertz 1973). Maxwell (1996) indicates that validity:

> "is not a commodity that can be purchased with methodological techniques. Instead, it depends on the relationship of your conclusions to the real world, and there are no methods that can assure you that you have adequately grasped those aspects of the world that you are studying" (p. 86).

The limitations in qualitative methodologies include reactivity, reliability, and generalizability. Qualitative work has been criticized on the assumption that the findings of a study are influenced by the researcher. In qualitative research, *reactivity,* or the influence of the researcher on the individuals in a study is difficult, if not impossible, to eliminate. Hammersley and Atkinson (1983) suggest that correcting this problem lies in understanding this influence rather than trying to eliminate it.

In recognition of the problems with reliability and reactivity in a qualitative study, I provided a copy of this project to one of the individuals that participated. I asked that participant to read the entire project, and to focus specifically on the analysis. I wanted to insure that reactivity did not completely interfere with my interpretation.

Qualitative methods have been discredited because they do not meet the assumptions of reliability and generalizability that social scientists are encouraged to pursue and achieve. The problem with qualitative methods meeting the assumption of reliability lies in the personal nature of the interpretation. A researcher conducting a study may observe and analyze a phenomenon in a different way than another researcher using the same data. This is where symbolic understanding and interpretation separate qualitative and quantitative methods (Blumer 1969; Lofland and Lofland 1984). The data collected in a study are analyzed according to the interpretation of the researcher. It is unlikely that a study of this nature could be completely and identically replicated by another researcher to the point that the same interpretation of the results and observations are given. This is the uniqueness of utilizing qualitative methods.

Generalizability is another criticism about qualitative methods. Since qualitative research generally includes such a small number of subjects, using probability sampling would not be useful. Because qualitative methodologies do not employ probability sampling in the research design, no explicit claims about generalizing to a larger population can be made. However, qualitative designs can abdicate themselves to internal generalizability that occurs within the setting or the group being studied (Maxwell 1986; Cook and Campbell 1979).

In-depth interviews were used as the primary source of data collection due to the extensive amount of information one can obtain by utilizing this method of inquiry. A quantitative approach to this project could have been applied, however, it would not yield the depth and amount of information necessary to make assumptions about the HIV/AIDS population. It is appropriate that, since, this project is testing no specific hypotheses, a qualitative approach be used for this study.

In-Depth Interviews

A qualitative approach was implemented to gain an interactive understanding of the concept hegemony as it relates to experiences with health care, medical therapies, social support, and stigma among people living with HIV/AIDS in the mid-south. Twenty-seven in-depth interviews were conducted for this study. There were seven females and twenty males that participated in this study. The subjects in the study are demographically represented in table VII.

Table VII. Demographics of subjects in the study.

	Males	**Females**	**TOTAL**
White	13	6	19
Black	3	0	3
Hispanic	2	1	3
Native American	2	0	2
TOTAL	20	7	**27**

The interviews were tape recorded and notes were taken as a back up. The IRB approved the tape-recorded interviews because there were few ethical concerns (see appendix F). The tape recorded interviews were transcribed verbatim so that the data could be reported accurately. Accurate reporting of the data when using qualitative methods, is necessary if validity is to be achieved (Maxwell 1986). It was necessary to record the interviews given the sensitive nature of the issues that were discussed during the interview. I was able to devote my time listening to the person being interviewed rather than constantly being engaged in note-taking.

The interviews lasted from 1 to 3 hours. On average, the interviews lasted two hours, with the female subjects having the longest interviews. The interviews were conducted at an agreed upon location. On all but two occasions, I met the subjects at their home. The other two subjects I met in restaurants during off peak hours. I made it clear to the subjects that I would travel so as to avoid interviewing over the phone.

The interview schedule that I used initially for this study was revised after eleven interviews. I began to realize that I was not getting the information that I wanted. I also realized that it was difficult to avoid the subjects' entire HIV/AIDS history. Once I realized that their HIV/AIDS stories were very relevant and unavoidable, I altered the interview schedule to reflect that. I wanted all the information that I could get to understand their experiences with this disease and hegemony. The questionnaire in appendix A is the initial interview schedule. The revised interview schedule is in appendix E. Although, the number of questions asked during the interview were decreased, I was still able to get at the health care and social support information necessary for this study, and at the same time, I was able to obtain additional information that might have otherwise been omitted had I not changed the questions.

The transcribed data were coded according to the following categories: health care and medical therapies, social support, and stigma. Quotations from the transcribed interviews were coded according to these three main categories and then recoded according to particular sub-categories within the main category.

Participant Observation

Participant observation was also employed in this study. Participant observation was used during the interviews, at support groups meetings, the HIV/AIDS food pantry, and at the HIV/AIDS Health Care Consortium. By obtaining these observations my analyses of this phenomenon were more inclusive. Because this method only accompanies that of the interview, there will not be a detailed description of the observational accounts, however, it did allow me to gain additional insight that otherwise might not have been revealed.

I engaged in both the 'participant-as-observer' and 'observer-as-participant' roles (Denzin 1970). During the interviews, I took on the role of the 'observer-as-participant'. Due to the nature of interviews, it is not uncommon to only see the subject once and to collect the information necessary during that encounter. I engaged in the role of 'participant-as-observer' during my encounters with support groups, while attending the consortium meeting, and while recruiting participants at the food pantry. I made myself known in each of those encounters, although I was able to participate more acceptably in the support groups and at the food pantry than at the consortium meeting.

During my encounters with the support group, I was able to fully integrate with the group. I was allowed to introduce myself and to freely discuss issues with the group. I was very well accepted during the support group meetings. While at the food pantry, I interacted with the clients and the volunteers. I answered questions about my study, handed out flyers, and talked to many people that I had met at previous engagements.

While visiting the monthly consortium meeting, I was able to sit and observe interactions between the state health department, the state HIV/AIDS organizations, physicians, and the health care consumers. I sat in on the needs assessment committee meeting and observed as individuals from these organizations discussed the statewide needs assessment that was being conducted by the University of Oklahoma, School of Nursing. This consortium met for an entire day and I only attended one meeting. I was watched very closely throughout the entire meeting and I never said a word. It has added a very interesting piece to my analyses while attempting to understand the experiences of people living with HIV/AIDS when framing those experiences in hegemony.

Gaining Access to the HIV/AIDS Population in the Mid-South

Gaining access to any population that one chooses to study can be difficult. There are issues that the researcher must address before beginning a research project. These issues include trust, especially with regard to the population that is being accessed (Johnson 1975). Gaining access to the HIV/AIDS infected population, in itself, is difficult, but when coupled with accessing this population within a rural sociocultural context, gathering data can potentially become a problem.

The first attempt at trying to gain access to this population in a rural area took place in 1997. I discovered that gaining access to the HIV/AIDS infected population in rural areas was a barrier in itself. This barrier is what encouraged me to pursue this topic further, as I was determined to get to this population somehow. My focus remained on the rural context because I thought that it was a significant factor in my inability to gain access and get to this specific HIV/AIDS infected population.

In the fall of 1999 I placed an advertisement in the *Gayly Oklahoman*, after carefully reviewing the demographics of their readers, (see Appendix D, advertisement), to avoid the intervention of any large HIV/AIDS associated organizations in the area. I thought that by placing this advertisement, I would get to more people within this population that I might not otherwise reach if I were only to go through the large HIV/AIDS organizations. The advertisement ran in 5 issues (October 1st and 15th, 1999; January 1st and 15th, 2000; and February 1st, 2000) for a cost of $293.96. The paper reaches approximately 66,000 readers per month in a four state area. The response from the advertisement, however, was not as good as I had anticipated.

I also gained access to the population by mailing flyers to small, non-profit organizations such as RAIN (Regional AIDS Interfaith Network); the local HIV/AIDS food pantry (which I also visited), and to places that offered low income housing for people living with HIV/AIDS. During October I also contacted a large support group asking for permission to attend their monthly meeting to promote my project. I attended their meeting in November, 1999 and February, 2000. I later mailed flyers to the large HIV/AIDS organizations in the state and to other interest groups (see flyer appendix C).

There were responses from all of these resources. Had I not exhausted each of them, the number of people included in this project would be much less. It is still perplexing, however, that even though this many resources were used, there were only twenty-seven participants included in this project. Many of the participants that were interviewed stressed there desire to be included in this project and to tell their story. It seems that there would be many more people that would also like to tell their stories but did not~~. This indicates that there are many issues surrounding one's~~ decision to participate in such a project, especially when the populations being accessed is characterized by rural ideologies.

Gaining access to this population within the rural context has energized many thoughts with regard to this disease. Namely, understanding this disease and those that are experiencing it within this context. Pursuing this topic and overcoming the barriers to accessing this population in the mid-south has brought about a perspective and understanding that might not have been revealed.

Ethical Issues

This project did not pose any ethical concerns despite the sensitive nature of the issues being studied. The participants who choose to participate in this study were assured anonymity and confidentiality with regard to their participation and responses. The participants were given the opportunity to decline responding to questions that they found disturbing. The participants were required to sign a consent form (see appendix B). The consent form served as a reminder to the participant about the confidential nature of the study and who to contact if they decided to withdraw their responses or if they had any additional questions. This study was reviewed by the OSU Institutional Review Board and was approved. See the IRB approval letter in appendix F.

The methods employed in this study allowed me to explore the impact of hegemony on experiences of health care and medical therapies, social support, and stigma among people living with HIV/AIDS. Using qualitative methods for this project has allowed me to gain an understanding of people living with HIV/AIDS in this region and the impediments that they encounter. Had I used other methodologies to explore this phenomenon, I would not have gotten the rich descriptive accounts that I did using qualitative methods.

The issues discussed in this chapter will be addressed throughout the data analysis. The following chapter focuses on my interpretations of these issues as well as the accounts of the people experiencing them.

CHAPTER FIVE

ANALYSIS OF THE DATA

Introduction

This chapter will focus on the data that were gathered through in-depth interviews and through participant observation. In this chapter I will present the experiences of health care and medical therapies, social support, and stigma of people living with HIV/AIDS within the context of professional and cultural hegemony. Throughout this chapter, I will reflect on my accounts and observations that support the theoretical framework, hegemony.

Health Care and Medical Therapies

Health care is a main concern for people living with HIV/AIDS. There are issues that the geographically rural HIV/AIDS population must deal with including access to adequate health care, securing a physician that is knowledgeable about the disease, and having pharmacies that are financially able to obtain needed medications. In contrast, people that are living in a socioculturally rural area must also deal with similar issues such as procuring physicians that are knowledgeable about the disease, understanding how the disease is experienced, knowing how medications impact the body, and problems associated with getting medications.

There are a number of issues that are relevant to health care and medical therapies. In this section I will present those issues as they relate to health care and medical therapies. The issues that I will discuss in this section are; receiving adequate health care, HIV/AIDS diagnosis, insurance, discrimination, and obtaining and taking medications.

Receiving Adequate Health Care

Many physicians that are not adequately equipped to treat HIV/AIDS patients will often refer those patients to facilities that are equipped to handle such clientele. This occurs most often within the geographically rural context. Physicians that are not trained to treat HIV/AIDS often refer their patients to larger cities where there are clinics designated for HIV/AIDS patients (Shreffler 1996; Berry and Seavey 1994). One rural subject revealed that her family physician informed her of her HIV status and encouraged her to see a physician who specialized in treating this disease. She said:

> "he (the family physician) referred me to someone more knowledgeable,... he did not feel adequate in treating this disease, since I was his first HIV patient."

People that suffer other chronic illnesses such as cancer and HIV/AIDS, who reside in a rural context, are often forced to seek medical care outside of that area. However, when cancer patients seek health care in another town, they may not be as vigilant as people with HIV/AIDS because they suffer less stigma (Fife and Wright 2000).

Traveling to receive health care can be overwhelming to people that have chronic illnesses. When a patient must drive to receive adequate health care this can hinder their receiving care because often they must find transportation. Many lack the financial resources to secure their own transportation (Voelker 1998). When residing outside of town where there is no access to public transportation one must either find someone available to take them or miss their appointments. People that live within a larger area where public transportation is available, must also have the financial resources available to ride the bus or take a taxi. Because buses are usually less expensive than a taxi, it seems logical that a person who may be financially strained could afford to take a bus and not miss appointments. However, riding a bus when you are infected with HIV/AIDS can pose serious health risks because of an already deficient immune system. One female respondent had encountered an issue with transportation and funding, she said:

> “They're [the organizations] are making it hard for the consumers to use the money that was given for these [transportation] purposes. It really upsets me. I've had so many people tell me and there's one just last week that told me, that they don't have a car. If they want to get bus tokens they have to go all the way over to get the bus tokens and they don't have the money to get all the way across town to get the bus tokens. Then they have to walk like 4 or 5 blocks to get to the closest bus pickup. So, [they say] 'Heck! I'm not going (to my appointments).' They're (the HIV organizations) putting too many obstacles in the way for the consumer. [When you have to ride the bus] to get to the doctor you have to leave way ahead of time to make sure you're gonna get your appointment. If you're 15 minutes late [to the clinic], they can deny your appointment and reschedule it.”

People with HIV/AIDS that live and access medical care in the city are also discouraged in many ways. In the region, where this study was conducted, there is a large clinic that specialize in treating patients with HIV/AIDS. There are also many other hospitals and clinics including a teaching hospital, the Veterans Administration Hospital, and Baptist Hospital. Health care is available in this area. However, there is much progress needed with regard to improving the knowledge about this disease and those living with it. One respondent revealed her experience with one of the large health care facilities. She said:

> “I went to the VA Hospital. They tested me for mono. I told them that I was a drug addict and that I had used all these drugs and they should test me for HIV. They didn't. They wouldn't. I didn't look like I had HIV [they said]. They didn't know what was wrong with me. They sent me out the door with ibuprofen. That was after a 10 hour wait in the ER. I had to go back for a follow-up, so I go back. They said, No, you don't have mono because you would have lumps everywhere. I said, you should test me for HIV. There's something wrong with me, seriously wrong. They still didn't and sent me out the door with some more ibuprofen. I did

> not look like I had HIV. I didn't act like I had it. I fit their chronic PMS syndrome. Another female with chronic PMS. I hate that."

Women are often treated differently than male patients, especially those that have HIV/AIDS (Malterud 1999). Women's bodies are viewed differently than other bodies because of the traditional hegemonic role played by physicians (Foucault 1973). Women continue to experience health care with regard to sex and gender because of the role males have historically played in the medical community.

One respondent indicated that she did not like the way health care was delivered in this state, she said:

> "The state the way it is, people are going to die sooner due to lack of care. Lack of getting medication. Lack of understanding. Lack of knowledge. That's even in the medical field. I've even seen doctors run and give a patient less care because they were HIV-AIDS, and treated them like shit. Wouldn't even give them their pain medication. I think they [the physicians] are still uncaring. I think they think they are demi-gods. They are still practicing walking on water. They are not accessible. They are just trying for that perfection and they want you to believe it. 'I am God and I will rule your life. I am the one taking care of you. You will do as I say.' They told me to quit smoking. They said lose weight. Then they run and hide (and smoke). [I would think] This is killing me, that is killing you."

Another respondent suggested that there was a difference in the systems here as opposed to where he have lived previously, he said:

> "I was extremely happy with the health care in California. I am very lucky because I have been able to keep government insurance, but that expires this month. I'm really kind of nervous about using the Medicare system. I don't quite know what that is going to do. Because I am American Indian, I have access to Indian Health. Some of my prescriptions will be covered through them. I really have not accessed those 2 programs much at all. I'm a little uneasy about that. As far as health care [I have witnessed] for other people in this state, I don't look forward to this upcoming battle. I know it has not been a good road. To a lot of people there is no health care. It is just not available. In California it was all county ran, you couldn't pay them. I had full insurance, they wouldn't take it. Everything was done. It was an excellent set-up. I'm sure money and the proper use of it was why they have what they have out there. It's different here."

HIV/AIDS Diagnoses - Death Sentences

The physicians that are in this region may not be adequately prepared to provide health care for people living with HIV/AIDS (Willard 2000). With the invent and proper use of combination therapies, people are continuing to live much longer lives (Frumkin and Leonard 1997). Physicians in this region are prescribing those medications and in many cases are in clinics that are funded to provide these medications for their patients. It seems as though the physicians would see that the patients are living longer lives and not be inclined to provide their patients with an early death sentence (Curtis et al. 1999. Providing patients with death sentences in spite of advanced treatment modalities suggests that medical hegemony is present among practitioners who treat persons living with HIV/AIDS in this area.

Many participants revealed that their physicians had given them a death sentence when they were diagnosed. One male respondent said:

> "When I was diagnosed - the physician gave me the results over the phone and said you'll be lucky to be around six more months - he gave me a death sentence."

Another subject said, who was female said:

> "The medical profession has been quick sometimes to say, 'Well, this is what you've got left.' But as more of us live with the disease for longer periods of time then that is always being adjusted. Yes, you may have had 9 people that passed away in three years, but if there may be a 10th person who lived 20 years, you can't really tell someone they're only going to live 3 years.[Because] there's that 1 in 10 possibility that you might be the one that lives 20 years."

Another male subject said:

> "When I was diagnosed in [July 1999] my doctor told me to go home and make my final arrangements and get my affairs in order. I was devastated when he told me this. He told me that in 6 months I would be dead."

Many of the people that I interviewed did not accept their diagnosis as a death sentence. It is disturbing that this disease has been around nearly twenty years and there are physicians still giving their patients death sentences at the time of their diagnosis, despite the fact that there are new therapies allowing people to live longer healthier lives (Lewis 1997). HIV/AIDS is no longer deemed a terminal disease, rather it is seen as a chronic controllable illness (Beaudin and Chambre 1996).

Insurance and Discrimination

Insurance is an issue that is very prevalent within the health care system today. Treating HIV/AIDS patients add to the burden of providing health insurance given the cost of their invariable treatment and therapies (Frumkin and Leonard 1997). For people who do not have access to insurance or who do not qualify for federal funds to receive HIV/AIDS health care or drug assistance programs because of their income or non-disability status, they must pay for their own care and medications.

The prices of HIV/AIDS medication can cost from $1200 to $2000 per month. When someone with HIV is initially diagnosed, the cost of medication will vary depending upon the progression of their disease. If a person is diagnosed when they are first exposed to HIV (before their disease has progressed to AIDS), they are likely to be prescribed costly combination therapies to discourage disease progression. If a person has private insurance the cost of the medication is greatly reduced, however if a person does not have private health insurance and does not want to quit their job to receive federal assistance for medical care or drug therapies, they often don't receive health care or medication because they can't afford it.

Inadequate or no health care coverage for persons infected with HIV/AIDS can be detrimental to their health. The sooner newly infected HIV/AIDS patients seek and sustain health care and therapies, the more likely they are to remain healthy for a number of years. Those that lack adequate health care coverage are less likely to seek health care or obtain medical therapies if they don't have coverage because it is very costly.

Because health care is expensive and life-sustaining for people living with HIV/AIDS it is understandable that the health care community would want to provide services for those that have a means to provide compensation. There were several participants who suggested that their inability to pay for health care services hindered their receiving services.

There were participants who felt some discrimination because they did not have insurance. The system within which many of the respondents have had to operate discourages them from seeking health care or being able to receive medications. People accessing the health care system seem to have problems that the general population (even those that are economically disadvantaged) don't have. For those patients that have private health insurance, they can not access federal HIV/AIDS monies for clinic visits or medications. Persons infected with HIV/AIDS must 1) be on disability and receive medicare, 2) qualify economically to receive benefits from the large HIV/AIDS support organizations, or 3) have private health insurance (which many do not have). One subject (who was a gay male) revealed how the health care system deals with people who have no insurance. He said:

> "It's a fight all the time [To get care with no insurance] - the clinic I go to (a Ryan White funded clinic) they treat you like crap if you don't have insurance."

Another gay male respondent said:

> "Because I don't have insurance, I'm treated like crap. I've been through that with _____ [the HIV clinic]."

Another gay male respondent said:

> "I was in there [the clinic] one time and I said, [to the nurse] 'Well that guy just got in the room. Within 5 minutes his doctor was right there.' "Well, ____ you have to understand, he has insurance, you don't.' I went, 'Uh-oh.' In my mind, I'm like, 'That's ridiculous.' Somebody is getting paid good money. I know there are millions and millions of dollars being spent not only on research, but the assistance of us to live well and comfortably, not wealthy, but comfortable. We're treated like dirt. Does that make sense?"

In these instances, the respondents felt some discrimination. They indicated that their observations about discrimination were not due to lack of insurance, when seeking health care, but because of their lifestyle. All of these respondents were openly gay. One respondent said:

> "There is more to not getting health care than just being HIV+, it also has to do with being gay."

Another respondent said:

> "People with HIV get put aside, there doesn't seem to be enough money to treat HIV. HIV patients are not treated fairly because they are looked at differently than other patients."

Another respondent said:

> "I don't like the health care that I receive, in _______ hospital, they treat you like a dog. The threw me in a corner in a mop closet when I needed HIV treatment."

Many respondents indicated that this state has some major problems with regard to insurance and the health care system. One respondent said:

> "There are serious problems in this state. I lost my insurance. I had always paid for my medical tests until I had to put them on my insurance because they were too expensive. And then the next month [after the insurance was filed] I mysteriously did not get my payment in within the grace period, the mail must have been really

> slow that month. That was also, of course, before the law was passed where they couldn't cancel you for this type of thing [HIV]. I could get it [insurance] again if I could afford it."

Another respondent encountered a different aspect of the medical community when he visited a dental office, his experience was also negative, he said:

> "[I had scheduled a dental appointment] A lady, named Rose gave directions for me to find this place, they were a joke. How many brick building are in that area? She gave me no landmarks. No distinctions. No nothing to get to this place. I went out there for my appointment two hours early. I walked and I walked and I looked and I looked. I went through 3 or 4 buildings trying to find where I was supposed to be. I went to one. We called the actual clinic. Couldn't get in because it was busy. I said, 'Fine.' By that time I had gotten exhausted and tired, so I decided, 'Well, I'll just go home. I will call them when I get home and explain what happened.' I did. I finally got hold of them. Rose said, why didn't I make my appointment? She also said that if I do this again [I would lose my dental privileges], I explained I had gotten fatigued, I was tired from walking up and down all those hills. I told her that I was HIV- positive. She says, 'Well, sir, all of our patients have some sort of one kind or another of infection and yours is no different than the others. They made their appointment. I want to tell you if you don't make your next appointment, you will be kicked off the program.' I said, 'Is that a threat?' She goes, 'Oh, no sir.' I said, 'It sounds like a threat to me. I tried to make my appointment. I was there 2 hours early to locate it and I couldn't find it. That's not my fault.' She was just livid. I laid into her. After I hung up I was just waiting to meet the woman. I was going to say, 'Oh, you are the compassionate one.' It's just rudeness and threatening. They say in our lifestyle as it is today, we are supposed to endure as little stress as possible in our life. Stress problems can deteriorate, if you get enough of them, your health, if you don't have a very strong positive attitude. For me I have a very strong attitude. I'm very positive. For someone who is not, and there are many different attitudes out there. It could have totally devastated them. It could have put them in the hospital. I still have yet to meet the woman. I am looking forward to it. I'm not done with her yet. I [think it is] a gay issue not an AIDS issue."

Obtaining and Taking Medication

There are patients that have had to do without medications or health care and there are others that have chosen to do without these services rather than hassle with the system. One respondent indicated that he could not get free medication because he was working, and had limited insurance, he said:

> "My insurance would not cover what I needed, so I took no meds for 1 year. My mother who is an LPN (more than a mother) would swap samples of HIV meds for me."

He was forced to get medications in this manner because he could not afford them financially, but could not afford to be without them and maintain his health. Another respondent who was barely over the limit to receive federal assistance revealed a similar experience, he said:

> "If you are gonna get help with meds and health care you have to totally give up everything. You are more likely to get help if you don't have anything."

One respondent revealed that getting HIV/AIDS medications are easier now than in the past. In the past, regardless if a person lived in a city where there were many pharmacies or in a rural area where there were few, it was very difficult to get medication. He said that:

> "Prescriptions are considerably easier to get now. When I was first diagnosed I would bring a new prescription to the pharmacy and it would be a week before they could get the meds into the pharmacy. Now within a day or two the meds are there even if it's a relatively new medication. Back in the early days that wasn't the case. They just didn't have the medications in the pipeline, until they were requested. Now there's a pretty quick turnaround."

Another respondent indicated that she had trouble getting medications where she lived. She did not live in the city nor in a rural area, but indicated that she drove 40 miles to get medications, she said:

> "I have had to drive at least 40 miles sometimes to get my prescriptions filled. Here in ____, the pharmacies can't carry these medications because they are too expensive and there aren't very many people around here that need them."

There were other respondents who indicated that they had no problems purchasing medications, nor getting access to them. One respondent indicated that getting prescriptions and even paying for them was not problematic. He said:

> "I was very leery when I moved here to make sure I used a big [pharmacy] chain. When I lived here before I used the smaller pharmacy and would like to actually use those smaller pharmacies, but because of the meds [that I take] and all I choose to use a major chain of drug stores. I wouldn't use Wal-Mart over here because the pharmacist may live next door to me. The possibility is there at Eckhart too, but at Eckhart they tend to have a large turnover, most of them seem to just be there and gone."

This subject indicates that where a person chooses to get medications filled has little to do with the medication being available and more to do with the association of having to take HIV/AIDS medications and being perceived in that way by the pharmacy. The same subject continued by saying:

> "They [those taking the prescriptions to fill] look at you kinda weird sometimes. They just look quizzical, like 'wait a minute, he doesn't look gay. He doesn't look like an [IV] drug user. He looks like anybody else in this town. If he has it [HIV] then who else do I know that might?', or 'who do I know that might have it and not know it?'. In some ways I'm just about as average as they come, except for the fact that I'm HIV positive."

Being perceived in this manner is discouraging to those that are affected by this disease. Those that have HIV/AIDS may feel as though they must get their prescriptions filled at larger pharmacies or across town or in pharmacies that have a high degree of turnover just to avoid disclosing their HIV status to others.

There are other people living with HIV/AIDS that are able to get their medications through the large local HIV organizations (CarePoint) or through the local HIV/AIDS clinic. Having access to needed medications and avoiding community banter may be less dissenting for those living with this disease. One respondent who did not have to access the large HIV/AIDS organization for health care and therapies because she received VA medical benefits said:

> "I'm fortunate to have the VA and infectious disease clinic [care], which is wonderful. I get all my meds free. I get my meds, period. It's so important to take these meds everyday, and that you take them at the same time everyday, within an hour or so. It's a very strict regimen. That's the way it has to work to attack the virus. They put this cocktail together to attack that virus. It attacks that problem 3 different ways. You have to do these things. You have to have a roof over your head and be responsible and you have to have food. These things are so important. The nightmare stories that I hear about ____ [the HIV organization] trying to get meds for people. They go a couple of days without their meds. They can't afford $1,000.00. My meds alone, its way over $1,000.00 a month. I hear these horror stories and I have my meds every month. I have them. I have what's available. I can pick up the phone and I can leave a message and the doctors will call me back. I don't have to worry about the meds. I have them. I know I will have them every month. Other people that I've talked to, you can't afford to miss a days medication. [When] You can't afford them, you just can't survive. When there are agencies out there that have money and resources and they are not doing what they are supposed to be doing, it's distressing to me. My experience with _____ [the HIV organization] has been good, but I don't have to deal with them for meds or medical care."

This respondent was very fortunate to have access to services and insurance that provided her with the proper care and needed medications. She was treated much differently because she did not need to exhaust other resources to receive adequate care. There are others who must resort to alternative means for getting medications. One subject said that:

> "I hate going where I have to go (to get health care) but its the only place I can get my medications free, all you are there is a test tube and a number, and that is the way you're treated."

A person that must resort to such means in order to get care is treated very differently than those who do not have to access those services. Another respondent who utilized clinical trials in order to receive medical care said:

> "In 1997 I started clinical trials with a hospital, they focused only on the study, they did not care about me, it was not a big motivation to continue."

Accessing alternative resources for those living with this disease is often not an option if they are to stay healthy. Consequently, being treated in the manner described by these subjects does not encourage them to stay healthy either. One respondent described his experience with the HIV clinic, he said:

> "I chewed someone's ass out one day at the clinic because I was left waiting for 4-5 hours. Because of (having no insurance), and then all my meds got cut off."

Access to medications is only part of the struggle with HIV/AIDS therapies. There are many people living with this disease that are required to take numerous medications to sustain their health. They are often dissuaded by the amount of drugs consumed on a daily basis and the side effects associated with taking them. There are some people that have chosen not to take HIV/AIDS medications because of the side effects. One respondent indicated his lack of desire to take these medications by saying:

> "It's hard to maintain the desire to live, I can't take meds because they [the side effects] make me feel worse than I feel anyway. I surprised the medical community by not taking the medications and they have threatened to cut my health care."

Those living with this disease feel that they must conform to the medical community and take medications prescribed for HIV/AIDS. Many fear that they will not receive benefits from HIV/AIDS support networks, including the medical community and

HIV/AIDS organizations if they do not adhere to recommended medical regimens. The HIV/AIDS organization has threatened to cut off all services to people who choose not to take HIV/AIDS medications. In turn, people living with HIV/AIDS must make a choice to deal with repudiation from these support networks or deal with rejection from the medications.

There are people who do not take the medications because of the side effects. Several respondents described their experiences with taking HIV/AIDS medications. One female respondent said:

> "You do get discouraged and fed up with taking these pills. Sometimes you just feel like a pill factory. It gets tiring doing the same thing, taking all these pills, [you get] tired of swallowing them all. Then you're gonna have the side effects. Some people have trouble taking all their pills. Maybe it's not so much a depression, it's just taking them all the time. It's the depression of taking that pill knowing you're going to get sick. You're going to be nauseated or you're going to have diarrhea. Or you're gonna have a headache. You know that this pill, when you take it, is gonna cause this. Then the doctor will give you another pill that will help some of that. That's another pill. The first thing that comes in my mind is 'Oh my God, another pill.' Subtract, don't add or put that with another pill where I can take just one pill. You take that pill, you're thinking of all this and about all the things it's going to do. I could lose my kidneys over this pill. You're thinking 'I'm taking all this medicine to stay alive and to be able to proceed in life the best you can , but then, [I think], I'm killing myself too."

Another respondent described her experience, she said:

> "I get up in the morning. I have my coffee. I go struggle and make my coffee. I get my little thing of pills. I have my coffee. I go outside and I light a cigarette. I usually count the pills just to make sure. I set them up in the med boxes. I set 2 med boxes up. That's 2 weeks and still you can mess up on that. I usually count them to make sure that I'm taking the right amount. I sit out there [on the porch] with a pill box. I have these pills. I hate them. It's a love hate relationship going on. I'm counting my pills and I'm choking them down with coffee. Thinking, thank you for my life. This is my life now. This is my life, it's there in the little pills. It's amazing to do this. For the rest of my life I will be dependent on these."

HIV/AIDS is a very difficult disease with which to live. There is a constant struggle to maintain both mental and physical health. People that are affected by this disease often need immense support in order to deal with it. In the area where this study was conducted, it seems as though there is a significant amount of support for people that are affected by this disease. There are numerous organizations that offer support as well as one specific HIV/AIDS clinic, however when reporting the participants' experiences with health care in this region it appears as though the support is limited. In the next section of this chapter, I will describe some of the experiences with social support networks among the subjects who participated in this study.

Social Support

Social support for people living with HIV/AIDS is attained in many ways. Social support may be obtained from the medical community, from organizations that provide services exclusively to persons affected by HIV/AIDS, from family and friends, from co-workers, from support groups, and from religious affiliations (Johnston, Stall, and Smith 1998). Support networks from these resources provide emotional well being that is necessary to sustain physical health (McGinn 1996; Bor and Elford 1998).

Many people affected by HIV/AIDS become detached from support networks when their HIV/AIDS status is disclosed. People affected by this disease are careful about disclosing their status for fear of losing relationships. All of the people in this study revealed having not disclosed their status at some point for fear of losing relationships and support.

Because there are several means by which social support is obtained among people living with HIV/AIDS, this section will be presented in accordance to those. I will discuss the experiences of social support among the people in this study with regard to family, friends, coworkers, religious affiliations, and HIV/AIDS organizations. A discussion of hegemony as it relates to these support networks will be provided at the end of this chapter.

Family

Family is one of the most important support networks for people affected by this disease. It is difficult to imagine not having support from family members when confronting a disease such as HIV/AIDS. One subject expressed his thoughts on not having support from family, he said:

> "Not having the support of your family and friends makes you feel like you are standing in a river and dying of thirst."

Another subject said:

> "My mother accepted it, some relatives were ok with it, and others didn't want to touch me."

There are many people that have been rejected by family members because they are affected by this disease. One subject talked about his relationship with his children, he said:

> "This last May [1999], my older son graduated from college in Indiana. I was told to be sure to not attend the graduation ceremony. He's going to regret that someday. He's at a Pentecostal seminary. He didn't want me there and I have never been so hurt in my life. My parents went. I was planning to attend when [my son] he called me. We had a conversation, which is unfortunate. He threatened me if I ever spoke to his Mother and brother again. I basically told him, 'You just do

> whatever you think you need to do. Whatever you have to do. You go right ahead.' In time he'll understand that comment. He sure doesn't now."

Another subject said:

> "I don't know if I'm going to tell my 16 year old. She went to live with her father when she was 9. I don't know that I could hurt her. It would hurt."

Another respondents' HIV/AIDS status was revealed tacitly without her consent. She said:

> "I called my mom. She had gotten some [of my] mail at her house. She opened it [and called me]. It was from the infectious disease department. She knew. That was the last time I talked to her until I phoned her recently. My mother wanted nothing to do with me."

There were subjects in this study who divulged that partners had been rejected by their families because they were with someone who had HIV/AIDS. One subject, in revealing his experience said:

> "I was surprised about my families reaction. I actually did not tell my mother until about 15 years after I was diagnosed because she was very sick. I told her because I was in the hospital and had PCP in 1996 and I was allergic to Bactrim and I had hallucinations from that and I called my whole family and told them, I wasn't in my right mind. They were all very accepting. My mothers side of the family is very medical oriented. My partners family was a different story, his family has kicked him out of the family because of us. They are very religious, Baptist-type, always quoting the Bible, and I know a lot more about the Bible than they do, I guarantee you. And turning your back on your loved ones in their time of need was not what God had in mind. They don't deal with him being gay. They don't talk about it. It was all OK until I came along and of course, they blame me for his gayness although he had had partners before me. I guess they could really ignore it until my HIV was just too much in their face."

The same respondent when on to say that there was a male family member whom he and his partner were suspicious about. They had suspected he had HIV and may be gay and were trying to help him be revealing to the family that they had experienced this disease.

They were concerned that the family member would not seek medical attention because he feared being ridiculed by the family. The respondent said:

> "His [my partner] older sisters' son is gay and had AIDS (I know he's got AIDS or has had an HIV diagnosis). He and the whole family are very much in denial, obviously, look at what happened to us [partner and I] with the family. I basically came out and revealed my status to the family for his sake. Because he was ignoring it and I have been living with it for 16 years, at the time. We revealed it so that he could see that people live longer if they take care of themselves. We tried to help him get over that denial. He has been tested, in the hospital when he was sick, but won't go get a CD4 count, he's been positive for five years. He's now got all the signs of AIDS. Not only is he in denial but the family is in denial and after kicking my partner out of the family and everything else, has just put him further into denial. So they've probably killed him when it's all said and done."

There were also participants in this study who admitted to having not disclosed their HIV status to family members for fear of being rejected. One subject had recently gotten married and had a child. She had HIV but her husband and child did not. She had not told her in-laws that she was positive for various reasons, and they both worked in health care, she said:

> "I was so scared [for the protection of my family/in-laws]. So scared because they did not know [I had HIV and my baby was carrying a viral load]. It was for their protection. He [my husband] insisted that I not say anything. I had to hide our medication. It's crazy. Usually, they [in-laws] don't come over [and visit] often because they work second shift. They both work the same shift on the same floor at ______ Hospital. But we do see them frequently. I often have to hide things. Ding-dong. They may be on their way to work bringing me some or whatever. One time I was in the middle of filling my med boxes. They were all open. I've got tons of pill bottles. Watching out there and, yeah, having to hide medication. I usually keep it on the counter. I don't like that. I don't like living like that. For now it's the best thing to do. I just have to deal with it. I'd rather live with hiding things in my life than live with them rejecting me."

It seems that knowledge about this disease would have increased, at least to the point where people that are affected by this disease could inform their families that they or someone that they are close to has it without being rejected or ostracized by the family. One subject, that has been living with HIV/AIDS for 19 years, did not tell his family for several years after being diagnosed. He said:

> "As far as family members, a lot of them didn't really know until the latter part of the 80's. I was very uneasy about telling them. [Because] back then it really wasn't something that you announced to the world. My mother knew. Some of my close aunts knew. Now, all the cousins know, second cousins, everybody in the family knows."

If people today are still fearful of being rejected by their family when they disclose their status, should this indicate that knowledge about this disease is no higher than it was ten years ago? The same subject indicated that revealing his status was positive for the family, he goes on to say:

> "It [disclosing HIV status] really, in a lot of ways, has helped the family. Number one, they ask me questions. They have questions about it and it doesn't bother them a bit to call me and ask me if something is a route of transmission."

Despite that this respondents' family has had many years to deal with and comprehend that he is living with HIV/AIDS, he did have to contemplate how disclosing his status would impact his family. Many people affected by this disease are not as lucky. There were several participants who indicated that this disease is not even discussed in the house. One subject revealed a reason for that, he said:

> "HIV is not talked about in my family, everyone knows, even indirectly, but we don't talk about it. They don't deal with it because then they would have to deal with my homosexuality."

Another subject said:

> "I had a lot of resentment [toward my partner] when we were diagnosed, because he wouldn't ever talk about much, he was Native American."

Friends

Friends are another important component that make up support networks for people affected by HIV/AIDS. Many of the subjects interviewed for this project had dealt with issues with friends that were similar to those that they had encountered with their families. Many were rejected by their friends, just as they had been with their families, although in some cases it happened more quickly with friends. One subject, when revealing his experiences, said:

> "When I first got the news that it was confirmed in '84, I lost some friends that didn't want to deal with it. At that point I don't even think there was a name for it. At that point it was still GRID or something like that. I lost some friends because of it, but that really didn't bother my partner and I. We kinda both figured that if they were friends and they were going to walk away at that point then they really weren't friends we wanted to have in our lives anyway."

There were some participants who do not discuss their disease with family and friends, because they thought that their friends and family knew they had HIV/AIDS. One subject said:

> "My friends and family don't want to hear about it (my disease), they don't want to face it. Some friends fizzled out because of it - there was never a chance to make it an issue."

There was another respondent who avoided the whole issue by not revealing his HIV/AIDS status to many friends and acquaintances. He thought that at times it was easier to not reveal his status if the person was not a potentially close friend. He said:

> "One of my good friends from high school that I graduated with, we talk about every two or three months. We've met on a couple of different occasions and had coffee and that type of thing. He's got his life. He's a very well adjusted straight man. He's got 4 kids now by three different wives. He's living with a lady. It's like, he's almost got too much in his life for me to deal with. We haven't discussed the AIDS-thing. I haven't told him. But he does know I'm gay, he has met my partner."

Many people affected by this disease choose to make friends only with people that are understanding of HIV/AIDS. Many only become friendly with others who are active in support groups. Many of the respondents in this study indicated that having friendships was much easier with similar others than with people that may not be understanding of this disease. One subject said:

> "As far as the friends that I have now basically I met through the [support] group. I disclosed my status at the group, so it's not an issue. I don't know if my neighbors found out, how they would take it. This is a very lily-white community. That would be the best way to put it?"

Another subject said:

> "It's much easier to tell somebody if they're just an acquaintance, and for whatever reason, maybe they found out, if it's somebody that you really don't care about, it's easier to tell them that you got it from a transfusion than it is to come right out and tell them because, as far as my personal life, I don't feel like it's any of their business. If it's someone who becomes a friend, then at one point in time, you have to sit down and be honest about things. By that point, usually they've figured it out. If it's someone who's become a friend it's because they've been around you and they know your lifestyle, and they have probably picked up on it."

One subject revealed how he often people are shunned by the gay community as well others who have HIV/AIDS when someone reveals their status. He said:

> "In 1982 about 19 or 20 of us decided to get together. We formed a group and we all went and got tested. I was the only one, of that group, that had a bad result (I didn't test positive because at the time because there was not an HIV test). I still look at that result today as a positive diagnosis. Everybody shunned me - It was like if they were seen with me then everybody would think that they had it and then they wouldn't be able to get a date on Saturday night. All of that group of 20 are dead now except for me, eventually all of them tested positive which is kind of ironic considering that they all shunned me at the time, one by one. Then when my last friend came down with it, I shunned him, I am not proud of it. I was afraid, I guess it was classic denial, even though I had accepted it. When I saw it [death] starring me in the face like that, I couldn't deal with it."

Co-Workers

Work relationships can be an important facet to a person's network of social support. Although, such relationships are often less intimate than those with family and friends, they can still be significant. People often spend a substantial amount of time in the workplace and the relationships that are formed within the confines of that situation can have an influence on a persons mental well-being. In workplace situations it is often very difficult to conceal personal issues from co-workers. People living with HIV/AIDS, especially, may have a difficult time keeping their status harbored given that many have excessive physicians appointments and absences due to illness. One subject expressed his positive experience about this by saying:

> "Because of my health I revealed my status to people at work. My co-workers and my supervisors knew. When I revealed my status I talked to each one of them individually, about 20 of them. Actually at the time that I did that it was because I was doing an interview on the radio station on the military base where I worked, about HIV and AIDS. I thought they needed to know before they heard anything on the radio. They were very supportive, backed me 100%, and dared anyone to come and say anything."

This person had spent some time near the west coast and his experience differed significantly from those that live in this area who have chosen not to reveal their status to co-workers. One subject said:

> "I don't tell people that I work with - I just tell them that I have a health problem. They never ask why I'm on disability, they just assume I'm on it because of a car wreck I was in. People aren't as open minded as I thought, even on a college campus [in a populated city]. In getting to know these people [that I work with], they surprised me, they would make snide remarks about gay people."

Another subject also indicated that he worked in a similar environment although he had not disclosed his HIV status. He said:

> "I work at _____, a major private university, at least for this part of the country. I don't hide the fact that I'm gay. I don't flaunt myself. There is no problem there. They like me very much. As far as being [positive], I don't think I'd ever have a reason to, or need to divulge that. I don't think they would have a problem [if I told them I had HIV]. I may be surprised."

Religious Affiliations

Many subjects in this study expressed a desire to maintain a spiritual outlet in the form of religion. The religion constituent of social support networks has been the most informative piece of this project particularly with regard to cultural hegemony. Most everyone that participated in this project had had some encounter with the institution of religion since being diagnosed with HIV/AIDS.

One subject revealed an experience within his religion, he said:

> "For 40 years I had served the church. I had friends, hundreds of friends, from coast to coast. Now I'm dealing with a disabling disease, with death. I, sincerely, thought at the time I was facing death, I had a very short future. We had all grown up together. We were like family. My personal family abandoned me. People that I had run with for years, I never, with the exception of two people, I never, ever received any phone calls, any cards. I had been the type, the caretaker, of people for all of my life. Caring for people, helping people out what little bit I could financially, or just emotional support or with things. All the time that I gave to the church, I never received a thing back [when I was diagnosed with HIV]."

Another subject expressed feelings of guilt if he did not disclose his status, especially to his church. He said:

> "I feel like I am deceiving people if I don't disclose - people in my church don't know - I am scared (to tell them) - I am afraid that they will pass judgment on me."

Another respondent indicated that she also had a similar experience, she said:

> "My church doesn't know. I haven't disclosed to them. I'm scared. I'm afraid that they won't accept me. My husband feels that way too. He's not ready to reveal that. Sometimes I feel like I'm deceiving people if I don't. When I first found out I wanted to call everybody that I knew and tell them for their benefit, for their safety, just in case something ever happened. I had a friend of mine tell me, 'Stop, think about what you are doing. You could lose visitation with your daughter, which I haven't seen in a year anyway. You don't need to go out and advertise that you have HIV because that will harm you."

Another subject revealed almost the same thing, she said:

> "I think I have about a year now in that church. The message in that particular church has been positive in my life. The people have been accepting and loving. I don't know, I'm afraid that that would change [if I told them that I had HIV]. That maybe it would become superficial because of my HIV. People hurt people. If I were to reveal my status to even one person in the church I would feel obligated to reveal it to everyone. I think I would want the opportunity to give my own personal testimony of my life and go into all of that. I'm not ready to do that. I want to share God with them. I don't want to share this horrible disease. There are things that they don't understand."

Based on these affirmations it seems as though many religious organizations do not offer the support from which they stand including forgiveness and not judging others. For those that have not disclosed their HIV status these are the things which they are most afraid.

HIV/AIDS Organizations

There are many facets within the HIV/AIDS organizations that encourage and dissuade individuals from seeking social support services. The people that participated in this study had both positive and negative experiences when seeking support from this resource.

For many of the people living with HIV/AIDS that access the services from these organizations it is described as a power game. The largest HIV/AIDS organization in the state has been portrayed by many as 'game players.' One respondent revealed his experience with that organization, he said:

> "[To get good services and good direction] it is who you know [at the organizations]. The organizations get too involved with certain clients - its a personal thing - they play favorites. If you don't know about the resources, they like that, you walk in an organization feeling stupid and you leave feeling more stupid. The more resourceful you are, the more help you're going to get."

Another subject also indicated that the more resourceful a person is, the more likely they are to get help. This subject said:

> "I had a good experience with ______ [the HIV organization]. I came in with all the information I needed. I followed their rules. That's the thing. Follow the rules. Prepare yourself. Carry around your life history in a briefcase wherever you go to get whatever services in that system. Everybody is going to want something. They are going to want confirmation of HIV from a doctor. They are going to want your history, everything."

Many of these participants suggested that caseworkers at this organization did not do there jobs well. They claimed that one reason was because the case workers were not trained to do their jobs and the other reason was that they were not allowed to do their jobs. One subject said:

> "You know it's really sad because they are hired to help the consumer, not to play games. Like 'You do this or you caused that, well then I'm gonna show you I've got the power to control it'. That's basically a lot of it. There's a lot of politics naturally in it. I will say there are some agencies, certain people in that agency that are running it that do care. Generally you get someone in a higher up position that is trying to make their organization really good and keep money going. I don't understand it all, naturally, but there are some that really do genuinely care. The ones that are really good are gone."

Another subject said:

> "Some of the case managers come in and have no idea what it is to be a case manager for someone with HIV. They need more training on the issue of what they are working with, and that's HIV-AIDS people."

Another respondent also suggested that the case managers' hands are tied because of those that are running the organization, he said:

> "I could not be a case manager and a client come to me needing some kind of assistance, whatever it might be, and know it's there but I was told from my higher ups don't cross that line. I could not do it. That's the reason that so many of the case managers end up leaving because they did cross that line."

Many subjects in this study have suggested that people are not getting the services that these organizations are suppose to provide. They have indicated that the allocation of funds for services are not being rendered properly. One subject said:

> "I don't know if it is a level of not caring. I don't know what happens to the money. I don't see it. I think the majority of consumers that have to access that organization , to them that money does not exist. If there is a specific service that they do provide, and you ask about it, they will say there is no money. Then at the end of the year they have hundreds of thousands of dollars left over. I have not been in the situation where I've needed medicine from them or prescriptions, but I know of other people who have. They do not get them. Yet at the end of the year there will be money left over. Why didn't that person get that prescription? It doesn't happen. It just doesn't happen. I really don't understand it. This organization in _______ probably needs to start over from the top down. Their reputation is really in that bad of shape. People do not trust them. If you are told something, the word out there is Don't believe it until it happens."

Another respondent that had had some experience with HIV/AIDS organizations in a different states talked about how the local organization here compared to those, he said:

> "I think back in the early 80's there wasn't as many social service organizations as there are today. I think they were better organizations especially around the end of the 80's, beginning with the 90's. They were made up of volunteers who probably were living with the disease, the majority of them, personally or in a relationship or whatever the case may be. They were living with it. They knew how to get things accomplished. They knew what was available and how to put that in someone's hands. I think the service organizations in California are still a lot like that. I've

> only dealt with 3 of them there. They were taught how to be a service organization by the people who started it. By the people who fought in the trenches before there were any federal funds. I think they learned how to get things accomplished. Here in ______, being an outsider coming in, and only having to access that for about 18 months, it almost seems like it's run more like a business, a for profit business, than it is a non-profit. 'The more money we save, the more money we have at the end of the year, type thing."

The respondent compared HIV/AIDS services provided in Oklahoma to those offered in California. He continued by saying:

> "Service organizations in California, when they got money, it was budgeted enough to pay the bills through the end of the period and then everything else went to the client. If somebody needed rent paid this month it's like 'Well, we have to look at the amount and see what it is'. When it got toward the end of the year they might run short of money, but if they had it and you needed it, it was provided. It was a done deal. There was no checking to see this, that, or the other things. There's a lot of money out there. There's a lot of federal funds out there. Basically here it seems like we're told that nothing is available. California and Colorado are really the only two states I've lived in where I've accessed services. They manage to have the money. California has a lot bigger population of people with HIV. Yes, they have a lot more people, but they have a lot more people they're servicing. They are not scared to use the funds. That's what it's there for. It really seems like here that you're dealing with a corporation to try to access the services they offer. You basically have to be in dire straits before you can access anything. Then you have to ask for it. They're not going to tell you it's available unless you know what to ask for. The only way you know that is through different support groups, things like that. If it wasn't for the support groups you really wouldn't know where to start and where to stop. You wouldn't know the questions to ask. And that's the only way you're going to get anything is to know what questions to ask. You also have to have people that will take those questions further and, I don't want to say care about what they're doing, have compassion for the people they work for, because the service organizations do work for the people. They don't look at it that way here, but if it wasn't for the consumers they wouldn't exist. They really need to think about that. If we're not accessing their organizations then they won't get the funding unless they are falsifying reports. I didn't say they were, I said unless they are."

The HIV/AIDS organization and the state eventually realized that there were clients who were becoming aware of the practices taking place within the organization.

The consumers of these resources and services were then allowed positions on the state HIV/AIDS Health Care Consortium. Although they were offered a minimal voting platform from which to offer their advice and voice their concerns about HIV/AIDS issues, they have not been acknowledged as well as many consumers would like. One subject said:

> "You sit there and you bring out points and most of the time it doesn't make any difference. It's not getting responded to. It's like, they let the consumer talk and say what they want to say and then your other people in the agencies, your higher up people that sit on most of these, just talk like you never said nothing. Then if it was a good topic that you started and a good idea to try to seek, then maybe 2 or 3 months down the road where the agencies will produce that and make it look like the consumer never even addressed it or suggested it. They just look at you like, You're a consumer, you really don't have the knowledge or know what you're talking about. You are just talked over. They're polite enough to listen. We have a couple of them that will roll their eyes and say that we need to go on to another topic. This has been brought up. This has been addressed to them at some of these meetings. Doesn't do any good. Doesn't do a bit of good. That's where the consumers are. They're [the organizations] not listening."

There are issues with regard to HIV/AIDS organizations that many of the respondents in this study have recognized. I attended one consortium meeting. The meetings are held monthly and are open to the public. There are physicians, organization and health department administrators, voting and non-voting consumers, case workers, and smaller service organizations that attend these meetings. There was some animosity between the consumers, the organization administrators, and health department officials. When consumers spoke or provided insight about how monies are allocated their comments were either disregarded or blatantly ignored.

My perception about the support services offered by this large HIV/AIDS organization is that they mishandled their clients and their funds. As one subject who was a voting member of the HIV/AIDS health care consortium indicated, 'there are funds available,' people must know exactly how to access services and be knowledgeable about what is provided. For a person that is physically and mentally stressed because of having a disease like HIV/AIDS, being overly resourceful about services that the state and federal government provide only add to the difficulty of accessing those services.

The experiences that have been depicted in this section indicate that social support networks are important for people affected by this disease. Relationships and/or encounters with family, friends, co-workers, religious affiliations, and HIV/AIDS organizations can hinder or facilitate support for people living with this disease.

Stigma

There is a considerable amount of stigma associated with this disease. People living with this disease may be considered to have a particular status within society. A deviant status is primarily bestowed upon those affected by HIV/AIDS because of the understanding of disease transmission. Society deems a person infected with this disease a deviation from normality. Consequently, they have a more difficult time establishing identities that society considers normal (Goffman 1963).

In this section I will discuss the experience of stigma among the participants in this study. The issues that will be presented include transmission stigma, discrimination, and fear.

Transmission Stigma

Those that have acquired this disease through deviant means are often more stigmatized than those that are considered 'innocent victims' (Crandall, Glor, and Britt 1997). People that are affected by this disease recognize that there is a difference between acquiring HIV/AIDS sexually or through IV drug use as opposed to acquiring it through a blood transfusion. One subject supported this by saying:

> "It does matter how people have acquired it (HIV)- if its acquired sexually, it means that you are promiscuous, or through drug use, these have bad connotations. It is better to have gotten it through a blood transfusion."

Another subject said:

> "People who get it accidentally (medically or transfusion) get more sympathy."

There were several participants who suggested that there should not be less stigma attached to those that acquire HIV/AIDS by non-deviant means. One subject indicated that medical treatment and social support should be the most important things with regard to this disease, he said:

> "I think there's a lot of stigma attached to the method of transmission. I don't understand it. If a person is sick, they're sick. It doesn't matter how they got what they got. The fact is they have it. It's like cancer or anything else. Does it matter whether it's lung cancer from smoking or breast cancer? The person still needs the medical treatment. They need the support of the family, the friends. There should not be a difference, but there is. There's an extreme amount of difference."

There were several people that I interviewed who brought up some interesting points with regard to HIV/AIDS transmission. One subject said:

> "There's a lot of public opinion that's based on how you got the disease. It really, to me, is wasted energy. If as much energy was put into how to cure the disease as there is into how people got it, we would be miles ahead at this point in the fight."

Another subject said:

> "I think IV drug users or using needles is another bad connotation. That doesn't mean that all people are bad just because they happen to have done drugs. Blood transfusions probably are more acceptable. Getting it through dental work is probably more acceptable. If anyone were to say, 'That's how I got it.'. They may not actually be telling the truth, just to get accepted. I could say I got it through a blood transfusion. That probably would be accepted a lot easier. Once they know I'm gay and I've got it, it's a whole different story."

I think that there are many people who would lie and say that they acquired this disease through a blood transfusion rather than admit having possibly acquired it through sexual contact or IV drug use. Many people speculate about how someone has contracted the disease once they disclose their status. Even those that are affected by this disease are not immune to that. I remember being in a support group meeting for the first time and pondering how some of the participants had acquired HIV/AIDS. One subject indicated that there were many people that do this, he said:

> "In social groups and in the medical community, everyone assumes when you reveal you are HIV positive, that you are gay and that is how you got it."

There were several subjects who suggested that the HIV/AIDS theory that prevails, (that HIV is spread through certain bodily fluids) is questionable and that there may be other unknown ways in which this disease is transmitted. One subject supported this by saying:

> "Everybody gets labeled, because people think that this is a 'gay disease' or for 'IV drug users', there are labels placed on us and no one (really) knows how they got this disease."

The public may discern those that are living with this disease as something that they brought on themselves. Doing so suggests that people who acquire this disease deserve it because they have been engaged in deviant acts. One subject supported this by saying:

> "The real world is not friendly, and the workforce is not friendly to people with HIV, those with mental illness, or addiction problems. They don't cater to people who bring things on themselves."

It seems as though the stigma associated with HIV/AIDS would have diminished substantially over the last 10 years, given that this disease has been around for at least 20 years. There are still many people suffering from the stigma associated with this disease. One subject said:

> "Attitudes (about HIV) have changed in the last 20 years but it is way lacking - we're not where we need to be because we are not being handled with respect and dignity - we already have issues that decrease our standing in the world (being gay)."

Discrimination

People that are affected by this disease are being discriminated against even today. Most discrimination has to do with fear and lack of knowledge about the disease. One subject suggested that by saying:

> "There is a low percent of people who understand the whole issue - [you] are discriminated against and shunned when people find out that you're positive. Because of the stupidity of people, people have a lack of knowledge, people do not know and understand what it is."

People that are living with this disease are discriminated against in the workplace and when seeking housing. One respondent said:

> "I was diagnosed in 1996, I was working [in ER registration] at ______ hospital. In May [of that year] I was fired. I was fired for tardiness [they said]. A girl that I worked with [there] was late everyday - she's still there. Now I don't say anything to anyone about being HIV+."

Many people that are affected by HIV/AIDS feel as though they can not disclose their status because they fear discrimination. One respondent experienced this when he sought housing with a voucher from the HIV/AIDS organization. He said:

> "I had gotten a housing voucher to help with rent where I receive HIV services, we were so discriminated against, it took me over a year to get the help with housing, no one would take us because our housing help was coming from the HIV organization. The word AIDS appeared on the housing approval letter, nobody would take us. We never got one landlord that would accept it, not one. No landlord in this town would accept it, and the organization was going to pay everything, it was pure discrimination."

Another subject has tried to avoid experiencing discrimination. He indicated that he would like to pursue other employment but understands that there are problems associated with trying to work in specific areas. He said:

> "Social Security tells me I can get a job, right. That's not always true. Once you disclose your status they back off. The only reason why I'm working now is because I'm in a dance business that understands and is compassionate to my illness. They are all on my side. It would be demeaning and embarrassing, not to myself, but just the things that they would say and think. I don't want to put myself through that emotionally so I would stay away from it. I would be less likely to go get a job because of the opinions or feelings of most people. Whether they be in a food service business. They are not going to hire an HIV person in foods."

Fear

The fear and lack of understanding about HIV/AIDS reinforces the stigma associated with this disease and perpetuates actions of discrimination. People that are affected by this disease are likely to experience some form of stigma or discrimination especially if they disclose their status.

Several respondents in this study suggested that the public needs more education and awareness of this disease. One subject said:

> "The public is informed [about HIV], but there is not enough advertisement, they're afraid to advertise it because of ignorance and fear and stupidity."

It's not as though there is a lack of information available to the public about HIV/AIDS. It has more to do with how and to what extent the information is disseminated. There are not many advertisements about HIV/AIDS in the media. One subject indicated that the media has promoted this disease negatively, he said:

> "The media has damaged it [HIV], this never was a gay disease but they've made it out that way. People don't care about those that have it."

The lack of education and fear that prevails among the public fosters identity issues for those that have this disease. One subject indicated that the public needs to become more educated so that this disease is more accepted. She said:

> "Society looks down on you (when you have HIV), and you look down on yourself. People need to stop being scared and get educated."

There appears to be a lack of understanding about HIV/AIDS and people that are living with it. Because of a lack of knowledge, there is a great amount of stigma associated with HIV/AIDS. Despite that there is a vast amount of literature concerning this disease, many people living with it must struggle with a spoiled identity. The perceptions of deviance associated with HIV/AIDS continues to promote a stigma about this disease and those living with it.

There were many respondents who indicated that literature was available if people wanted to be educated about the disease. One respondent said:

> "[The] Oklahoma public is very uninformed. [There is] not enough advertisement. People are afraid to advertise it. [Because of] ignorance and fear. I'm not afraid of it but a lot of people are. It is stupidity."

They also suggested that the media could play an important role in aiding the public to understand more about HIV/AIDS. However, when there are people within the medical community who lack an adequate understanding of this disease, the public becomes less responsible for their lack of knowledge or interest. There are plenty of people with HIV/AIDS in this area to warrant a higher level of knowledge and understanding.

Many subjects insinuated that there was much more contributing to the present lack of knowledge and understanding about HIV/AIDS than mere education. They suggested that education and information about HIV/AIDS was available but the public just had to seek it. The participants referred to the ideology in the area that could influence positive promotions about HIV/AIDS. There were comments made about being in the 'Bible belt', living in a conservative and religious area, and how these ideologies shape the attitudes present in this region.

In the next section of this paper I will discuss professional hegemony based on the narratives of people who have experienced it. The experiences of the individuals in this study are daunting with regard to hegemony. The following section should provide a deeper comprehension of the data that I have presented in this chapter as well as the exposure of both professional and cultural hegemony that impact how people living with HIV/AIDS experience their disease.

Professional Hegemony

The experiences of people who participated in this study are reflective of both types of professional hegemony; medical and organizational. The medical community and the HIV/AIDS support organizations play a key role in how people living with this disease are treated in both realms. People living with this disease are deemed as irresponsible and as persons who lack the knowledge to make their own decisions. This is evident when participants describe their experiences of being late to appointments because they are unable to find the building or when they refuse to take medications because they are not tolerant of them. These participants' health care and benefits were threatened because of their 'irresponsibility' and desire to control their own bodies. A gay male respondent indicated how much control the clinics have over your receiving care, he said:

> "In my business, I have been in business with the dance studio for 24 years. It is an instinct knowledge that you take care of your customers and you are respectful to their time and their money, equally. I had been going to [the HIV clinic] for about 3 years. Every time I went in I was stuck in a cubicle for 4 to 5 hours waiting to be helped. With my work, I have to be on time for my clients. I am on time. I had appointments one day and I had no idea that I was going to be in [the clinic] for 4 or 5 hours. I had to leave for an appointment. I wrote them a note. 'Couldn't stay. Got to go. I'm going to be late for an appointment.' I did that 4 or 5 times. Well, the next time, they [medical personnel] decided to show up early to give me my ass chewing, basically. That is the only time they showed up early. They threatened to throw me off the program. They told me if I missed another appointment, I would no longer be able to go to the [HIV] clinic. All my medications would be cut off. I snookered my way back in. Basically that's why they put me on Paxil, because I was getting claustrophobic, sitting there alone for 4 or 5 hours [waiting in a cubicle]. Anybody would be. There is only so many drawers you can go through, being curious. What do you do when you are sitting there reading a pamphlet on everything? Then you see the little wall decorations. By the time you get through with that you still have 3 hours left. What do you do? That's why they put me on Paxil, thinking it would curb my claustrophobia. My way of getting around it was, I told them I already had it figured out, I was going to bring somebody with me into the room so that I would have somebody to talk to if it [the clinic visit] was going to last 4 or 5 hours. Also, knowing it's going to be that long, I could change my appointments so that I wouldn't have to miss

> them. Now I just assume when I have an appointment at the clinic, I cancel the whole day, which is money out of my pocket to live."

The notion of irresponsibility may be indicative of their economic condition, this person was economically independent, but still needed some medical assistance. People who seek public assistance because they lack financial resources are often treated in the same manner. The people in this study that were threatened in some way were receiving assistance from the HIV/AIDS support clinic that is funded with Ryan White monies. And because these organizations work closely with the medical community, they can threaten to cut off medical benefits if persons are acting irresponsibly or powerfully. Professional hegemony is reiterated among this population when this occurs.

Medical hegemony is also present when individuals suggest either alternative or additional treatment or tests. Two persons in this study experienced medical hegemony after being taken to the emergency room. One, who was female, was denied access to an HIV/AIDS test in the hospital, the other, a gay male, did not receive adequate health care when he was re-admitted to the hospital after having surgery and being misdiagnosed.

> "I had an experience with my liver. I had surgery on Tuesday. I went to the emergency room on Saturday [after going home], because my liver had stopped functioning on Friday and I had started retaining fluid in a major way. By Saturday I was about 16 pounds heavier than I was the day before. I went to the emergency room and basically was told, You need to drink, you need to drink, you need to drink. That's all that's wrong with you is you're not getting enough fluid. You're still trying to shake off the anesthesia. It's all because you have HIV'. It wasn't because I had HIV, it was because I had had surgery and that had injured my liver. The following Friday I was advised by my doctors office to go back to the emergency room. My doctor was out of town but had talked to the on -call doctor who happened to be at the hospital. By that time I had gone from 215 up to 245 (I had gained about thirty pounds). The emergency room doctors' attitude when he walked through the door was 'Well, I've read your chart. All that's wrong with you is you still haven't shaken off the anesthesia. He was the doctor I had seen the Saturday before. He said it's because you're HIV positive. That's all it amounts to. He never called the other doctor who was at the hospital until mid-night, this was

> 7:00 at night. He never called the doctor down to talk to him. In fact, he told me to go home and do a major cleansing out of my stomach and intestines for the next 12 hours, with no sleep or anything but drink fluids, drink fluids, drink fluids. It was the following week that my doctor put me in the hospital. He never called the doctor who was at Baptist at the time. He knew exactly what it was that was wrong and basically sent me home doing the same thing I had done the week before, which was nothing. Finally, enough was enough, and [my HIV] doctor said 'That's it. You'll have a bed waiting for you when you get to the hospital. That's when we found out about the liver, that the liver had stopped functioning. The doctor went down to the ER. He wanted a CAT scan and some other tests done. The ER doctor, did not run any of the tests that my doctor requested, but he [just] knew that [my doctor] was wrong."

This particular respondent had a very close brush with death. Neither he nor his HIV physician was shown any deference with regard to his condition. The ER physician was acting in a very hegemonic manner. The participant attributed the behavior of the ER physician to a lack of knowledge, he continued his story by saying:

> "I think because they [ER physicians] don't deal with HIV once they hear that word then [they think] that's the root of all problems. That wasn't the root of my problems. I know other people who have been in the same situation. They go in because they're having a problem. Well not everything that happens to a person is HIV related. People with cancer, people with HIV, we get the flu, we get bronchitis, we have to have gall bladder surgery. Just like normal people. Things happen. Your body, a part of you is out or something goes crazy. It's not the HIV. These [problems] have to be taken care of just like [they do] in anybody. But they hear HIV and it's like 'Well that's all it is, HIV'. That's when they stop. They know the answer. I'm real uneasy about seeing a different doctor."

When these encounters occur, people living with this disease are the ones that suffer, medically, financially, and emotionally. Many already have issues that are difficult to manage but when these are coupled with stigmatizing identities such as homosexuality or HIV/AIDS, they are likely to suffer further consequences. What I have observed from this study, is that the people who are likely to receive better treatment from both the medical community and HIV/AIDS service organizations are the ones who willingly play the game and who have not acquired this disease through deviant means (drug use or homosexuality).

One female that I interviewed had acquired HIV/AIDS through her health care occupation. She was very ill when she was diagnosed with the disease. She had a very positive attitude toward the HIV/AIDS organization and the health care community. She was able to access the Medicare and receive disability within less than 5 weeks of diagnosis. She had no problems getting her medications or adequate health care. Other people that I interviewed called attention to the length of time it took to receive their disability benefits. My understanding of the disability process is that it can take a very long time to receive the benefits. The amount of time it takes to receive those benefits depend upon the physicians recommendations and how sick the patient is.

One female respondent indicated that she followed the rules and eventually received services, she said:

> "I received services for housing, nutrition, and dental care- it took a while - but I followed the rules (of the organization) and got help."

Another respondent indicated that being resourceful was important to receiving assistance and care. She said:

> "I'm very fortunate that I'm a resourceful person. I know how to get things done. I know how to make phone calls. I know how to do research in services and support and things like that. I knew that there were things out there but I had no idea what exactly was out there. I feel fortunate that I put a lot of time and a lot of effort into making phone calls, going to appointments, talking with the people about getting set up in a new life. There are people out there that don't know what to do, and especially women. Who do they have? It's discouraging to think that there are people out there that have limited information and they don't know how to be resourceful to pick up the phone and find out what is out there and what's available. There is money out there? There are places to live. There is medical care

> available although from what I understand [through] the HIV clinic and the university hospital clinic [although it may] not be the best place [to go]."

This respondent indicated that her experience with the HIV/AIDS organization was positive because she was organized and had improved morally. Although this respondent had acquired HIV/AIDS through drug use, she was willing to play the necessary game in order to receive help, she went on to say:

> "I had a good experience [with the HIV organization]. I came in with all the information I needed. I followed their rules. That's the thing. Follow the rules. Prepare yourself. Carry around your life history in a briefcase wherever you go to get whatever services are in that system. Everybody is going to want something. They are going to want confirmation of HIV from a doctor. They are going to want your history, everything. I had lived a somewhat responsible life. I went to the Air Force. I had married before I had a baby. I was the average normal person with a drug problem. I became a low-life. I tried to file for Social Security for my disabilities and drug addiction, that wasn't the ticket. I've been homeless and destitute. In hell of situations. Even when you're in that situation and you've got HIV you can get help. Of course you have got to be willing to give up your street life, your drugs, your alcohol. You have got to do that [before you will get help]."

Professional hegemony is evident in these narratives. Organizations and the medical community manage their clients and their patients through power and coercion. I had the opportunity to attend a monthly meeting of the HIV/AIDS health care consortium in this state. The meetings are suppose to be 'open' to the public. When I visited the meeting, I sat with the people on the consortium that I knew (the consumers), who just happened to be HIV positive. I walked into the meeting located a seat and was soon after approached by a woman affiliated with the health department. She asked if I had signed in outside, and of course, I had not. She handed me a clipboard and attached was a piece of paper with a list of voting members and some blank spaces for visitors to sign. I signed my name and as she sat back down at the table, the man to her left (the director of the HIV/AIDS and STD division of the state health department) took the paper from her, looked at my name and then glared at me. My perception was that they were intolerant of 'outsiders'(especially ones that may having opposing interests) attending these public meetings. There were several instances where I observed such intolerance throughout that meeting.

The first instance occurred when one of the consumers made a comment about the consortium not advertising their meetings publicly. This person indicated that they tried to keep them from being disclosed so that more consumers would not attend. The respondent, later in an interview addressed this:

> "All these meetings are supposed to be open to any consumer that wants to go to these meetings. Is it published? No. Do they know where? When? What time? No. Do they know if they [the meetings] exist, if they could go? No. Just the ones that stay involved [in the HIV community] learn this. [We are] publishing a newsletter and we are going to publish this meeting in every month, where the meetings are held, we need to let consumers know they are welcome to any of these meetings and can have a voice. Whether they want to come or not is another issue because of disclosure. We're hoping that the ones that would come up and address their opinions will. There are very, very few consumers at any of them [consortium meetings]. A lot of them [that are there] speak up. When they say something they'll get shut off on a lot of their comments. Naturally the agencies are not going to say they will [take care of things, whatever it is that is going on]. On some of them [comments] they'll have a reason [excuse] why [something happened]. The paperwork got lost, got misplaced. It goes on all the time."

Later in the day, a very knowledgeable female, who had worked with a large HIV/AIDS organization in San Francisco, made a comment about proper funding for this population. The comment was immediately addressed by the executive director of the large HIV/AIDS organization and the director of the HIV/AIDS division of the state health department.

After the meeting had adjourned, I observed the director of the state health department HIV/AIDS division discussing her comment with another person, who had been called out of the meeting when the comment was made. The director of the HIV/AIDS division of the health department glared at her, as he explained to the lady that had left the room, what comments the lady had made, as though she had no business attending the meeting or speaking.

It was only recently that consumers could have voting positions on the consortium, which is a requirement of states that receive Ryan White funding. The consumers on this consortium are living with HIV or have been affected by it. There were indications that the consortium did not like the consumers having their own support group. The support group offers the consumers the opportunity to voice their concerns to the voting members of the consortium. She indicates that the consortium does not listen to what they have to say. One female indicated that many times, they feel completely disregarded. She said:

> "We've [the consumers] have even got called down [by having our own consumer-like support group], that we were representing ourselves. When you go to these big board meetings and they have consumers sit there, that is for the consumer to represent all the consumers. Some call that can't attend [the meetings]. If there are any issues that need to be brought to the table at some of these big meetings, they give it to us to present. We get called down on all that because they want letters from these consumers. They want to know who these consumers are. We're not going to disclose them. We know in the past that some of these consumers did let them know who they were, and they were affected [by that]. From not getting their meds on time, late, a month late, some even later. There was one even 5 or 6 months ago who actually ended up dying. These are things that we really don't have enough proof to present. These things are happening. [What the other consumers tell the voting members] is verbal. It's all verbal. In order to address all this they want consumer's to write out their complaint, sign it and give it to their case manager or give it to the agency. You can't do that. Nine times out of 10 they're going to show you that they're in power and you're going to do what they say and you're not going to complain."

There are some consumers, as this respondent indicated, that have voiced their concerns and lost their benefits. The people who challenge the system struggle to receive services when they voice their complaints. The organizations may think that the consumers, who access their services are getting the services for free and have no reason or justification to voice their concerns, complaints, or observations. Because the organizations are directly connected to the health care services that these people receive, loosing paperwork, etc. prolongs people of receiving medical services.

The social service organizations and the health care community may not be conspiring together so that people who do not follow the rules and show them deference are not given the proper health care. Because the organizations control the federal Ryan White monies they reimburse the service providers for the services rendered to their clientele for health care and medical treatments. People infected with HIV/AIDS may not be allowed to access those services if their paper work is mysteriously lost or mismanaged. This poses some concern for the HIV/AIDS clients who do not follow the rules of the organization.

When people living with this disease are treated negatively and are manipulated by the professional community, it creates an unreceptive atmosphere that gets projected into the larger community. People living with this disease not only must deal with the hegemonic influences produced by the professional world of organizations and the medical community, but must also deal with the larger social world and the cultural hegemonic influences present within it. In the following section I will discuss and present the narratives of experience among people living with HIV/AIDS with regard to cultural hegemony.

Cultural Hegemony

The data that has been presented throughout this chapter has been a reflection of the experiences of people living with HIV/AIDS in the mid-south. Although the data were gathered in and around a large metropolitan city, the experiences that are presented in this chapter suggest that a unique perspective exists with regard to cultural hegemony and rural ideologies.

The people that were interviewed for this project have revealed that ideologies present within this region contribute to their experiences with this disease. People living with HIV/AIDS in this study have experienced both professional and cultural hegemony within the realms of health care, medical therapies, social support, and stigma. There were many references made to the ideologies present within the area where the data were collected.

Rurality is significant for the framework of cultural hegemony because it offers a unique perspective from which to explain experiences among people living with HIV/AIDS in the mid-south. Because most of the people interviewed for this project lived in a metropolitan area, and the prevalence of HIV/AIDS is not extremely high, people living with this disease were able to keep to themselves and not disclose their status. One respondent indicated that it easy to stay hidden when living in a city this size, he said:

> "Living in this city you blend in the wood work, people don't have to see you as a problem because you're not in anyone's face. Your [HIV] problem is easier to

> ignore, people as a rule, see you negatively, people have little education about it and I guess they think it's your reward."

This respondent was an openly gay male who thought that it was easier to hide and keep his HIV/AIDS status to himself rather than deny being accepted by society. He had moved from a geographically rural area situated near the southeast corner of the state. He had experienced some problems with family members who did not accept his HIV status or his lifestyle. He moved from that rurally geographic area to escape the ridicule and questioning of people in the small town.

There are many people that think they will never be affected by this disease. Therefore, there is a tendency to not recognize that this disease exists even though there are many people living with it. One gay male respondent supported this by saying:

> "[It is different here because] On the whole, I think the population doesn't believe it's going to happen to them. Unfortunately the Republican governor that we have and some of the remarks that he has made, I don't think that's going to be changing anytime in the near future."

The remarks recently made by the governor of this state reflect the ideologies present within this region, especially with regard to homosexuality.

One respondent who resides in the suburbs had moved back to the area where he had grown up. He had traveled and lived in several states before moving back to this area. He commented that the attitudes in this area had not changed since he left. He moved away twenty years ago and had just returned within the past two years. He said:

> "I talk to the neighbor on one side, her dog gets in the back yard occasionally. They're just as friendly as they can be. We don't socialize but we see each other and wave or honk, stuff like that. I grew up in this town. I kinda knew what the attitude was then. It hasn't changed any."

He was not disclosing his HIV/AIDS status because of the potential reactions he might get from his neighbors. He and his partner were very careful about how others might perceive them. He went on to say:

> "I don't really think that most of them [neighbors] click with what's going on. I don't think they see it because they don't want to see it. It's not that they don't know it's happening or that it's living right next door to them or across the street. They just don't want to see it, so therefore, they're oblivious to it. The HIV thing, I would be real careful about that. We're real careful, if a child comes by selling candy or something - school candy, Cub Scout popcorn. Whatever it is, we go out on the porch and talk to them. Whoever happens to be here. We're not going to invite someone in. Because if it's out on the porch, then, you know, nothing is ever going to be said. We're very particular on the type of Halloween candy we buy. It's got to be sealed wrapped not just twisted. It is that type of thing so that nothing would ever be said. We're extremely careful about the way we do things."

If he were living in an area that were more open-minded about homosexuality and HIV/AIDS he would not have to be so concerned about these things. He had moved to this area from the west coast.

A gay male respondent indicated how ideologies about homosexuality are present in this area. Although his experience occurred more than twenty years, he suggested that things really haven't changed, he said:

> "People hide what they don't accept, especially if it is against the law. They hide it even more. One time me and my ex-ex-ex-ex here in Oklahoma were driving down the highway. We were having an argument. Part of the way we decided to make up. I bent over and kissed him. We got pulled over by the cops for kissing. He said, 'You know that's not allowed?' I went, 'What?' 'We don't want to see you doing that again.' This was about in 1976 when that occurred. I just laughed. I've had lovers and boyfriends in the past that would not let people know that they are gay."

This response is a reflection of the conservative ideologies present within this area. The same respondent went on to say that the degree of conservatism in this state may hinder people from expressing themselves because of their intolerance of homosexuals. He said:

> "The reason why I think we are having so many problems with men going into bathrooms and parks, and things like that is because they are having to hide what people are afraid to see. If it was more open they would be more likely to not do those things. If it was more out in the open and people were more accepting to it, they wouldn't hide and they wouldn't have to get caught and they wouldn't have to go to jail for lewdness or whatever if it was more acceptable. People would be more willing to open up. They are restricted because of the Bible belt. That's why they have it and they are not doing anything about it to fix it. They just keep putting them in jail and they get out and do it again, because they have no other place to go to express who they are. There are a lot of married men out there playing around with boys."

His respondent is suggesting that the ideologies about homosexuality in this region manifest these types of experiences among people who do not feel comfortable expressing their sexuality. He suggests that if homosexuality were more accepted by society that people would not have to engage in 'hidden sexual activities' and they would be more likely to seek knowledge about issues such as HIV/AIDS. One respondent indicated that she and others had to 'be careful' when delivering information about HIV/AIDS to public schools and universities in this area. She said:

> "A lot of the agencies that do the outreach were going to some of these schools. You have to watch a lot of what you say. You get some of these parents that just don't want it taught in the schools. They think their kids are never going to have sex, I guess."

The ideologies about sex and HIV/AIDS education in this region powerfully influence the information that gets disseminated about this disease and people living with it. There are influences that encourage information dissemination in this culture. One of those influences is conservatism and maintaining morality, especially through the ambit of religion. One female respondent suggested that people in her church refused to attend if she was there because they had a problem with her having HIV/AIDS. She was married and had a child, and they looked down upon her because she had this disease.

"People at my church were so scared (of me) that no one would show up." Another respondent suggested that attitudes about this disease have improved, however conservative attitudes play a role avoid confronting this disease.

> "Attitudes about HIV have changed but here, they want to do what is politically correct [and conceal it]."

The cultural hegemony present due to religious and conservative ideologies is reflected in the media. Because these influences are so powerful in our culture, they impact how information is framed, disseminated, and advertised (Maggard 1983). If there is a lack of public advertisement about such information the public does not learn about this disease. They can therefore, sustain their attitudes about this disease and the groups associated with it. There is still an enormous amount of fear about this disease. One female respondent supported this by saying:

> "When someone doesn't know about something that's when fear occurs. They do not have enough information first off to make the opinion but they make it anyway with a lack of information."

Another respondent suggested that there is a fear about the advertisement of HIV/AIDS in this area, he said:

> "[The] Oklahoma public is very uninformed. [There is] not enough advertisement. People are afraid to advertise it. [Because of] ignorance and fear. I'm not afraid of it but a lot of people are. It is stupidity."

When people do not understand a disease like HIV/AIDS or are not exposed to people with it, fear will exist because it is the 'unknown.' During one interview a male respondent indicated that there are many people who think that it cannot happen to them, he said:

> "If you want to get a reaction, stand in a crowded room, whether it be a restaurant or whatever, and just say the word AIDS. I guarantee that everyone in that restaurant will turn around and look. It's just not something that people think about here. It can happen to anyone."

Another respondent indicated the same thing. He had never been exposed to this disease but was always one to ridicule those that had it. He acquired HIV/AIDS through a blood transfusion in 1987, he said:

> "I am guilty of making fun and joking about this disease. When I learned that I had HIV I was devastated. It is a sad lessen to learn, I would not wish it upon anyone."

It is difficult for people living with this disease to maintain proper physical and mental health when dealing with the religious ideologies prevalent in this area. When contrary attitudes about HIV/AIDS exist among the public it influences other institutions, such as health care, which, in turn, affects those living with this disease. One subject indicated that she had attended a conference in this state and was disappointed that the local research and teaching hospital was not represented. She said:

> "I think _____ [this state] does need more awareness. They definitely need it. They have always been behind on everything. I think we need more money. We need to reach out to rural areas. They need awareness so those people that are born and raised out there [rural areas], they can remain there. Instead of having to migrate to the cities to get all the health care and all of the other needs here. There needs to be more compassion." It really upset me that I went to Tulsa for the state Women's HIV-AIDS Conference and our [state] Teaching and Research Hospital was not represented at all. I was mad. It was so good for me to hear about those things that are going on elsewhere. It's like, come on! Where are we in this?"

I also attended this conference in the summer of 1999. I was surprised to see such diverse representation of HIV/AIDS clinics. This respondent was correct, however, when she observed that the state teaching hospital was not represented at this meeting. There were some local physicians that presented information. Persons representing larger HIV/AIDS treatment facilities attended and presented information on their existing programs. One of the large treatment facilities that were represented was located in Houston.

There was another respondent who suggested that health care delivery in this region may suffer due to the religious ideologies that are present. This comment came from a gay male who had private insurance, he said:

> "Religion is a major issue. It could also be related to how far back _____ [this state] is compared to San Francisco, Chicago, New York, where health care is probably a lot better. It would be a shame to think that I would have to move to another state just to get better care."

Negative attitudes toward HIV/AIDS and people living with it are present within society. The ideology or mentality present in society may contribute to the revelations and experiences that the participants have contributed to this study. It appears as though attitudes toward homosexuality may be related to the experiences people with HIV/AIDS have had. Those that reside in this region have considered the impact of the present ideology on their experiences with health care, social support, and stigma. One subject said that:

> "In general, there is still a lot of redneck mentality here toward people living with HIV, being in the Bible belt. Where I worked, everyone seemed to be, if not

> outright Christians, definite leanings toward how people should be living their lives."

Understanding the experiences of people affected by HIV/AIDS with regard to sociocultural rural ideologies has been enlightening. One interviewee verified that my approach to this topic was merited when he said:

> "This is a big town but people here are still country people - they have that mentality."

I knew after I interviewed him that ideologies characterized as rural may not have anything to do with sparsely populated areas. People that live in densely populated areas are affected by prevailing attitudes inherent in the culture. When ideologies about HIV/AIDS, homosexuality, morality, and conservatism are widespread throughout the culture, people affected by this disease are likely to encounter those attitudes through their experiences.

The public should be aware of the causes and consequences of HIV/AIDS given that there is literature available about these issues. Although, there may not be much advertisement about the literature that is available it is there and people can get it (if they want it). There may be many people that do not see HIV/AIDS as a problem in this region. Because of the association of this disease with deviant activities and groups, people may be less willing to become educated about this disease and to understand what people living with it must cope.

The hegemonic influences from the professional community and cultural ideologies perpetuate the attitudes about this disease as well as those that are living with it. Because this disease is associated with deviant activities such as homosexuality, promiscuity, and drug use, negative connotations become attached to this disease and people affected by it. This, in turn, promotes the negative stigma already associated with this disease. Consequently, the experiences of people affected by this disease will reflect the stigma and disapproval of this disease that is brought about by hegemonic influences present within the professional community and cultural ideology.

I chose to focus this project on the lives and experiences of these individuals to clarify that having this disease does not make them bad people. Every time I left an interview I thought, why would this person encounter and experience the things that they have. All of them had something special to offer.

One gentleman that I interviewed did not get out much and did not attend support groups. I was very surprised that he contacted me for an interview after I met him. He was a fascinating man who was interested in art and very knowledgeable about it. When I stepped into his house I immediately noticed that every wall in his house was covered with elaborately framed art work. There was not one piece of any wall left uncovered. After our interview was over he gave me a tour of his art gallery. I was most amazed with his collection of Peruvian art that was dated from 800 AD He had pottery and fabric that had been in his family for many years. He took the time to remove it from the closet and unwrap a few pieces for me. I was very touched that he would do this with a stranger. He told me that these pieces had not seen light but once in the last twenty years. He planned to donate the art to a museum after his death.

Chapter Summary

This chapter provides an analysis of the experiences of people living with HIV/AIDS in terms of health care and medical therapies, social support, and stigma. The analysis clearly indicates that hegemony offers an interesting way to understand and interpret the experiences of people living with this disease. Framing the experiences of these individuals in terms of hegemony offers a suitable approach to understanding this disease.

In chapter six, I provide a synopsis of the project. I also discuss the contributions to the literature as well as the limitations of this project. In addition, I provide a discussion about future research.

CHAPTER SIX

CONCLUSIONS

Project Overview

In this thesis I have provided an historical and socially constructed perspective of HIV/AIDS. These components were included to create the interpretive frame used in this project, hegemony. I then provided a discussion of two types of hegemony, professional and cultural. Both of these hegemonic aspects necessitate interesting approaches when looking at the experiences of people living with HIV/AIDS.

Professional hegemony consisted of the medical community and HIV/AIDS social support organizations. Cultural hegemony was explored through the concept of rurality, which refers to the degree of sociocultural ideologies present within society that are characterized as rural. Rural ideologies consist of religiosity, conservatism, and traditional values. These can be reflected in terms of geographic region, population density, or sociocultural ideologies.

The purpose of framing the experiences of people living with HIV/AIDS in terms of cultural hegemony and rurality was to provide an additional approach to professional hegemony. The experiences of people living with this disease were substantiated by the claims they made to conservatism and only enhance the understanding of hegemonic influences present within society. The concept rurality was used to suggest that there are people living in populated areas that have experienced their disease within the cultural framework of rural ideologies. Both aspects of hegemony were evident in the narratives provided by the respondents in this study.

In this research, I explicated the sociological literature of hegemony by integrating the two hegemonic frameworks; professional and cultural. The data indicate that they are both significant in understanding the experiences of people affected by HIV/AIDS and may collaborate when the ideologies of both hegemonic aspects are examined.

People that are affected by this disease experience both aspects of hegemony as their narratives point out in chapter five. Their experiences with physicians in health care and pharmacists providing medical therapies, social support networks including family, friends, co-workers, and religious institutions, and stigma provide a number of occurrences that may be attributed to professional and cultural hegemony. If people continue to experience the stigma associated with this disease within the context of professional organizations and the medical community in large metropolitan areas characterized by sociocultural rural ideologies, their experiences will likely remain the same as these hegemonic influences that perpetuate the attitudes present within them.

Qualitative methodologies were utilized in this project. The methods that were used included in-depth interviews and participant observation. Although, the data were gathered primarily through semi-structured, in-depth interviews, participant observation supplemented that method. There were twenty-seven participants that were interviewed for this study. The data were organized according to the arenas where experiences were likely to occur, these included health care and medical therapies, social support, and stigma. The narratives and experiences were then presented within the context of professional and cultural hegemony. Data were presented in the analysis based on sub-categories. The sub-categories that were included within the main categories were: Health care and medical therapies: receiving adequate health care, HIV/AIDS diagnosis, insurance, discrimination, and obtaining and taking medications; Social support: family, friends, coworkers, religious affiliations, and HIV/AIDS organizations; and Stigma: transmission stigma, discrimination, and fear.

Briefly, the three sections from chapter five discussed health care and medical therapies, social support, stigma, and professional and cultural hegemony. The participants' narratives were then presented according to their experiences.

The first section covered health care and medical therapies. The data clearly indicated that the experiences with the medical community were reflective of the ideologies that are ubiquitous about people living with this disease. The occurrences to which I am referring include blatantly not testing someone for HIV/AIDS because they 'don't look like they had it.' Because this person was female and didn't look like someone who would have HIV/AIDS (male and homosexual or an IV drug user), she was not tested. And using pharmacies with high turn-over so that prescriptions could be filled without seemingly ridiculous comments and actions by employees. This kind of conduct among professionals fosters negative actions toward HIV/AIDS and those affected by this disease. If these are role models for the public then we should expect attitudes to remain the same and people affected by this disease to continue to experience many of the same things.

The second section included a discussion on social support. Everyone in this study had had at least one experience with a social support network. About half of the interviewees had encountered rejection from family members, while others had positive experiences with family members. Interestingly, those that experienced the most rejection from family members, were those whose family members were also dealing with religious issues. This is supportive of the sociocultural rural ideologies present with society since many people associate deviant activities such as homosexuality and drug use with this disease and the people living with it. Because there are strict limitations placed on deviant activities such as homosexuality among most religious affiliations, people affected by this disease will experience disapproval among those people affiliated with them, including family members. Since there is a strong association between HIV/AIDS and deviant activities, people often lose social support networks such as friends and co-workers when they disclose their HIV positive status. If the connection with this disease to deviant activities were not present or if the public had a better understanding of this disease, it is likely that social support networks would be stronger for people affected by this disease.

In the third section of chapter five, I presented experiences the individuals had had that were reflective of the stigma associated with HIV/AIDS. There were revelations about discrimination toward people living with HIV/AIDS as well as the fear people had about the disease. The stigmatizing experiences that the respondents had were symbolic of the lack of knowledge present within society today. It was astonishing to hear what these individuals recounted about their experiences. To think that today, in the year 2000, people affected by HIV/AIDS are still experiencing this degree of stigma. There is still a substantial amount of stigma associated with this disease, but how is that to be explained or interpreted. Again, hegemony and the ideologies associated with that concept are very suitable in explaining the experiences that the individuals in this project have encountered.

The fifth section that was discussed in chapter five was professional and cultural hegemony. I chose to discuss that section as I concluded chapter five so each of the categories and data that were presented could be framed and understood with regard to the hegemonic framework. Because there were so many participants who referred specifically to professional and cultural hegemony in their narratives, I felt that a presentation of these specific concepts within the context of the data was important. I thought that it was necessary and relevant to include a section on professional and cultural hegemony in that chapter. The data presented in chapter five suggest that hegemony is an excellent framework to interpret the experiences that these individuals had encountered and revealed to me.

In chapter three I discussed hegemony as a primary framework. In chapter three, I also provided a discussion on secondary frameworks. I suggested that HIV/AIDS is inclusive of a social (secondary) framework as opposed to a natural framework because of how the disease is spread and the societal connotations attached to disease transmission. Although a natural framework is relevant due to the process of disease transmission (through bodily fluids), a social framework is more appropriate in the case of HIV/AIDS because people attach symbolic meanings to how this disease is spread.

Deviant activities have symbolic meanings in our society especially homosexuality and IV drug use. These activities have become associated with this disease and produce symbolic meanings about this disease as well as those living with it. In addition, there are regions of the country where these symbolic meanings are reinforced throughout societies institutions including religion, health care, family, and organizations. When substantial meaning is placed upon these activities and they become associated with a disease like HIV/AIDS it is difficult to redirect such symbolism when there is a high value placed upon the ideologies present in the professional and cultural realms of society.

Attitudes toward this disease and people living with it become reinforced by the hegemonic ideologies present within society. The relationship between the primary framework, hegemony, and the social framework, is that HIV/AIDS is perceived within a social framework by the organizations, the medical community, and by society. People affected by HIV/AIDS must experience their disease through the social framework created and maintained by the hegemonic influences in society. The social framework that has been created about this disease is inherently deviant. Therefore, this social framework that has been created by hegemonic influences force people to experience their disease in the arenas that are critical to their lives, including health care and social support.

I acknowledge that there are problems with this interpretation just as there are with many sociological interpretations. However, exploring this phenomenon from these perspectives has been challenging and mentally stimulating. This project offers many opportunities from which to expand theoretical and conceptual ideas. I will discuss the limitations of this study as well as directions for future research in the following sections.

Limitations of the Study

The purpose of this study was to give meaning to the experiences that individuals who are living with HIV/AIDS have had with regard to health care and medical therapies, social support, and stigma. The primary framework utilized in this study was hegemony.

The data suggests that this framework is suitable when interpreting these individuals' experiences.

Because I employed qualitative methods in this project, there are issues concerning external validity and reliability. This was certainly the most difficult research project that I have conducted. I constantly struggled with how my personal feelings would impact data interpretation. I understand that this is a substantial component of qualitative research, but I was very careful to report the data accurately and not misinterpret what any respondent revealed. I feel that I have depicted the responses in this study as precisely as possible. However, there are still limitations to this study.

First, I have included only those people that are living with HIV/AIDS in this study. I chose not to interview people who create professional or cultural hegemonic experiences for people living with this disease namely. I did not interview people in the health care community, people that worked in the large HIV/AIDS organizations, family, friends or co-workers of people living with HIV/AIDS, or anyone on the AIDS Health Care and Consortium board. I chose not to interview these people because I thought that they may provide me with an ideological interpretation of how people living with HIV/AIDS are treated by them. And in order to maintain theoretical and methodological consistency with Frame analysis, only the perspectives of persons experiencing HIV/AIDS could have been included in this project. Perhaps in the future I will solicit narratives from the populations that were excluded from this project and provide theoretical alternatives for understanding this phenomenon.

Because I chose to interview only HIV/AIDS infected individuals, who have encountered these people or groups, my results provide a one-sided view of hegemony. Again, to maintain theoretical and methodological constistency while employing Frame analysis it is necessary that only one perspective be provided and preferably from those who are experiencing the phenomenon being explored. Although, I can not provide narratives for the people who create professional and cultural hegemony in this project, I can provide a personal interpretation of my observations during my brief encounters with them. On a few occasions I was able to make contact with the large HIV/AIDS organization and the consortium. The observations that I made during these encounters allows me to interpret the data by confidently employing the framework of hegemony. Based on my experience with these two groups, the interpretation of these narratives that I have presented, within the context of hegemony, is justifiable.

The second limitation to this study was that I interviewed only those individuals who contacted me. This could bias the results because only those that chose to tell their stories participated in this study.

In the next section I look at directions for future research. I will discuss the contributions of this study as well as implications for future research.

Contributions and Future Research

This project has potential for contributing to the existing body of literature within medical sociology. In addition, there are many opportunities for me to elaborate on the ideas and the data provided in this project.

The first contribution offers an approach to framing the experiences of people living with HIV/AIDS in the context of hegemony. There has not been much literature published that combines any two of these concepts of HIV/AIDS, framing, and professional and cultural hegemony. In this project, the concept of hegemony fits well with Frame analysis because I have presented the experiences of people living with HIV/AIDS from their perspective. The narratives of people living with HIV/AIDS, as they have been conveyed, were framed within the context of hegemony.

In this project I have also attempted to elaborate on the meaning of the term rurality particularly with regard to its sociocultural meaning and cultural hegemony. Exploring other social phenomenon from this perspective would enrich the literature available in that area.

The second contribution to the sociological literature is the expansion of Frame analysis. There have been many ways in which Frame analysis has been utilized. This project explored hegemony and Frame analysis. Empirical results from this study may help to elucidate other projects with a similar interest in hegemony, HIV/AIDS, and Frame analysis (Singh 1998; Maggard 1983).

Looking at the interpretation of experience among people living with this disease in the context of hegemony specifically contributes to the social psychology literature. The bulk of the literature on HIV/AIDS within sociology deals with macro level data. Macro level analyses look at attitudes about the HIV/AIDS and people with it rather than how people who are living with it experience the disease. The contribution of this project to the sub-disciplines of medical sociology and social psychology are eminent because this project makes a theoretical contribution to the discipline as well as a conceptual contribution both, of which, are valuable areas within sociology.

The fourth contribution involves the categories that were explored in this study, namely, health care, medical therapies, and social support. These components could constitute research projects with some additional investigation. The literature on HIV/AIDS with regard to health care and medical therapies is lacking in the area of sociology. Much of the literature that is available stems from the medical community, public health, and health behavior and does not provide a sociological perspective to this disease. There is not much literature from the sociological perspective on how people living with have this disease experience health care, medical therapies, and social support. These are areas that are copious for future research.

One research project that would be replete with possibilities include the combination of both persons living with HIV/AIDS and employees of statewide HIV/AIDS organizations. It would be interesting to compare the responses of these two groups. I would predict that the responses would vastly contrast, provided that the goals of these two groups remain divided. Some research questions that could be addressed are what are the overall goals of these two groups? What are these groups doing to accomplish those goals? Are the current practices making things better or worse for the service beneficiaries?

A second project that would be interesting and fruitful for future research would involve exploring mental well-being among people with chronic or terminal illnesses, specifically HIV/AIDS. Many of the individuals that participated in this study revealed how they also dealt with issues relating to mental health. Because I picked up on a relationship between spirituality and mental health, this project could also address that aspect of well-being. Many of the people I interviewed had encountered religion and many had become religious gurus while others that were very religious had lost that desire. I am convinced that there is a connection between spirituality and chronic or terminal diseases, which may be a factor related to death. Research questions could address differences in religiosity and spirituality with regard to death. How disclosing an HIV/AIDS status influences an individual's choice between religion and spirituality?

In addition, a third project could include a longitudinal investigation exploring mortality among people living with HIV/AIDS. As treatment modalities continue to enhance the longevity among people with this disease, they will live longer and may eventually become more mainstream members of society. In future years, when this is likely to occur, it would be interesting and significant to compare the lives of people living with HIV/AIDS to those living with cancer. Research questions could address stigma management, perceptions about HIV/AIDS and cancer patients with regard to stigma, and attitudes about the disease.

REFERENCES

Abbey, A., Abramis, D.J., and Caplan, R.D. (1985). "Effects of different sources of social support and social conflict on emotional well-being." *Basic and Applied Social Psychology*, 43:315-323.

Aday, L., Pounds, M., Marconi, K. and Bowen, G.S. (1994). "A Framework for evaluating the Ryan White CARE Act: Toward a circle of caring for persons with HIV/AIDS." *AIDS and Public Policy Journal,* (9)3:137-144.

Adelman, Mara B. (1991). "Play and incongruity: Framing safe-sex talk. *Health Communication.*" 3(3):139-155.

Altman, Dennis (1986). *AIDS in the Mind of America: The Social, Political, and Psychological Impact of a New Epidemic.* Garden City, NY: Anchor Press/Doubleday.

Anderson, Odin (1983). "Book review of the Social Transformation of American Medicine." *Medical Care*, 21: 1243-1245.

Anderson, V.N. (1992). "For whom is this world just? Sexual Orientation and AIDS." *Journal of Applied Social Psychology*, 22, 248-259.

Andrulis, D.P. (1998). "Access to care is the centerpiece in the elimination of socioeconomic disparities in health." *Annals of Internal Medicine*, 129(5):412-417.

Annandale, E. (1989). "Proletarianization or restratification of the medical profession? The case of obstetrics." *International Journal of Health*, 19(4): 611-634.

Antonovsky, A. (1967). "Social class, life expectancy, and overall mortality." *Milbank Quarterly*, 45: 31-73.

Ashley, Laura and Olson, Beth (1998). "Constructing reality: Print media's framing of the women's movement, 1966 to 1986." *Journalism and Mass Communication Quarterly*, 75(2): 263-277.

Bailey, Marvin E. (1991). Community-based organizations and CDC as partners in HIV education and prevention." *Public Health Reports,* 106(6): 702-707.

Barre-Sinoussi, F. Chermann, J.C., and Rey, F. (1983). "Isolation of a T-lymphotropic retrovirus from a patient at risk for acquired immune deficiency syndrome (AIDS)." *Science*, 220; 868-871.

Bateson, Gregory. (1972). *Steps to an Ecology of the Mind: Collected Essays in Anthropology, Psychiatry, Evolution, and Epistemology.* New York: Ballantine Books.

Bauman, Zygmunt (1992). "Soil, blood, and identity." *The Sociological Review,* 40(4): 675-698.

Bayer, R. (1997). "Science, politics, and AIDS prevention policy." *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology,* 14(2): S22-29.

Bealer, Robert, Willits, Fern, and Kuvlesky, William (1965). "The meaning of rurality in American Society: Some implications of alternative definitions." *Rural Sociology*, 30; 255-66.

Beaudin, C.L. and Chambre, S.M. (1996). "HIV/AIDS as a chronic condition: Emergence from the plague model." *American Behavioral Scientist,* 39(6):684-707.

Becker, Howard S. (1973). *Outsiders: Studies in the Sociology of Deviance.* 2nd edition. New York: The Free Press.

Becker, Howard S. and Geer, Blanche (1957). "Participant observation and interviewing: A comparison." *Human Organization.* 16:28-32.

Berger, Peter L. and Luckman, Thomas (1966). *The Social Construction of Reality. A Treatise in the Sociology of Knowledge.*

Bernard, L. L. (1917). "A theory of rural attitudes." *American Journal of Sociology,* 22(5):630-649.

Berry, Kate A., Markee, Nancy L., Fowler, Nanci, and Giewat, Gary R. (2000). "Interpreting what is rural and urban for Western U.S. counties." *The Professional Geographer*, 52(1): 93-105.

Birenbaum, A. and Sagarin, E. (1976). *Norms and Human Behavior.* New York: Praeger:

Blendon, R. and Donelan, K. (1988). "Discrimination against people with AIDS: the public's perspective." *New England Journal of Medicine.* 319: 1022-1026.

Blumer, Herbert (1969). *Symbolic Interactionism: Perspective and Method.* Englewood Cliffs, NJ: Prentice Hall.

Bor, Robert and Elford, Jonathon (1998). "The Family and HIV." In *The Family and HIV Today.* R. Bor and J. Elford, eds. New York: Cassell.

Brock, Rita N. (1996). "Clearing the tangled vines." *Amerasia Journal*, 22(1): 181-188.

Brown, Phil (1990). "The name game: Toward a sociology of diagnosis." *The Journal of Mind and Behavior*, 11(3-4): 2.

Browner, C.H. and Press, Nancy (1996). "The production of authoritative knowledge in American prenatal care." *Medical Anthropology Quarterly*, 10(2): 141-156.

Brownlee, S., McDonald, M., and Ackerman, E. (1997). "AIDS comes to small town America." *U.S. News and World Report.* 123(18):52-56.

Bruder, Paul (1998). "Showdown: The dark side of medical power and academic pandering." *Hospital Topics.* 76(3): 31-32.

Buchanan, Robert J. and Chakavorty, Bonnie J. (1999). "Assessments of the Coverage of HIV-related Care by Public Programs: A Survey of AIDS Service Organizations." *Social Work in Health Care*, 29(3): 19-43.

Buehler, James W., Frey, Robert L. and Chu, Susan Y. (1995). "The migration of persons with AIDS: data from 12 states, 1985 to 1992." *The American Journal of Public Health.* 85(11):1552-6.

Bunting, Sheila M. (1996). "Sources of stigma associated with women with HIV." *Advances in Nursing Science.* 19(2)64-74.

Burgess A. and Catalan J. (1991). "Health-related quality of life in HIV infection." *International Review of Psychiatry*, 3:357-364.

Burns, Tom (1992). *Erving Goffman.* New York, NY: Routledge.

Cain, R. (1997). "Environmental change and organizational evolution: reconsidering the niche of community-based AIDS organizations." *AIDS Care*, 9(3): 331-344.

Carpenter, Laura M. (1998). "Virginity is a gift: A distinctive approach to early sexual experiences." Paper presented at the American Sociological Association.

Carroll, William K. and Rafner, R.S. (1996). "Master framing and cross movement networking in contemporary social movements." *Sociological Quarterly*, 37(4): 601-627.

Cassel, J. (1974). "An epidemiological perspective of psychosocial factors in disease etiology." *American Journal of Public Health.* 64: 1040-1043.

Catalan J., Brener N., Andrews H., Day A., Cullum S., Hooker M., and Gazzard B. (1994). "Whose health is it? Views about decision-making and information seeking from people with HIV infection and their professional carers." *AIDS Care*, 6(3):349-56.

Catz, S.L., Kelly, J.A., Bogart, L.M., Benotsch, E.G., and McAuliffe, T.L. (2000). "Patterns, correlates, and barriers to medication adherence among persons prescribed new treatments for HIV disease." *Health Psychology*, 19(2): 124-133.

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

------ (1981b). "Kaposi's Sarcoma and Pneumocystis pneumonia among homosexual men - New York City and California." *Morbidity and Mortality Weekly Report,* 30;305-308.

------ (1982a). "Opportunistic infections and Kaposi's Sarcoma among Haitians in the United States." *Morbidity and Mortality Weekly Report,* 31;53-361.

------ (1982b). "Pneumocystis Carinii pneumonia among persons with hemophilia A." *Morbidity and Mortality Weekly Report,* 31;366.

------ (1982c). "Possible transfusion associated Acquired Immune Deficiency Syndrome (AIDS), California." *Morbidity and Mortality Weekly Report,* 31;652-654.

------ (1982d). "Update on acquired immune deficiency syndrome (AIDS) - United States." *Morbidity and Mortality Weekly Report,* 31;508.

------ (1998). *HIV/AIDS Surveillance Reports.* Midyear 1998 edition, 10;1.

Charles, Cathy; Whelan, Tim, and Gafini, Amiram (1999). "What do we mean by partnership in making decisions about treatment?" *British Medical Journal,* 319(7212): 780-784.

Chayko, Mary (1993). "What is Real in the age of Virtual Reality? 'Reframing' Frame Analysis for a Technological World." *Symbolic Interaction.* 16(2): 171-181.

Cherlin, Andrew J. (1992). *Marriage, Divorce, Remarriage* (2nd edition). Cambridge, Massachusetts: Harvard University Press.

Chesney, M.A., Morin, M. and Sherr, L. (2000). "Adherence to HIV combination therapy." *Social Science and Medicine*, 50(11): 1599-1605.

Christensen P. and Bender L. (1994). "Models of nursing care in a changing environment: Current challenges and future directions." *Orthopedic Nursing*, 13(2):64-69.

Clark, Martin (1977). *Antonio Gramsci and the Revolution that Failed.* London: New Haven: Yale University Press.

Coates, J., Graham, L., Boeglin, D., and Tielker, S. (1990). "The effects of AIDS on the family system: Families in Society." *Journal of Contemporary Human Services.* 4:195-201.

Cockerham William C (1993). "The changing patterns of physician-patient interaction." In *Sociomedical Perspectives on Patient Care*, J. Clair and R. Allman, eds. The University Press of Kentucky: Lexington, Kentucky.

Cockerham, William C. (1998). *Medical Sociology*, 7th Edition. Englewood Cliffs, New Jersey: Prentice Hall.

Cohn, S.E., Klein, J.D., Mohr, J.E., Horst, C.M., and Weber, D.J. (1994). "The geography of AIDS: Patterns of urban and rural migration." *Southern Medical Journal,* 87(6):599-606.

Connors, M.M. (1995). "The politics of marginalization: The appropriation of AIDS prevention messages among injection drug users." *Culture, Medicine, and Psychiatry*, 19(4): 425-452.

Conrad, Peter (1987). "The noncompliant patient in search of autonomy." *Hastings Center Report*, 17: 15-17.

Cook, T.D. and Campbell, D.T. (1979). *Quasi-experimentation: Design and analysis issues for field settings.* Boston: Houghton Mifflin.

Crandall, C.S., Glor, J., and Britt, T.W. (1997). "AIDS-related stigmatization: Instrumental and symbolic attitudes." *AIDS Weekly Plus.* 3:37-38.

Creed, Gerald W. and Ching, Barbara (1997). "Recognizing Rusticity: Identity and the Power of Place." In *Knowing your Place: Rural Identity and Cultural Hierarchy* B. Ching and G. Creed, editors. New York: Routledge.

Crook, Steve and Taylor, Laurie (1980). "Goffman's Version of Reality." In *The View from Goffman*, Jason Ditton, editor. New York: St. Martin's Press.

Crystal, Stephen and Jackson, Marguerite. (1992). "Health Care and the Social Construction of AIDS: The Impact of Disease Definition." In *The Social Context of AIDS,* Joan Huber and Beth Schneider, eds. Newbury Park: Sage Publications.

Cullum, Betsy (1992). "Behavior in Public Places: A frame analysis of gynecological exams." Paper presented at the American Sociological Association.

Cunningham W., Mosen D., Hays R., Andersen R. and Shapiro M. (1996). "Access to community-based medical services and number of hospitalizations among patients with HIV disease: Are they related?" *Journal of Acquired Immune Deficiency Syndrome and Human Retrovirology*, 13:327-335.

Curtis, J.R., Patrick, D.L., Caldwell, E., Greenlee, H., Collier, A.C. (1999). "The quality of patient-doctor communication about end-of-life care: A study of patients with advanced AIDS and their primary care clinicians." *AIDS Weekly Plus*, 13(9): 1123-1131.

Davidson, James D., Pyle, Ralph E., and Reyes, David V. (1995). "Persistence and change in the Protestant establishment, 1930-1992." *Social Forces*, 74(1): 157-175.

Davis, Dennis and Abelman, Robert (1983). "Families and Television: An application of frame analysis theory." *Journal of Family Issues.* 4(2):385-404.

Davis, N. J. (1980). *Sociological Constructions of Deviance: Perspectives and Issues in the Field.* Dubuque, IA: William C. Brown.

Denzin, Norman K. (1986). *The Alcoholic Self.* Beverly Hills: Sage.

Denzin, Norman K. (1970). *The Research Act: A Theoretical Introduction to Sociological Methods.* Chicago: Aldine Publishing Company.

DeNoon, D.J. (1999). "CDC warns of HIV clusters in low-prevalence areas." *AIDS Weekly Plus.* July.

Downe, Pamela J. (1997). "Constructing a complex of contagion: The perceptions of AIDS among working prostitutes in Costa Rica." *Social Science and Medicine*, 44(10): 1575-1584.

Duesberg, Peter H. (1995). *Infectious AIDS: Have we been misled?* Berkeley, California: North Atlantic Books.

Eaton, Gail and Webb, Barbara (1979). "Boundary encroachment: Pharmacists in the clinical setting." *Sociology of Health and Illness*, 1(1): 69-89.

Eddy, D.M. (1990). "Anatomy of a decision." *JAMA* 263: 441-443.

Edmonson, Brad and Fontanez, Will (1995). "Where are the boonies?" *American Demographics*, 17(2): 60-61.

Elling, Ray H. (1981). "Political economy, cultural hegemony, and mixes of traditional and modern medicine." *Social Science and Medicine*, 15A(2): 89-99.

Epstein, Steven (1995). "The dynamics of scientifically sophisticated movements: AIDS treatment activists and the encounter with biomedical research." *Paper Presented at the Annual Meeting of the ASA.*

Eriksen, Nancy (1999). "Developing a continuum of care for HIV positive women." Presentation at the Second Regional Conference on Women and AIDS, University of Tulsa, Tulsa, Oklahoma, June 14, 1999.

Ervin N., Walcott-McQuigg J., Chen S., and Upshaw H. (1992). "Measuring patients' perception of care quality." *Journal of Nursing Care Quality*, 6(4):25-32.

Evans, Robert G., Barer, Morris L., and Marmor, Theodore R. (eds.) (1994). "*Why are some people healthy and others not?*" New York: Aldine De Gruyter.

Ferguson, W. J. (1994). "The physician's responsibility to medically underserved poor people." In *It Just Ain't Fair: The Ethics of Health Care for African Americans.* A. Dula and S. Goering, eds. Westport, CT: Praeger.

Fife, B.L. and Wright, E.R. (2000). "Stigma: The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer." *Journal of Health and Social Behavior*, 41(1): 50-68.

Fife, B.L. and Wright, E.R. (1999). "The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer." *Sociological Abstracts,* 47.

Fischer, Edward F. (1993). "The West in the future: Cultural Hegemony and the politics of identity (a response to Jonathan Friedman)." *American Anthropologist*, 95(4): 1003.

Fischer, Edward F. and Friedman, Jonathan (1993). "The west in the future: Cultural hegemony and the politics of identity." *American Anthropologist*, 95(4): 1000-1002.

Fitchen, Janet M. (1991). *Endangered Spaces, Enduring Places: Change, Identity, and Survival in Rural America.* Boulder, CO: Westview Press.

Fleishman, J.A., Mor, V., and Piette, J. (1991). "AIDS Case Management: The Client's Perspective." *Health Services Research*, 26(4): 447-470.

Ford, Thomas K. (1965). *The apothecary in 18th Century Williamsburg.* Williamsburg, VA: Colonial Williamsburg Foundation.

Fordyce, E.J., Thomas, P. and Shum, R. (1997). "Evidence of an increasing AIDS burden in rural America." *Statistical Bulletin*, 78(2):2-9.

Foucault, Michel (1974). *The Archeology of Knowledge.* London: Tavistock Publications.

---------- (1973). *The Birth of the Clinic: An Archeology of Medical Perception.* New York, NY: Random House.

---------- (1978). *The History of Sexuality, Volume I An Introduction: The Will to Knowledge.* New York, NY: Random House.

--------- (1984). *The History of Sexuality, Volume II: The Use of Pleasure.* New York, NY: Random House.

Friedland J., Renwick R., and McColl M. (1996). "Coping and social support as determinants of quality of life in HIV/AIDS." *AIDS Care*, 8(1):15-31.

Frank, Arthur W. (1979). "Reality construction in interaction." *Annual Review of Sociology*, 5: 167-191.

Frankenberg, Ronald (1988). "Gramsci, Culture, and medical anthropology." *Medical Anthropology Quarterly*, 2(4): 324-327.

Frans, Douglas (1994). "Social work, social science and the disease concept: Directions for Addiction Treatment." *Journal of Sociology and Social Welfare*, 21(2): 71-89.

Frumkin Leonard and Leonard John (1997). *Questions and Answers on AIDS.* Los Angeles, California: Health Information Press.

Fuchs, V.R. (1997). "A tale of two states." In *The Sociology of Health and Illness*, 5th edition. Peter Conrad (ed). New York: St. Martin's Press.

Gallo, Robert C., Salahuddin, S.Z., and Popovic, M. (1984). "Frequent detection and isolation of cytopathic retroviruses." *Science,* 224; 500-503.

Ganster, D. and Victor, B. (1988). "The impact of social support on mental and physical health." *British Journal of Medical Psychology.* 61:17-36.

Garry, R. F., Witte, M.H., and Gottlieb, A.A. (1988). "Documentation of an AIDS virus infection in the United States in 1968." *JAMA*, 260; 2085-2087.

Geertz, Clifford (1973). *The Interpretation of Cultures: Selected Essays.* New York: Basic Books.

Gelone, Steven and Kostman, Jay R. (1998). "Managing HIV infection: Update and review." *American Druggist*, 215(9): 58-66.

Gessler, Wilbert M. (1992). "Therapeutic landscapes: Medical issues in light of cultural geography." *Social Science and Medicine*, 34(7): 735-746.

Gewirtz, A. and Gossart-Walker S. (2000). "Home-based treatment for children and families affected by HIV and AIDS: Dealing with stigma, secrecy, disclosure, and loss." *Child and Adolescent Psychiatric Clinics of North America*, 9(2): 313-330.

Giddens, Anthony (1984). *The Constitution of Society.* Cambridge, MA: Polity.

Glaser, Barney (1978). *Theoretical Sensitivity.* Sociological Press: Mill Valley, California.

Glaser, Barney and Strauss, Anselm (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research.* Aldine: Chicago, Illinois.

Goffman, Erving (1974). *Frame Analysis: An Essay on the Organization of Experience.* Boston : Northeastern University Press.

Goffman, Erving (1963). *Stigma: Notes on the Management of Spoiled Identity.* New York: Simon & Schuster.

Goffman, Erving (1959). *The Presentation of Self in Everyday Life.* Garden City, New York:Doubleday Anchor.

Goicoechea-Balbona, A. (1997). "Culturally specific health care model for ensuring health care use by rural, ethnically diverse families affected by HIV/AIDS." H*ealth and Social Work*, 22(3):172-180.

Gramsci, Antonio (1957). *The Modern Prince and other Writings.* New York, NY: International Publishers.

Gramsci, Antonio (1971). *Prison Notebooks.* New York, NY: International Publishers.

Grasmick, Harold G., Patterson-Wilcox, Linda, and Bird, Sharon R. (1990). "The effects of religious fundamentalism and religiosity on preferences for traditional family norms." *Sociological Inquiry*, 60(4): 352-370.

Grant, L.M. and Ostrow, D.G. (1995). "Perceptions of social support and psychological adaptation to sexually acquired HIV." *Social Work*, 40(2):215-225.

Greer, Scott (1969). *The Logic of Social Inquiry.* Aldine Publishing Company: Chicago.

Guizzardi, Gustavo (1976). "The rural civilization: Structure of an ideology for consent." *Social Compass*, 23(2-3): 197-220.

Haas, D.M., and Coe, R.M. (1998). "Do physicians discuss HIV and AIDS with patients? A survey of physician practices." *AIDS Weekly Plus*, January 19: 31-33.

Hammersley, M. and Atkinson, P. (1983). *Ethnography: Principles in Practice.* London: Tavistock.

Hansen, Robert W., Ranelli, Paul L., and Ried, Douglas L. (1995). "Stigma, conflict, and the approval of AIDS drugs." *Journal of Drug Issues*, 25(1): 129-139.

Hays, Robert, Magee, Robert, and Chauncey, Sarah (1998). "Identifying helpful and unhelpful behaviours of loved ones: The PWA's perspective." In *The Family and HIV Today.* R.Bor and J.Elford, eds. New York: Cassell.

Heckman, T.G., Somlai, A.M., Peters, J. Walker, J., Otto-Salaj, L. Galdabini, C.A. and Kelly, J.A. (1998). "Barriers to care for people living with HIV/AIDS in urban and rural areas." *AIDS Care.* 10(3):365-375.

Heckman, T.G., Somlai, A.M., Kelly, J.A., Stevenson, L.Y., and Galdabini, K. (1996). "Reducing barriers to care and improving quality of life for rural persons with HIV." *AIDS Patient Care and STD's.* 10(1):37-44.

Hellinger, F.J. (1993). "The lifetime cost of treating a person with HIV." *JAMA*, 270(4):474-478.

Henderson, C.W. (1997). "HIV and AIDS pose special challenges in rural areas." *AIDS Weekly Plus*, November 17, 25-26.

Hendrixson, L.L. (1997). "The psychosocial and psychosexual impact of HIV/AIDS disease on rural women: A qualitative study." *Dissertation Abstracts International,* 57(12):5312.

Herrell, Richard K. (1996). "Sin, Sickness, Crime: Queer Desire and the American State." *Identities: Global Studies in Culture and Power*, 2(3): 273-300.

Heyward, W.L. and Curran, J.W. (1988). "The epidemiology of AIDS in the U.S." *Scientific American*, 259:4; 72-81.

Hills, S. (1980). *Demystifying Social Deviance.* New York: McGraw Hill.

Himes, Joseph S. (1991). *The South Moves into its Future: Studies in the Analysis and Prediction of Social Change.* Tuscaloose, Alabama: The University of Alabama Press.

Himmelstein, D.U. and Woolhandler, S. (1999). "Race and infant mortality." In *Health, Illness, and Healing: Society, Social Context, and Self.* Kathy Charmaz and Debora Paterniti (eds). Los Angeles, California: Roxbury Publishing Company.

Hoare, Quinton and Nowell-Smith, Geoffrey (1972). *Selections from the Prison Notebooks of Antonio Gramsci.* New York, NY: International Publishers.

Hobson, Fred (2000). "The anatomy of the south." *Southern Cultures*, 6(1): 114-115.

Holstein, M. (1997). "Reflections on death and dying." *Academic Medicine*, 72(10): 848-855.

House, J.S. (1981). *Work Stress and Social Support.* Reading, MA: Addison-Wesley.

Hubbard, Amy S. (1994). "Using media frames to examine the impact of violent and nonviolent strategies." Paper presented at the American Sociological Association.

Huminer, D. Rosenfeld, J.B., and Pitlik, S.D. (1987). "AIDS in the pre-AIDS era." *Review of Infectious Diseases.* 9; 1102-1108.

Hunt, Linda M., Jordan, Brigitte, Irwin, Susan, and Browner, C.H. (1989). "Compliance and the patient's perspective: Controlling symptoms in everyday life." *Culture, Medicine, and Psychiatry*, 13: 315-334.

Hurt, Douglas R. (1981). *The Dust Bowl: An agricultural and social history.* Chicago: Nelson Hall.

Jankowski, S., Videka-Sherman, L., and Laquidara-Dickinson, K. (1996). "Social support networks of confidants to people with AIDS." *Social Work*, 41(2):206-214.

John, T. Jacob (1995). "Sexuality, sin, and disease; Theological and ethical issues posed by HIV/AIDS to the churches: Reflections by a physician." *World Council of Churches.*

Johnson, S.D. (1995). "Model of Factors Related to Tendencies to discriminate against people with AIDS." *Psychological Reports*, 76(2): 563-572.

Johnston, D. Stall, R. and Smith, K. (1998). "Reliance by gay men and Intravenous drug users on friends and family for AIDS related care." *In Family and HIV Today,* R. Bor and J. Elford, eds. New York, NY: Cassell.

Jones, E.E., Farina, A., Hastorf, A.H., Markus, H., Miller, D.T., and Scott, R.A. (1984). *Social Stigma: The Psychology of Marked Relationships.* New York: Freeman.

Juengst, E.T. (Ed) (1989). *The Meaning of AIDS: Implications for Medical Science, Clinical Practice, and Public Health Policy.* New York, NY: Praeger Publishers.

Kadushin, G. (1996). "Gay men with AIDS and their families of origin: An analysis of social support." *Health and Social Work.* 21(2) 141-150.

Katz, I. (1981). *Stigma: A Social Psychological Analysis.* Hillsdale, NJ: Erlbaum.

Kayal, Phillip M. (1993). *Bearing Witness: Gay Men's Health Crisis and the Politics of AIDS.* Boulder, CO: Westview Press, Inc.

Kearns, Robin A. (1996). "AIDS and the medical geography: Embracing the other?" *Progress in Human Geography*, 20(1): 123-131.

Kegeles, S.M., Coates, T.J., Christopher, A. and Lazarus, J. (1989). "Perceptions of AIDS: The continuing saga of AIDS-related stigma." *AIDS.* 3(suppl):s253-s258.

King James Bible (2000). http://www.kjvb.com.

King, Lester S. (1984). *American Medicine Comes of Age, 1840-1920.* Chicago, IL: American Medical Association.

Krinsky, John D. (1997). "Representing the Homeless to Abolish Homelessness: The Framing of Collective Identity in a Poor People's Movement." Paper presented at the American Sociological Association.

Larson, Olaf (1978). "Values and beliefs of rural people." In *Rural U.S.A.: Persistance and Change.* Thomas R. Ford, editor.Ames, Iowa: Iowa State University Press.

Leach, Belinda (1997). "Culture, globalization, and the politics of place." *Anthropologica*, 39(1-2): 3-5.

Lears, T.J. Jackson (1985). "Concept of cultural hegemony: Problems and possibilities." *American Historical Review,* 90: 567-591.

Lee, Burton J. (1990). "Attitudes: physicians, AIDS, and the American Public." *Archives of Internal Medicine*, 150(1): 29-31.

Leiker, J.J., Taub, D.E.,and Gast, J. (1995). "The stigma of AIDS: Persons with AIDS and social distance." *Deviant Behavior.* Oct.-Dec: 215-228.

Leontidou, Lila (1996). "Alternatives to modernism in (southern) urban theory: exploring in-between spaces." *International Journal of Urban and Regional Research*, 20(2): 178-196.

Lemert, Charles and Gillan, Garth (1982). *Michel Foucault: Social Theory and Transgression.* New York, NY: Columbia University Press.

Levy, Alan J. (1993). "Stigma management: A new clinical service." *Families in Society*, 74(4): 226-231.

Lewis, C. E. (1997). "Management of patients with HIV/AIDS: Who should care?" *JAMA*, 278(14): 1133-1135.

Lincoln, Yvonne and Guba, Egon (1985). *Naturalistic Inquiry.* Newbury Park, CA: Sage Publications.

Lindenbaum, Shirley (1992). "Knowledge and action in the shadow of AIDS." In *The Time of AIDS: Social Analysis, Theory, and Method.* G. Herdt and S. Lindenbaum, eds. Newbury Park, CA: Sage Publications.

Lofland, John and Lofland, Lyn (1984). *Analyzing Social Settings.* Belmont, CA: Wadsworth.

MacLaughlin, Jim (1993). "Place, politics, and culture in nation-building ulster: Constructing nationalist hegemony in post-famine Donegal." *Canadian Review of Studies in Nationalism*, 20(1-2): 97-111.

Maggard, Sally W. (1983). "Newsmaking, cultural hegemony and social change in Eastern Kentucky." *Paper presented at the Rural Sociological Society.*

Manning, Philip (1992). *Erving Goffman and Modern Sociology.* Stanford, CA: Stanford University Press.

Malterud, K. (1999). "The (gendered) construction of diagnosis interpretation of medical signs in women patients." *Theoretical Medicine and Bioethics*, 20(3): 275-286.

Maxwell, Joseph A. (1986). *Qualitative Research Design: An Interactive Approach.*Thousand Oaks, California: Sage Publications.

McCann, Jean (1997). "The AIDS front: are cures and compliance within reach for patients?" *Drug Topics*, 141(4): 60-66.

McGinn, F. (1996). "The plight of rural parents caring for adult children with HIV. *Families in Society,* 77(5):269-278.

McGovern, Stephen J. (1997). "Cultural hegemony as an impediment to urban protest movements: Grassroots activism and downtown development in Washington, D.C." *Journal of Urban Affairs*, 19(4): 419-444.

McInerney, F. (2000). "Requested death: A new social movement." *Social Science and Medicine*, 50(1): 137-54.

McKinney, M.M. (1998). "Service needs and networks of rural women with HIV/AIDS." *AIDS Patient Care and STD's*, 12(6):471-481.

Miller, Michael K. and Luloff, A.E. (1981). "Who is rural? A typological approach to the examination of rurality." *Rural Sociology*, 46(4):608-625.

Miller, R.D. (1981). "Recent developments in antitrust: Challenges to medical autonomy." *New Directions for Mental Health Services*, 41: 69-80.

Mitchell, Katharyne (1999). "What's culture got to do with it?" *Urban Geography*, 20(7): 667-678.

Montoya, I.D., Trevino, R.A., and Kreitz, D.L. (1999). "Access to HIV services by the urban poor." *Journal of Community Health*, 24(5): 331-46.

Mookherjee, Harsha N. (1995). "Attitudes of Tennessee college students toward women." *Perceptual and Motor Skills,* 80(3): 863-867.

Mosby's Medical and Allied Health Dictionary (2000).

Mouton, C., Teno, J.M., Mor, V., and Piette, J (1997). "Communication of preferences for care among human-immunodeficiency virus-infected patients: Barriers to informed decisions?" *Archives of Family Medicine*, 6: 342-347.

Munch, Richard (1994). *Sociological Theory: From the 1920's to the 1960's. Volume Two.* Chicago: Nelson-Hall Publishers.

Myntti, C. (1988). "Hegemony and healing in rural north Yemen." *Social Science and Medicine,* 27(5): 515-520.

Nykamp D., Barnett C., Lago M., Parham D., and Fernandez E. (1997). "Cost of medication therapy in ambulatory HIV-infected patients." *The Annals of Pharmacotherapy*, 31:303-7.

Oklahoma Department of Health (1999). *Oklahoma HIV/AIDS Reports*, December 31, 1998.

Parmet, W.E. & Jackson, D. J. (1997). "No longer disabled: The legal impact of the new social construction of HIV." *American Journal of Law and Medicine,* 23(1):7-43.

Pellow, David N. (1999). "Framing emerging environmental movement tactics: Mobilizing consensus, demobilizing conflict." *Sociological Forum*, 14(4): 659-683.

Pfuhl, E.H., Jr. (1980). *The Deviance Process.* D.VanNostrand: New York.

Plummer, K. (1975). *Sexual Stigma: An Interactionist Account.* London: Routledge.

Pristave R., Becker S. and McCarthy L. (1995). "Development of provider networks for specific diseases." *Health Care Innovations*, 5(4):9-12, 16-20, 32-7.

Proctor, V.E., Tesfa, A., and Tompkins, D.C. (1999). "Barriers to adherence to highly active antiretroviral therapy as expressed by people living with AIDS." *AIDS Patient Care and STDs*, 13(9): 535-544.

Quam, M.D. (1990). "The sick role, stigma, and pollution: The case of AIDS." In *Culture and AIDS,* Douglas A. Feldman, ed. New York, NY: Praeger.

Reinig, Timothy W. (1990). "Sin, Stigma, and Society: A Critique of Morality and Values in Democratic Law and Policy." *Buffalo Law Review*, 38(3): 859-901.

Roberts, K.J. and Volberding, P. (1999). "Adherence communication: A qualitative analysis of physician-patient dialogue." *AIDS*, 13(13): 1771-1778.

Robinson, N. (1998). "People with HIV/AIDS: who cares?" *Journal of Advanced Nursing*, 28(4): 771-778.

Rosenberg, C.E. (1988). "Disease and Social Order in America: Perceptions and Expectations." In *AIDS: The Burdens of History,* E. Fee and D.M. Fox, e eds. Berkeley: University of California Press.

Rueschemeyer, Dietrich (1987). "On the power of knowledge." *Contemporary Sociology*, 16(4): 461-463.

Rundall, Thomas G., Kwait, Jennafer, and Marconi, Katherine (1999). "Impact of the Ryan White CARE Act on the Availability of HIV/AIDS Services." *Policy Studies Journal.* 27(4):826-839.

Rushing, W. A. (1984). "Social factors in the rise of hospital costs." *Research in the Sociology of Health Care.* 3: 27-114.

Saleebey, Dennis and Hunter, Mary (1980). "The Power of Situations: An Approach to Understanding Powerlessness and Oppression." *Journal of Sociology and Social Welfare.* 7(2):177-187.

Sandstrom, Kent L. (1990). "Confronting deadly disease: The drama of identity construction among gay men with AIDS." *Journal of Contemporary Ethnography.* 19(3):271-294.

Scasta, David (1998). "Historical Perspectives on homosexuality." *Journal of Gay and Lesbian Psychotherapy*, 24: 3-4.

Schiller, Nina G. (1992). "What's wrong with this picture? The hegemonic construction of culture in AIDS research in the United States." *Medical Anthropology Quarterly*, 6(3): 237-245.

Schulte, Alleen (1999). "Consensus versus disagreement in disease-related stigma: A comparison of reactions to AIDS and cancer patients in a university sample." *Paper presented at the Annual Meeting of the ASA.*

Schroeder, Steven and Beachler, Michael. (1995). "Physician shortage in rural America." *The Lancet*, 345(8956):1001-3.

Seligmann, Linda J. (1995). "Gender and rurality." *American Political Science Review*, 89(3): 789-791.

Semmes, Clovis E. (1992). *Cultural Hegemony and African American Development.* Westport, Conn.: Praeger.

Shemtov, Ronit (1999). "Taking ownership of environmental problems: How local NIMBY groups expand their goals." *Mobilization*, 4(1): 91-106.

Sherer, R. and Goldberg, D. (1994). "HIV disease and access to care: A crisis within a crisis." In *It Just Ain't Fair: The Ethics of Health Care for African Americans.* A. Dula and S. Goering, eds. Westport, CT: Praeger.

Sherwood, T.A. (1992). "Is nursing under new management or is it a matter of semantics?" *Nursing Administration Quarterly*, 24:72-5.

Shibley, Mark A. (1991). "The southernization of American religion: Testing a hypothesis." *Sociological Analysis,* 52(2): 159-174.

Shilts, R. (1987). *And the Band Played On: Politics, People, and the AIDS Epidemic.* New York, NY: Penguin.

Sigal, Pete (1998). "Ethnohistory and Homosexual Desire: A Review of Recent Works." *Ethnohistory*, 45(1): 135-141.

Singh, S. (1998). "Challenging racial hegemony in the Caribbean: The use and manipulation of cultural symbols in the black power and Rastafarian movements." *Paper presented at the annual meeting of the International Sociological Association.*

Slezak, Michael (1998). "Rite Aid rolls out HIV training." *American Druggist*, 215(11): 10B.

Smart, Barry (1985). *Michel Foucault*. New York, NY: Tavistock Publishers.

Smythe, Fiona (1998). "Cultural constraints on the delivery of HIV/AIDS prevention in Ireland." *Social Science and Medicine*, 46(6): 661-673.

Snow, David, Rocheford, E. Burke, Worden, Steven K., and Benford, Robert D. (1986). "Frame alignment processes, micromobilization, and movement participation." *American Sociological Review,* 51(4): 464-481.

Sontag, Susan (1978). *Illness as Metaphor.* New York: Farrar, Strauss, and Giroux.

-------- (1989). *AIDS and its Metaphors.* New York: Farrar, Strauss, and Giroux.

Starr, Paul (1982). *The Social Transformation of American Medicine.* New York, NY: Basic Books, Inc. Publishers.

Stein, Howard F. and Hill, Robert F. (1993). "The Culture of Oklahoma: A group identity and its images. In *The Culture of Oklahoma*, H. Stein and R. Hill, editors. Norman, Oklahoma: The University of Oklahoma Press.

Stephens, Regina M. (1998). "Inequalities in adequate health care and therapies among people with HIV/AIDS in the rural mid-south." Paper presented at the annual meeting of the Oklahoma Sociological Association, Oklahoma City, OK.

Stephens, Regina M. (1998). "A needs assessment: An exploratory analysis of people living with HIV/AIDS." Paper presented at the annual meeting of the Mid-south Sociological Society, Kansas City, MO.

Stine, Gerald J. (1993). *AIDS: Biological, Medical, Social, and Legal Issues.* Englewood Cliffs, New Jersey: Prentice Hall.

Stone V., Seage G., Hertz T., and Epstein A. (1992). "The relation between hospital experience and mortality for patients with AIDS." *JAMA,* 268(19):2655-61.

Strauss, Anselm L. (1996). *Qualitative Analysis for Social Scientists.* Cambridge University Press: Great Britain.

Strauss, Anselm L. and Corbin, Juliet (1998a). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory, second edition.* Newbury Park, California: Sage.

Strauss, Anselm L. and Corbin, Juliet (1998b). Grounded theory methodology: An overview. In *Strategies of Qualitative Inquiry,* Norman K. Denzin and Yvonne S. Lincoln (eds.). Thousand Oaks, California: Sage.

Sundwall, D.N., and Bailey, D. (1988). "Meeting the Needs of People with AIDS: Local initiatives and federal support." *Public Health Reports*, 103(5): 293-298.

Sumner, William G. (1906). *Folkways.* Dover: New York.

Swierenga, Robert P. (1997). "The little white church: Religion in rural America." *Agricultural History*, 71(4): 415-428.

Taylor, Christopher C. (1990). "AIDS and the Pathogenesis of Metaphor." In *Culture and AIDS,* edited by Douglas Feldman. NewYork, New York: Praeger.

Tevis, Cheryl (1999). "Religious faith may be good for what ails you." *Successful Farming*, 97(4): 68-69.

Thoits, P.A. (1982). "Conceptual, Methodological, and theoretical problems in studying social support as a buffer against life stress." *Journal of Health and Social Behavior.* 23:145-159.

Thomas, James C. and Thomas, Karen K. (1999). "Things ain't what they ought to be: Social forces underlying racial disparities in rates of sexually transmitted diseases in a rural North Carolina county." *Social Science and Medicine*, 49(8): 1075-1076.

Thomas, S.B. and Quinn, S.C. (1994). "The AIDS epidemic and the African-American Community: Toward an ethical framework for service delivery." In *It Just Ain't Fair: The Ethics of Health Care for African Americans.* A. Dula and S. Goering, eds. Westport, CT: Praeger.

Tittle, Charles R. and Hill, Richard J. (1967). "Attitude measurement and prediction of behavior: An evaluation of conditions and measurement techniques." *Sociometry*, 30(6):199-213.

Torres, Carlos A. (1992). *The church, society, and hegemony: A critical sociology of religion in Latin America.* Westport, CT: Praeger Publishers.

Treichler, Paula A. (1992). "AIDS, HIV, and the Cultural Construction of Reality." In *The Time of AIDS: Social analysis, theory, and method*, G. Herdt & S. Lindenbaum (eds) Newbury Park, CA: Sage Publications.

Turner, H.A., Pearlin, L.I., and Mullan, J.T. (1998). "Sources and determinants of social support for caregivers of persons with AIDS." *The Journal of Health and Social Behavior*, 39(2):137-152.

Ungvarski, P.J., Wainberg, M.A., and Friedland, G. (1998). "Improving patient compliance with HIV treatment regimens." *JAMA*, 280(20): 1741-1750.

United States Bureau of the Census. (2000). *Population Report.* Washington, D.C.

Urbinati, Nadia (1998). "From the periphery of modernity: Antonio Gramsci's theory of subordination and hegemony." *Political Theory,* 26(3): 370-392.

Vladeck, B.C. (1983). "Equality, access, and the costs of health services." In *Securing access to Health Care.* President's Commission for the study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Vol. 3, Washington, D.C. U.S. Government Printing Office.

Voelker, R. (1998). "Rural communities struggle with AIDS." *JAMA*. 279(1):5-7.

Waitzkin, Howard (1989). "A critical theory of medical discourse: Ideology, social control, and the processing of social context in medical encounters." *Journal of Health and Social Behavior*, 30(2): 220-239.

Walkey, F.H., Taylor, A.J., and Green, D.E. (1990). "Attitudes to AIDS: A comparative analysis of a new and negative ideology." *Social Science and Medicine*, 30(5): 549-552.

Wang, Janet F. (1997). "Attitudes, concerns, and fear of acquired immunodeficiency syndrome among registered nurses in the United States." *Holistic Nursing Practice*, 11(2): 36-50.

Weitz, Rose (1989). "Uncertainty and the lives of persons with AIDS." *Journal of Health and Social Behavior.* 30:270-281.

-------- (1991). *Life with AIDS.* New Brunswick, NJ: Rutgers University Press.

Whatmore, S. (1993). "On doing rural research (or breaking the boundaries)." *Environment and Planning*, 25(5): 605-608.

White, Bruce D. (1994). "Health care and the rural poor: Focus on Appalachia." In *It Just Ain't Fair: The Ethics of Health Care for African Americans.* A. Dula and S. Goering, eds. Westport, CT: Praeger.

Whiteis, D.G. (1998). "Third world medicine in first world cities: Capital accumulation, uneven development and public health." *Social Science and Medicine*, 47(6):795-808.

Willard, Cynthia L. (2000). "Is experience with HIV disease related to clinical practice? A survey of rural primary care physicians." *JAMA,* 283(8):985.

Willems, Herbert (1998). "Elements of a Theory of the Theatricality of 'Indecent' Behavior." *Berliner Journal fur Soziologie*. 8(2):201-222.

Willits, Fern K. and Ke, Bin (1995). "Part-whole question order effects: Views of rurality." *Public Opinion Quarterly*, 59(3): 392-404.

Willits, Fern K., Bealer, Robert C., and Timbers, Vincent L. (1990). "Popular images of rurality: Data from a Pennsylvania survey." *Rural Sociology*, 55(4): 559-579.

Williams, David R. and Collins, Chiquita (1999). "U.S. socioeconomic and racial differences in health: Patterns and explanations." In *Health, Illness, and Healing: Society, Social Context, and Self.* Kathy Charmaz and Debora Paterniti (eds). Los Angeles, California: Roxbury Publishing Company.

Wilson, Pamela (1995). "NBC television's operation frontal lobes: Cultural hegemony and fifties' program planning." *Historical Journal of Film, Radio, and Television*. 15(1): 83-105

Yin R. K. (1984). *Case Study Research: Design and Methods.* Beverly Hills: Sage.

Young, Allan (1983). "Rethinking Ideology." *International Journal of Health Services*, 13(2): 203-219.

Zuger, Abigail and Sharp, Victoria L. (1997). "HIV Specialists: The time has come." *JAMA*, 278(14)1131-1133.

APPENDIX A

Appendix A
Initial Questionnaire

Demographics

1. Gender
2. Age
3. Race (ethnic identity)
4. Education level
5. Do you have a telephone in your home?
6. Do you have access to transportation?
7. Income (addressed as - How adequate is your income in meeting your daily living expenses? Enough; Barely possible; Totally inadequate).
8. What is your living arrangement (family, partner, friends)?
9. Are you working?
10. What year did you learn you were HIV+ (and how was this given to you)?
11. **Where** did you learn of your HIV status (county and state)
12. If you have been given an AIDS diagnosis - what year was it given to you?
13. Where did you receive your AIDS diagnosis (county and state)?

General Questions

14. Why are you living here in this area? What made you move or decide to stay here?
15. How is living in a rural area with HIV for you (in terms of health care, other people, getting medication, family)?
16. What does quality health care mean to you?
17. Is there anything that bothers you about the medications you are taking?
18. What does quality of life mean to you and what effects your quality of life?

Health Care Quality

Tell me about your health care. Where you go to the doctor, where you get your medications, how you pay for each of these?

1. Do you see the same doctor or have a regular health care provider each time you have to seek medical treatment?
2. Do you see a physician regularly (weekly, monthly, etc)? Why?
3. If not, why?

4. Do you ever have to travel to receive health care, to get medications, or to get other services? Why? How Far?
5. How well does your health care provider communicate with you (can you understand?)
6. Could your health care provider improve his/her communication with you? Why or why not?
7. Does your health care provider explain your different health problems and why you have each one?
8. Does your health care provider explain your different medications and why you are taking each one?
9. Do you know your last CD4 count? Does your health care provider willingly give you that information?
10. Is your health care provider monitoring your viral load?
11. Do you feel that your health care provider understands the problems you have with HIV ? Why or why not?
12. Do you ever have questions that you feel you can not ask you doctor or his/her staff? why?
13. Are there support services such as counselors or social workers in the clinic where your doctor is? If yes, do you seek there services for help?
14. If not would like to have people in the clinic that could help you with your problems that you are not comfortable discussing with your doctor?
15. Have you been hospitalized in the past year for an HIV/AIDS related problem? If so, how many times?
16. Have you ever been refused medical care because you had HIV/AIDS? If so, was it in a small community or large city? Also, why do you think that you were refused medical care?
17. Do you feel that people living with HIV/AIDS have problems getting the treatments or care that they need? Why?

Therapies

1. How many prescribed medications are you currently taking?
2. Where do you get your medications? Do you purchase them or are they provided to you through an organization?
3. Have you ever had trouble getting all the medication your doctors prescribes? Why?
4. Has your health care provider ever had to change your medication(s) because you could not take something?
5. Do you ever forget to take your medication? Why?
6. Do you participate in any pharmacy clinical trials? If not why?
7. Of those drug therapies you are taking, are you able to get what you need?

8. Do you have medical insurance? If so, does it cover all of your expenses relating to HIV/AIDS treatments?
9. Have you ever missed a doctors appointment since having found out about your HIV status? If so, why?
10. Do you find it difficult to follow advice from your physician? Why?

Social Support

1. Do you have a primary support or caregiver that helps you (significant other, mother, friend, etc.)? Do you require a lot of help from them?
2. Who all have you told about having HIV/AIDS? (family, friends, coworkers, etc.)
3. If there are people you know that you have not told - why have you not told them?
4. If your family knows of your HIV status - how do you think that they feel about it?
5. Does anyone you know have a problem dealing with you or your family because you have HIV?
6. Have you ever been looked down upon within your community, church, at work, etc. because you have HIV?
7. Does your community offer HIV/AIDS support groups? **If not, why**? **If yes, why**? (What is it that you like about the support groups)?
8. Do you attend? **If not, why**? **If yes, why**?
9. Would you attend an HIV/AIDS related support group if there were one available?
10. Who do you think should be able to attend the support groups if one were offered in the community?
11. How do or would support groups benefit you or others with HIV/AIDS that live in rural areas?
12. Do you think that the community you live in is supportive of people with HIV/AIDS? Why or why not?
13. If the community is not supportive of people infected with HIV/AIDS how could they improve to make things better?

More general questions -

1. How is living with HIV for you? (Depressed, symptoms affecting life, etc.)Do you think that it could be better/worse?
2. Do you think that the health care you receive could be better? How?
3. How do you think or know you were exposed to HIV (male-male sex, IV drug use, male-female sex with IV drug user)?
4. Where do you think you got HIV - here in this town or another place?

5. How do you think that the public in rural communities feel about HIV/AIDS and people living with HIV/AIDS?
6. Do you think that the health care professionals in your community could have an influence on the public's attitudes in your community toward HIV/AIDS? How and Why?
7. Do you think that rural communities could and should offer more support (medical, social, emotional) to people living with HIV/AIDS? How?
8. Are there any other people that you know that would be willing to participate in this study?

APPENDIX B

Appendix B

INFORMED CONSENT

Living with HIV/AIDS in the Rural Mid-south: Experiences with Health Care, Medical Therapies, and Social Support

Explanation

You are being asked to participate in a research interview designed for the purpose of understanding the needs of individuals living with HIV/AIDS that reside in rural areas. An understanding of things such as; Health care (knowledgeability of providers, access to and affordability of adequate medical care), Therapies (adherence to and availability of medication), and Social support (from both family and community) are very important in relation to living in a rural area. Understanding the needs of people infected with HIV/AIDS living in rural communities is necessary if people are to better understand this disease and provide better care for those living with it.

If you decide to participate, you will be asked a series of questions which may require anywhere from one and a half hours or more of your time.

Risks and Discomforts

There may be some emotional discomfort when thinking about some of these issues.

Confidentiality and Anonymity

The information provided by the interviewee will be kept in strict confidence. Although, some of this information may be published for scientific purposes, your name will not be associated with any answers that you provide.

Benefits

The information gathered from this project will attempt to gain an understanding of the issues that are faced by those living with HIV/AIDS in Oklahoma. With this information, it is hoped that the health care and social service organizations providing services to people with HIV/AIDS in the community will better understand their needs and adopt services that will aid in providing necessary care.

Your answers and responses are very important.

I understand that participation is voluntary, that there is no penalty for refusal to participate, and that I am free to withdraw my consent and participation in this project at any time without penalty after notifying the project director. I may contact Regina M.

Stephens at (405)377-5127 or (405)744-6105 or Chuck Edgley (405)744-6124. I may also contact Gay Clarkson, IRB Executive Secretary, 203 Whitehurst, Oklahoma State University, Stillwater, OK 74078; (405)744-5700.

I have read and fully understand the consent form. I sign it freely and voluntarily. A copy has been given to me.

Date: _________ Time: ___________

Signed: ____________________________
(Signature of subject)

____
(or person authorized to sign for subject, if required)

Witness(es) if required: ____________________________

I certify that I have personally explained all elements of this form to the subject or his/her representative before requesting the subject or his/her representative to sign it.

Signed: ____________________________
(Project director or his/her representative)

APPENDIX C

Appendix C

Flyer

WOULD YOU LIKE TO PARTICIPATE IN A RESEARCH STUDY????

I am conducting a dissertation research project entitled:

"LIVING WITH HIV/AIDS:
EXPERIENCES WITH HEALTH CARE, MEDICAL THERAPIES, AND SOCIAL SUPPORT"

If you are at least 18 years of age and HIV+ and would like to participate, please contact:
Regina Stephens at (405)377-5127
(in Stillwater)
or 1-800-745-1709 access code 04 or by email at RMStephens@aol.com

APPENDIX D

Appendix D -
Gayly Oklahoman Advertisement

This advertisement will run in four issues beginning October 15, 1999 and running through December 15, 1999. I actually ran through February 15, 2000.

WOULD YOU LIKE TO PARTICIPATE IN A RESEARCH STUDY????

I would like for you to be a part of my doctoral dissertation project entitled:

"LIVING WITH HIV/AIDS:
EXPERIENCES WITH HEALTH CARE, MEDICAL THERAPIES, AND SOCIAL SUPPORT"

If you are HIV+ and at least 18 years of age and would like to participate please contact:
Regina Stephens at (405)377-5127 (in Stillwater)
or 1-800-745-1709 ACCESS CODE 04 (in Stillwater)
or by email at RMStephens@aol.com

If you would like to be interviewed - I will travel to talk with you. I look forward to hearing from you.

APPENDIX E

Appendix E
UPDATED QUESTIONNAIRE
December 5, 1999

Age:

Sex:

1. How long have you been positive? AIDS diagnosis?
2. How do you think you were exposed to HIV?
3. Have you always lived here in (OKC, Tulsa)? Oklahoma? Why, or Why not?
4. What kind of experiences have you had since being diagnosed? Family, Friends, health care, organizations, employers, churches?
5. Of those experiences that were positive - why do you classify them as positive? Specifically where did they come from and why?

6. Of those experiences that were negative - why do you classify them as positive? Specifically where did they come from and why?
7. How do you feel about the treatment of people living with HIV/AIDS (in general, in Oklahoma) - With regard to ~~health care, medical~~ therapy access, social support?
8. How do you feel as a person living with HIV in Oklahoma?
9. How do you think people in general feel about those living with HIV/AIDS? What about here in OK? If there is a difference, why do you think that may be?
10. What are some of the reasons (you believe) people feel the way they do about those who are living with HIV/AIDS?

11. Do you think it matters to people in general how someone acquired HIV/AIDS? How and why?
12. What about to those that have HIV, does it matter how others have acquired it?
13. What about the health care community and support organizations, do you think that it matters to them how someone acquired HIV?
--- If means of transmission is an issue, why do you think that is? Are there some people or groups better or worse than others about distinguishing that, why?

14. How do you think Oklahomans feel about people living with HIV, why? Where do the feelings come from, is there anything that can be done about it, if so, what?
15. What services are here in Oklahoma for people living with HIV? Have you utilized any of them, which ones, and why?

16. What did the service providers offer? Where you satisfied with what you received, why or why not?
17. Have you had any positive or negative experiences with the health care or service organizations? What were they? Why did you experience what you did?
18. Do you have health insurance? What does it cover?

19. Do you think people (with HIV) that lack adequate health coverage or have no health coverage have different experiences based on the issue of insurance? Why or why not?
20. What are some health care or organization issues that you feel need to be addressed in this state, (or nationally) why?

21. Is there anything that the health care, organizations, or citizens of Oklahoma could do for people living with HIV (financially, emotionally)?
22. What could make (or not make) these things better or worse?
23. If you could stress the most difficult thing about living with HIV to others what would it be?
24. You've been living with HIV/AIDs for _____ years/months, have things changed with regard to this disease? What are they and how have they changed? What has not changed, why?

25. What do you foresee happening to yourself as this disease takes you into the millennium?
26. What does the future look like for this disease, In OK, regarding health care, discrimination, funding?
27. Is there anything else that you would like to add?

APPENDIX F

Appendix F
IRB Approval

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD

DATE: 02-25-99 **IRB #: AS-99-040**

Proposal Title: LIVING WITH HIV/AIDS IN THE RURAL MID-SOUTH: HEALTH CARE, MEDICAL THERAPIES, AND SOCIAL SUPPORT

Principal Investigator(s): Charles Edgley, Regina M. Stephens

Reviewed and Processed as: Expedited

Approval Status Recommended by Reviewer(s): Approved

Signature: Carol Olson

Date: February 25, 1999

Carol Olson, Director of University Research Compliance
cc: Regina M. Stephens

Approvals are valid for one calendar year, after which time a request for continuation must be submitted. Any modification to the research project approved by the IRB must be submitted for approval. Approved projects are subject to monitoring by the IRB. Expedited and exempt projects may be reviewed by the full Institutional Review Board.

APPENDIX G

Appendix G

Oklahoma HIV/AIDS Demographics

Oklahoma reports on both cases of HIV and AIDS. The HIV and AIDS cases from Oklahoma will be presented as those cases reported prior to December 31, 1998. These data were gathered by the Oklahoma State Department of Health. This section will not include the number of HIV and AIDS cases by exposure category as related to sex or AIDS related mortality by sex and race/ethnicity because Oklahoma does not provide that information.

Oklahoma HIV and AIDS cases

The number of reported cumulative cases of HIV and AIDS in Oklahoma is 5,280. This is the reported number from the recognition of this disease to December 31, 1998. Of the 5,280 reported cases of HIV and AIDS in Oklahoma, 1941 of those cases have resulted in death. Therefore, there was, as of December 31, 1998, 3339 people living with HIV or AIDS in Oklahoma (see table 8).

Table 8 reveals that males overrepresent females in reported HIV and AIDS cases in Oklahoma. In table 8, males represent approximately 88% of the cumulative HIV and AIDS cases while females represent roughly 12% of the reported HIV and AIDS cases in Oklahoma.

In Oklahoma, the reported number AIDS cases is not reflective of the estimated AIDS cases in the United States when looking at sex. Figure 1 represents the estimated number of AIDS cases in the United States by sex. Males represent 80% of all estimated AIDS cases, while females represent only 20%. When looking at the reported AIDS cases in Oklahoma (see table 8), males represent 91% of all AIDS cases and females represent 9% of all reported AIDS cases. When comparing the percentage of AIDS cases and sex in Oklahoma to that of the estimated AIDS cases in the United States, females represent fewer cases of AIDS in Oklahoma than the estimated AIDS cases for the United States. Although overall, Oklahoma still reflects the percentage of AIDS cases as related to sex in the United States, since males represent a more significant amount of AIDS cases than females.

Table VIII. HIV and AIDS in Oklahoma

OKLAHOMA	**AIDS**	**% of AIDS Total**	**HIV**	**% of HIV Total**	**TOTAL**
Male	**2909**	**91%**	**1741**	**84%**	**4650**
Female	**297**	**9%**	**333**	**16%**	**630**
TOTAL	**3206**		**2074**		**5280**

Source: Oklahoma State Department of Health, 1998.

Table 9 represents the number of reported HIV and AIDS cases in Oklahoma by race/ethnicity and exposure category. Again, reported HIV and AIDS cases in Oklahoma reflects the proportion of AIDS cases in the United States when looking at race/ethnicity. White, non-Hispanics in Oklahoma make up the majority of HIV and AIDS cases (71%), while black, non-Hispanics make up approximately 19% of the total HIV and AIDS cases in Oklahoma. American Indian/Alaskan Natives in Oklahoma make up roughly 6% of the total number of reported HIV and AIDS cases, while Hispanics make up only 4%. In table 1, which is the estimated number of AIDS cases in the United States by race/ethnicity, white, non-Hispanics make up 45% of the estimated number of AIDS cases, black, non-Hispanics make up about 36%, Hispanics make up about 18%, and American Indian/Alaskan Natives make up 0%. This likely has something to do with the composition of the population of the United States as well as that of Oklahoma.

Table IX. HIV/AIDS cases in Oklahoma by race/ethnicity and exposure category

RACE/ETHNICITY	HIV and AIDS cases	% of TOTAL
White, non-Hispanic	3743	71%
Black, non-Hispanic	981	19%
Hispanic	188	4%
Asian/Pacific Islander	19	>1%
American Indian/Alaskan Native	332	6%
TOTAL	5263	

VITA

Regina M. Stephens

Candidate for the Degree of

Doctor of Philosophy

Thesis: MAKING SENSE OF THE EXPERIENCES OF PEOPLE LIVING WITH HIV/AIDS: AN APPLICATION OF GOFFMAN'S FRAME ANALYSIS

Major Field: Sociology

Biographical:

Personal Data: Born in Ft. Smith, Arkansas, On December 30, 1971.

Education: Graduated from Alma High School, Alma, Arkansas in June of 1990, received a Bachelor of Arts degree in Sociology and Psychology from Arkansas Tech University, Russellville, Arkansas, in August of 1994, and a Master of Science degree in Sociology from the University of Central Arkansas, Conway, Arkansas, in December of 1995. Completed the requirements for the Doctor of Philosophy degree with a major in Sociology at Oklahoma State University in December, 2000.

Experience: Employed at OSU from 1997 to 2000 as a teaching assistant. From 1996 to 1997, I was employed as a research director in the School of Nursing at the University of Alabama at Birmingham. From 1994 to 1995 I was a graduate assistant at the University of Central Arkansas, Department of Sociology.

Professional Memberships: Mid-West Sociological Society, American Sociological Association, Alpha Kappa Delta, Phi Kappa Phi.