

CHAPTER 1

INTRODUCTION

Acquired immune deficiency syndrome (AIDS) has much in common with other diseases whose prevention requires behavioral change, such as syphilis or lung cancer from smoking (Rosenberg, 1995). Both public-health workers trying to distribute condoms to prevent syphilis at the turn of the 19th century and AIDS activists distributing condoms and/or clean needles at the end of the 20th century have met with ‘values-based’ resistance, which Rosenberg describes as the debate between ‘innocent’ (i.e., hemophiliacs and babies) and ‘deserving’ (i.e., gay men and drug users) victims. Yet, in many ways, AIDS does not mold to any traditional pattern, including the explosiveness of its geographic spread and the relative quickness of its identification – a rapidity of both that would not have been possible mere decades earlier due to globalization and improved technology (Rosenberg). Previously, disease outbreaks may have had a better chance of containment. However, due in part to modern society’s possessing worldwide transportation capabilities, the geographic spread of the disease has outpaced earlier epidemics (Rosenberg). Another consequence of AIDS in the modern era has been the relatively fast pace of its identification due to new medical techniques (Rosenberg).

As we enter the beginning of the third decade of the fight against the human immunodeficiency virus (HIV), it is necessary to examine the evolution of this modern day pandemic from its initial death sentence approximately 20 years ago, to its reconstruction as a more chronic-type illness, thanks to new medical and social interventions. It is equally important to remember the millions of individuals living with

this dreaded illness, as well as the multitude of families affected by the infection of a loved one.

Chapter 1 will illuminate the various issues affecting, and affected by, HIV/AIDS – including an overview of the virus and its origins, modes of transmission and scope of the problem, as well as the current research highlighting the effect of HIV/AIDS on society-at-large, the child welfare system, and families. Chapter 2 examines the stress-coping model, the theoretical framework for use in this proposed study, and its previous applicability with other forms of stressful situations from war to cancer. Previous studies of HIV infected/affected individuals will also be scrutinized from this model's perspective. Lastly, the model will be discussed within the context of the proposed study with relevant research questions posed. Chapter 3 will look closely at each research question's hypotheses and provide supporting documentation for its position. The proposed study's methodological underpinnings (i.e., research design, sampling, data collection and analysis strategies) will be discussed in Chapter 4. In addition to the findings of the proposed study, Chapter 5 will also include the results of the relevant diagnostic tests, as well as the reliability and validity of the instrumentation. The final section, Chapter 6, will discuss the implications of the findings for practice, policy and future research into the area of families and children infected/affected by HIV/AIDS.

THE HUMAN IMMUNODEFICIENCY VIRUS

HIV infection causes or contributes to an illness spectrum ranging from asymptomatic to critically ill. HIV is characterized by a progressive failure of the immune system; HIV destroys the body's defenses against opportunistic infections and cancers.

HIV, “the most complex and extensively studied virus in medical history”, has undergone several name transformations as scientists struggled to identify its source (Mellors, 1999, p. 6). Due to the sexual orientation of its first victims in the United States, it was initially called gay-related immunodeficiency disease (GRID) (Reeders, 1998). Americans discovering the virus referred to it as human T-cell lymphotropic virus type III (HTLV-III), the third in a series originally identified as human t-cell leukemia viruses (Gong & Rudnick, 1987; Reeders). French scientists called it lymphadenopathy-associated virus (LAV) (Gong & Rudnick; Reeders). Others named the virus AIDS-associated retrovirus (ARV) (Gong & Rudnick). Still others referred to an early symptomatic phase between the illnesses latency and AIDS as AIDS-related complex (ARC) (Kalichman, 1998). However, all the names were found to be identifying a similar virus, and, in accordance with a unifying recommendation from the International Committee on Nomenclature of Viruses, were subsequently called human immunodeficiency virus (HIV) (Gong & Rudnick). The most severe HIV-related disease is acquired immune deficiency syndrome (AIDS).

The typical course of HIV in adults involves a period of primary infection in which the individual may experience mononucleosis-like symptoms (3-6 weeks) (Mellors, 1999). Within the following months, the virus’ antibodies are detectable in the infected individual ending in a period of clinical latency, which has a median time of 10 years (Mellors). Ultimately, the end stage of the illness results in a diagnosis of AIDS from which the individual eventually dies (Mellors).

Although a somewhat similar trajectory is noticed between adults and children, the process occurs much more rapidly in cases of pediatric HIV than with infected adults.

Since, for the vast majority of children, infection is assumed to be at birth, the disease is classified into two main segments. The first is the incubation period - the time from initial infection with the human immunodeficiency virus to an AIDS diagnosis. In general, this time frame has been approximately 3 years (Caldwell & Rogers, 1991). The second segment is from a diagnosis of AIDS to death (survival time). In 1989, 83% of children survived only 12 months from the time of an AIDS diagnosis (Krasinski, Borkowsky & Holtzman, 1989). With the advent of improved treatments, this time has extended, with some children remaining asymptomatic for as long as 7 years and some remaining healthy until the preteen years (Caldwell & Rogers). However, these amounts are hard to estimate, as differences in survival time vary greatly depending upon the clinical course of the particular child and the specific infection or disease present (Genieser, Krasinski, Roche, & Ambrosino, 1998). Genieser and her colleagues admit that reasons for prolonged periods of apparent good health in infected children are not entirely understood, yet posit that factors impacting the trajectory may include age of presentation and genetic determined host responses.

The Pandemic

The devastation caused by infectious diseases throughout history is well documented. As such, the word pandemic has been reserved for those infectious diseases so widespread and death producing that its effects can be felt throughout all sectors of the developed and developing worlds. This impact can be seen through a recent enactment by the National Security Council identifying HIV/AIDS as a threat to national security (Gellman, 2000). This is the first time a disease has ever been designated such a threat,

with the potential to topple foreign governments, touch off ethnic wars and destroy years of efforts to build free societies (Gellman).

This section will examine the epidemiological distribution and determinants of HIV/AIDS by tracing its origins and the path of infection over the years. The scope of the pandemic will be scrutinized for patterns, as well as for geographic, gender, age and race distributions. Modes of viral transmission will be explored with rates and trends highlighted. In addition to the diagnosis of AIDS, which may encompass numerous opportunistic infections and cancers, other non-life threatening illnesses often co-occur in persons with HIV/AIDS. Those afflicting adults and children will be reviewed. Many treatments have emerged since HIV was discovered, lengthening infected individuals' lives. Medications, including adherence, side effects and service delivery issues, as well as psychosocial and alternative treatments will also be surveyed in this section.

History

The exact origin of HIV and its introduction to humans is unknown, although there is much theorizing about when, where, and how it first evolved. There is growing evidence that the first *documented* case may have occurred in central Africa in Leopoldville, Congo in 1959, as antibodies specific to HIV have been identified in blood samples from that time period (Gallo, 1987; Gallo, 1988). The virus found in 1959 was a member of the M class, which is responsible for most of the modern HIV cases. However, genetic analyses of the more than 160 strains of HIV have confirmed that this was not the "mother of all HIV's" (Garrett, 2000, p. 1).

Based upon mathematical calculations utilizing the world's largest super-computer at Los Alamos National Laboratory, it has been estimated that the virus first

appeared in man in approximately 1930 (Manier, 2000). This estimate has a margin of error of approximate 15 years, placing the actual time to between 1915 and 1945 (Garrett, 2000).

Through a process called ‘zoonosis’, it is believed that the virus passed from a subspecies of chimpanzee to humans when bushmeat hunters became exposed to infected blood (Doepel, 1999). The virus’ quick spread is attributed to several hypothesized factors such as unsanitary vaccine campaigns in which, for example, one clinic used six needles to immunize more than 89,000 people for sleeping sickness in 1916 (Zhu, Korber & Nahinias, 1998). Other suspected influences are the end of colonialism, large-scale urbanization, greater access to transportation, and an increase in sexual freedom (Zhu et al.). It is thought that it may have gone unnoticed because its clinical manifestations are often diagnosed as more recognizable illnesses (Reeders, 1998).

The oldest *suspected* case of AIDS in the United States dates back to 1969 (Garry et al., 1988). An African-American teenager from St. Louis died of AIDS-like symptoms. Upon examination, HIV or a closely related virus was found in tissue samples frozen at the time of his death. This may indicate that HIV was present in the United States long before the first officially *identified* case of AIDS in the spring of 1981. At that time, the Centers for Disease Control and Prevention (CDC) reported that five previously healthy, young, gay men living in Los Angeles had been diagnosed with a rare form of pneumonia (CDC, 1981a; Reeders, 1998). The following month, they reported an additional 10 cases of this strain of rare pneumonia, as well as 26 cases of Kaposi’s sarcoma (a rare form of cancer seen previously only in older men of Mediterranean or Jewish decent, as well as in children and young adults in tropical Africa). It was found

that all of these incidences had occurred among previously healthy, young gay men in New York City, San Francisco or Los Angeles – with the earliest cases traced to a man identified as ‘patient zero’ (CDC, 1981b; CDC, 1981c; Kalichman, 1998).

A second HIV virus, subsequently named HIV-2 (with the previous one dubbed HIV-1), was discovered in West Africa in 1986. This related virus was detected from individuals already diagnosed with AIDS. It has remained primarily in West Africa and has some distinctions from HIV-1 such as only rare occurrences of mother-child transmission, as well as a longer incubation period (Bindels & Coutinho, 1998). Unfortunately, HIV-2 also results in the ultimate death of the infected individual. There are, as of 1998, ten genetic subtypes of HIV-1 and five of HIV-2, each with numerous strains (Bindels & Coutinho).

Most information on the natural course of HIV has been derived from studies of males, with the majority of these focusing on homosexual males and the remainder on male intravenous drug users or those individuals receiving blood products. In fact, the *Annotated Bibliography of Scientific Articles on AIDS for Policymakers* lists none of the 53 studies available at that time as focusing on women (U.S. Department of Health and Human Services, 1987). As such, the clinical manifestations in women are less well documented (Boer & Godfried, 1998). HIV was first recognized as a threat to women in Africa and the Caribbean, where the heterosexual link was identified. Unfortunately, as an example of the construction of women’s role in the infectious process, they have often been viewed more as “vessels of infection” (i.e., transmitters to their children through birth and to men through intercourse) than as a population with needs, both similar to the typical HIV infected individual, as well as unique due to gender, role and power

differentials (Anderson, Landry & Kerby, 1991). This has resulted in a dearth of information on infected women. However, one cannot separate the impact of HIV/AIDS on children and families from its impact on women.

The first *acknowledged* case of pediatric AIDS in the United States was identified in 1982 (Caldwell & Rogers, 1991). However, McCarroll (1988) reports that as early as 1977, there was a mother who gave birth to a child who showed signs of AIDS within the first year. Of the mother's three children, two had died of AIDS by 1984 and the third was HIV positive. The mother died in 1987. There have been numerous criticisms lodged that women and children are the unheralded victims of the pandemic. The criticisms appear to have merit when examining the paucity of research focusing on the impact of HIV/AIDS on children and families. The 1987 *Annotated Bibliography of Scientific Articles on AIDS for Policymakers* lists only 9 of the 53 studies available at that time (17%) as targeting pediatric populations (U.S. Department of Health and Human Services). However, an even worse picture is painted by Bor (1993), who notes that out of over 4,400 papers published in the Abstracts from the 9th International Conference on AIDS and the 4th STD World Congress, only 1% (n=46) addressed the impact of AIDS on the family. He further comments that this trend is unchanged over the previous two years (Bor). Although the continuation of this trend is not clearly delineated in the literature, Dr. Phyllis Hansell, Professor and Acting Dean of the College of Nursing at Seton Hall University has confirmed this dearth of research. Dr. Hansell acknowledged the paucity of research in the area of pediatric HIV/AIDS and the families caring for them, stating that researchers are forced to utilize proxy research from other illnesses

such as childhood cancer when comparing findings and creating intervention strategies (personal communication, December 3, 1999).

Scope of the Problem

HIV/AIDS affects a significant number of persons in the United States, as well as internationally. The World Health Organization (WHO) places estimates for prevalence rates at over 47 million infected people worldwide, with more than 2.2 million deaths in 1998 (WHO, 2000). The WHO reports that AIDS is now the 4th leading cause of mortality in the world, and is projecting its impact to increase (WHO).

Within the United States, the most methodologically rigorous and most widely recognized prevalence estimates are disseminated from the CDC. They estimate that over 640,000 individuals had been infected in the United States through June 1998 (CDC, 1999a). By December 1998, that number had risen to over 680,000 with an additional 58,000 new cases projected annually (CDC, 1999b; CDC, 1999c). Unfortunately, over 410,000 of those infected had died as of December 1998 (CDC, 1999c).

Transmission rates are reported to be as low as 1.5 per 100,000 persons (South Dakota) to as high as 188.7 per 100,000 persons (Washington, D.C.) in epidemiological catchment area studies (Jones, DeCock & Jaffe, 1999). However, in the United States over 50% of the HIV cases have been concentrated into four epicenters – New York, Florida, California and Texas (CDC, 1999a).

Historically, Maryland, the area under investigation in this study, has consistently ranked in the top ten most-concentrated regions of HIV infected individuals (CDC, 1999a; CDC, 1999d, Murphy, 2000). It ranked, as of December 1998, 9th among the 50 states and Washington, D.C. in the *cumulative* count of reported AIDS cases (CDC,

1999a; CDC, 1999d). However, for the 12 months ending June 30, 1998, Maryland had the 4th highest prevalence rate in the country (32 cases per 100,000 population) – after Washington, D.C. (178.3), New York (62.5), and Florida (37.5) (CDC, 1999a). The discrepancy between the high rate of current HIV positive individuals and the lower ranking of cumulative AIDS cases can be influenced by a variety of factors such as access to health care, discrimination and receiving a diagnoses later in the disease trajectory. However, this trend appears to be shifting as the data presented in Table 1 illustrates. According to the age-adjusted rates, Maryland has caught-up and now ranks 4th in the country in AIDS-related deaths for 1998 (Murphy, 2000). It ranks 7th in actual AIDS-related deaths (Murphy, 2000).

Additionally, Maryland ranked 17th in the country for all types of deaths during 1998, even though it ranks 20th in actual amount of deaths (Murphy, 2000). In contrast, during the same period, Maryland ranked 4th in the country in AIDS-related deaths (age-adjusted rate) – almost twice the national average (Murphy, 2000). This illustrates the disproportionate impact that AIDS has had upon Maryland. To illustrate, AIDS-related deaths as a percentage of all deaths during 1998 places Maryland with the 3rd highest proportionate death rate (1.2%) - behind Washington, DC (4.1%) and New York (1.4%) (Murphy, 2000).

Table 1: Top 20 States Ranked by Age-Adjusted Death Rates* (1998)					
<i>State</i>	<i>All Causes</i>	<i>Rate</i>	<i>State</i>	<i>AIDS</i>	<i>Rate</i>
Washington, D. C.	6,054	684.8	Washington, D. C.	250	41.3
Mississippi	27,847	606.6	New York	2,195	11.0
Louisiana	40,337	575.2	Florida	1,546	10.2
Alabama	43,950	565.9	Maryland (4 th)	502	8.7
Tennessee	53,415	557.0	Georgia	692	8.2
Arkansas	27,510	551.0	Louisiana	361	8.2
South Carolina	34,827	550.8	New Jersey	730	8.0
West Virginia	20,767	547.9	Delaware	55	6.6
Georgia	60,428	539.8	South Carolina	270	6.5
Nevada	14,464	539.1	North Carolina	436	5.4
Kentucky	37,832	533.6	Mississippi	140	5.0
Oklahoma	33,929	529.5	Connecticut	168	4.7
North Carolina	67,993	518.6	Texas	938	4.6
Missouri	55,070	511.1	California	1,444	4.1
Delaware	6,578	496.9	Virginia	307	4.0
Indiana	53,477	496.5	Tennessee	231	3.9
Maryland (17 th)	42,059	494.8	Nevada	73	3.9
Ohio	105,891	489.8	Alabama	175	3.8
Michigan	85,160	484.6	Illinois	488	3.8
Illinois	104,480	480.5	Massachusetts	213	3.1
United States	2,337,256	471.7	United States	13,426	4.6

*** Includes Washington, D.C. Age-Adjusted Death Rates are affected by the population composition of the area. (Source: Murphy, 2000)**

Individuals who suffer from HIV/AIDS are not a single homogenous group. Infected individuals vary widely from each other in terms of their illness and in their demographics. In terms of demographic differences, studies have discussed the impact of several factors, including race and ethnic issues, age, gender, sexual orientation, and substance abuse history. Rates also tend to be growing among the most vulnerable categories of persons, i.e., those individuals who have been disempowered such as the poor, women and minorities.

Although African-Americans comprise only 12% of the total population in the United States, they make-up over 35% of all AIDS cases (CDC, 1999e). It is estimated that 2% of African-American men (1 out of every 50) and approximately ½% of African-American women (1 out of every 160) are infected (CDC, 1999e). As such, African-Americans have a higher prevalence rate than any other racial/ethnic group surveyed, with a 1998 rate of 66.4 per 100,000 population – twice as high as Hispanics and 8 times greater than Caucasians (CDC, 1998; CDC, 1999e). Of persons newly diagnosed with AIDS, African-Americans accounted for 47% and 45% in 1997 and 1998, respectively (CDC, 1998; CDC, 1999e). African-American women and children accounted for over 60% of their respective categories of AIDS cases (CDC, 1999e). Unfortunately, Hispanic individuals are also at higher risk of infection, accounting for 20% of persons diagnosed with AIDS in 1998 (CDC, 1998), although they represent only 11.8% of the population in the United States (U.S. Census Bureau, 2000a).

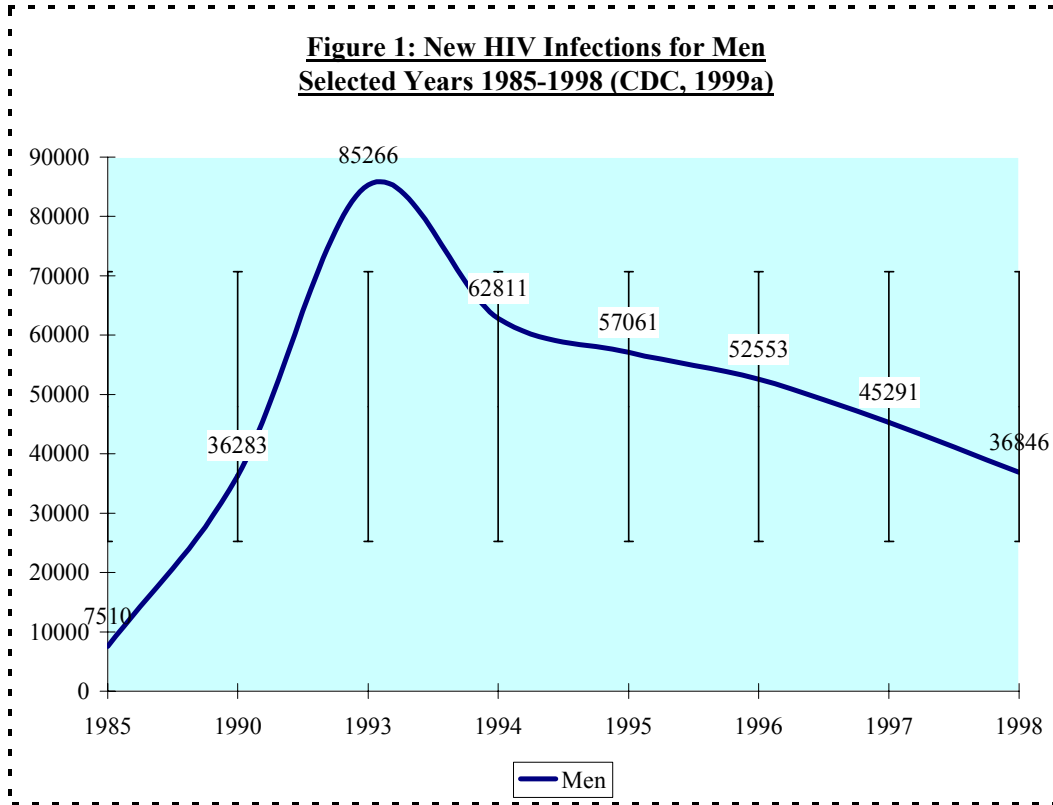
Men

The overwhelming majority of reported cases of HIV/AIDS continue to be adult men, with over ½ million individuals (83% of the total reported cases) attributed to this group. The highest infection prevalence rates (60%) continued to be reported from men who have sex with men (MSM¹) (CDC, 1998). However, from 1996 to 1997, AIDS incidences among MSM declined 18% and deaths declined 49% (CDC, 1998). The other

¹ MSM's include all men who have sex with men whether or not they identify themselves as gay, thus including gay and bi-sexual men as well as straight men (as some men who are not the receptors of same sex relations do not consider themselves gay – i.e., a married man who receives oral sex from a man may not identify himself as gay or bi-sexual when asked) (HIV InSite, 2000).

primary source of HIV infection among men continues to be intravenous (IV) drug use (approximately 29%) (CDC, 1999a). The remaining cases are split variously between blood disorders/transfusions (1.7%), heterosexual contact (3.7%), heterosexual contact with an IV drug user (1.3%), and undetermined (7.2%) (CDC, 1999a).

As can be seen in Figure 1, new cases of HIV in men exploded from 1985 to 1993 when it peaked at over 85,000 new cases reported that year. However, new infections have been steadily declining since 1993 at an average annual rate of 15% (CDC, 1999a). While transmission rates have decreased dramatically due to new medications and changes in human behavior, the rate will eventually plateau at an unknown amount as new infections will continue to occur until a vaccine and/or cure is found. The biggest drop occurred from 1993 to 1994, where the number of new cases declined 26% (CDC, 1999a). Although that pace has not continued, within the past two cycles (1996-1997 and 1997-1998) the reduction has remained in the double digits at 14% and 19%, respectively (CDC, 1999a).



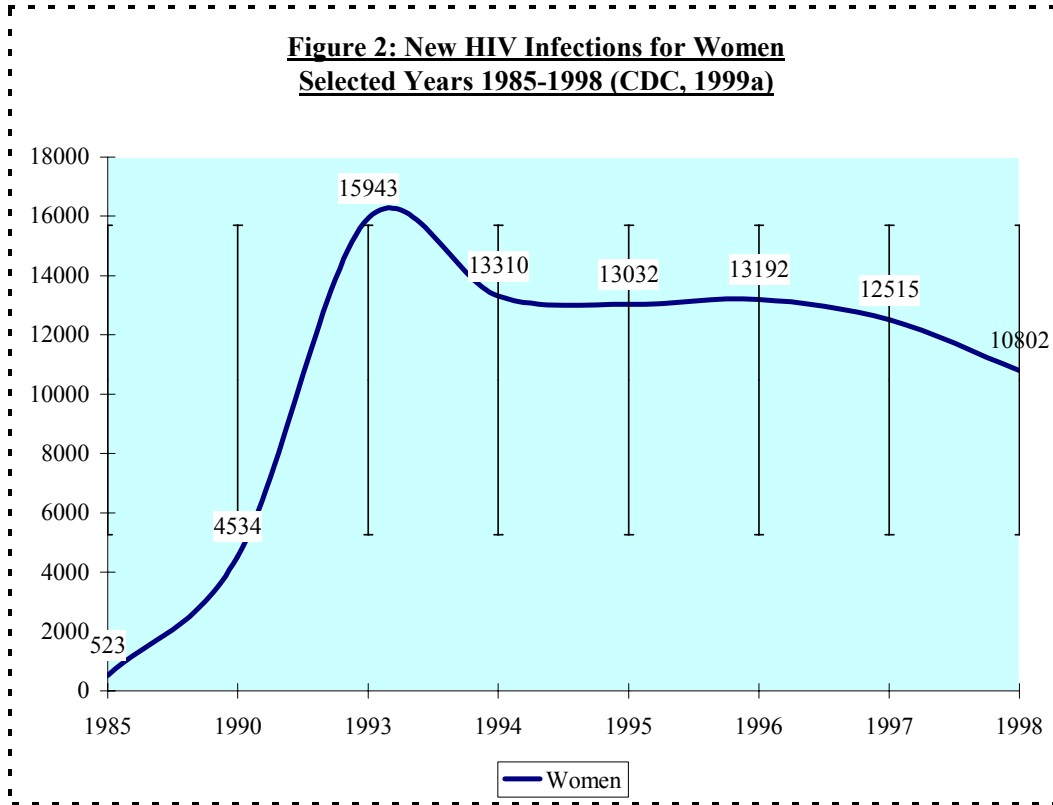
Women

Women comprise the fastest growing segment of people with AIDS, representing almost 20% of all new cases, up from 13.8% in 1992 (CDC, 1999f). Estimates place between 120,000 and 160,000 women with HIV/AIDS in the United States (CDC, 1999f).

In 1996, AIDS was reported to be the 4th leading cause of death among women between 25 and 44 years of age; however, among African-American women in that age group it is the leading cause (CDC, 1996; CDC, 1999f). HIV positive women are overwhelmingly non-white, economically disadvantaged, and disenfranchised from the health care system (S. Andrews Williams & Neil, 1993). As such, the impact of this

disease upon minority communities has been devastating. Indeed, African-American and Hispanic women account for almost 25% of all women in the United States, yet represent over 75% of AIDS cases (CDC, 1999f). In addition, Kalichman (1995) argues that women with AIDS experience greater prejudice and ostracism than men, especially those women with HIV+ children; thus placing greater stress upon already overburdened family systems.

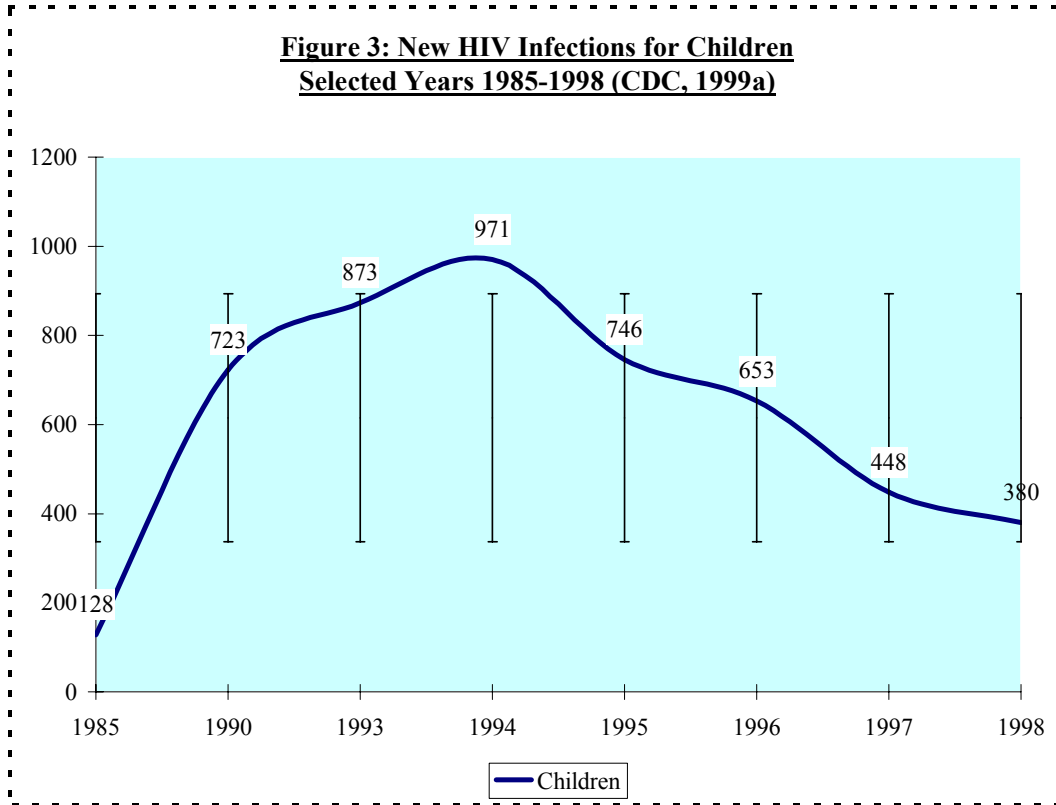
Figure 2 below illustrates the trend of new cases of HIV in women, which appeared to explode from 1985 to 1993 when it peaked at almost 16,000 new cases reported that year. New infections have been steadily declining since that time at an average annual rate of 7.4% (CDC, 1999a). The biggest drop occurred from 1993 to 1994, where the number of new cases declined 17% (CDC, 1999a). Although that pace has not continued, within the most recent cycle available (1997-1998) the reduction was 14% (CDC, 1999a).



Children

The number of HIV positive children in the United States (<13 years of age) represents a small, but vulnerable, group of individuals afflicted with HIV/AIDS. In 1997, children accounted for less than 2% of all reported cases in the United States; which is approximately the same incidence of childhood cancer (Jones et al., 1999; Pizzo, 1990). However, this percent, which may sound insignificant, does not reflect the fact that over 8,400 children have AIDS (CDC, 1999c). Of those infected, almost 5,000 had died as of December 1998 (CDC, 1999c). In addition, paralleling the trend for women, HIV disproportionately affects minority children, with over 80% of HIV infected/affected children either African American (61%) or Hispanic (20%) (CDC, 1999a).

Since the beginning of the pandemic, the incidence of children diagnosed with HIV/AIDS in the United States has escalated to almost 3,600 children in 1997 – rising almost 26% since 1992. Although this trend is alarming, thanks to new drug interventions, the number of deaths in children due to AIDS has decreased from a high in 1994 of 576 to 217 in 1997, and the increase of reported cases from 1996 to 1997 was only 3%. Figure 2 below illustrates the trend of new infections in children. Reports of new cases grew annually until 1994 when it peaked at over 970 cases reported that year. New infections have been declining steeply since that time at an average annual rate of 20.25%, with double digit declines every year since 1994 (CDC, 1999a).



It is clear that this disease affects a significant number of individuals. However, there are limitations to the estimated prevalence rates discussed in the literature, and Mellors (1999) posits that surveillance of AIDS cases alone does not accurately reflect the magnitude and direction of the pandemic. For example, as a result of a new inclusive definition of AIDS implemented in 1993 (which was the 3rd such change – 2 others, in 1985 and 1987, also resulted in large fluctuations), thousands of cases were reclassified; thus accounting for much of the upsurge in cases at that time (Bindels & Coutinho, 1998; CDC, 1999f; Mellors). As described above, this increase was followed by declines in the number of AIDS cases reported in 1995 and 1996, which reflected a waning effect of the more inclusive definition (Mellors).

In addition, developing a comprehensive system for pediatric HIV classification has posed numerous challenges that may have influenced the amounts reported (Fleming & Gwinn, 2000). They argue that the “spectrum of HIV-related diseases and the natural history of HIV infection are less well described for children than adults” (Fleming & Gwinn, p. 52). As such, they report that the Council of State and Territorial Epidemiologists has proposed to the CDC an expanded surveillance for HIV identification in children (Fleming & Gwinn).

Lastly, the WHO (2000) reports that in the early years of the pandemic, increases in the prevalence rate was almost always driven by a rise in new infections. However, this relationship changes as the pandemic matures. For example, stable prevalence, which may appear positive, implies that there is one new infection for every person dying. Therefore, stabilizing rates may be indicative of flattening rates of new infections, rising death rates to nullify corresponding increases, changes in the age structure of the infection, and changes over time in the survival time of infected individuals (WHO). With the advent of new therapies, the slower progression from HIV to AIDS has also confounded projected trends, and “it is not yet known whether...there will be any predictable pattern” (WHO, p. 6).

Modes of Transmission

Due to the stigma associated with the disease, many myths have evolved regarding transmission methods. However, transmission cannot occur through household or social contact, properly administered vaccines, or contact with insects or bodily fluids such as sweat or tears (Bindels & Coutinho, 1998). The epidemiological pattern indicated, and medical tests have concluded, that the disease, although infectious, is

transmissible through only a few specific means – with the primary agents being blood and semen. As such, transmission may occur through: 1) homosexual or heterosexual intercourse where there is an exchange of semen and/or blood from an infected to a non-infected individual; 2) exposure to infected blood via needle sharing among IV drug users; 3) the receipt of tainted blood products used by individuals with Hemophilia and other blood disorders or injuries; or 4) vertically from an infected mother to her child (Bindels & Coutinho).

HIV can be transmitted through sexual contact with an infected person. MSM's continue to represent the largest group of infected individuals with 16,642 cases reported in 1998, and accounting for 60% of all cases for men in 1997 (CDC, 1998; CDC, 1999g). Anal intercourse has a transmission rate of approximately .5-3% per receptive exposure to an infected individual's ejaculate (Bindels & Coutinho, 1998).

Heterosexual contact has historically accounted for the greatest number of worldwide infections, although this has not been true of the United States. However, with over 6,700 men and women infected through heterosexual contact in 1997, this mode of transmission is increasing as a percentage of overall transmissions in the United States (CDC, 1999g; Kalichman, 1998). HIV appears to be more transmissible from men to women than vice versa (Bindels & Coutinho, 1998). Overall, heterosexual contact is a women's primary method of infection (38-54%) (CDC, 1999a; CDC, 1999f). Additionally, 32% of transmissions for women are classified as unknown; however, historically, more than 65% of these have later been re-classified as heterosexual contacts (CDC, 1999f). This picture is slightly different for African-American women who report heterosexual contact (37%) second to IV drug use (44%). Lastly, although rare (<1%),

transmission through sexual contact with a child (i.e., sexual abuse/rape) has been reported (Gellart, Durfee & Berkowitz, 1990). The rate of transmission through vaginal intercourse is lower than anal intercourse, with an estimated transmission rate of .1% probability per sexual contact (Downs & de Vincenzi, as cited in Bindels & Coutinho).

IV drug use as a mode of transmission (i.e., through the introduction of blood from an infected individual to a non-infected one) has remained fairly constant over the recent history of the illness, ranging from 23-28% (CDC, 1999a). The transmission rate among minorities due to IV drug use is much higher for Hispanic individuals (34%) and African-Americans (37.5%) (CDC, 1999a). Among the various sub-groupings, it is highest among women (43.6%) (CDC, 1999a). Infection through blood products has been virtually eliminated in the United States since April 1985 when screening of donated blood became routine. In developing countries it continues to be a source of transmission (Genieser et al., 1998).

For children, vertical transmission between mother and child has historically, and currently, accounted for the vast majority (over 90%) of infected children (Kalichman, 1998). Other modes of childhood infection include transfusions of blood and blood products (which, from a high of 11% of pediatric HIV infections, has been reduced to almost nothing), sexual contact as stated previously, and undetermined (3%) (Caldwell & Rogers, 1991; Kalichman, 1998).

Mother-child transmission may occur through a variety of methods such as exposure to the infected mother's blood and other body secretions during delivery. Infection, it has been determined, can also occur at some point prior to delivery in utero

(Genieser et al., 1998). Infection may also occur post-delivery through the infant's ingestion of the infected mother's breast milk (Levy, 1992).

In the early years of the pandemic, the mother-child probability of transmission in the United States was between 25-35%, and over 40% in developing countries (Caldwell & Rogers, 1991; Kalichman, 1998). However, the introduction of zidovudine (AZT) prenatally, and continued during delivery and the first few weeks of life has reduced mother-child transmission to approximately 8% in the United States (Connor, & Mofenson, 1995; Connor, Sperling & Gelber, 1994). Although, new concerns are emerging with larger numbers of women of child-bearing age becoming HIV positive, the pandemic may continue to grow despite new drug therapies.

Thousands of children are born to HIV infected mothers in the United States, yet it remains a mystery as to why some children born to infected mothers become infected and others do not (Kalichman, 1998). It has been hypothesized that giving birth while in the early or later stages of the illness has higher transmission rates, as higher levels of the virus have been detected during these times rather than during the latency period (Lee, Nahmias & Lowery, 1989, as cited in Caldwell & Rodgers, 1991; O'Brien, Shaffer & Jaffe, 1992). As such, it is clear that the health of the mother can influence the acquisition of the human immunodeficiency virus among newborns. Thus, it is important to review the health impacts of the disease, as well as other co-occurring problems which may exist, to get a clearer context of the issues for children.

Health and Co-Occurring Problems

After infection, acute clinical symptoms may occur, which have been described as mononucleosis-like; however, other manifestations may also occur such as skin rashes,

fever, and a flu-like illness (Bindels & Coutinho, 1998). The virus then enters an incubation period that may last, for over 90% of infected adults, 8-10 years (less than 10% will continue to be free of AIDS more than 15 years). The incubation period is 3-7 years in children (Caldwell & Rogers, 1991; Mellors, 1999). Unfortunately, despite the overall reconceptualization of HIV as a chronic illness, infection eventually results in death. However, in addition to the illness' trajectory, other health and psychological issues may co-occur, increasing stress and decreasing an individual's ability to battle the disease and manage other life issues, including child-rearing. For caregivers of children with HIV, in addition to caring for a child with an infectious, life-threatening disease, elements of various other factors such as developmental disabilities are often present (Diamond & Cohen, 1992; Nehring, Malm & Harris, 1993, as cited in Cohen, F., 1994). These co-occurring health issues, combined with the illness' associated stigma and social unacceptability, can be overwhelming (Cohen, F.)

The clinical path of the illness differs significantly between children and adults. The virus infects adults that may otherwise be healthy. However, the vast majority of children are infected either *in utero* or shortly thereafter. As such, children born exposed to HIV will not be able to sufficiently develop the necessary humoral and cellular immune systems to protect against infections (Roth, 1992). Humoral immunity is transmitted from the mother and is active in the child for 3-6 months after birth; thus, if the mother is HIV positive, this system is compromised (Roth). Cellular immunity is developed by the child through the immune system's experience over time with alien bacteria and other foreign objects (Roth). Unfortunately, for children born exposed to HIV "the development of cellular immunity is already hindered" (Roth, p. 375).

There are also several common AIDS indicator diseases for adults; however, there is still no one clear marker that can predict the clinical course in children (Caldwell & Rogers, 1991). The presenting signs and symptoms of HIV are often nonspecific, and, thus, a high level of suspicion is generally needed for early identification. In addition, HIV infected children are often afflicted with other health related issues requiring frequent medical appointments. As many as 90% of children with HIV experience neurological effects, cognitive deficits, loss of previously achieved developmental milestones and/or developmental delays (Spiegel & Mayers, 1991). Almost 85% of HIV positive children fail to meet normal developmental milestones of height and weight gains (Oleske et al., 1983; Rubinstein et al., 1983). An illness central to children with AIDS is HIV encephalopathy (which is considered to be the equivalent to AIDS dementia in adults) (Diamond & Cohen, 1992). Manifestations may include intellectual deficits, impaired brain growth, weakness and seizures (Diamond & Cohen). Lastly, the increase in developmental delays is not isolated to HIV positive children. Birth children born to HIV infected mothers, yet subsequently testing HIV-negative, are also at higher risk for lower birth weight and other developmental difficulties due to associated factors such as maternal substance abuse, poor prenatal care, poor diet and other bad health habits (Leeds, 1993). Diamond and Cohen contend that primary importance be placed in the interactive effects of the child, the virus and the environment which may include such factors as “in utero exposure of the fetus to drugs...[and] other factors” (p. 34). Postnatal factors include psychosocial influences, “such as unstable family structure and absence of consistent patterns of nurturing by caregivers” (Diamond & Cohen, p. 34).

HIV positive individuals may experience emotional and/or personality changes as a result of the deterioration that accompanies the disease (Worden, 1991). These factors can be compounded due to the other stressors correlated with infection such as extreme poverty, drug dependence and social isolation (Kalichman, 1998). Empirical studies have shown that individuals may experience withdrawal, apathy, distractibility, agitation, angry outbursts, and the inability to sustain attention and affective states (Zegans, Gerhard & Coates, 1994). In addition to, or as a result of the stigma of infection, depression, often accompanied by suicidal ideations, is common for individuals with AIDS (Walker, 1998).

The issues confronting families with an HIV positive child are more complex than those of other childhood chronic and terminal illnesses. Guilt and self-blame from birth mothers regarding their perceived inability to protect their children from harm contribute to feelings of helplessness (Septimus, 1990). The high rate of drug usage, although a maladaptive coping mechanism, ultimately becomes another stressor (Septimus; Tross & Hirsch, 1988).

A dilemma for both caregiver and child is the decision regarding if and how to tell the infected child of his/her diagnosis. Caregivers may believe the child too young to understand, or instead take a perceived protective stance to spare the child undue anxiety (Boland, Tasker, Evans & Keresztes, 1987). Boland and her colleagues argue that for infected children who will have to undergo many frightening medical experiences to remain healthy, this lack of information for the child may serve to heighten fears. Additionally, another less appreciated but devastating impact of HIV on children is the loss of their mothers. So, even if the child manages not to be HIV positive, having at

least one infected parent means the child will experience a significant loss. It is also not unusual for families to have multiple members infected, with some having entire inter-generational families wiped-out (Siegel & Gorey, 1994). It has been estimated that the number of AIDS orphans in the United States will surpass 110,00 this year (Caldwell, Fleming, & Oxtoby, 1992). As they occur, children may experience 'bereavement overload' from the overwhelmingness of these multiple losses (Kastenbaum, as cited in Siegel & Gorey). Thus, caregivers of children infected and/or affected by HIV/AIDS are under great strain due to the increased needs of these children.

Treatments

In terms of long-term outcomes, HIV positive individuals have experienced an almost doubling of life expectancy due to new drug therapies. However, despite medical advances, HIV remains a serious health threat. Treatment regimes can be complex and costly, and may not work for all individuals. When they do work, drug combinations can reduce the virus to almost undetectable levels. Unfortunately, this has had the unintended side effect of having some individuals believing they are cured and re-engaging in high-risk behaviors (CDC, 1999g). As discussed below, treatment approaches, to be effective, must encompass the full bio-psychosocial spectrum.

Medical

In the absence of a cure, the goal of drug treatment is to suppress the amount of virus present in the infected individual. Full suppression is paramount, otherwise viral replication will continue and resistant strains may emerge (Deeks & Volderbing, 1999). Therefore, to the extent possible, treatment regimes are designed to suppress viral replication and the emergence of drug resistant strains. To that end, on March 19, 1987,

the Food and Drug Administration (FDA) approved AZT – the first drug approved for the treatment of AIDS (FDA, 1996). Two and a half years later, after successful results had been demonstrated on adults, AZT was approved for utilization under a protocol for the treatment of HIV positive children (FDA). Expanded use of AZT was approved for infected children in May 1990, and “is the only antiretroviral agent readily available for parental administration” (Deeks & Volderbing, p. 99; FDA). The overall success of this drug contributed greatly to the reconstruction of HIV infection in children and adults. Thus, as the second decade of the pandemic began in the United States, health care providers, armed with this new weapon, began for the first time to view HIV as a chronic and manageable illness (Beaudin & Chambre, 1996; Meyers & Weitzman, 1991). A second drug, Videx, was approved for use with infected individuals over 6 months of age (FDA). Since that time, over a dozen additional drugs have been introduced for utilization with adults and/or children (Deeks & Volderbing). Deeks and Volderbing note that although these advances are promising, only those with considerable resources have access, leaving a grim prognosis for the many millions of infected individuals in developing countries.

Medical treatments have not only prolonged the lives of countless individuals, but have helped thousands of potentially infected children born to HIV positive mothers reject the virus as stated earlier. Early in the pandemic, mother-child vertical transmission rates were between 25-35% (Caldwell & Rogers, 1991). However, with the advent of zidovudine (AZT), which can be started prenatally, that amount has been reduced to between 8-11% (Bindels & Coutinho, 1998). Although the overall mother-child transmission rate is dropping, the amount of childbearing age women infected with

HIV is increasing. Therefore, a rise in the number of pregnancies, even with a smaller transmission rate, may still result in an increase or stasis in the overall amount of pediatric HIV cases. However, it is important to note that even if no new cases occurred, HIV disease would still be affecting families for many years to come due to its often long incubation period.

Lastly, there is no cure for HIV infection or AIDS. However, the Bangkok Metropolitan Administration is currently heading a clinical trial on a potential vaccine (CDC, 1999h). This vaccine is the first to obtain approval for large scale human testing, although a smaller similar vaccine trial is also underway in the United States that will be completed in June 2001 (CDC, 1999h).

Adherence

HIV positive individuals struggle with medication adherence for a variety of reasons including the expense of the drugs, the inconvenient administration schedules, and significant side effects (Deeks & Volderbing, 1999). In addition, there is the fear that medication adherence may still not result in long-term suppression (Deeks & Volderbing). Hecht and Chesney (1999) in a review of the adherence research found that demographic characteristics such as race/ethnicity, sex, occupation and income are poor predictors of treatment adherence, although they found one study that indicated a significant relationship between low education levels and lower adherence rates.

Despite the difficulties, medication adherence is paramount in maintaining low viral loads and resisting the creation of resistant strains. Missed doses reduce the efficacy of the medication thereby allowing drug-resistant mutations to develop (Hecht & Chesney, 1999). This not only places the infected person in increased jeopardy, but any

subsequent individual infected by that person would then be infected with the stronger strain, thus making treatment for the second individual more difficult (Hecht & Chesney).

Side Effects

People treated with AZT and other similar nucleoside analog drugs may suffer early in the treatment from such side effects as headaches, insomnia, nausea, vomiting, abdominal pain, diarrhea, fatigue, rashes, muscle pain and fever, although most subside within weeks (Deeks & Volderbing, 1999; Kalichman, 1998). In addition, prolonged use of AZT can cause bone marrow suppression and anemia (Kalichman). Protease inhibitors, which inhibit viral replication, may cause nausea, abdominal cramping, diarrhea, fatigue and taste disturbance (Deeks & Volderbing). The most common side effect of the non-nucleoside reverse transcriptase inhibitors are rashes (Deeks & Volderbing). Given the estimate 20 medications taken daily, HIV infected individuals must also contend with not only the unique side effect of each drug, but with the potentially toxic interactions (Deeks & Volderbing). An expectation of adverse side effects is one of the most common reasons given for refusing drug treatment (Perry, Ryan, Ashman & Jacobsberg, 1992).

Service Delivery

Further exacerbating these problems are issues related to the delivery of services to this population. Public programs are the primary coverage source for people infected with HIV; however, the complexity and length of time to become eligible for some programs (up to two years) can severely impact the long-term outcome of an infected individual (Buchanan & Chakravorty, 1999). Problems with the present Medicaid system include limited coverage of medications, limited physician participation, and difficult

spend down requirements (Buchanan & Chakravorty). Hospice, home health care, residential facilities and mental health/psychosocial services are necessary services that are not covered by Medicaid for people with AIDS (Buchanan & Chakravorty).

Although some of these services are covered by other government programs, such as Title I of the Ryan White CARE Act, multiple eligibility criteria and other related tasks may overburden these already stressed individuals and families (Buchanan & Chakravorty).

In addition, in most communities the current system consists of separate systems for children and adults with HIV (Alemán, Kloser, Kreibick, Steiner & Boyd-Franklin, 1995). This separation serves as a barrier to both existing services and the development of specialized or integrated services, with, for example, “pediatric care to be provided in one facility while care for women is provided on infectious disease or OB/GYN units in another facility” (Alemán et al., p. 101). Therefore, families with both an infected mother and child must often coordinate travel to different locations and/or see different doctors in an attempt to adhere to the dual treatment regimes. Medical regimes for individual infected with HIV can be difficult on many levels; the unknown toxicity of many drugs upon one’s self which may result in potentially painful side effects, the availability of drug treatments due to restrictive eligibility requirements, as well as the energy and resources needed to maintain treatment in different locales. These examples illustrate the difficulties faced obtaining medical treatment. The next section will discuss how these problems may adversely impact the psychosocial system.

Psychosocial

HIV positive parents with children who are subsequently infected/affected with HIV/AIDS frequently require a broad range of supportive services to survive (Levine & Stein, 1994). Without these services, families may not be able to maintain a suitable living arrangement. Therefore, Levine and Stein have identified several psychosocial service needs of families struggling with HIV, such as mental health counseling and respite care. These services allow families a reprieve from the stresses related to HIV. The great need of these families have also fostered the creation of many innovative programs. For those families socially isolated due to the failing health of the infected individual, telephone support groups have been found to alleviate feelings of abandonment and increase feelings of universality and support (Wiener, 1998).

The Impact on Families, the Child Welfare System, and Society-at-Large

HIV does not occur in a vacuum. As noted previously, the systems impacted by this disease stretch far beyond the boundaries of the infected individual. A. Hall and Fagan (1956), when discussing the interaction of people, social issues, and social phenomena, defined a system as, “a set of objects together with relationships between the objects and between their attributes...the [systemic] environment is the set of all objects, a change in whose attributes affect the system and also those objects whose attributes are changed by the behavior of the system” (pp. 18-21). Therefore, although the primary system of attention in this paper is the impact caring for a child infected/affected by HIV/AIDS has upon his/her caregiver, it is important to highlight the link that for every person infected with HIV there is an affected family. Thus begins the setting for the social context of the illness. In addition, suprasystems, which are external to and

encompassing of the primary system, must also be recognized as influencing factors (Robbins, Chatterjee, & Canda, 1998). Within this context, the three systems of focus are the family, the child welfare system and the larger socio-cultural suprasystem. The influence of HIV on each system will be reviewed in this section.

Families

Considerable attention has begun to be focused on the impact of HIV/AIDS on families - a group that has historically been ignored in the professional literature (Bor, Elford, Hart & Sherr, 1993). Families are social systems, and are expected to perform a variety of functions including providing for the nurturance and care of its members. This has historically included caring for members who are ill (Chatterjee, 1996). However, the experience of caring for an ill family member both interrupts and transforms the entire family's life (Caliandro & Hughes, 1998; Grosz & Hopkins, 1992). Although the impact on caregivers due to this illness in any family member would appear to be obvious, it has only been a recent phenomenon that these changes have been investigated in a systematic and scientific manner (Andrews, S. et al., 1993; Fanos & Wiener, 1994; Mellins & Ehrhardt, 1994; Sherwen & Boland, 1994). The results of this research have borne out the tremendous objective and subjective burdens placed on these caregivers (Caliandro & Hughes, 1998; Hackl, Somlai, Kelly & Kalichman, 1997; Hansell et al., 1998; Hansell et al., 1999).

The vast majority of biological families affected by HIV are headed by single women, most are minorities and living in poverty. Thus, while most persons with AIDS may have experienced discrimination, "to be a poor African American woman with AIDS is to live with oppression" (Dicks, 1994, p. 125). Upon this stack, this author would add

the monumental task of caring for an HIV positive child. Melvin and Sherr (1993) contend that parenting an HIV positive child is often disrupted by not only the effects of the illness, but also its associated factors such as hospitalization and environmental stressors. Unfortunately, many of these families are faced with difficult or unsupportive home situations, as the woman has often burned family bridges and is quite alone (McCarroll, 1988). These birth mother caregivers are often seen as causing or exacerbating problems and not as a potential source of strength and support.

Family members can lend assistance, and some woman find solace among kin. However, families are not immune to the stressors associated with caregiving and may experience similar problems as those that affect the infected member. Feelings of shame, stigma, social isolation, guilt and loss plague all members of the family, from grandparents to uninfected children and siblings (Bor, Elford, Hart & Sherr, 1993). Although most of the few studies conducted have been on the female parent of a child with HIV/AIDS, other familial relationships have been investigated as well. The burden of this relationship has been investigated, and the impact of HIV/AIDS on the family has been shown to exert a great influence on the normal family trajectory. Caliandro and Hughes (1998) found that grandmothers caring for HIV positive children felt that this task went beyond the time and developmental expectations for them as older adults. It is hypothesized that similar difficulties would be experienced for other family members.

Lastly, the siblings of infected children must not be forgotten. McCarroll (1988), who has parented several HIV positive children, writes that he usually “thinks of the troubles Melissa and Rachel [two HIV infected children in his care] will face, but David [an uninfected child] also will be victimized by this awful plague. Despite all the security

and help we will give him, he may be carrying the pain of loss for much of his life” (p. 154-155). In the only study to include siblings (n=14), Mellins and Ehrhardt (1994), using an open-ended qualitative interview, report that older siblings of HIV positive children possessed significant anger and feelings of burden from assisting in the caregiving tasks with few outside support resources. Drawing from other sources (i.e., the chronic illness literature and clinical experience), Fanos and Wiener (1994) surmise that siblings of children with HIV may experience feelings of sadness, confusion and survivor’s guilt. These feelings may be exacerbated when the infected parent(s) die and the child may have to be placed with relatives or foster/adoptive parents.

Child Welfare

Large numbers of children have been, and will continue to be, orphaned due to parental deaths due to AIDS. In 1992, Michaels and Levine calculated that 18,500 children had been left motherless due to AIDS. Predictions are that many thousands more will follow, with estimates ranging from 70,000 to 150,000 (CDC, 1996; Forehand et al., 1999; Michaels & Levine). In addition, with the advent of new drug therapies, children born to HIV positive mothers now have a better chance to be HIV negative. The side effect of this success is the swelling numbers of children outliving their parents and needing permanent homes. Therefore, regardless of the exact number, it is generally agreed that many thousands of children will require assistance and placement into a foster or adoptive family when other relatives are not available.

A comprehensive program for HIV infected children and their families found that 42% of the children were previously known to the state’s child welfare system, and 35% had experienced difficulties necessitating foster care placement prior to the HIV

diagnosis (Boland, Evans, Connor & Oleske, 1988). In addition to economic and psychosocial factors, the disease itself poses obstacles to a family's preservation. Because of the high incidence of substance abuse and parental inability to care for the child's needs due to incapacitation or death, children infected/affected by HIV/AIDS are more likely to end up involved with the child welfare system when compared to similar groups of chronic/terminally ill children with other diagnoses. Rudigier, Crocker and Cohen (1990) noted that 63% of the children in their study were not living with their parent due to parental incapacity that precluded the parent from appropriately caring for the child. As such, child welfare practitioners are faced with an influx of children at-risk of entering (in addition to many of whom have already entered) the child welfare system due to the enormous stress levels associated with caring for children infected and/or affected by HIV/AIDS.

This population has forced child welfare professionals to re-think their traditional goals of reuniting children with their parents (Groze, Haines-Simeon & McMillen, 1992). HIV has changed the dynamics of child welfare, prompting questions of confidentiality, foster/adoptive parent training, as well as placing children transracially, and board payments for seroconverted children (Emery, Anderson & Annin, 1992; McMillen & Groze, 1991). Determining who needs to be aware of a child's HIV status (which by default indicates the mother's status) can be difficult. Child welfare agencies must be vigilant in ensuring that the family's confidentiality is maintained, and not report status to satisfy the curiosity of others (Emery et al.). Agencies have also had to change policies to establish specific trainings for foster/adoptive parents and staff regarding universal precautions, caregiving and bio-psychosocial treatment issues (Emery et al.). Child

welfare agencies continue to struggle with the question posed by McMillen and Groze, who ask, “Once the child is found to be uninfected, placement with a same race family becomes more likely. Should the agency disrupt a stable transracial placement to move the child to a same race family?” (p. 60). They also question if enhanced subsidies should be continued after a child seroconverts, in order to maintain a placement that might otherwise disrupt (McMillen & Groze).

In response to the challenges faced by traditional foster and adoptive services, many family connections have been maintained through kinship care (the placement of children with biological relatives) (Forehand et al., 1999). Forehand and his colleagues found that although the incapacitation and/or death of the parent are traumatic, placement with a close relative helped the child traverse the grieving process. Fewer disruptions were reported, as well as no significant increase in difficulties in child psychosocial adjustment following the mother’s death (Forehand et al.).

Lastly, the program under investigation, the **Family-Centered Transagency (FaCT)** Model was designed to coordinate services for families who were involved with multiple agencies and services such as child welfare, housing, substance abuse, education, and AIDS administration (Groze, Berlin, Haines-Simeon & Woodruffe, 1992). The goal of this innovative project was to promote permanency to families infected/affected by HIV/AIDS (and/or substance abuse) through the provision of support in navigating the maze of providers (Groza, Sibley & Proctor, 1997). Permanency planning for HIV infected mothers was also provided, as was special preparation for foster and adoptive parents, to assist children infected/affected by HIV/AIDS live in a stable family structure (Groza et al.). Results show that these family systems are stressed

due to a general lack of resources (including social supports) and poor health, as well as stigma and discriminatory practices of the part of care providers (Groza et al.). However, despite these pressures, parent-child relationships were reportedly positive, and caregivers, equipped with the services provided by the program, continued to work to maintain the family unit. This was shown through significantly decreased levels of risk for birth families over a one year period, this was evidenced through the increased suitability of family living conditions, from having partial support to marginal support, and reduced substance usage (Groza et al.).

Society

HIV/AIDS has generated a great need for a variety of services such as medical, public health, social, educational and other sources. However, society has largely ignored the needs of women and families, and instead focusing on the needs of gay men. Programs for women have not received much attention, creating a deficit in resources for the many disempowered, infected minority women (Dicks, 1994). Due to this lack of resources, women with AIDS's are far less likely to have established networks to which they can turn to (Weitz, 1989). Dicks asserts that, "Truly to be a poor African American woman with AIDS is to live with oppression" (p. 125).

Individuals stricken with the disease, as well as families, friends, and most areas of the public and private sectors have felt the financial impact. The economic costs are both direct and indirect. Direct costs are those expenses generated by the resources used in treating or coping with the virus, including expenditures for medical care and the treatment of the illness (i.e., hospital care, physician services, home health aides, drugs, etc.). The primary component of the direct costs is the medical care of the infected

individual, as shown in Table 2, is considerably less total cost than other illnesses such as cancer, diabetes, and heart disease. However, on a per capita cost basis, HIV far exceeds all other illnesses.

Table 2: Annual Cost of Diseases in the United States*			
<i>Disease</i>	<i>Annual Prevalence</i>	<i>Approximate Direct Cost (Billions)</i>	<i>Approximate Indirect Cost (Billions)</i>
<i>Diabetes</i>	16,000,000	90	45
<i>Depression</i>	17,400,000	70	75
<i>Heart Disease</i>	56,000,000	70	60
<i>Cancer</i>	10,000,000	25	65
<i>Alzheimer's</i>	4,000,000	17.5	70
<i>HIV/AIDS</i>	58,000	10	42.5

***Source: Songer & Ettaro (1998)**

In addition to the direct costs enumerated above, total cost assessments must also include the indirect human costs such as lost productivity. Indirect costs address the potential resources that are lost as a result of the illness, including the societal costs of disability and premature death. These costs are not as easily measured as direct costs, as they represent the impact, present and future, of opportunities lost to the individual and society as a consequence of the illness. Because of the large numbers of individuals becoming ill, society is robbed of their potential contributions, especially due to the relative youthfulness of its victims [the CDC reports that 90% of persons with AIDS are between 20 and 49 years of age] (CDC, 1999a). As shown in Table 2, indirect costs to society are estimated to exceed \$42.5 billion.

According to the National Conference of State Legislatures (1999), the lifetime costs for treating an infected adult has been estimated to be \$154,402. However, the cost of treating pediatric AIDS is far higher than treating adults, costing \$491,936 per child based on the median survival time of 120 months (National Conference of State Legislatures). The perinatal prevention costs in the United States has been estimated to be \$67.6 million. Although this may appear high, this investment prevents 656 HIV infections among newborns, and saves \$105.6 million in direct medical costs (CDC, 1999i).

With the advent of antiretroviral drugs, survival and wellness have drastically improved. Nevertheless, societal distribution of these costs has met, and continues to meet, with much debate (Fumento, 2000). This prompted one physician to comment that; “We’re spending resources to keep people healthy rather than spending resources on sick people” (Reuters Health Information, 2000).

SUMMARY

HIV has been shrouded in controversy since its emergence. Its origin, governmental response and politicalization are still hotly debated. However, what cannot be denied are the thousands, indeed millions, of families affected by this illness and the struggles they have endured to survive. Many HIV positive mothers living in poverty continue to breast-feed their newborns, thereby increasing the chances for transmission. Medications, while dramatically enhancing and lengthening the lives of HIV positive individuals, have side effects which can be debilitating. These factors, as well as those due to service inaccessibility, contribute to the adverse effects on caregivers’ psychosocial needs. Thus, it is clear that the impact of this virus on families,

as well as society and its infrastructure has reached enormous proportions. When all of this literature is taken together, it can be surmised that those individuals caring for children infected and/or affected by HIV/AIDS would have high levels of stress. Yet, this stress may be able to be buffered by various modes of social support. However, although this would be a logical outgrowth, these findings have not yet been clearly demonstrated in the empirical literature. This study will attempt to fill this gap in the literature. In addition, this study, by focusing on the complexity of caring for a child infected and/or affected by HIV/AIDS, will help to illuminate other areas of practice and research including the impact of social support upon caregiver functioning when caring for children involved with foster/kinship care, cancer and other life threatening illnesses.