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The changing face of HIV/AIDS: an anthropological and epidemiological study of the Baton Rouge area

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**THE CHANGING FACE OF HIV/AIDS:
AN ANTHROPOLOGICAL AND EPIDEMIOLOGICAL STUDY
OF THE BATON ROUGE AREA**

A Thesis

Submitted to the Graduate Faculty of the
Louisiana State University and
Agricultural and Mechanical College
in partial fulfillment of the
requirements for the degree of
Master of Arts

in

The Department of Geography and Anthropology

by
Erica Brooke Gibson
B.A., University of Houston, 1998
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DEDICATION

This thesis is dedicated to all of the HIV-positive people that are living their lives to the fullest, and to all of the people who continue to fight against HIV/AIDS, and fight for the rights of the people that are affected.

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I would like to begin by thanking my advisor, Dr. Helen Regis, for all of her support and encouragement. Dr. Miles Richardson and Dr. Andrew Curtis were also an integral part of this project. Without the assistance of these professors, this project would have never been completed. Many thanks. To the above-mentioned professors and the other professors I have had during my stay at LSU, thank you for all of your knowledge and experience that you have been kind enough to share.

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ABSTRACT

The Human Immunodeficiency Virus (HIV) and the resulting Acquired Immune Deficiency Syndrome (AIDS) became widespread in the early 1980's. At the beginning of the epidemic, HIV/AIDS was affecting mainly gay men. As the disease began to spread, more diverse populations were affected. Now, two decades later, the face of HIV and AIDS has changed.

In the year 2000, the Baton Rouge area (which includes the parishes of Ascension, East Baton Rouge, East Feliciana, Iberville, Pointe Coupee, West Baton Rouge, and West Feliciana) had the highest detected rate of HIV/AIDS cases in the state, and the 16th highest detected rate of HIV/AIDS cases in the nation. This study was developed to determine why the HIV/AIDS transmission rate is so high in the Baton Rouge area, what methods are being used to lower transmission rates and prevent the spread of HIV/AIDS, and what needs to be done to bolster the efforts already underway.

Statistical data were collected from the Louisiana Office of Public Health to determine what populations were being affected by HIV/AIDS. Officials from HIV/AIDS community based organizations, public health clinics, universities, and governmental service organizations were interviewed to determine what is being done to slow the spread of HIV/AIDS. A survey was

also developed to better understand the effects of HIV/AIDS on the people living with the disease.

The results of the study indicate that HIV/AIDS is spreading most rapidly in the African-American community, with 89% of all new cases reported in 2000 affecting African-Americans. The areas of prevention that are lacking include minority audiences, low-income areas, as well as education in public schools. One of the main concerns of people with HIV is the lack of health care options, as Earl K. Long Hospital is the only place to obtain free or low-cost treatment for HIV/AIDS. To better serve the HIV-positive community, and prevent the spread of HIV/AIDS, more funding should be directed towards prevention and towards healthcare. Also, the Baton Rouge community-at-large needs to be educated about HIV/AIDS so that a greater level of tolerance and understanding about the disease can be achieved.

CHAPTER 1 INTRODUCTION

HIV/AIDS is an epidemic in transition, which is clearly seen in the Baton Rouge area. Baton Rouge has the highest case rate in the state, and the 16th highest rate of transmission in the nation. What was once considered a "gay" disease is now rapidly rising in the African-American heterosexual population, changing the face of HIV/AIDS.

This killer disease is a reality for over 40 million people in the world that have been diagnosed with AIDS (www.unaids.org January 2001). There are two strains of HIV, with both strains leading to a final stage of AIDS. The HIV-2 strain is found mainly in West Africa, and the HIV-1 strain is prevalent in Europe, Asia, the Americas and the rest of Africa. HIV-1 is the strain that this study deals with, and will simply be referred to as HIV for the remainder of the paper.

HIV is a retrovirus that attacks the immune system by injecting T-cells, which help rid the body of disease, with a copy of the genetic code of the virus. The virus causes the T-cells to become altered versions of themselves, slowly reducing immunity, HIV takes over more and more cells. Once the infected person's immune system begins to shut down, their body is unable to fight off disease and infection. The disease can take as long as ten years to reach a symptomatic stage. At this stage

of HIV, the infected person is diagnosed with AIDS. AIDS enables other types of diseases, known as opportunistic infections, to begin to invade the body. The opportunistic infections weaken the immune system further, and often lead to death.

HIV/AIDS is spread through bodily fluids such as blood, semen, vaginal secretions, and breast milk. The most common ways that people become infected with HIV/AIDS in the United States include sexual transmission, contact with infected blood through sharing needles, and perinatal, or mother-to-infant transmission. HIV transmission can be prevented for the first two methods listed above, and the chances of mother-to-infant transmission can be greatly reduced by the mother taking antiviral medications during the pregnancy. So why is HIV still infecting large numbers of people each year?

Although HIV/AIDS has been prevalent since 1981, many countries did not acknowledge that this disease was a problem until the past few years. The United States has been fighting this disease since the early 1980's with limited success. When HIV/AIDS was first discovered, it was infecting mainly gay men. This led to the original name of Gay Related Immune Deficiency, or GRID. When the disease was found in non-gay populations, such as hemophiliacs who had contracted the virus through

transfusions that contained infected blood, the disease was renamed AIDS.

AIDS was thought of as a "gay disease" since it was not affecting heterosexuals at the beginning of the epidemic. In the face of indifference from the government, medical establishment, and anti-gay prejudice in the early 1980's, the gay community mobilized in an effort to educate and save themselves. The protesters demanded funds for medical research and acknowledgment from public health institutions. Once HIV/AIDS began to show up in heterosexual populations, people began to realize how devastating this disease could become. Due to the beginnings of the epidemic, HIV/AIDS began with certain stigmas attached to the way the disease and people infected are perceived.

One of the main problems in preventing the spread of HIV/AIDS is with the way that the disease is transmitted. People in the United States do not like to talk about their sexual history, or about illegal drug use, both of which include behaviors that transmit HIV. If people are having unprotected sex, they are at risk for contracting HIV. If people are intravenous drug users and are sharing needles with other users, they are also at risk of contracting HIV. Both of these behaviors have an aura of taboo around them. Many people that are at risk for HIV due to having unprotected sex do so outside of marriage, at a young

age, or they may be engaging in same-sex partnerships.

Puritanical norms and heterosexism is common in the dominant culture in the United States and inhibits open discussions about HIV/AIDS.

This is especially true in Baton Rouge, Louisiana and surrounding areas. The capitol is a religious mix consisting of mainly Protestants and Catholics. Baton Rouge is also a college town, with the large campuses of Louisiana State University and Southern University. The university setting provides an ever-changing student population and a large annual influx of college freshmen. Baton Rouge is situated in between two other metropolitan areas: Lafayette and New Orleans. While Baton Rouge is subjugated to being the restrained political center of Louisiana, New Orleans and Lafayette are portrayed as having a free and candid way of life. The active gay communities in both cities that are not seen in Baton Rouge evidence this openness. The lack of an organized gay community in Baton Rouge has certain implications on the way that HIV/AIDS is perceived.

No one wants to think of their teenage child having sex, or their spouse having an extra-marital affair, or their boyfriend using drugs, yet these things are everyday occurrences in Baton Rouge. Adolescents are having sex at earlier ages, and many of them are not aware of the risks involved because they are not taught sex education in schools, and parents are unwilling or

embarrassed to talk about it at home. Injection drug users are susceptible to HIV because they are more concerned about getting high than about using clean needles. This leads to a high infection rate of not only themselves, but also their sexual partners who may or may not know of their drug use.

Americans, especially Southerners, have certain cultural and social mores that dictate what *is* and *is not* talked about in polite society. Because AIDS is a result of a type of behavior that is not often talked about publicly, people also do not discuss the disease. When people are diagnosed with cancer, their family and neighbors are sympathetic, but when people are diagnosed with HIV/AIDS, they are stigmatized because of the behavioral associations that are made with the disease. Family members and HIV/AIDS patients themselves sometimes lie about their diagnosis because of the stigma attached to the disease (Lang 1991).

To facilitate understanding of the HIV/AIDS epidemic and the effects on Baton Rouge, Chapter Two will discuss a review of the relevant literature, and Chapter Three will cover the methods and materials used in the collection of data. The epidemiology of HIV/AIDS will be presented in Chapter Four. This chapter will detail the statistical aspects of who is being affected by HIV/AIDS in Region II, which includes the parishes of Ascension, East Baton Rouge, East Feliciana, Iberville, Pointe Coupee, West

Baton Rouge, and West Feliciana. Chapter Five will present the landscape of HIV/AIDS and Chapter Six will cover the anthropological aspects of HIV/AIDS in the Baton Rouge area. By interviewing local care givers, as well as people living with HIV, a human perspective on the disease is given. Rather than just quantifying the disease with numbers, the epidemic is seen through the eyes and thoughts of people affected by the disease in this part of Louisiana. The final chapter of this study focuses on discussion and conclusions about HIV/AIDS. When all of the gathered data is taken into account, the problems are seen, and the community fighting this disease can continue to find effective solutions to slow the spread of HIV/AIDS and help the people who are already HIV-positive.

CHAPTER 2 A REVIEW OF THE RELEVANT LITERATURE

Epidemiologists are concerned with the origin, occurrence and prevalence in populations, surveillance, transmission, and modeling of the disease (Kaslow and Francis 1989).

Anthropologists are interested in how the disease is perceived, theories of sickness, methods of education about disease, and the effects of the disease on the social and cultural environments of the people. Robert Hahn effectively explains the role of both the epidemiologist and the anthropologist in his book *Sickness and Healing: An Anthropological Perspective* (1995). These two disciplines, when taken together, can lead to a better understanding of how to deal with HIV.

Numerous studies of an epidemiological or anthropological nature have been done which cover different aspects of prevention and treatment of HIV/AIDS. Some of these studies show cultural data and others show statistical data in HIV-positive populations. Several of these studies, which are based in Louisiana, or based on affected populations, will be covered in this literature review.

Epidemiology

Origins and Surveillance

The origin of HIV and AIDS is often speculated on, but not fully understood. In epidemics of the past, such as syphilis,

people have tried to blame a certain population or country for the spread of a disease. The French called syphilis a disease of the English, whereas the English called syphilis a disease of the French, and so on. AIDS has been blamed on Africans, Haitians, homosexuals, and the government of the United States. According to Paul Farmer, a physician with the U.S. National Cancer Institute reported that AIDS was suspected to come from Haiti (1992:2). Farmer later discovered that cases of AIDS were actually imported to Haiti through other North American channels (Hertzman 2001). Other scientists added that HIV/AIDS was possibly linked to voodoo practices in Haiti. The rumors associated with Haiti lead to the destruction of their tourism industry, and caused discrimination against Haitian immigrants in other countries. With HIV and AIDS the place of origin is not as important as how the disease originated (Kaslow and Francis 1989). Africa is where HIV/AIDS originated, although scientists are not sure if HIV is derived from a simian immunodeficiency virus (SIV), or if humans have been harboring the virus for ages and HIV is just now emerging (Feldman and Miller 1998). Research has shown that HIV-2 is closely related to the SIV in a group of monkeys in West Africa known as sooty mangabeys, and that the disease may have been spread through animal bites or the butchering and consumption of their meat (Feldman and Miller 1998). A group of scientists at the

University of Alabama at Birmingham have found the origins of HIV-1 in a group of chimpanzees native to West-Central Africa (Gao et. al. 1999). The scientists believe that transmission of this strain of HIV was similar to HIV-2 above. There are still debates on whether the virus was transmitted solely by the chimpanzees, or if humans and animals have been passing the virus back and forth for decades.

The first cases of AIDS were reported in the United States in 1981 under the name GRID, although it is now believed that a form of AIDS existed as early as 1959 (Feldman and Miller 1998). In September of 1982, GRID was renamed AIDS, and in 1983 Dr. Luc Montagnier discovered the virus that causes AIDS. This virus was originally named LAV but was renamed HIV in 1986. HIV/AIDS has now reached pandemic status as people worldwide are infected. Quarantine was impossible because many people inadvertently infected others, not knowing that they were infected or how HIV/AIDS was spread, while HIV was in its infancy.

The World Health Organization (WHO) accepts surveillance reports from all nations about the numbers of people with AIDS (Kaslow and Francis 1989). The Centers for Disease Control (CDC) is the reporting agency for the United States. Every week the CDC issues a surveillance report detailing the statistical trends of HIV infection. Through the compilation of data from these reports, models of how the disease will progress can be

made. Epidemiologists are able to project trends in infection and death rates, and these projections can be used in prevention and treatment efforts.

Transmission

As mentioned above, HIV is transmitted through bodily fluids. Transmission can occur through sexual contact, using needles or other medical paraphernalia that has come into contact with infected blood, mother-to-infant (perinatal) transmission, and through transfusions of infected blood. The former method of transmission rarely occurs in the United States because blood is now thoroughly screened for HIV before it is transfused. Blood donor screening began in 1985, as did testing donated blood for HIV antibodies (Kaslow and Francis 1989).

Many people know that the HIV virus is transmitted through sex. Certain sexual practices, such as unprotected anal or vaginal intercourse, put a person into a higher risk category. Oral sex is less risky, but any type of activity where a person comes in contact with bodily fluids such as semen or vaginal secretions puts the participants at risk for contracting HIV. Because intercourse disrupts mucosal membranes and can cause tearing of skin tissue, HIV infection is more likely to occur (Kaslow and Francis 1989). If a person already has another sexually transmitted disease (STD), they are more likely to contract HIV if exposed. This increased risk is due to a

depressed immune system already fighting off a disease, as well as ulcerations or sores caused by the STD itself that may allow blood or secretions to be exchanged. While using condoms can help prevent the transmission of sexually transmitted diseases, many people still do not insist on condoms for protection during sexual intercourse. This pattern has been well documented among sex workers (prostitutes), since many sex industry workers do not feel that they can impose condom usage on paying customers (Ottomanelli 1992). Also, if a person is abusing drugs or alcohol, their inhibitions may be lax, and they may participate in sexual behaviors or relations that they otherwise would not. A major portion of HIV-related risks for prostitutes relates to those whose steady sexual partner uses intravenous drugs, or prostitutes who are users themselves (Ottomanelli 1992). When the use of a condom becomes an economic matter, sex workers often do without. If customers are willing to pay more for sex without a condom, sex workers often take them up on the deal. Also, if a sex worker is in a hurry to get a fix, she may not require that a customer use a condom in order to get the trick over with faster. When this happens, the need for a fix often overrides the need for a customer to use a condom (Sibthorpe 1999). Thus two modes of transmission may be linked.

HIV transmission in injection drug users occurs primarily through sharing used needles (Ottomanelli 1992). Injection drug

users seeking to get high may go to a "shooting gallery," which is usually an abandoned house where they can buy the drugs and rent a "set of works," or needle and syringe. This method of renting works is preferable to carrying one's own needle and syringe due to the illegality of IV drug use and the possibility of being stopped and searched by the police. When injection drug users rent sets of works, they are usually renting a needle that has been used previously and that is not clean. Some injection drug users also share needles as a part of the behavioral norm in the injection drug using community. Merrill Singer questions what messages an injection drug user would be sending if he refuses to share a needle with a fellow user (1992). Sharing needles serves to bind two users together through a gesture of camaraderie, as well as being efficient. If an injection drug user has just finished taking a hit, a friend may come along and ask to do a "wash" of the empty syringe. This is a means of getting high off of the dregs of what was left in the syringe by drawing a small amount of water into the syringe, swishing the water around, then injecting the contents (Ottomanelli 1992). However, these types of behavior are variable across ethnic and geographic regions, and are not applicable to all injection drug users (Singer and Weeks 1996). In many injection drug user communities, needle sharing is based on necessity rather than camaraderie. This may be due to the

fact that many areas require a prescription to acquire clean syringes, or that injection drug users have pooled their resources to buy drugs, so they have to use the same needle to get a hit off of the shared purchase (Singer and Weeks 1996).

Studies have been done on how much blood, and how much of the virus is actually transmitted while sharing needles. If a user has HIV and shares needles, approximately 0.6 to 6.0 tissue-culture-infective-doses (TCID) of HIV is transmitted per use. If the user has progressed to AIDS and shares a needle, 70-700 TCID per shared use is transmitted. Approximately 10 to 100 microliters of blood is transmitted when needles are shared. The amount needed to transmit HIV may be around 30 TCID per milliliter of blood, as this is the amount of HIV necessary in the blood to obtain a positive culture in a lab (Ho, Moudgh, and Alam 1989).

Research has also been conducted on whether or not addicts know they are at risk for contracting HIV, and a high percentage know that using dirty needles is a cause of HIV transmission. The risks of contracting HIV are often outweighed by the dependency on the drug and the availability of whatever is there at the moment to use for injection. When a user is having symptoms of withdrawal, he/she is not concerned with finding a clean needle to use. Ottomanelli explains that drug dealers in large metropolitan areas have adapted to the threat of HIV by

providing a clean set of works with a \$25 or \$50 bag of heroin (1992). This is also true in Baton Rouge, where an ex-dealer reported that injection drug customers were offered a clean needle with their purchase for an extra dollar (personal communication October 15, 2001). This method of offering a clean needle has proven to be a good business move in keeping customers in these times of HIV/AIDS.

Another way to prevent the spread of HIV through intravenous drug use is to offer a needle exchange. Needle exchange programs have proven successful in cities that allow them. A needle exchange program consists of a facility; usually a concession truck-type operation for mobility, where an injection drug user can bring used needles and exchange them for new sterile needles free of charge. Unfortunately these types of programs are highly controversial since there is the implication that a needle exchange sanctions intravenous drug use, as long as a clean set of works is used (Ottomanelli 1992). According to local care facilities, there are no current plans to try a needle exchange program in Baton Rouge, in part due to the controversy that surrounds this prevention method.

In both sexual transmission and transmission through dirty needles, pleasure is often cited as the factor that prevents people from using condoms or clean needles. A person in a sexual relationship can insist that their partner use

protection, and a drug addict can use a bleach solution to kill the HIV virus on a dirty needle. Most people will rationalize that the odds are they will not contract HIV "this time" and can persuade themselves that they are not at risk (Ottomanelli 1992). In the United States, people often talk about doing what feels good, rather than doing what is right or healthy.

Pleasure is a culturally constructed concept that is used as an excuse for a certain type of action or inaction in certain situations. For instance, men in the U.S. often cite that condoms interfere with their natural sensations, or pleasure, during sex. This is a way of evading condom usage. Many people have contracted HIV by putting their need for pleasure over their need to lower their participation in risky behavior.

Perinatal transmission is different in several ways. Sometimes a woman knows that she is HIV-positive when she becomes pregnant, but often women find out that they are HIV-positive when they are tested as a part of their prenatal care. If a pregnant woman does not have insurance, she may qualify for Medicaid. Medicaid provides prenatal care, and postnatal care for up to a year for pregnant women living at the federal poverty level. Single women must make less than \$1290 per month, and the amount increases slightly for each additional family member she may be supporting (www.hcfa.gov/hiv January 2002).

When a pregnant woman is HIV-positive, doctors recommend a treatment of zidovudine (AZT), which is an antiviral medication used to lower levels of HIV in the bloodstream. AZT is given to the pregnant woman before and during delivery, and is then given to the infant for six weeks after birth. If a pregnant woman agrees to the drug therapy, she lowers her risk of having a baby born with HIV. There are some risks associated with drug therapy, and use of the therapy is up to the individual. Drug therapy is provided to women who qualify for Medicaid. Many HIV-positive women decide that the risks are worth taking due to the evidence that AZT is highly successful in keeping newborns HIV-negative. Babies born to women taking AZT have as low as an 8% chance of being HIV-positive, while women who do not use the drug therapy have a 20 to 30% chance of having an HIV-positive baby (CDC National AIDS Hotline February 2002). Birth can cause transmission if the proper precautions are not taken. In certain circumstances, mothers may be given a cesarean section, so that blood vessels can be cauterized and infant exposure to infected blood can be kept to a minimum. If a woman has progressed to AIDS, a cesarean is not usually done due to increased morbidity due to infection and inability of the immune system to fight back. Breaking the amniotic sac is not recommended, nor is an episiotomy for vaginal deliveries (Finger 1997). Transmission to infants is also possible if the new

mother chooses to breastfeed, as HIV is found in breast milk. Most mothers choose to use formula so that their baby will not be further exposed to the virus.

The decision to become a mother when HIV status is known is often a hard one to make. A study was conducted on the reproductive decisions of HIV-positive women who were also injection drug users. In this study, the authors note that healthcare workers have observed that HIV-positive status has not deterred women from having children (Pivnick et al. 1991). One of the major concerns of the HIV-positive injection drug using women studied was that of coresidence with their children. HIV-positive women who had been separated from their children in the past were more likely to terminate new pregnancies. The authors feel that injection drug using women need more support to restore their identities as mothers, as this maternal factor may be key in preventing the spread of HIV.

Anthropology

Psychology has been the dominant field of the social sciences to study HIV/AIDS (Mann and Tarantola 1996). Psychology uses a conceptual approach that focuses on individuals and their behaviors to understand how HIV is transmitted in different populations. Anthropological research puts more emphasis on social and cultural aspects of behavior rather than conceptualizing an approach that centers on the individual. The

anthropological perspective allows medical researchers and health care workers to implement a socially and culturally aware program of medicating and educating people effectively. Medical anthropology prioritizes cultural, political, and economic variables of biomedicine (Johnson and Sargent 1990).

Anthropology is useful in the study of HIV/AIDS because the nature of risk behaviors are poorly understood in underserved communities, ethnographies allow a broader insight into communities than self reporting surveys, and anthropology often leads to unexpected discoveries about the culture or illness being studied (Singer 1992).

Disease and illness may be distinguished in the broad category of "sickness." Sickness may be defined as an unwanted condition in one's person (Hahn 1995). A disease specifies the physical manifestation of the sickness, and an illness is a personal perception of what is wrong with one's self (Johnson and Sargent 1990). While people may be infected with HIV and have AIDS, which allows for opportunistic infections to produce disease, their perception of their illness may not be defined in the way biomedicine sees the sickness. Sickness is an abnormality that disrupts one's sense of self and can forever alter one's social roles (Hahn 1995).

Culture affects the patterns of disease and mortality in different populations for several reasons. Culture may shape

behaviors that affect disease transmission. Examples of this would be diet, activity patterns, and especially relevant to HIV, sexual practices. People often change their behaviors and their environment through culture (Johnson and Sargent 1990). This, in turn, can affect their health.

Anthropologists also explore the effects of socioeconomic gradients on cultures, and the health and well being of the people being affected (Hertzman 2001). Certain social circumstances are tied to human resilience, and people who live on the margins of society are often left out of health care programs and prevention efforts. Government officials and health professionals in many countries have not realized that organizing prevention and treatment methods according to cultural practices can reduce HIV transmission, and ultimately save lives.

Focusing on social networks, and discourse used to talk about HIV/AIDS may also help prevention techniques. Rumor and gossip play intrinsic roles in transmission of community information, especially about illness and death. In analyzing conversations about HIV and AIDS in a Baltimore self-help group, researchers were able to understand how rumor and gossip are used to convey information about HIV/AIDS in the community (Smith et. al. 1999). Many respondents said that HIV was just not talked about in their communities, although much of the information the

informants knew about HIV/AIDS was "picked up on the street" (Smith et. al. 1999:125). Usually, gossiping occurred in reference to one specific person in the neighborhood. Gossip also serves to dispel rumors and provide information about transmission of the virus. The use of gossip and rumor may continue the stigmas associated with HIV/AIDS, but in understanding how gossip is used disparagingly in social networks, educators can be provided with more effective ways to educate communities. Luckily, in the United States, studies are being conducted to understand cultural differences, and the information learned from these studies is used to shape treatment and education systems.

Significant Studies

Several studies on sexually transmitted diseases have been conducted in Louisiana. One such study was conducted in Baton Rouge to determine why syphilis was so prevalent in certain areas. The syphilis epidemic was of particular concern because syphilis facilitates transmission of HIV, and the syphilis epidemic in Baton Rouge occurred in populations that also had high rates of HIV infection (Farley et. al. 1999). The survey included people infected with syphilis, their sexual partners, and people in their neighborhoods. The results of the study found that people with syphilis were less likely to be exposed to outreach programs and other forms of intervention that are

used to prevent the spread of STDs and HIV. Syphilis occurred when people had poor access to healthcare, and transmission occurred through a group of core transmitters with large numbers of sexual partners (Farley et. al 1999). People that engaged in moderately risky behavior also contributed significantly to the syphilis epidemic. This study shows that more efforts need to be made in areas where syphilis infection is high to help prevent the spread of HIV.

A study conducted in New Orleans on the Louisiana male AIDS cases shows the relationship between lower education levels and a more rapid decline to death. The study found that men with lower education levels suffered a higher incidence of mortality, while men with higher education levels demonstrated the least severity in decline to death (Sorensen et. al. 1999). When used as a factor, education, along with transmission group and race, is extremely important in determining morbidity rates. A sub-population of higher educated minority men with a history of drug use proved to have a higher rate of decline than similarly educated white injection drug users. This evidence should be integrated into the development of educational programs to prevent HIV transmission in this population (Sorensen et. al. 1999).

Another factor in survival patterns in HIV-positive populations is the utilization of health care resources. A

study was conducted in New Orleans to determine how the utilization of inpatient services for the first visit affected death or disease progression in HIV-positive patients. The study consisted of 3402 HIV-positive patients, 805 of which used inpatient services. Researchers found that patients first utilizing inpatient services were significantly more likely to have a diagnosis of AIDS upon entry into the study (Welch and Morse 2001). HIV-positive individuals using inpatient services were also more likely to miss all scheduled outpatient visits after their initial hospitalization, more likely to be diagnosed with psychosis, and twice as likely to be dead at the end of the study (Welch and Morse 2001). The significant factors associated with inpatient services include African-American race, injection drug user status, drug/alcohol abuse, and older age. These factors may impede faster access to proper medical care and early intervention. The authors of this study point out "innovative and culturally acceptable approaches are needed to improve this group's access to early HIV care" (2001:219).

Condom usage is a key preventative measure in the sexual transmission of HIV. Previous surveys have found that people at high risk for contracting HIV understand that condoms can lower their risk, but many of those in lower socioeconomic brackets are unwilling to purchase condoms. In 1993, Louisiana began making condoms accessible for free at all public health clinics.

Businesses in neighborhoods with high STD rates were invited to make condoms available to their customers as well (Cohen et. al. 1999). The number of condoms distributed was tracked for a two-year period and surveys were conducted to see if a change in behavior had occurred in areas where free condoms were made available. The results of the study show that condom distribution went from 323,000 in 1992 to the distribution of 13,360,000 condoms in 1996. The number of condoms sold commercially stayed at a constant rate throughout the study. Across the board, percentages increased in survey participants using condoms, obtaining condoms, and knowing where free condoms can be located. Although behavior was self-reported, data from STD rates seems to support the validity of the percentage increases (Cohen et. al. 1999).

Some resistance to distribution of condoms was initially shown by healthcare workers and elected officials, but these complaints died down as statistical analysis of the STD rates in Louisiana were made available. Patient and consumer appreciation also quelled the primary protests. The results of the study shows that the condom social marketing did not affect commercial condom sales, and was effective at reaching a population that was not purchasing condoms previously. Condoms are still available for free in many locations around Baton Rouge.

A program in California focused on a cultural method to increase condom usage by low-income, African-American women. The initiative was called the "Healthy Mamas" program, and focused on educating the women in preventing HIV infection on a personal level (Barker et. al. 1998). Most of the women stayed to finish the three-month initiative, although the program was not always successful in changing basic ideas or beliefs about HIV prevention and condom usage. Women who were in long standing stable relationships were more agreeable to condom usage than women who were trying to establish a sexual partnership. The demands of a young woman insisting that her partner use a condom are often misconstrued and can lead to violence. Short-term goals, such as establishing a sexual partnership often become a priority over long-term goals such as staying HIV-negative. This study uses cultural beliefs to help get the prevention message out to low income African-American women who are at high risk for contracting HIV. The study also shows how the lack of more accurate cultural knowledge and specific interactions of members of the groups can impede education and behavior changes.

Another study conducted in Memphis, Tennessee shows how using focus groups can enhance understanding of opinions and attitudes about disease transmission among low income African-Americans. Questions about HIV/AIDS and syphilis were targeted

at four groups of nine participants to better understand their current perceptions about disease and transmission (Okwumabua et. al. 2001). Results showed that most people in the focus group had a lack of accurate information on transmission of HIV. There were also cultural barriers to condom usage and getting tested. Members of the focus groups thought that condoms inhibit natural feelings in sexual relations, as mentioned above. There was also concern about health workers negative attitudes towards individuals being tested. All of the people in the group emphasized the need for community based prevention efforts to help slow the spread of HIV and other STDs in their community (Okwumabua et. al. 2001). Participants in the study agreed that there is a need to develop community support to prevent HIV, and to use cultural approaches to help in the understanding of prevention and transmission of all STDs.

Tony Whitehead argues that to effectively reach low-income African-American men, studies must be conducted to better understand sociocultural meanings attached to HIV/AIDS, as well as manhood and masculinity (1997). Whitehead uses data from ethnographic studies in Maryland and the Washington D.C. area to support his ideas. For example, a man's sexual prowess is often valued over behaviors that prevent the spread of a disease, such as condom usage. Study findings indicated that since condom usage is supposed to help prevent sexually transmitted diseases,

condoms are associated with "dirty" or "diseased" women. Therefore some groups of low-income African-American men understood the need for condoms, but only used them when they were having sex with someone they considered as a "dirty" woman (Whitehead 1997). Some men in the study did not use condoms at all because they did not have sex with these types of women, so they did not think that they needed to wear a condom with the "clean" women they were sleeping with. When the researcher understands this type of distinction being made, changes can be made in the presentation of educational and prevention materials.

A study of the HIV epidemic in the United States at the turn of the century shows the trends in transmission. Deaths of persons with AIDS continued to increase until 1994, and then began to decline thereafter (Karon et. al. 2001). The decrease in mortality was the least among African-American women and women from the South (2001:1062). Rates of HIV infection were also high for African-American women from the South. This is certainly true of the epidemic in the Baton Rouge area, where rates of HIV infection are rapidly rising among African-American women. Forty percent of the 300 new cases of HIV/AIDS in Region II during 2000 were African-American women (OPH 2000). Increasing numbers of African-Americans, Hispanics, and women are being diagnosed with AIDS as the epidemic continues.

Beliefs about HIV/AIDS are variable among many populations, which may give rise to higher HIV transmission rates. A study was conducted on five populations of Latin and Anglo-Americans to determine how culture affects one's beliefs about HIV/AIDS. Cultural differences were reflected in the inability to come to a consensus on answers to questions such as "Can you get AIDS from a public bathroom?" due to limited access to such facilities in certain survey populations (Baer et. al. 1999). Two of the five groups believed that prayer was an acceptable form of treatment for AIDS. Both of these populations were mostly evangelical Protestants, so prayer as a form of healing was considered a part of their religious and cultural belief system. None of the Latin or Anglo-American populations believed that AIDS was curable through herbal remedies, and all agreed that biomedical treatment was necessary. This may be due, in part, to the fact that AIDS is a disease that is recent and therefore, has not had time to enter the realm of traditional folk illnesses.

Ethics

HIV/AIDS affects private individuals, but the epidemic is a public health concern. HIV/AIDS is an infectious disease, and people can be infected for years before they are aware of any illness. There is no known cure or vaccine for HIV/AIDS, there is an extremely high death rate, physical suffering of the

patient is great, and there is a high cost of health care to treat HIV/AIDS patients (Reamer 1991). There was a great public debate in the late 1980's about who should pay healthcare costs of HIV/AIDS patients due to prejudices and moral judgments made by the general public (Feldman and Miller 1998). Many religious and political leaders often find education about HIV and modes of transmission morally offensive, and this type of stigmatization carries over from the message being projected to the people supplying the information. Leaders of the Religious Right, such as Pat Robertson, Jerry Falwell, and Pat Buchanan have often portrayed homosexuals as evil and as the cause of AIDS. Senator Jesse Helms has blamed AIDS on homosexuals for many years, but as his last term in the Senate comes to a close, he has vowed to keep AIDS on his political agenda, and help fight the spread of the disease (www.cbs.com February 22, 2002). People infected with HIV/AIDS have to undertake lifelong behavior changes to effectively deal with the disease, and the responses they receive to the news that they are HIV-positive. Individuals often have a new construction of their social role imposed upon them by their status as HIV-positive (Lang 1991). There are stigmas attached to HIV-positive people due to the way that HIV is contracted, and because of this, studies involving HIV-positive patients must be conducted with great care. Confidentiality in HIV/AIDS studies is key (Loue 1995). The

researcher must understand that individuals are exposed to certain social repercussions as a result of their participation in studies on HIV/AIDS. People that have openly disclosed their HIV-positive status have been subjected to social isolation, loss of employment, eviction, and discrimination in their everyday lives (Loue 1995).

When a person is HIV-positive, they are labeled as members of a risk group. Meira Weiss discusses the "deviance" of behaviors attached to the person with HIV/AIDS (1997:457). The labeling of these people continually emphasizes and reinforces the stigma attached to HIV/AIDS. Often, groups that are already disenfranchised, such as homosexuals, drug users, and minorities, are labeled as risk groups. In Weiss' study of Israeli health care workers and university students showed that AIDS was framed as a disease of pollution and transformation (1997:460). The way that HIV is contracted is seen as polluting, and the way HIV/AIDS takes over the body is seen as transforming the affected individual. When Weiss asked participants to visualize and describe AIDS, many pictured an amoeba-like substance infiltrating the body without being seen (Weiss 1997). Drawing the disease representation also showed that participants isolated HIV/AIDS and the patient from the outside world. Thus the disease causes not only a physical

death but also a social death according to the representations given.

An HIV diagnosis may be particularly stigmatizing to a person who is not in a disenfranchised or high-risk population. A study was conducted on the effects of HIV/AIDS on middle-class Caucasian women, and the ways that they cope with the stigma attached to the HIV diagnosis (Stanley 1999). Many of these women were found to use religion as a coping mechanism and a way to transform the negative stigma of HIV/AIDS into a more spiritual, if not positive, identity. In accepting their HIV status and focusing on the diagnosis as a gift given to them by God to change their lives, the women are able to cope and refocus their energy around the disease. As one woman said, talking about AIDS takes away the power from the disease (Stanley 1999). By using this rhetoric and working to transform their ideas of self, these women are able to frame their identities using their HIV-positive status to benefit themselves and others.

Research must be done to continue the fight against the spread of HIV/AIDS, but care must be taken along every step of the way to insure that people already living with the disease are protected.

CHAPTER 3 METHODS AND MATERIALS

In researching HIV and AIDS in the Baton Rouge area, efforts were made to uncover as much data as possible about the current state of the epidemic. Different types of data were collected through several means and sources including public health authorities, community based organizations, universities, and other state institutions.

Statistical data on the prevalence and breakdown of HIV/AIDS in Region II, including the parishes of Ascension, East and West Baton Rouge, Iberville, Point Coupee, and East and West Feliciana, was obtained from the state epidemiologist at the Louisiana Office of Public Health. An annual report, along with parish case rates of HIV infection and progression to AIDS was reviewed to determine the current trends in Region II. Generalized mortality data were obtained from the East Baton Rouge Parish Office of the Coroner. The data were analyzed to determine if reporting trends were accurate for death rates in certain groups. The data reported by the coroner's office consisted of the age, race, and sex of the deceased, where AIDS was listed as the cause of death. The report consisted of deaths from 1991 to 2001. Other statistical facts about the state and city rankings were obtained from the Centers for Disease Control. Statistical data on the population of

Louisiana and specific parishes was obtained from the U.S. Census Bureau.

Ethnographic data were gathered from several sources as well. In order to gain access to members of the HIV/AIDS community, I attended three public meetings about HIV/AIDS, and I also attended an AIDS 101 class given by a local outreach worker at the Baton Rouge AIDS Society. One of the meetings consisted of the board of directors for the local HIV/AIDS Alliance for Region II (HAART). HAART is the consortium to which other community based organizations apply for funding, and ultimately report to with financial reports. The HAART meeting reported the past few months' findings and data on HIV and AIDS in the various community based organizations. Another meeting for the Regional Community Planning Group introduced issues that concerned the Baton Rouge area, and strategies to resolve these issues by involving the community. The third meeting involved the staff of the Family Services care facility. Through contacts made at all three of these meetings, I interviewed multiple directors, caseworkers, and health care workers about the state of HIV/AIDS in Baton Rouge and surrounding areas. Places I visited to determine services being offered, and to interview individuals working in the HIV community included: Family Service of Greater Baton Rouge, Volunteers of America Food Bank, Friends for Life - AIDS Resource Center, Baton Rouge

AIDS Society, LSU Wellness Center, Metro Health, and the Early Intervention Clinic at Earl K. Long Hospital. I talked with approximately 15 to 18 people to gather information of HIV/AIDS services offered, as well as, to ask them why they thought the HIV transmission rate was so high in the Baton Rouge area.

I tried to contact a public school official to gather information about HIV/AIDS education programs. I was unsuccessful in contacting her; all information about public school programming came from other interviews. I was also unsuccessful in contacting the Baton Rouge Police Department about statistical information regarding injection drug use in Baton Rouge.

From an anthropological perspective, gathering data from the HIV-positive population was needed to understand the full impact of the epidemic in Region II. I attended several public AIDS awareness rallies, including Know AIDS Week at Louisiana State University, and Black HIV/AIDS Awareness Night at Southern University. In order to evaluate personal aspects of the epidemic, a survey was written to determine more about the lives of HIV-positive people in the Baton Rouge area. In order to protect the identities of the people responding to the survey, no names were collected and the survey was completely voluntary. I will use pseudonyms to distinguish particular respondents in the analysis of survey data. Participants were not required to

answer all of the questions if they did not feel comfortable doing so. If the participants had a different response to a question than the choices listed, their answer was written down. The complete survey, and tabulated results can be found in the appendix of this study. The survey was conducted in an interview setting at two support groups at one of the local HIV care facilities, as well as at the local food bank. I was able to interview 19 people at these organizations. Surveys at the support groups were conducted in a separate room in tandem with the support group meeting. Participants left the support group to come to a separate room and took between 10-30 minutes to complete the survey. I was unable to conduct surveys after the conclusion of the meeting because many of the people attending the group used free shuttle transportation and had to leave together at the end of the session. The survey at the food bank was also conducted in a separate room. As the participants waited their turn to shop, I asked them if they would take a quick anonymous survey about HIV. Many were wary, and were tired of being surveyed.

A confidential informant, Marie, was also enlisted to tell her story of contracting HIV, and how she is currently living and dealing with AIDS. Marie's story was used throughout the study to tie together aspects of the epidemic in Baton Rouge, and her personal struggle with AIDS.

The data from the statistical portion of the research were converted into graphs and charts and analyzed to determine which racial, sex, or age group is being affected, and where the trends in HIV infection are going. Some of the survey data were also converted to graph format. Interviews and other data from caregivers and community based organizations were used to provide relevant information about the status of care and services available for HIV-positive individuals.

CHAPTER 4

AN EVALUATION OF THE STATISTICAL DATA

Louisiana AIDS surveillance began in 1984 as part of a national effort to monitor the epidemic in the United States. In February of 1993, Louisiana also began collecting data on HIV cases. Perinatal surveillance began in January of 1996 to track the HIV status of infants born to HIV-positive women. Pregnant women are offered an HIV test when they begin prenatal care, or enter the hospital to give birth. Surveillance is performed by collecting data on HIV/AIDS cases from a system of public and private clinics, hospitals, and laboratories.

While HIV infection numbers reported give the minimum number of infected individuals, studies indicate that Louisiana successfully reports on 85% of AIDS cases (OPH Annual Report 2000). HIV cases may be detected at any time during the infection, and therefore people who test positive for HIV may be at the stage of a clinical diagnosis of AIDS. There is a potentially lengthy delay between HIV infection and testing positive. Therefore, newly reported HIV infections may not be representative of newly infected individuals.

There are two options for people taking HIV tests. They can choose to test anonymously, where a control number is given to the person to access their test results. The other choice is confidential testing where a person gives identifying

information including their name to the testing facility. The numbers reported for HIV-positive tests come from confidential testing only. People who choose to be tested anonymously do not give their names or any identifying statistics, so the data are unreportable. In 2000, approximately 16% of HIV tests were performed anonymously. In Louisiana, HIV name reporting is required. These cases are reported when a confidential re-test is done. Consequently, the anonymous tests are not reported because there would be an overlap in the data. Once a positive HIV test is recorded, all dynamic characteristics associated with the case are also reported. By reporting characteristics such as race, age, sex, and geographic location, the Office of Public Health and the CDC can study trends, plan prevention and outreach programs, allocate funding, and improve access to health care and social services to areas in need.

In order to determine the need for public health services in Louisiana, the state has been divided into nine actual health regions (see Appendix D for a map of Louisiana). Region I is the New Orleans area. This region is the only one in Louisiana that qualifies for Ryan White Care Act Title I funds. Title I funding gives more money to metropolitan areas with over 2000 cases of AIDS reported in the past five years to fund HIV/AIDS services. While New Orleans has more HIV/AIDS cases in total than Baton Rouge, Region II that includes Baton Rouge has the

highest case rate (50 per 100,000 people) in the state, and has maintained a higher rate than the New Orleans area for the past five years.

The next level of governmental funding for HIV/AIDS is a Title II grant, which allocates money to the states according to the number of AIDS cases reported in the state. Louisiana has the 10th highest rate of cumulative AIDS cases diagnosed per 100,000 residents in the nation. Region II currently receives the largest share of the Title II funds in the state. Baton Rouge is also designated as an "emerging community." This designation means that Baton Rouge has not yet reached Title I levels of AIDS infection, but is rapidly approaching the numbers needed to qualify for the funding.

In Louisiana, as of November 30, 2001, there were a cumulative total of 21,062 reported cases of HIV infection (OPH Annual Report 2001). The population of Louisiana in 2000 was 4,468,976 according to the United States Census Bureau (Census Bureau 2001). Of the reported cases, 13,329 were diagnosed with AIDS, and 7,981 of the cumulative cases were deceased. The remaining 13,081 cumulative cases make up 0.3% of the population. Every parish in Louisiana has people living with HIV. In 2000, 55 of Louisiana's 64 parishes reported new cases of HIV or AIDS.

Region II accounted for 20%, or 4,132 cumulative cases of the 21,062 HIV-positive cases reported in Louisiana. Over half of

these cases (2,404) had progressed to AIDS, and 1,384 people in Region II were deceased by the end of November 2001. East Baton Rouge Parish had the greatest number of HIV and AIDS cases in the region. Because the case rate is so high in East Baton Rouge Parish, the majority of the funding for HIV/AIDS for Region II is directed there. Figure 4.1 shows the number of cumulative HIV and cumulative AIDS cases in each parish in Region II.

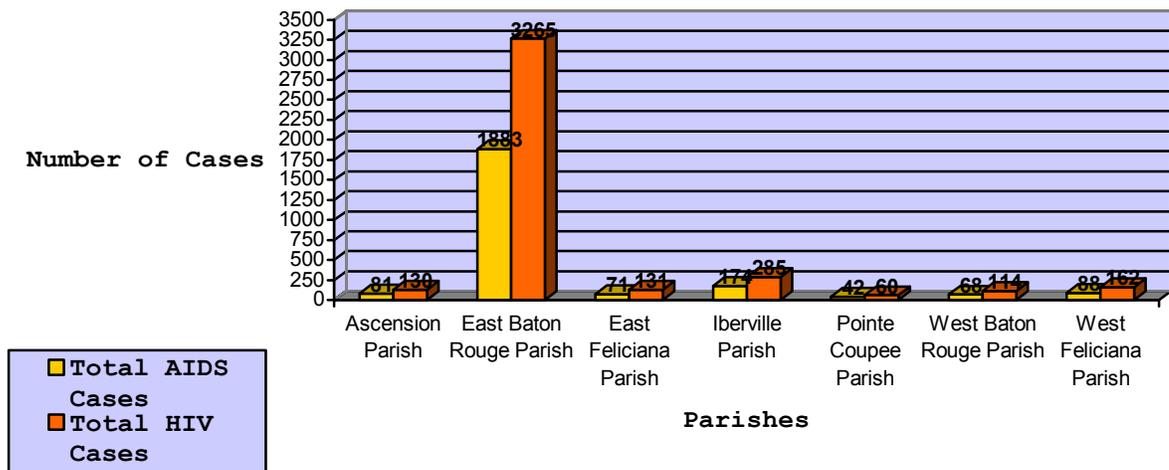


Figure 4.1 HIV/AIDS Trends in Region II

Pointe Coupee Parish had the least number of cumulative cases of HIV by the end of November 2001, with only 60 cases reported. West Baton Rouge Parish had 114 cumulative cases of HIV, Ascension Parish had 130 cases, East Feliciana Parish had 131 cases, West Feliciana had 162 cases, and Iberville had the second highest caseload in the region with 285 cases.

Statistical information from the Office of Public Health gives the breakdown of HIV cases in Region II by current age, race/ethnicity, and exposure categories. Within the race and exposure categories, cases are also divided into male and female sections. In 2000 alone, there were 300 new cases of HIV in Region II, 89% of which were among African-Americans (Region II Surveillance Report 2000). In all nine regions in Louisiana, African-American men have the highest transmission rate. African-Americans only account for 32.5% of the population in Louisiana, but they make up 64% of the cumulative adult cases of HIV in the state (Census Data 2000). In 2000, African-Americans accounted for 75% of the 1,130 new cases of HIV in the state. The pie chart in Figure 4.2 shows the differences in percentages of cumulative HIV cases in Region II by sex and race (adult cases only).

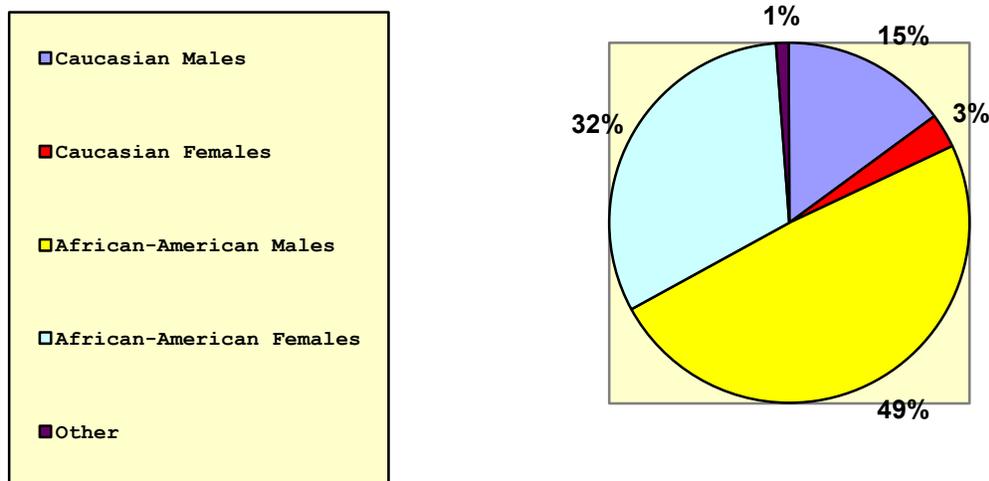


Figure 4.2 HIV Cases by Race in Region II

In the past, homosexual men were impacted the most by HIV/AIDS. As the epidemic spread, all genders, races, ages, and sexual orientations have been affected. Currently, different populations are beginning to emerge as high-risk candidates for contracting HIV. From 1995 to 2000, African-American men had a five times greater HIV detection rate than Caucasian men. African-American women had a detection rate 22 times greater than Caucasian women. The trend for both African-American and Caucasian men has pointed downward in the past decade (OPH Annual Report 2000). African-American women are experiencing an increasing number of new HIV cases, and have been for several years. This upward trend is due in part to a shift in the trends of the modes of exposure.

In the eight regions of Louisiana not including Region II, the exposure category of men who have sex with men (MSM) had the highest transmission rates. However, in Region II, injection drug user (36%) and high-risk heterosexual contact (34%) exposure categories surpassed MSM (21%) transmission rates in 2000. In the cumulative case totals for Region II, injection drug user remains the highest exposure category (40%). Other categories of exposure include MSM who are also injection drug users, heterosexuals, individuals who receive blood or tissue donations, and pediatric cases. The cumulative exposure category percentages are shown in Figure 4.3 below.

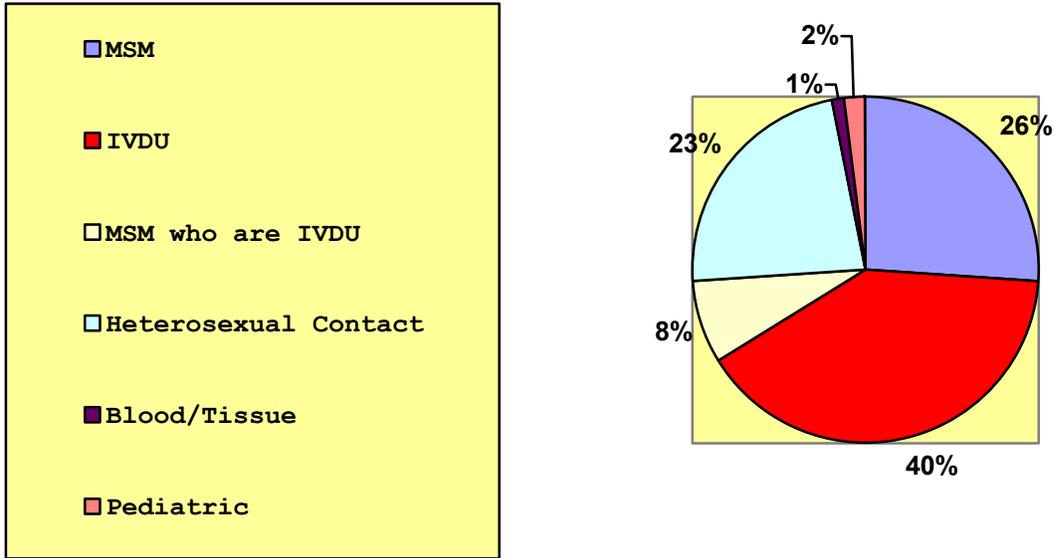


Figure 4.3 Exposure Categories for Region II

Most of the HIV/AIDS cases in Louisiana have been detected in the 25 to 34 year age range. The cases in this age range have been declining steadily since 1996, and account for much of the decline in HIV/AIDS cases seen in recent years (OPH Annual Report 2000). Men outnumber women in all new HIV/AIDS cases for 2000 except the 15 to 24 year age group. Women outnumber men 54% to 46% in this younger group, possibly due to an increase in testing availability for young women (OPH Annual Report 2000). This increase in testing can be attributed to pre-natal testing as well as more free testing available in the area.

Region II and Louisiana as a whole, have similar statistics for different age ranges. For the year 2000, the Baton Rouge area had a higher rate of new HIV cases for the 15-24 year old

age range. In all other age ranges, Region II was the same or lower than the Louisiana percentages. This can be seen in Figure 4.4 below.

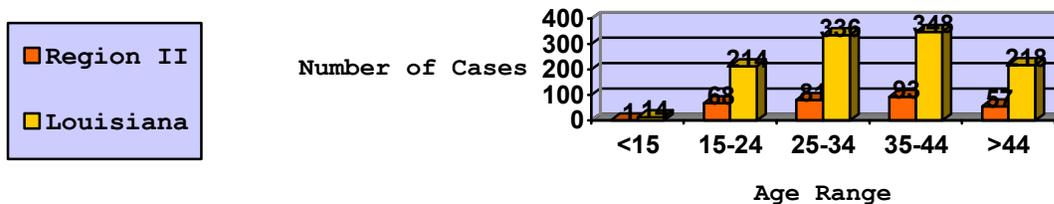


Figure 4.4 Ages of New HIV Cases in Region II and Louisiana for 2000

Special permission was obtained from the East Baton Rouge Office of the Coroner to use data related to AIDS deaths in East Baton Rouge Parish. The data were collected and divided into different races and sexes of AIDS deaths per year from 1991 to 2001 (EBRP Coroner 2001). AIDS deaths increased from 1991 to 1995, then decreased until 2000. In 2001, AIDS deaths began to increase again. The trend for Louisiana was similar from 1991-2000, but data was unavailable for 2001. The Louisiana HIV/AIDS Annual Report explains that the downward trend in AIDS deaths coincides with the emergence of new drug therapies (2000:21). In Figure 4.5 below, the general trends in East Baton Rouge Parish AIDS deaths for the past ten years are shown. The data for each year is subdivided into women and men.

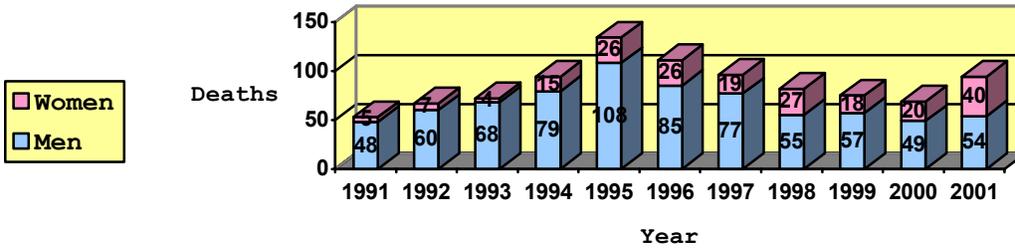


Figure 4.5 AIDS Deaths in East Baton Rouge Parish 1991-2001

As shown above, more men have died from AIDS each year. From 2000 to 2001, the number of women dying from AIDS doubled, and 2001 saw more women die from AIDS than in any previous year. This increase may be due to better reporting of in-patient deaths by hospitals and hospices. Also, commercial sex workers and homeless individuals lack access to proper health care and treatment, so these deaths may be reflected in the high numbers. AIDS deaths peaked in 1995 with a total of 134 deaths, but this figure may be surpassed in the near future as more and more cases of HIV/AIDS are diagnosed in East Baton Rouge Parish.

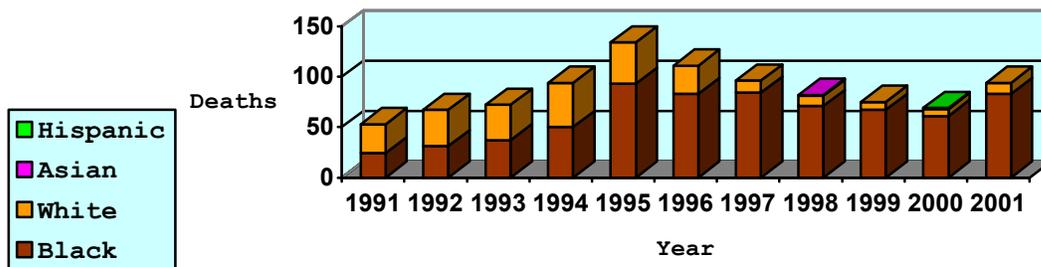


Figure 4.6 AIDS Deaths in East Baton Rouge Parish by Race 1991-2001

The graph above shows the same data set for East Baton Rouge Parish AIDS deaths, but with divisions made by race. The races are listed as Black, White, Asian, and Hispanic according to labels used by the Coroners Office. Only one Asian person and one Hispanic person have died from AIDS in East Baton Rouge Parish in the past ten years. As Figure 4.6 shows, the AIDS death trends have decreased for Caucasians, and increased for African-Americans over this period. It is worth noting that the Coroners Office does not use the race listed on the deceased individual's birth certificate, as race listed on the death certificate is usually determined at the time of death. This may conflict with self-reporting of race, or the race listed on the birth certificate (Hahn 1995).

General trends show that HIV/AIDS cases are on the rise for minorities, women, and IV drug users. This is true for the United States, Louisiana, and specifically Region II. While fewer cases have been diagnosed over the last five years, the amount of people living with HIV/AIDS has steadily increased. The newly diagnosed cases of AIDS have decreased for certain populations over the past five years as a result of access to new drug therapies. Women and African-Americans have seen an increase in AIDS cases, which may stem from a lack of medical resources available to these population subgroups. For East

Baton Rouge Parish, 2001 saw an increase in AIDS deaths for the first time since 1995. This increase serves as a reminder that HIV/AIDS cases are still a problem, and will continue to be a healthcare issue in the future.

CHAPTER 5

THE HIV/AIDS LANDSCAPE

This chapter will cover the functional aspects of HIV/AIDS services in the Baton Rouge area, as well as describing the public forums for discussion of HIV/AIDS. Baton Rouge has several community based organizations to serve the people affected by HIV/AIDS. Community based organizations are private not-for-profit organizations that contract with the state to receive Ryan White Care Act funds to use towards HIV/AIDS services. A table of these organizations, with associated abbreviations and locations can be found in the appendices.

Many people from the surrounding rural areas come to Baton Rouge for medical treatment and social services. The agencies listed below try to serve all aspects and needs of the HIV/AIDS community. Meetings involving these organizations, that are open to the public, are also discussed below. Local organizations sponsored several events in order to get the public talking about the risks of contracting HIV. These events include Know AIDS Week on the LSU and Southern University campuses, a "compassion arrest" on World AIDS Day, and celebration of Black HIV/AIDS Awareness Day with speeches and a candlelight vigil at Southern University.

The first agency to provide services to people living with HIV/AIDS in Baton Rouge opened its doors in 1985. This agency

was known as the Baton Rouge AIDS Task Force, and helped the people already infected with HIV/AIDS to cope with their diagnosis. These individuals were often close to death and facing discrimination and depression. As treatments advanced for HIV/AIDS, people were able to live longer, and the task force name changed to Friends for Life - AIDS Resource Center. Rather than providing a refuge for people that were dying from the disease, Friends for Life began programs to integrate clients back into the workforce and society.

Currently, Friends for Life (FFL) provides case management for women, adolescents, and children. Case managers assess the needs of these women and children to develop an appropriate assistance package. Direct assistance is provided to help with medication, transportation, emergencies, and dental care. Housing assistance is available to homeless HIV-positive individuals in the form of short-term rental assistance, which is funded by the Department of Housing and Urban Development. This program provides a deposit, and the first and sixth month's rent to qualifying individuals. Housing Opportunities for Persons with AIDS (HOPWA) is available to AIDS patients, who can receive a maximum of \$300 per month towards rent or mortgage payments, as well as assistance with utilities. FFL also provides a life skills program, which helps participants gain housing, access to transportation, education, and experience for

entry into the work force. HIV testing and condoms are available for free at FFL. Americorps VISTA volunteers are currently working at FFL to develop educational programs for churches and schools to help prevent the spread of HIV. One of the workers at FFL is trying to integrate services into the rural areas around Baton Rouge that are also affected by HIV/AIDS.

Another community based organization dedicated solely to fighting HIV/AIDS in the Baton Rouge area is the Baton Rouge AIDS Society (BRASS). BRASS was started as an agency dedicated to educating anyone and everyone on HIV/AIDS. AJ Johnson, a student programs director at Baton Rouge Community College, is the founder of BRASS. He takes time every Monday night to teach a free AIDS 101 class to the general public. This class is not federally funded, as Johnson does not target a specific risk group. He believes that educating each person is important. The class covers general information about transmission, HIV/AIDS symptoms, education, medication, testing, and condom usage. Johnson has seen the number of people reached by this class increase from 81 people in 1999 to 269 people attending in 2001. This is partly due to an advertisement in the local newspaper. Johnson, other workers, and volunteers provide street outreach and free condoms and testing. Street outreach consists of a team of volunteers going into high-risk

neighborhoods to talk to people about HIV/AIDS. Teams talk with people on the street about getting tested and using condoms correctly to prevent the spread of HIV. I asked Johnson if I would be able to go with them on a street outreach. He advised me that street outreach programs can be very dangerous and that he did not want me to go for several reasons. Johnson mentioned the fact that people in the neighborhoods they visit have learned to gain trust in the outreach workers, and he would not want to bring someone in for only one trip. Also, he said he feared for my safety and did not want to risk bringing me with him.

The workers at BRASS have had different types of training in HIV education and counseling. The street outreach for high-risk areas and certain educational materials are funded by the state Office of Public Health. BRASS also offers a free monthly newsletter with information for the public on HIV/AIDS happenings in the Baton Rouge community.

Other community based organizations that serve the HIV-infected community include Family Service of Greater Baton Rouge, Metro Health Education, and Volunteers of America (VOA). VOA runs a food bank for people with HIV/AIDS from Tuesday through Thursday. Family Services and VOA provide case management, direct assistance, housing assistance, and counseling services. Family Services and Metro Health also

conduct support groups for HIV-positive people. Metro Health does educational presentations, as well as street outreach programs, and provides special help to HIV-positive pregnant women and infants who may not be accessing medical care. AIDS Law, an organization based in New Orleans, provides representatives once a month to help HIV/AIDS patients with legal counseling. The Immunological Support Program (ISP) and St. Anthony's Home are associated with Our Lady of the Lake Hospital. The ISP has counseling and support, and St. Anthony's provides care for indigent HIV and AIDS patients. The Early Intervention Clinic at Earl K. Long Hospital provides primary medical care to many HIV-positive people, especially those without medical insurance, in Region II.

Most of these organizations provide updates to the HIV/AIDS Alliance for Region Two (HAART). HAART helps to distribute federal funds, and through a monthly Board of Director's meeting, reports show where money is needed, and where funds have been spent. The meetings are held at a local community center once per month at 8:00 a.m. A multitude of different topics were discussed at the January 17th HAART meeting. Updates given by Family Services included information on the end of their outreach programs, the number of people attending support groups, and an HIV prevention program. VOA gave survey results on food bank satisfaction rates among clients, and financial

information on the amount of money spent on services for clients. The Early Intervention Clinic representative gave information on the long wait times, up to 50 days, that clients have to wait to see a physician.

Although this meeting was open to the general public, there were not many people attending that weren't members of an HIV-related service organization. The meeting was handled in a business-like fashion, with the board members sitting around tables in a U-formation. The representatives and guests sat in rows of chairs facing the board. The meeting proceeded according to a formal plan, where reports were given, finances and grant proposals discussed, and time was given at the end for public comment. At the January meeting, there were no comments given by the public.

The Regional Community Planning Group meeting held at Family Services on January 24th had a distinctly different feel. Many of the same people at the HAART meeting also attended this meeting. All attendees were seated around tables in a square formation, and were able to give input throughout the meeting. Most of the attendees at this meeting were women. Each attendee discussed the projects they were working on, as well as ideas for future work. Topics covered included an injection drug user survey in the works, peer prevention in St. Gabriel, LA, a teen advocate program, and work on preventing HIV transmission during

pregnancy. The atmosphere was more relaxed than the HAART meeting, possibly due to the fact that reports were on services offered rather than financial expenditures. Towards the end of the meeting, the participants discussed the need for more representation by different members of the HIV-positive community. Each participant was willing to recruit one member of the community to bring to the next meeting. This strategy of bringing in HIV-positive individuals will be helpful in determining what services their community needs.

Another meeting I was invited to attend was held at Family Services. This was a weekly meeting to gain staff updates on HIV/AIDS services. The staff discussed general issues involving Family Services such as extended testing hours for Black HIV/AIDS Awareness Day, an open house to promote the agency to the medical and counseling community, and other meetings of interest to be held in New Orleans.

Throughout all of the community organizations, there seems to be a camaraderie and a willingness to help people afflicted with HIV/AIDS. Most of the caregivers I spoke with were genuinely committed to their jobs and the people they work with. Much of the work that is done is funded through the government. The people who work these jobs are constantly in meetings, working through piles of documentation and paperwork, writing grants, and caring for multiple clients.

I asked the people I spoke with why they thought the Baton Rouge area had such a high rate of HIV/AIDS. Responses to this question ranged from the positive to the negative aspects of what a high rate constitutes. One outreach worker said that he thought Baton Rouge has such high rates because people are getting tested and the figures are more accurate than other areas. A volunteer agreed, and explained that testing has become more socially acceptable and more testing is now available. Most of the other outreach and care workers did not agree. Some said that people don't think it will happen to them. Others said the HIV rate is high due to a lack of education, and cultural issues. One of the issues discussed focused on the African-American community, in that women are too trusting of men and will not ask that they use condoms during sex. This may also be due to a power differential, and stigmatization of being a loose woman, if a woman asks a man to wear a condom. Others agreed that IV drug use and the associated risky heterosexual sex was the main problem in the high numbers of people with HIV. While caseworkers feel that there are not as many people using injection drugs anymore, many HIV-positive people self-identified as former injection drug users. Caseworkers refer any clients who use drugs or alcohol to a detoxification clinic on Florida Boulevard.

All of the people I spoke with expressed concern about getting HIV-positive people into proper medical treatment, and making sure the patients follow up with their doctors and continue their care regimen. As wait times for free medical care are long, and many patients miss their appointments, this is a major concern of healthcare workers. Keeping clients healthy is one of the primary goals of the people I spoke with.

Unfortunately, there are many causative agents and the caseload for these caregivers is not decreasing. Several of the agencies work to promote public awareness of HIV/AIDS through community events to educate, and help prevent the spread of HIV.

In October, Know AIDS Week was sponsored by Louisiana State University and Southern University to educate students about the risks of contracting HIV, and the high rate of HIV/AIDS in Baton Rouge. On Wednesday the 24th, a rally was held on both university campuses. Speakers gave testimonials about living with the disease, public figures and educators talked about the alarming statistics for Baton Rouge and the need for students to get educated, get tested, and get involved. Both of the events were held in front of the student union at each university, and the weather was warm and sunny. The event at LSU drew an attendance of around 150 people, many of whom came to see the step show performed by a sorority and fraternity group from campus.

The program began with Chancellor Mark Emmert giving statistical data for Baton Rouge and Louisiana HIV/AIDS case rates. Patrick McCune and Mario Garner, student government representatives, spoke on student concerns about HIV/AIDS, as well as on the hope for research to find a cure. Julie Hupperich of the LSU Wellness Center gave information on HIV testing, as well as the AIDS Names quilt panel on display in the Union. Pamela Matassa, a local broadcaster and Board Chair of Friends for Life, gave more statistics on HIV/AIDS deaths, and services available at FFL. Janet Parker, a local AIDS activist, gave her personal testimony of being HIV-positive and living with AIDS. She explained that she had been diagnosed in 1990 and given six months to live. Rather than resigning herself to death, Parker educated herself and began to live with, and fight the disease. She does testimonials to show people the "face of AIDS." After Parker spoke, a step show was performed by the Delta Sigma Theta sorority and the Omega Psi Phi fraternity. The step show was dedicated to Know AIDS Week. The 50 or so students who were in attendance before the performance had listened attentively to the messages the speakers were giving, whereas once the show was over, many students thought the programming was over. Many of the rest of the speakers could not be heard over the dispersing crowd, so their messages fell on deaf ears. Luckily, information tables were set up for

students who were interested in learning more about HIV/AIDS. The LSU Wellness Center and Friends for Life had members available to answer questions about HIV/AIDS, testing centers, volunteer opportunities, and to distribute literature about educating and protecting oneself.

In honor of World AIDS Day on December 1, 2001, there were several events held in Baton Rouge. Friends for Life and the Bethel African Methodist Episcopal Church held a prayer breakfast, BRASS held it's second annual World AIDS Day Conference, several different churches had a special nighttime church service, and Metro Health sponsored a "compassion arrest" at the Leo Butler Community Center. The compassion arrest program involved more than thirty people who were arrested for showing compassion about HIV/AIDS and arraigned at a mock trial. The offenders consisted of local politicians and other religious and community leaders. Each person had to pay a "fine" of \$500 that they raised by enlisting the support of friends, family, and business partners. The goal was to raise \$10,000 to support funding for programs at Metro Health. The fund-raiser was a success, bringing in over \$12,000, and raising awareness of HIV/AIDS (Wold 2001).

On February 7, 2002, events honoring National Black HIV/AIDS Awareness Day were held in Baton Rouge. HIV testing centers were open late across the city. Friends for Life and Southern

University co-sponsored an event that night on the Southern campus. The night was cold and blustery, and although the event was held in the middle of the Southern dorms, attendance was low. Chancellor Edward Jackson began the program with a welcome speech. Reverend Samuel Johnson of the Bethel AME Church gave the invocation, the people attending sang an inspirational song, and two local people gave testimonials about living with HIV/AIDS. Ric Smith, the Executive Director of Friends for Life, led the following candlelight pledge found in the programs that were handed out at the beginning of the event:

We subscribe to the following principles: AIDS is not Divine punishment, no group or class of people deserves AIDS; people living with AIDS deserve full civil rights, including the right to retain their jobs and homes and to travel freely, all people should be educated and assisted in avoiding infection; and all governments must commit to assuring their HIV infected citizens access to comprehensive health care and the latest AIDS medications.

Following the pledge, the participants lit their candles and a march to the student union began. Once at the union, Avery Wilson, President of the Student Government Association, gave a speech of remembrance for all who have died from AIDS. After the benediction by Reverend Edward Hayes of the Shekinah Glory Christian Center, the participants in the march were asked to blow out their candles if their lives had been affected by HIV/AIDS. Almost all of the candles were blown out.

The events and agencies described above are not a comprehensive listing of all of the HIV/AIDS happenings in and around Baton Rouge. The above-mentioned items are just a sample of what is going on in the community to help ease the burden of HIV/AIDS. The local newspaper, *The Advocate*, has a reporter by the name of Amy Wold, who covers HIV/AIDS in Baton Rouge. Wold tries to keep HIV/AIDS in the public eye.

There are other agencies that are fighting this epidemic, and other events to raise money and keep HIV/AIDS awareness going. HIV transmission rates had been steadily decreasing from 1997 to 2000. In 2001, transmission rates began to increase once again. As HIV case numbers begin to rise again in Baton Rouge, more people and money will be needed to successfully combat this disease.

CHAPTER 6

HIV AND THE INDIVIDUAL

The most important aspect of this study is how HIV/AIDS affects the individual. I conducted an interview with a local woman living with HIV/AIDS. Her story is told, and her views on HIV/AIDS are given throughout this chapter. The name of the woman giving her story has been changed because she is just beginning to become active in public testimonials, and she would still like to retain some anonymity. She will be called Marie for the purpose of this study.

I met Marie while visiting a local community based organization. She looked busy, but I interrupted her and asked if I could question her about the HIV/AIDS epidemic in Baton Rouge. Immediately she told me she was HIV-positive and had AIDS, and what exactly did I want to know? I ended up talking to her for over an hour. By the end of our conversation, she offered to give me her story to help further the understanding of how HIV is affecting people in Baton Rouge. We met several times after this, and the bulk of information about Marie was obtained from a one hour interview. I tape recorded the interview, and transcribed her original words which are quoted throughout this chapter.

Marie is an African-American woman in her late twenties. She grew up in Baton Rouge and graduated from Southern University.

Up until three years ago, she was living the American dream. She had a good job, a new car, and she was engaged to the man she loved. Marie thought that since they were in love, she did not need to worry about infidelity or using protection. They had been having unprotected sex since they would soon be married and they wanted to have children. The romance did not last; she found out her fiancé had been cheating on her with another woman.

Marie was later hospitalized with an illness she thought was related to her diabetes. When the doctors could not find the cause of her illness, they conducted an HIV test. The test came back positive. She was handed an AIDS diagnosis several months later.

Marie explained that she had put herself into an imaginary category of people who did not need to worry about HIV and AIDS. She believed that since she was a college educated woman, in a serious relationship, and she said her prayers every night that she could not be affected by such a disease. HIV was the furthest thing from her mind.

Marie said she didn't think her ex-fiancé knew that he was HIV-positive when he infected her, but she found out he was at the Department of Health and Hospitals the same day she was. Marie was there to give her list of sexual partners to be notified about her HIV-positive status. Her caseworker was

reading over Marie's list of former partners, saw the ex's name and said, "Oh he's here right now." Marie was infuriated, and in order to avoid a confrontation, her caseworker made her leave through a back door. The next day her ex-fiancé called her because he had heard she was sick. He asked her if her illness was diabetes-related. She lied and told him that it was. She thought that this would be an opportunity for him to come clean, tell her he had HIV and that she needed to be tested.

Due to the fact that I was still in love with this person, I thought maybe he would come clean and this would be something we could fight together as a loving couple. He never said Marie maybe you wanna go get tested or nothin, he said "it was diabetes related?" I said yeah it was diabetes related. Okay let's move to the next victim.

That phone call occurred over three years ago and she has not heard from him since. She never learned directly if he had HIV. Her partners were notified through the Department of Health and Hospitals.

When Marie told her friends and close relatives that she was HIV-positive, they were shocked and angry.

My friends and family were angry that it happened to me, with a dash of shock on the side, we see it on TV, and in movies, but not at home in our backyard. I didn't lose any friends, and I am extremely blessed, not everybody can say that. Those that I have chosen to tell have not turned their back on me.

Marie was lucky because her friends and family gave her support after telling them of her HIV status. She had confided in her boss at her previous job, and this did not affect her job. She

has since quit that job due in part to her illness, and gone on to become a consumer advocate. The one problem plaguing Marie in regards to her HIV-positive status and familial relations is her father. He has not yet come to terms with his daughter being HIV-positive and he does not see the need for her to share her story with others. Her father is a deacon in their church and he uses his religion to back his feelings about her HIV-positive status. He feels that God will heal Marie and that she does not need to worry about HIV and focus so much energy on the disease. The rest of her family has encouraged her decision to talk about the disease rather than remaining silent.

In trying to educate others about HIV/AIDS, Marie has gotten many different reactions about people with the disease.

When I did a forum at Southern University, we had a question and answer session. One young man said "I think they should put a picture and name and address of all the people with AIDS in a book so we can know who these people are." I walked up and introduced myself as a Southern graduate, with HIV and an AIDS diagnosis. The room went silent, because no one had ever seen someone come out and say, I have it. I told him unless he knows his status, we could be in that book together, and wouldn't that be nice? Don't run from me now, at least I told you! That's a drop of the attitude we have in Baton Rouge, but since I put a face with the disease, that attitude changed in 5 seconds. The girls were crying cause they knew I had been in the same stomping grounds as them at Southern. AIDS does not discriminate, it does not care!

Marie says, "It's between me giving education and you choosing to receive it, if you don't it's not going to get through no matter what happens." She knows that most people in Baton Rouge

think of HIV/AIDS as the other person's problem. I interviewed some of the "other people" to understand what they deal with as HIV-positive individuals.

In studying HIV/AIDS in the Baton Rouge area, I surveyed individuals from several different support groups, as well as the local food bank to get input from the people actually living with the disease. I conducted the survey in an interview format. Because HIV/AIDS has such a stigma surrounding the people infected, surveying people with HIV/AIDS that do not use services would be next to impossible. People who are not using services are hard to find, and most likely do not want to be interviewed.

The survey conducted contained eleven multiple-choice questions, and five open-ended questions (see appendix). The survey participants answered the 16 questions, and were then asked to give their views on what they thought Baton Rouge needed for HIV-positive people. Participants did not give their names, so pseudonyms have been assigned to tell them apart.

Nineteen surveys were completed over a period of two weeks. Nine participants were female and ten were male. Of the nineteen, three were Caucasian, 16 were African-American, although two of the 16 self-identified as a different race. One said he was "plain Black" and another man identified as

“Creole.” All of the Caucasian participants were male. The age breakdown can be seen in Figure 6.1 below.

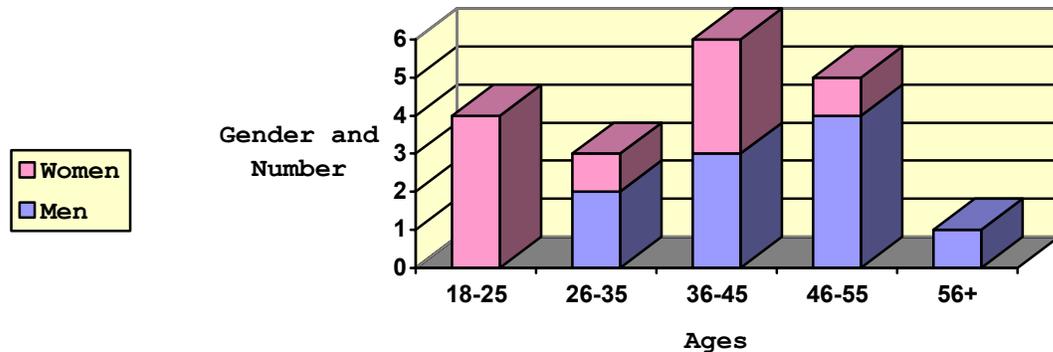


Figure 6.1 Age and Gender of Survey Participants

Several of the people were given an HIV-positive diagnosis in their teens, and three men, Fred, Louis, and Nick were all in their late forties/early fifties when diagnosed. The period since diagnosis for people surveyed ranged from a mere five months ago, to two people who were diagnosed with HIV in 1985 and 1986. Most of the participants have been diagnosed since 1995. Participants came from many areas in and around Baton Rouge. The zip code that was best represented was 70805. Other cities that were represented include Baker and Zachary in East Baton Rouge Parish, Ethel in East Feliciana Parish, and Sorrento in Ascension Parish.

Most of the people who chose to participate were very forthcoming about their answers, even to the multiple-choice questions. They explained their answers, giving more detail

where they felt it was necessary. Hardly any of the participants gave stock answers. The first four questions address the issue of telling family, friends, neighbors, and co-workers of their HIV status. Answers included: their reactions changed "a lot," "a little," "did not change," or "I have not informed them." Grace is the only person who answered "I have not informed them" for the question pertaining to telling their family. This response was given most frequently to the question asking if they had told the people in their neighborhood. Most people felt that telling their neighbors was unnecessary and could potentially cause harm to them by getting them evicted, or harming their families in some way.

The reactions garnered from those who told their families and friends ranged from changing "a lot" to not changing at all. Several women reported that after telling their mothers, they were treated like children again. Maxine said that she had to educate her mother about the disease so she would understand that she was not an invalid and that she could live with the disease so her mother would stop babying her. Arla's mother was scared when she found out her daughter was infected, and would not let the daughter get out of her car at the mother's house. Arla has encountered many problems after disclosing her HIV status. Several of her friends were gossiping about her HIV-positive status, and this led to her hairdresser putting up a

sign in the salon saying people with diseases could not get their hair done there. Since being diagnosed, Arla has moved out of her neighborhood. This shows the type of discrimination still evident in Baton Rouge.

Maxine described why she did not inform the people she works with. She currently holds several jobs, and said that informing her co-workers and employers would create lots of problems, and that she was afraid of being fired if they found out her HIV status. She has to miss her doctor's appointments sometimes because of her work schedule. Maxine also said she did not inform people in her neighborhood because they would gossip about her. Her friends and family were supportive, and did not let her HIV status affect their relationships with her.

Dennis, who was diagnosed in 1986 said that both his friends and family reactions changed for the worse when he informed them, but they have since changed their attitudes, and have become educated about HIV/AIDS. Although he does not work now, when he did work, he found that several people would not work with him when they found out he was HIV-positive. This reflects the validity of the fears of Maxine, mentioned above who was afraid to tell the people she worked with because of problems the disclosure might cause.

A support worker I spoke with explained his position on who people should tell when they find out that they are HIV-

positive. He tells them to ask themselves “What is the benefit to me to tell someone my HIV status?” This gives them an opportunity to address issues that they see with disclosing their status to different groups of people. If telling people at work one’s HIV-positive status is detrimental, then why should one feel the need to tell them?

The fifth question in the survey asked who had given the participant the most support since their diagnosis. Most of the people interviewed answered that their families have given them the most support since they found out they were HIV-positive. Health support groups were also mentioned often, but this finding is not surprising since around half of the surveys were done at local support groups. Church was mentioned by two of the participants as offering a supportive environment.

The next question dealt with how the participants contracted HIV. Figure 6.2 shows the percentages that gave each answer. The answer choices were: through sexual intercourse, through sharing needles, and other. If the participants chose “other” they were asked to explain how they thought they contracted HIV.

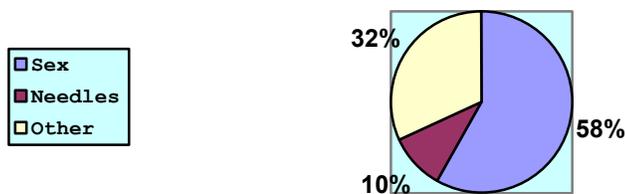


Figure 6.2 HIV Contraction Factors

Most of the survey participants thought that they had contracted HIV through unprotected sex. Several believed they had contracted it through sharing needles. Reggie said that he knew he had contracted it through sharing needles because he had knowingly used a syringe that had been used by an HIV-positive person. Reggie said his need for a hit was so great that he did not care that he risked contracting HIV, even though he knew the danger and knew that the other person was HIV-positive. For the people who chose "other," four said that they were unsure of how they contracted the disease, and several gave this response because they had engaged in both sharing needles and in unprotected sex. Crystal said that she had not had sex or shared needles. Grace believes she was infected on the job, as she is a healthcare worker. Iris said she believes her mother, who is an IV drug user, accidentally infected her. She did not specify how the infection might have happened.

Trey, who said he had been infected through sexual intercourse, had more to say on the issue of risk factors. Although he was not an injection drug user, he often smoked crack cocaine and used other drugs. He was adamant about the fact that this contributed to his practice of having unprotected sex. Trey said that when he was high, he did not care whether he had a condom, and he had casual sex with multiple women while under the influence of drugs. He thinks that this type of risky

behavior should be taken into consideration when educating people about HIV/AIDS.

Question seven asked the participants how often they worried about contracting HIV before they were diagnosed. Thirteen out of the nineteen respondents answered that they never thought about it. James, who contracted HIV through sexual intercourse, said that he thought about it all of the time because he knew he was engaging in risky behavior and he knew about the disease. Two people thought about it some of the time, and three people said they knew it was possible. Maxine responded that she never thought about it. She said that sex was fun and that she didn't know enough about the disease to prevent herself from contracting HIV. Trey said he thought about contracting HIV some of the time, but also said he thought about it too late. A lack of education about HIV/AIDS is a key issue for many of the respondents.

Participants were allowed to choose more than one answer for question eight, which asked what might have prevented them from getting HIV. Available answers included more education about sexual risk, free condoms, more education about the risk of sharing needles, free needles, none of these, and other. More education about sexual risk was the most popular answer. Free condoms and "none of the above" had five responses each. Not surprisingly, two people answered more education about the risk

of sharing needles. No one answered "free needles," and one of the men that identified as an injection drug user said that getting free needles in Louisiana was a joke. When asked why he thought that, he responded that a free needle program would never happen in Louisiana "due to the government." Six people responded that something else would have helped prevent them from getting HIV. Most of these people said that more general education about HIV would have helped. Arla said that leaving her husband would have helped since he was the one who infected her. Grace, who thought she had been infected at work said that using universal precautions, such as wearing gloves, would have helped prevent her contraction of HIV.

Questions nine through eleven asked participants if the dangers of HIV were mentioned enough on television, in school, and in their neighborhoods. In all three questions, the number one answer given was "no." Eight people said that they thought the dangers of HIV were mentioned enough on television, one thought they were mentioned enough in school, and four thought that they were mentioned enough in their neighborhood. From two to four people answered that they did not know on each of the questions. Some of the people who responded that they did not know if the dangers were mentioned enough had either been out of school since the HIV epidemic began, or they did not own a television, or they worked much of the time and did not have

time to watch TV or know what was going on in their neighborhood. One person answered "yes" to all three questions about the dangers of HIV being mentioned enough, and later said that more education about the dangers of HIV was needed! Shantel, who has been out of school since the epidemic began, said that she did not know if HIV education was provided in schools but she sincerely hoped it was. Arla answered that the dangers of HIV were mentioned enough in her neighborhood went on to say that this had only happened because of her diagnosis, and that before no one talked about HIV.

The participants were also asked to estimate how many of their friends, family, and neighbors are HIV-positive. Most people said they did not know, or they thought that none of their family, friends, or neighbors were infected. This shows the isolation that is felt by the HIV-positive individual. The participants were most likely to estimate the number of people on their block with HIV. Several people who had been living with the disease for a number of years answered that many of their friends were HIV-positive. This may be due to the fact that they have become active in HIV/AIDS community organizations or support groups where they meet other HIV-positive people. In other words, HIV-positive persons may be visible to each other if they are active in seeking help, but they may remain invisible to the HIV-negative population.

For question 15, the participants were asked to list centers or support groups that they use in the Baton Rouge area. The centers listed were: Early Intervention Clinic (EIC), Family Services, VOA Food Bank, Friends for Life, HIV Outpatient Clinic (New Orleans), Social Services, HAART, and Our Lady of the Lake (OLOL) Counseling Services. Fifteen respondents use the EIC and the food bank, and fourteen use Family Services. Four use Friends For Life, two use HAART, and HIV Outpatient Clinic, Social Services, and OLOL counseling were each listed by one person

The final survey question asked the participants what advice they would give someone who has just found out he/she is HIV-positive. The responses included the following answers, which have been paraphrased:

- Go to the doctor and get help.
- Don't do anything drastic, absorb it and live with it awhile.
- Take care of yourself.
- Take your medicine.
- Live your life to the fullest until you die.
- God can heal you.
- You can live with it. Have a positive attitude. It's just a disease but do what it takes to stay healthy. It can happen to anyone.
- Don't worry.
- I would try to educate them about the disease.
- Talk to somebody about the disease.
- Tell everybody.
- Take your medicine, don't give up, and use condoms.
- Don't share syringes.
- Seek support, any type, anywhere.
- Change your way of living for the better.

- Wear condoms, be safe, and don't be depressed.
- Change your behavior.
- Take things one day at a time, and don't let it get you down.
- Don't tell anyone what you've got but your family.

The respondents seemed especially concerned with telling a newly infected person to take care of their medical needs, and to seek support or talk to someone about HIV. Reggie, who said tell everybody, had not told anyone but his family. When asked about why he didn't tell anyone other than his family he replied that he was not strong enough to do this. Arla responded that no one should be told but the family. She was the same one discussed above who had encountered ill effects from disclosing her HIV status to friends and neighbors. Several people responded with behavioral changes such as wearing condoms, or not sharing syringes. These are behaviors that probably could have prevented them from contracting HIV, and behaviors that they now utilize in order to prevent the spread of HIV.

I asked Marie the same question to see what her response would be since she is sometimes confronted with people who have just found out they are HIV-positive. She says that she tells people to go to a private space, whether it is their room, bathroom, a park, or any other place where they can be alone.

Get it out your head that you are gonna die, don't think that all the time. Meditate on yourself, get in your own little space and get your thoughts together and think about what you want to do from here on out. Break something, pray a lot, cry

a lot, do whatever to help you get to a comfort zone, but only after you get it out of your head that you are gonna die.

She explains that this may be the first time they feel like this but it probably will not be the last. The thing to focus on is to get to a comfort zone within oneself, and Marie tells people to do whatever it is they need to do to get to that zone. Once they are ready to talk about their diagnosis, she offers her phone number. She knows that when a person finds out, they are not ready for education. Getting to that point takes time, and everyone is different. She shares the same feelings as the survey respondents. Newly diagnosed people need to take care of themselves first.

Once the survey was completed, I asked people what they thought Baton Rouge needed for HIV-positive people. The top three responses were the need for more financial support, more medical facilities and clinics, and more education for the people in and around Baton Rouge. Many of the people interviewed no longer work, and are supported by their families or social services. Several said that they needed more help to pay bills, more housing assistance, and help with transportation. Considering the only clinic that most of the non-insured HIV-positive people in and around Baton Rouge use is the Early Intervention Clinic, and that the wait to see a doctor is up to 50 days, the need for more clinics is understandable.

Shantel said that if clinics are built, they should be more accessible to low-income individuals.

Penny explained the need for more education. She said that people in Baton Rouge keep HIV "swept under the rug" and that if there was more community support and education, there would be more freedom for HIV-positive people. Dennis said that abstinence does not work, and teenagers should be educated about the risks of having unprotected sex rather than people telling them that they shouldn't have sex. Erin said that the discrimination has to stop. She believes that if Baton Rouge had more awareness and more testing, people would be less discriminatory. Arla said that people need to know that it is okay to be around others that are HIV-positive, and that HIV-positive people should not be ashamed of their diagnosis. Trey's answer to the education problem was to put more commercials about HIV/AIDS on television, and to provide an HIV/AIDS program in the schools. Only Crystal said that what Baton Rouge needs is a cure, although all of the participants would probably agree with her.

In the interview with Marie, we discussed the situation in Baton Rouge, focusing on political and religious leaders, especially those in the African-American communities. I asked her if she thought they were doing enough for the HIV/AIDS

community. Marie discusses the lack of support in the political and religious communities of Baton Rouge.

We have wonderful black leaders in Louisiana and Baton Rouge that haven't done all that much for HIV/AIDS. To me it's more than buying a table at a benefit dinner, that's a damn tax write off. I know this is killing off my people rapidly and I see it too much, I see more than people in the political arena. I don't think any of our black leaders in Louisiana are doing enough. There are a few good team players, but not enough. Ya'll ain't doing jack shit!

Marie has been successful in starting some grassroots religious community support. After her testimonial at the Bethel AME Church, the minister organized an AIDS ministry that meets every month. She is currently trying to get other churches involved, so that prevention and education can start at the foundation of people's beliefs.

Marie also believes that Louisiana needs a governor who cares about AIDS. The current governor, Mike Foster, supports a program that strictly promotes abstinence. Marie says, "Abstinence is not the answer or the reality, otherwise I wouldn't know 15-16 year old girls with HIV." She believes that if someone in the government lost a sister, daughter, or mother to the disease, this would bring the reality of the situation to light.

In this conversation, Marie consistently uses females to prove her points. She discusses knowing 15 and 16-year-old girls with HIV, and then she goes on to say that if someone in the

government lost a female relative, maybe they would start to support HIV/AIDS education. As Marie is a woman affected by HIV/AIDS, I believe she associates with other women with HIV better than men who are affected. A man who she used to love infected her, lied to her, and never told her that she should be tested. Marie probably has negative associations with HIV-positive men due to her past experience, so she empathizes with women more. Also, women seem to be hit harder by the stigma of the disease. In the South, men are seen as virile and masculine if they have multiple sex partners, whereas women are supposed to be innocent and virginal. Women are usually infected through sexual contact, and therefore may feel the stigma of both the disease and the sexual double standard. The fact that many people in Baton Rouge still associate AIDS with gay men, may also point to why Marie believes that talking about a woman with HIV/AIDS holds more power. Marie's words show that the Baton Rouge community needs to be aware of the complete spectrum of people that are affected by HIV/AIDS, rather than just the gay male or injection drug using populations.

Besides fighting to get community support for people with HIV/AIDS, Marie also has to fight the physical disease. This can put a heavy strain on her body. She currently takes one of the drug cocktails to keep her healthy and keep her t-cell count high. She is also taking a pain reliever to help her body

recover from stress, and insulin to keep her diabetes in check. These drugs combined give her a range of different side effects. On some days she wakes up feeling fine, and on other days, she can barely get out of bed. Her side effects range from nausea, vomiting and diarrhea, to constipation, tiredness, and constant night sweats. Her HIV status has forced her to make many changes in her life. She now takes more time to enjoy certain things, she listens to her body, and she tries to make different choices when it comes to men.

She is now back in the single world and trying to date. Marie has had several relationships since she has been diagnosed, but she has not found a man that was strong enough to deal with both her and her disease. She does not hide her diagnosis, but she is choosy on when she tells a person who is interested in her that she has AIDS.

Depending on how high the interest is, if it's really high I may wait maybe a month, couple of weeks. If I really don't have that much interest I'll tell you as soon as I meet you, straight up cause I really don't think its gonna go that far. If it's someone I really would like to get to know, I try to see where that person is coming from, maybe throw out a few questions about HIV and AIDS, "what do you think about that, what do you think about this?" You know, and depending on their answers then I go from there. And hope that whatever answer they throw back at me, I'll be able to deal with.

She says when men find out that a pretty, healthy looking woman like herself has AIDS, their first reaction is usually one of shock. Marie states, "The men usually say 'Damn! You don't

look sick!' when I tell them, and I say yep, that is the key to this disease."

Marie has also had to change her sexual behaviors. She insists that all men that she has sex with must wear condoms. She has never encountered a man who did not want to wear a condom after her diagnosis, but she has HIV-positive girlfriends who have had men refuse to wear a condom. She says that the HIV-positive women tell her the men want the natural feeling of sex without a condom. Many of these men are fatalistic, saying that they are going to die of something so why not have more pleasure now. Some of these men have wives or other girlfriends that they are also having sex with, and still do not use a condom. Marie said that if she ever meets a man that wants to have unprotected sex with her, she will make him sign a contract stating that he knows that she is HIV-positive and he knows the risks associated with unprotected sex. This would be a means of protection for her, because knowingly infecting someone is a felony, and she does not want the man to be able to take legal action against her if he was ever infected. Marie has a strong desire to have children, and she said she would have unprotected sex with a man in order to conceive. She explains that motherhood is important to her, and that she knows the risks of having a child with HIV, and possibly infecting a partner.

Again, she would make sure her partner was educated about transmission risks, and that he fully understood the situation.

HIV/AIDS has definitely changed Marie's life. She says that she doesn't think about her diagnosis all of the time. She is so concerned with friends and clients making it to their appointments, and taking their medicine that she sometimes forgets to take care of herself. She says that is part of her culture, and self-image. To be a strong Black woman, she has to take care of others, putting their needs first. She acknowledges that if she were still together with her ex-fiancé, she would be on his back about taking care of himself, but adamant that she would be fine.

Marie has a supportive family, and a positive self-image, both of which help her cope with her AIDS diagnosis. She projects a brave front, and uses her faith to hold her up when she is having a rough time. Her past experiences with health and relationships serve to make her stronger. One of her dear friends is Janet Parker, who was mentioned above in the previous chapter. Janet has been an HIV/AIDS activist in Baton Rouge since 1993. Marie draws strength from Janet, since she also has AIDS. Marie is a fighter and she does not plan on dying any time soon.

Marie also says that she does not think she has been chosen to do advocacy work. She explains her position below.

I am someone who willingly made a choice to participate in a high-risk act and I got caught up. I didn't realize I made such a terminal and deadly choice because I was in love. I had no idea you couldn't look at someone and tell that they were or were not sick. I am just one of millions that is living with a terminal illness that has a pretty nasty stigma attached, and I am one of the few that is trying to change that stigma. I do not let the virus define me.

Marie continues to fight HIV/AIDS, and fight for compassion for herself and others living with the disease. Her closing thoughts during the interview were, "Love does not make a person immune to HIV, and that everyone should get educated and get tested."

CHAPTER 7

RESULTS AND CONCLUSIONS

Why is the HIV/AIDS transmission rate so high in the Baton Rouge area, and who are the people contracting and living with HIV/AIDS? In seeking to answer these questions I attended public events and meetings, interviewed local public health administrators, healthcare workers, outreach workers, conducted a survey, and held an in-depth interview with a woman living with HIV/AIDS. I sought to determine what methods are being used to lower transmission rates and prevent the spread of HIV/AIDS, and what needs to be done to bolster the efforts already underway.

The results of this study show that the Baton Rouge area has a high rate of HIV/AIDS due to several factors. After talking to local healthcare workers, as well as people with HIV, one of the main problems affecting the rate of HIV/AIDS is denial about the possibility of getting HIV. People believe that AIDS is the other person's disease and they do not think that they are at risk of contracting HIV. Old stereotypes of how people contract HIV are still circulating. Several people I talked to who are HIV-positive said that before they got the disease they thought only gay men and IV drug users could get it. One man said before he found out he was HIV-positive, if he met someone with HIV he would not shake their hand or eat after them because he was afraid of getting sick.

Another problem is the lack of HIV/AIDS education in secondary schools. Public schools have limited educational programs on HIV/AIDS. State officials advocate abstinence over sexual education, which impedes discussions of HIV/AIDS. The Louisiana Department of Education provides teacher training in HIV/AIDS prevention for the 7th through 12th grade (Louisiana Department of Education March 2002). HIV/AIDS prevention is usually taught with a sex education course at the discretion of local or parish level school boards. No school in Louisiana requires HIV/AIDS prevention or sex education. Two professionals are available in the Baton Rouge area to instruct teachers in HIV/AIDS prevention.

The age range that has the highest HIV rate in Louisiana is the 25-34 olds, and since HIV can be dormant for up to ten years, some of the people in this age range were probably infected while still in high school. One of the Americorps VISTA volunteers at Friends for Life is working to start a peer education program at local public schools. Episcopal High School is one local private school that currently has an AIDS education program.

Cultural issues and racism may also hinder education about HIV/AIDS in the African-American communities in Region II. Survey participants explained that when AZT first came out to treat HIV/AIDS, there were rumors that the zidovudine therapy

would kill African-Americans. There have been several other false rumors about the transmission and treatment of HIV in the African-American community. One belief that persists is that people with AIDS look sick, and can be distinguished from healthy people. This idea, which was mentioned earlier in the literature review, is echoed in the Baton Rouge area. When people think about fatal illnesses they may picture a gaunt, sickly individual. When they meet someone like Marie, who has good days where she is vibrant, they see that AIDS does not have a "look". Also, many people still believe that gay men are the only people who really need to be worried about HIV. These beliefs persist because most people get their basic information about HIV/AIDS from gossip on the streets rather than from school or educational programs. Programs must be developed to integrate cultural beliefs about condom usage, transmission, and treatment, so the HIV levels will drop. Integrating churches in prevention efforts could also bolster support, especially in African-American communities. Another Americorps VISTA volunteer at Friends for Life is currently working on getting church support in and around Baton Rouge.

Intravenous drug use seems to be a continuing problem in the spread of HIV/AIDS in Region II. I spoke with a former drug dealer and several IV drug users about the drug problems in Baton Rouge. All three agreed that injection drugs are readily

available on the streets of Baton Rouge. I attempted to contact the Baton Rouge Police Department for information on the intravenous population to see if the officers in Baton Rouge had seen an increase or decrease in the amount of IV drugs found in Baton Rouge. Unfortunately, my phone calls were not returned. However, other healthcare workers explained that they still see new cases of HIV occurring in IV drug users every day. The healthcare workers said that most of these injection drug users have switched to alternative drugs that are easier to access, such as crack cocaine, which can be smoked rather than injected. The case rates for heterosexual partners of IV drug users are also high because the partners are not an easily accessible group to target and educate.

The last problem affecting people who are already HIV-positive, is a lack of affordable health care options. Earl K. Long Hospital is the only charity hospital in the city with a clinic specializing in the treatment of HIV/AIDS. Many of the people that are HIV-positive are without insurance, so they must use this facility. Wait times are up to 50 days to see a physician, and patients often miss their appointments due to work conflicts or public transportation issues. If a person is HIV-positive and does not have access to proper care, treatment, and education about the disease, they may unwittingly spread HIV, causing transmission rates to rise.

The Baton Rouge area does have a group of organizations and individuals dedicated to prevention and treatment of HIV/AIDS. Currently, there are several outreach programs that work in areas with high HIV/AIDS rates in and around Baton Rouge. The programs provide education, testing, and free condoms. These groups target high-risk populations. There are also several sites around Baton Rouge and in neighboring communities that provide free HIV testing and counseling. Free condoms are available at most HIV-related organizations, as well as some bars, convenience stores, and motels in high-risk areas.

Programs involving the community and local university students help to keep HIV/AIDS in the public eye. Fund-raisers are held every year to keep the HIV-related organizations running. Unfortunately, with the tragic events of September 11th, much of the monetary donations normally directed towards HIV/AIDS have been channeled into relief funds. However, due to the categorization of Baton Rouge as an "emerging community," more governmental funding has been directed towards HIV/AIDS prevention and treatment in Baton Rouge.

Overall, there are several things that must be done in an effort to lower transmission rates for Region II and help the people who are currently living with HIV/AIDS. There needs to be a more effective way to fully educate the general public about HIV/AIDS and prevention. Money is delegated from federal

funds to educate high-risk groups about HIV/AIDS, yet education is lacking in schools and for the general public. HIV/AIDS does not discriminate when choosing its victims, so everyone should have access to education about the disease.

In order to form better prevention programs for high-risk groups, a better effort needs to be made to create programs suited for cultural beliefs. Using focus groups may help researchers understand how to present educational materials effectively to certain groups. People in these high-risk groups need to be heard so that their attitudes and beliefs about HIV/AIDS will be understood.

Another way to get information on HIV/AIDS to the general public would be to use a musical jingle giving the telephone numbers to AIDS hotlines. There is currently a television and radio commercial using a rap beat to give listeners a number for a pregnancy hotline. I believe that a similarly styled message would be effective in a widespread campaign addressed to the younger age groups being affected.

Treatment and testing centers need to be more available to the general public. The current quality of healthcare is dependent on economic status. People in low-income areas have poor access to adequate healthcare. Funding for new treatment centers should be a top priority in order to get wait times down, and get people into effective treatment programs. Geographic

location is an important consideration in planning new clinics due to the fact that many people accessing treatment at clinics must use the public transportation system. Clinics built in areas where HIV/AIDS rates are particularly high could help reduce the rate of newly infected individuals if people who are already infected have easy access to medical care.

Also, basic changes in the way people view the disease need to be made. The Baton Rouge area lacks compassion for people with HIV/AIDS. Due to discrimination against people with HIV/AIDS, some Baton Rouge natives go to New Orleans to seek treatment so that word will not get back to their friends and neighbors that they are afflicted with such a stigmatizing disease. If discrimination against people with HIV/AIDS begins to decline, the associated stigmas will break down, and prevention campaigns will be more effective. Getting people in Region II to talk about HIV/AIDS, rather than ignoring the problem will help end discrimination. Everyone needs to understand that either they, or their family members and friends are probably at risk for contracting HIV/AIDS. Instead of ostracizing the people with the disease, the public should concentrate on fighting the disease itself so that no more of these valuable individuals will be lost to this ultimately preventable disease.

As HIV/AIDS becomes more of a class or race issue, discrimination will continue. Epidemiologists say that the face

of HIV/AIDS is changing from a gay male population to an African-American female population, therefore gender and race issues will continue to surface. There are already concerns about correct dosages of medicine for women, since most dosages are calculated for male body size averages. Labeling HIV/AIDS further ignites discrimination, much as it has done in the past. When HIV was thought of as a "gay" disease, the general population had no problem in dismissing the issues surrounding HIV/AIDS. The disease is also beginning to hit low-income groups harder. Similar issues may arise if the middle class begins to think that HIV will not affect them. HIV/AIDS is basically a human problem, no matter what group is being affected the most at the current point in time. All people are at risk of contracting HIV; labeling the high-risk groups impedes the general messages about transmission risks and reinforces racism and classism. This type of race and class reinforcement has been seen in reactions to Haitians who were HIV-positive due to the fact that Haitians were classified as a high-risk group at the beginning of the epidemic. Paul Farmer explains that "the president of the Haitian Medical Association attacked the 'unscientific and racist attitude' of epidemiologists from the U.S. Centers for Disease Control" as a response to their AIDS-related discrimination against Haitians (Farmer 1992:5). When considering possibilities for future

research, an interesting area of study would be the trends in HIV/AIDS compared to the public's perception about who the disease is affecting.

There is a great need for research to be done concerning the transient prison populations and the spread of HIV in South Louisiana. What happens to prisoners who are HIV-positive? How are HIV-positive people handled throughout the trial and sentencing phases of justice? What is being done to prevent the spread of HIV in federal prisons, state prisons, and local jails? Is anything being done to prevent HIV-positive parolees from spreading HIV once they are released?

Many opportunities for further studies on HIV/AIDS exist for the Baton Rouge area, and many questions have not been answered by this study. It is my hope that this study has provided some idea of the problems of HIV/AIDS occurring in the Baton Rouge area, and that by helping increase awareness of these problems, some of them may be solved.

REFERENCES CITED

- Baer RD, SC Weller, L Patcher, R Trotter, JG Garcia, M Glazer, R Klein, T Lockaby, J Nichols, R Parrish, B Randall, J Reid, SW Morfit, and V Morfit
1999 "Beliefs About AIDS in Five Latin and Anglo-American Populations: The Role of the Biomedical Model," *Anthropology and Medicine* 6:13-29.
- Barker JC, RS Battle, GL Cummings, and KN Bancroft
1998 "Condoms and Consequences: HIV/AIDS Education and African-American Women," *Human Organization* 57:273-283.
- Centers for Disease Control National AIDS Hotline: 1-800-342-AIDS
- Centers for Disease Control Website: www.cdc.gov
- CBS News Website: www.cbs.com
- Cohen DA, TA Farley, JR Bedimo-Etame, R Scribner, W Ward, C Kendall, and J Rice
1999 "Implementation of Condom Social Marketing in Louisiana, 1993 to 1996," *American Journal of Public Health* 89:204-208.
- East Baton Rouge Parish Coroners Office
2001 *AIDS Death Rates from 1991-2001*.
- Farley TA, RH Kahn, G Johnson, and DA Cohen
1999 "Strategies for Syphilis Prevention: Findings from Surveys in a High-incidence Area," *Sexually Transmitted Diseases* 27:305-310.
- Farmer, P
1992 *AIDS and Accusation: Haiti and the Geography of Blame*. University of California Press, Berkeley.
- Feldman DA and JW Miller
1998 *The AIDS Crisis: A Documentary History*. Greenwood Press, Westport.
- Finger WR
1997 "Reducing the HIV Risk from Mother to Infant," *Network*: 17.

Gao F, E Bailes, DL Roberston, Y Chen, CM Rodenburg, SF Michael, LB Cummins, LO Arthur, M Peeters, GM Shaw, PM Sharp, and BH Hahn

1999 "Origin of HIV-1 in the Chimpanzee *Pan troglodytes troglodytes*," *Nature* 397:436-441.

Hahn RA

1995 *Sickness and Healing: An Anthropological Perspective*. Yale University Press, New Haven.

Health Care Financing Administration Website: www.hcfa.gov/hiv

Hertzman C

2001 "Health and Human Society," *American Scientist* 89:538-545.

Ho DD, T Moudgh, and M Alam

1989 "Quantitation of HIV Type 1 in the Blood of Infected Persons," *New England Journal of Medicine* 321:1622-1625.

Johnson TM and CF Sargent

1990 *Medical Anthropology: A Handbook of Theory and Method*. Praeger Press, NewYork.

Karon JM, PL Fleming, RW Steketee, and KM DeCock

2001 "HIV in the United States at the Turn of the Century: An Epidemic in Transition," *American Journal of Public Health* 91:1060-1068.

Kaslow RA and DP Francis

1989 *Epidemiology of AIDS*. Oxford University Press, New York.

Lang NG

1991 "Stigma, Self-Esteem, and Depression: Psycho-Social Responses to Risk of AIDS," *Human Organization* 50:66-71.

Loue S

1995 *Legal and Ethical Aspects of HIV-Related Research*. Plenum Press, New York.

Louisiana Department of Education Website: www.doe.state.la.us

Louisiana Office of Public Health

2000 *Louisiana HIV/AIDS Annual Report*.

2000 *Louisiana Regional HIV/AIDS Surveillance Report: Region II.*

Mann J and D Tarantola

1996 *AIDS in the World II.* Oxford University Press, New York.

Okwumabua JO, V Glover, D Bolden, and S Edwards

2001 "Perspectives of Low-income African-Americans on Syphilis and HIV: Implications for Prevention," *Journal of Health Care for the Poor and Underserved* 12:474-489.

Ostrow DG and RC Kessler

1993 *Methodological Issues in AIDS Behavioral Research.* Plenum Press, New York.

Ottomanelli G

1992 *HIV Infection and Intravenous Drug Use.* Praeger Press, Westport.

Pivnick A, A Jacobsen, K Eric, M Mulvihill, MA Hsu, and E Drucker

1991 "Reproductive Decisions among HIV-Infected, Drug-Using Women: The Importance of Mother-Child Coresidence," *Medical Anthropology Quarterly* 5:153-169.

Reamer FG

1991 *AIDS and Ethics.* Columbia University Press, New York.

Sibthorpe B

1992 "The Social Construction of Sexual Relationships as a Determinant of HIV Risk Perception and Condom Use among Injection Drug Users," *Medical Anthropology Quarterly* 6:255-270.

Singer M

1992 "AIDS and US Ethnic Minorities: The Crisis and Alternative Anthropological Responses," *Human Organization* 51:89-95.

Singer M and MR Weeks

1996 "Preventing AIDS in Communities of Color: Anthropology and Social Prevention," *Human Organization* 55:488-491.

Smith LC, KJ Lucas, and C Latkin

1999 "Rumor and Gossip: Social Discourse on HIV and AIDS," *Anthropology and Medicine* 6:121-131.

Sorensen W, HS Park, and K Corson

1999 "The Relationship between Educational Background and Decline in Death in a Sample of Louisiana Male AIDS Cases," *International Journal of STD and AIDS* 10:195-198.

Stanley LD

1999 "Transforming AIDS: The Moral Management of Stigmatized Identity," *Anthropology and Medicine* 6:103-120.

Weiss M

1997 "Signifying the Pandemics: Metaphors of AIDS, Cancer, and Heart Disease," *Medical Anthropology Quarterly* 11:456-476.

Welch KJ and A Morse

2001 "Survival Patterns Among HIV+ Individuals Based on Health Care Utilization," *Journal of the National Medical Association* 93:214-219.

Whitehead TL

1997 "Urban Low-Income African-American Men, HIV/AIDS, and Gender Identity," *Medical Anthropology Quarterly* 11:411-447.

Wold, Amy

2001 "AIDS Fund-Raiser Reaches Goal with Tongue-in-Cheek Arrests," *The Advocate*.

United Nations AIDS Website: www.unaids.org

APPENDIX A
HIV/AIDS SURVEY

This is a survey being conducted to aid in my thesis research on HIV/AIDS in the Baton Rouge area. As a graduate student at LSU, I am trying to determine why the HIV transmission rate is so high, and if there are adequate resources available to HIV+ people in the Baton Rouge area. One of my goals in writing this thesis is to find ways to prevent the spread of HIV and help the people that are HIV+. Participation in this survey is voluntary. You DO NOT have to answer any of the questions contained in this survey.

Participation in this survey is anonymous. Your name will not be needed to participate in this survey. If you understand that this survey is a voluntary activity and that your name will not be associated with this survey in any way, please check the box below.

I understand that this is a Voluntary and Anonymous survey, and I am willing to participate by checking this box.

Age: 18 - 25 26 - 35 36 - 45
 46 - 55 56 - above

Sex: male female

Ethnicity: Caucasian African-American Hispanic
 Asian Other_____

Length of time since being diagnosed as HIV+:

Neighborhood: _____ Zip Code: _____
Education level completed: _____

1. When you informed your family you had HIV, did their reaction to you:

- A. Change a lot
- B. Change a little
- C. Did not change
- D. I have not informed them

2. When you informed your friends that you had HIV, did their reaction to you:

- A. Change a lot
- B. Change a little
- C. Did not change
- D. I have not informed them

3. When you informed the people you worked with you had HIV, did their reaction to you:
 - A. Change a lot
 - B. Change a little
 - C. Did not change
 - D. I have not informed them
 - E. I do not work

4. When you informed the people in your neighborhood you had HIV, did their reaction to you:
 - A. Change a lot
 - B. Change a little
 - C. Did not change
 - D. I have not informed them

5. Who would you say has given you the most support since you found you were HIV+?
 - A. Family
 - B. Friends
 - C. Neighborhood groups
 - D. Health support groups
 - E. Church

6. How do you think you contracted HIV?
 - A. Through sexual intercourse
 - B. Through sharing needles
 - C. Other (please specify)

7. Before you were diagnosed with HIV did you worry about getting the disease?
 - A. All of the time
 - B. Some of the time
 - C. Knew it was possible
 - D. Never thought about it

8. Which of the following may have prevented you from getting HIV?
 - A. More education about sexual risk
 - B. Free condoms
 - C. More education about the risk of sharing needles
 - D. Free needles
 - E. None of the above
 - F. Other (please specify)

9. Are the dangers of HIV mentioned enough on television?
 - A. Yes
 - B. No
 - C. Don't Know

10. Are the dangers of HIV mentioned enough in school?
 - A. Yes
 - B. No
 - C. Don't know

11. Are the dangers of HIV mentioned enough in your neighborhood?
 - A. Yes
 - B. No
 - C. Don't know

12. Estimate how many people on your block have HIV:

13. How many of your family members have HIV?

14. How many of your friends (besides those you met at support groups) have HIV?

15. Name the centers or support groups available to someone with HIV that you use.

16. What advice would you give someone who has just found out he/she is HIV+?

APPENDIX B
EVALUATION OF SURVEY RESULTS FOR QUESTIONS 1-11

	# of Answers	A.	B.	C.	D.	E.	F.
Question #							
1.		6	3	9	1	-	-
2.		1	2	9	7	-	-
3.		2	0	3	2	12	-
4.		1	1	1	16	-	-
5.		13	3	0	7	2	-
6.		11	2	6	-	-	-
7.		1	2	3	13	-	-
8.		7	5	2	0	5	7
9.		8	9	2	-	-	-
10.		1	14	4	-	-	-
11.		4	13	2	-	-	-

**APPENDIX C
HIV/AIDS RESOURCES IN REGION II**

Organization	Abbreviation	Address	Bus Route	Federal Funds	HIV Only
HIV/AIDS Alliance for Region Two	HAART	4550 North Blvd. 70806	Yes- with a walk	Yes	Yes
Baton Rouge AIDS Society	BRASS	4550 North Blvd. 70806	Yes- with a walk	Yes	Yes
Metro Health Education	Metro Health	950 E. Washington St. 70802	Yes	Yes	No
Early Intervention Clinic	EIC	5825 Airline Hwy. 70805	Yes	Yes	Yes
Family Service of Greater Baton Rouge	Family Services	4727 Revere Ave. 70808	Yes	Yes	No
Friends for Life: AIDS Resource Center	FFL	660 N. Foster Dr. 70806	Yes- with a walk	Yes	Yes
Volunteers of America Food Bank	VOA	2055 Wooddale Blvd. 70806	Yes	Yes	No

APPENDIX D
MAP OF LOUISIANA WITH PARISHES

Region II in Louisiana



VITA

Erica Brooke Gibson was born on November 30, 1976, in Slidell, Louisiana. Her family moved to Houston, Texas, in 1988. She graduated with a Bachelor of Arts degree in anthropology from the University of Houston in 1998. After taking several semesters to teach high school in Houston, Erica returned to college to pursue a Master of Arts degree in anthropology. Erica's interests lie in medical and forensic anthropology, and after graduating from Louisiana State University, she hopes to work in the field of applied anthropology for a public health agency, or continue her teaching career.