CAREGIVERS OF CHILDREN INFECTED AND/OR AFFECTED BY HIV/AIDS

by

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Submitted in partial fulfillment of the requirements

for the degree of Doctor of Philosophy

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January, 2001

This dissertation is dedicated to my sister, Pamela Marie Ryan (1960-1984), and our parents, who understand what it is to care for and lose a child from HIV/AIDS.

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Acknowledgements

I wish to thank all of my friends and colleagues who believed in me and pushed me to complete this work. Specifically, my friend, mentor and dissertation chair, Victor Groza. His unending support, as well as his sharing of knowledge and humor, has significantly impacted my work and life. I also extend my gratitude to the other members of my committee, David Miller, Jerry Floersch and Sana Loue, for their participation and feedback on my work and ideas. This work has been enhanced by their contributions.

To my wonderful wife, Kimberley Ryan, and darling daughter, Connor Ryan, although it seemed at times that this dissertation was the center of my life, rest assured that you both are always. It is from you both that I have drawn my strength. Kim, your love and warmth has always helped me to see life beyond the dissertation. Connor, you have been a joyful distraction, and writing our 'dissertations' together on the computer was a great time that I will never forget.

My deepest thanks to the rest of my family, Martin Ryan, Rita Barnes, Jim Barnes, Bruce Ryan, Tracy Ryan, and my nephew, Brendan Ryan. You all define support through the many things you all do - talking, babysitting, helping with tuition and too many other things to mention. I never would have gotten this far without your help.

Lastly, to the families in this study caring for children infected and/or affected by HIV/AIDS. I never met you, but you have changed my life. I can only hope that from this work and my professional career I can touch the lives of families struggling with this illness and ease their burden. Thank you.

Caregivers of Children Infected and/or Affected by HIV/AIDS

Abstract

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This study examines the experiences of individuals caring for children who have been infected and/or affected by HIV/AIDS. This experience may include stressors that interrupt and transform the entire family's life. These stressors include juggling the HIV positive child's medical appointments and hospitalizations, as well as the emotional impact of the birth mother's own illness. Unfortunately, many of these families are faced with difficult or unsupportive social networks, as many HIV positive caregivers may have alienated previous relationships. This study builds upon the previous research through the utilization of a clear theoretical frame, the Stress-Coping model, that provides specific factors whose relationships can be measured and explored. As such, this research attempts to examine the differences between birth mothers and other caregivers on key demographic, stressor and social support variables. In addition, this study, utilizing a multiplicative interaction regression model, explores the buffering effect of specific sources of social support upon the caregiver.

A sample consisting of 212 caregivers was obtained. Many caregivers are in poor health, with some also caring for additional sick children. However, birth mothers have more health difficulties that place limits on their activities in the home, lower formal education, less support from their family, friends, and church/spirituality than their counterparts. Birth mothers also reported more perceived stress and less arousal than did other caregivers. Yet, it was also found that other caregivers provide care for significantly more HIV positive children, as well as more other ill children. There were no differences between birth mothers and other caregivers on illness management, support from the index child, connections with the community, and formal service support. However, the most consistently significant variable in the regression equations was caregiver health limits, with two social support variables also showing significance. Support from friends has a main effect , and child support's interaction with illness management had a significant impact. Thus, it may be that some sources of social support exert a buffering effect while others demonstrate a main effect, depending upon the specific crisis at hand. This possibility demands further examination, and could greatly influence future practice and policy development.

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 i*dentified* 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)

State	*All Causes*	*Rate*	*State*	*AIDS*	*Rate*
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 (4th)	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 (17th)	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 (MSM[1]) (CDC, 1998). However, from 1996 to 1997, AIDS incidences among MSM declined 18% and deaths declined 49% (CDC, 1998). The other

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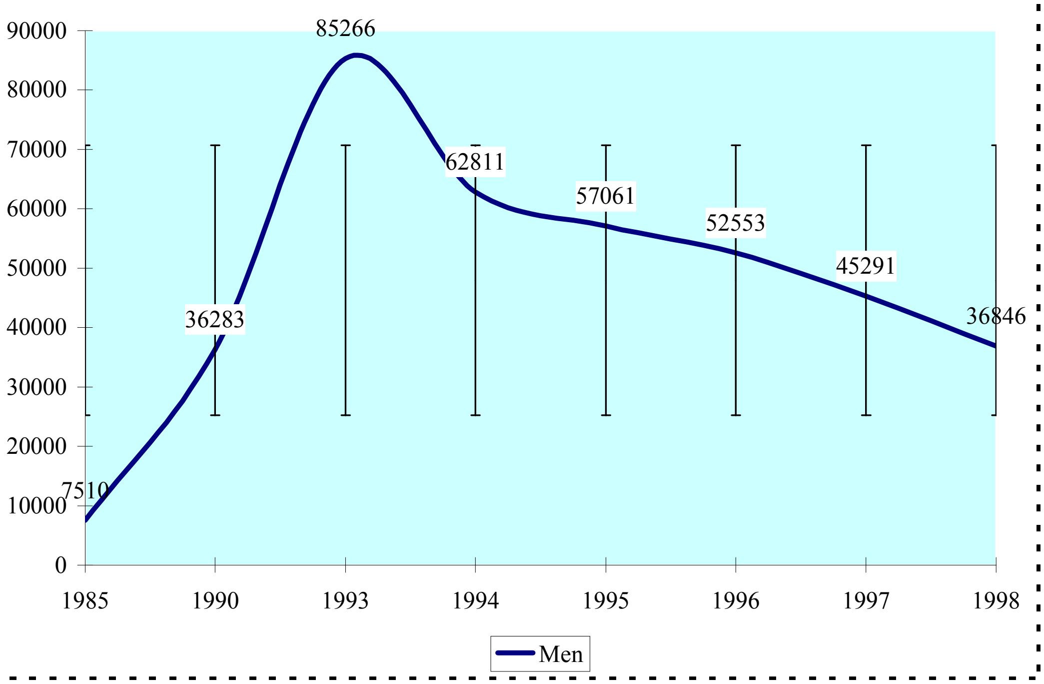
[1] MSM's include all men who have sex with men whether or not they identify themselves as gay, thus including gay and bi-sexual men as well as straight men (as some men who are not the receptors of same sex relations do not consider themselves gay – i.e., a married men who receives oral sex from a man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

Figure 1: New HIV Infections for Men Selected Years 1985-1998 (CDC, 1999a)



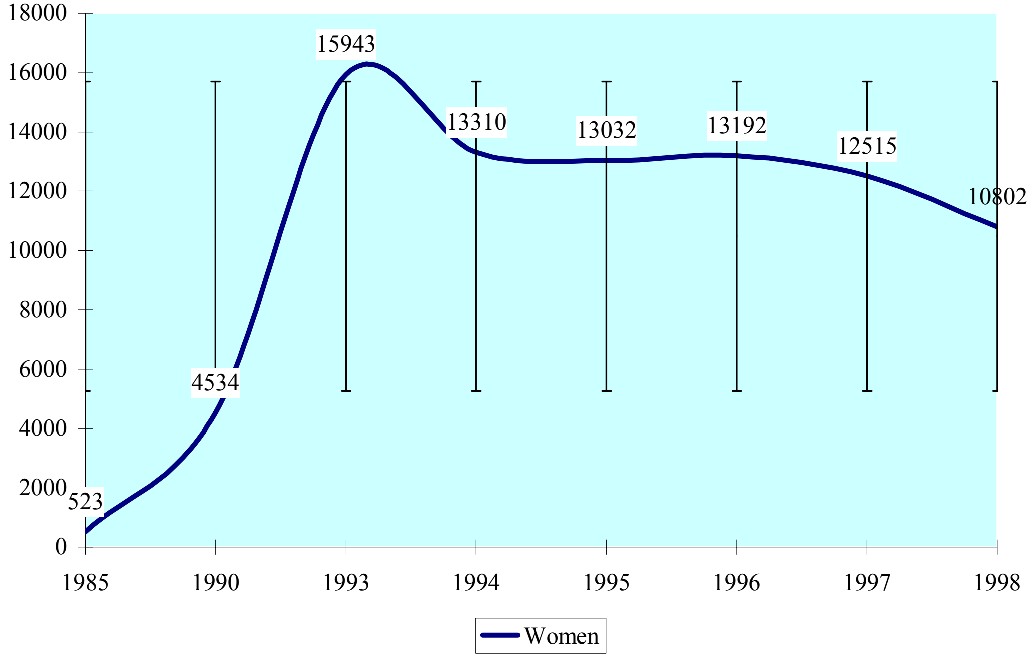
Women

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).

Figure 2: New HIV Infections for Women Selected Years 1985-1998 (CDC, 1999a)

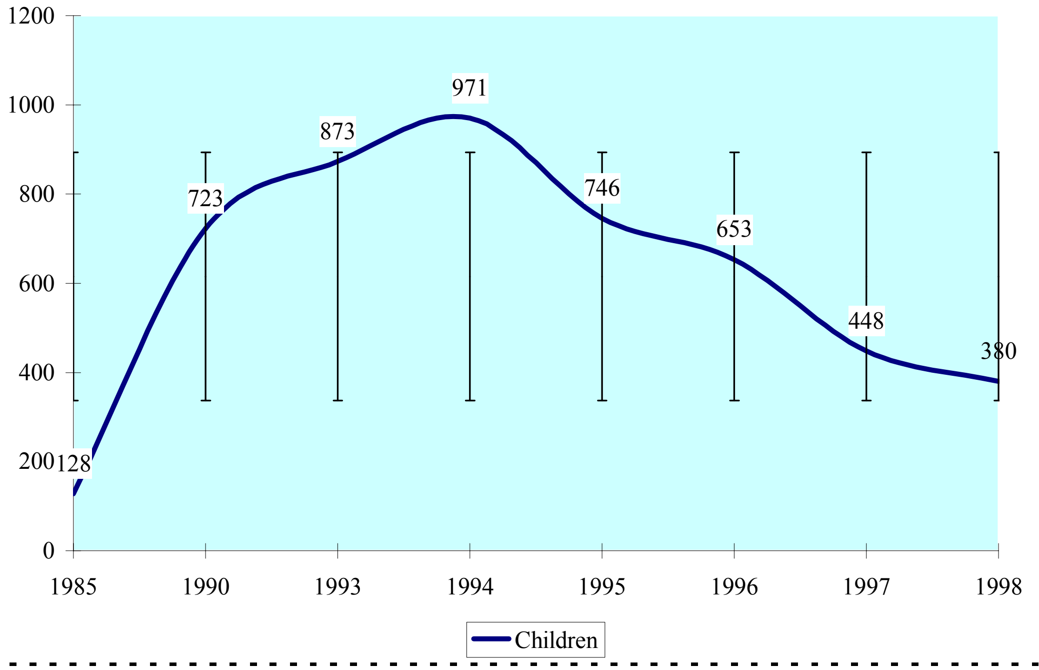


Children

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 is 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).

Figure 3: New HIV Infections for Children
Selected Years 1985-1998 (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 an 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 & J7affe, 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 by 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 undo 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 trail 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 reprisal 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 **Fa**mily-**C**entered **T**ransagency (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*

Disease	***Annual Prevalence***	***Approximate Direct Cost (Billions)***	***Approximate Indirect Cost (Billions)***
Diabetes	16,000,000	90	45
Depression	17,400,000	70	75
Heart Disease	56,000,000	70	60
Cancer	10,000,000	25	65
Alzheimer's	4,000,000	17.5	70
HIV/AIDS	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 changes 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.

CHAPTER 2

THEORETICAL FRAMEWORK: The Stress-Coping Model

This chapter will begin by exploring the conceptual origins and definitions of stress, coping and social support. The utilization of these concepts by other populations will then be examined, followed by a discussion of its applicability within the adult HIV literature. The pediatric HIV caregiving literature will subsequently be discussed and critiqued from this framework. Lastly, the study under investigation will be presented, with relevant research questions posed.

Selye (1970) was the first theorist to link stress with physical disease and ill health in human beings. This link, however, is not considered to be a direct link, but is instead affected by other social forces that allow the individual to adapt, or cope, to the stress. Rooted in the work of Durkheim, the concept of social support is now considered to be integral to this process (Waltz, 1994). As such, social support plays an important role in health and illness. Although the exact mechanism of this relationship has yet to be definitively established, social support has been correlated with increases in well-being, as well as positive increases in an individual's immunology (Broadhead et al., 1983; Leavy, 1983; Mitchell, Billings & Moos, 1982; Pilisuk, 1982; Pilisuk & Froland, 1978). Thus, it is posited that social support assists the person experiencing a stressor, such as caring for a child infected/affected by HIV/AIDS, by 'buffering' the caregiver from the potential negative influences of this stressful event. The model that puts these three concepts together – i.e. stressor, moderation by social supports, and outcome/perceived burden has become known as the Stress-Coping Model.

STRESS

The impact of stress upon humans' psychological and physiological well-being has been occurring since antiquity. Even prehistoric people must have recognized feelings such as exhaustion and fear when faced with starvation, disease or severe weather that threatened their existence. Selye (1993) writes that Hippocrates recognized the *vis medicatrix naturae* (healing power of nature) – yet stopped short of distinguishing the concept distress from stress. This is important, as distress always connotes unpleasantness; however, stress can occur from either positive or negative events (Selye). In addition, the same event can be have both positive and negative factors (Selye). McCarroll (1988), although acknowledging the feelings of despair, depression and isolation an AIDS diagnosis may have, also notes the profound positive effect subsequently experienced by some women who:

> transcend the limits of their previous existence. For the first time they develop deep relationships with other people, especially other women with AIDS and women who are caregivers. There is, at times, a blooming of a woman's personality that has led more than one victim to describe the months since diagnosis as a cherished time (p. 88-89).

Although Weiner (1994) suggests that Aristotle may have been the first person to clearly articulate this concept, it is only within the last few centuries that humans have begun to scrutinize and study the various facets of the stress process. One of the first recorded stress theorists was Charles Darwin, who suggested the concept of stress as an organism's struggle with the environment in competition with other organisms in order to survive. These outside forces, causing a threat or challenge to the integrity and survival of a particular organism, have generally been understood to be the concept of stress (Weiner, 1994). In addition, Darwin (1955) believed that expressive behaviors (i.e., loud and rapid speech) resulting from a stressful event were associated with emotions (as cited in Siegman, 1993). Further, it is posited that these resultant behaviors have a biological basis and serve as communicative functions with clear-cut survival value (Darwin, 1955, as cited in Siegman, 1993). This concept later became codified into a theory through the experiments and works of Cannon (1929) and Bernard (1865). These theorists and researchers conducted a series of experiments on animals that supported their belief in the biological effects of environmental stress on an organism.

Selye (1936), while in medical school, discovered a similar process experienced by organisms when exposed to toxins, irrespective of the specific toxic source. He identified three stages through which an individual progresses, and labeled the process the *General Adaptation Syndrome* (GAS) (Selye). Attempting to maintain a level of homeostasis, an individual exposed to a noxious agent or event will enter the first stage, adaptation. An 'alarm reaction' calls to arms the individual's internal and/or external defense mechanisms. Next, after the individual survives the initial reaction, comes a stage of resistance. However, this resistance is not infinite and, finally, just as a machine under stress wears out, so does an individual. The constant strain of living under stress takes its toll and the individual subsequently enters the stage of exhaustion. As the individual's 'adaptation energy' becomes depleted, resistance is lowered and death eventually occurs (Selye). The GAS aptly describes the rudimentary stages of linear progression within the stress cycle, yet falls short in discussing the multi-level complexity of this topic.

Indeed, researchers have been largely unable to even agree on any one definition of the concept of stress. In fact, Selye (1993) asserts that “remarkably few people define the concept in the same way or even to bother to attempt a clearcut definition” (p. 7). To that end, Monat and Lazarus (1991) have delineated stress into three types – physiological, social and psychological. Physiological stress is concerned primarily with the disturbance of tissue and other physical systems. Social stress views the social unit as the disrupted factor. Psychological stress encompasses those threats to the individual’s psychological well-being. While these factors may be related, the nature of the relationship is not entirely clear (Monat & Lazarus). Monat and Lazarus, in their attempt to include all pertinent factors, define stress as “any event in which environmental demands, internal demands, or both *tax* or *exceed* the adaptive resources of an individual, social system, or tissue system [italics in text] (p. 3).

Therefore, stress can be assumed to arise when one appraises a situation (or combination of events) as threatening or otherwise too demanding and does not have an appropriate coping response (Cohen, S., & Wills, 1985). This is the type of situation in which the person perceives that it is important to respond, but an appropriate one is not available. One single event may not place great demands on an individual’s ability to cope with the situation; however, when the problem is persistent and on-going, as is HIV, it may strain the resources and problem-solving capacity of the individual (Cohen, S., & Wills). Feelings of helplessness arise because of the perceived inability to cope with the situation, taxing one’s skill and emotional levels beyond capacity. Without adequate assistance, this may subsequently lay the groundwork for maladaptive stress reactions such as illegal drug use.

COPING

Although stress and its damaging effects have been studied for over a hundred years, the concept of coping can trace its roots to the 1940s and 50s, during World War II and the Korean War, when numerous studies into the effects of stress under military combat were spawned (Lazarus & Folkman, 1984). Lazarus and Folkman posit coping as a constantly changing process involving cognitive and behavioral aspects. As such, they contend that coping is a process that it is concerned with what a person actually thinks and does in reaction to the specific stressful event (Lazarus & Folkman).

Therefore, coping is something that protects an individual from being psychologically or physically harmed by an outside force exerting stress upon the organism (Monat & Lazarus, 1991). Individuals may engage in several different forms of coping such as problem-focused coping in which the individual attempts to improve his/her concrete situation (Monat & Lazarus). Another type, emotionally-focused coping, refers to the thoughts or actions taken to relieve the emotional toil of the stressful event, yet does not actually remove the condition (i.e., it helps make a person feel better') (Monat & Lazarus). Other forms of coping include defense mechanisms such as denial, which may help a person keep from feeling overwhelmed. Unfortunately, denial can also result in an avoidance of doctors and/or medication adherence. Thus, it is recognized that all coping mechanisms may have positive and negative influences on the individual (Monat & Lazarus). In addition, coping can also be determined by the use of adaptation resources. One such coping resource that has received considerable focus, and is the one under investigation, is social support.

Social Support and the Buffering Concept

There has been a rapid growth in the literature suggesting the potential benefits of social support for various populations that Lazarus and Folkman (1984) classify as falling under the heading of coping. Social support, usually thought of as positive factor, may intervene between a stressful event and the stress reaction by attenuating or preventing a stressful appraisal of the situation, thus increasing the person's ability to respond appropriately to the situation (Maguire, 1991; Monat & Lazarus, 1991). That is, the perception that others can provide necessary resources may redefine the potential for harm posed by a situation and/or bolster one's perceived ability to handle the additional demands (Cohen, S., & Wills, 1985).

One of the themes in the literature is that social support acts as a buffer to stress and its destructive consequences. It can help prevent stress by making harmful experiences seem less consequential or provide valuable resources for coping when stress does occur (Sarason, Sarason & Pierce, 1990). The case for the buffering hypothesis is still being debated (Baron & Kenny, 1986; Cobb, 1976; Cohen, S., & Wills, 1985; Thoits, 1982; Thoits, 1986; Zedeck, 1971). Blaney et al. (1991) found no statistical buffering relationship between social support, life events, hardiness and the individuals level of stress. However, Pearlin, Menaghan, Lieberman and Mullan (1981) reported mixed results in their exploration of the buffering effect of coping and social support upon stress related to job loss, with support and/or coping buffering the effect of job loss upon the respondents economic strain, self-esteem, feelings of mastery and level of depression. Other studies have also reported mixed results. For example, Bass, Noelker and Rechlin (1996) examined the moderating influence of service use upon caregivers of elderly individuals. They found that several forms of service support (i.e. personal care, household assistance, etc.) were significant buffers of caregiver depression, social isolation and caregiver health deterioration.

One reason for the confusion is the diverse ways of defining and measuring the social support variable (Cohen, S., & Wills). Another common error has been equating social networks, the number of relationships a person has, with social support, the perception of the value of the social interaction (Lazarus & Folkman, 1984). Many studies treat the concepts interchangeably. However, inherent in this equivalence is the assumption that a larger and broader network is better than a smaller one (Lazarus & Folkman). Additionally, it is assumed that having a relationship is the same as perceiving/receiving support from it (Lazarus & Folkman). Thus, *socially supportive relationships* may serve as a buffer against the effects of stress and protecting people from some common physical/psychological reactions such as lethargy and/or guilt (House, 1981).

When assessing social support, perceived support is the most proximal feature utilized by an individual as to the level of supportiveness (Lazarus & Folkman, 1984). Vaux (1988) posits the importance of the individual's perception of supportive relationships, and asserts that this follows a long tradition of emphasizing a person's construction of the world. Citing the Roman philosopher Epictetus, Vaux writes, "Men are disturbed not by things, but by the views which they take of things" (p. 16). This has been illustrated in modern times by Gore (1978) who found that unemployed men who *felt* unsupported had higher levels of illness than those who *felt* supported. Similarly, G. Andrews, Tennant, Hewson and Schonel (1978) found that psychological impairment in a crisis was associated with low levels of expected support from friends, relatives and neighbors. Network measures were unrelated to the impairment (Andrews, G. et al.). The basic assumption put forth by Lazarus and Folkman is that "people will have better adaptational outcomes if they receive or *believe that they will receive* social support when it is needed" [italics added for emphasis] (p. 259).

In general, social supports comprise a 2X3 matrix consisting of two modes and three functions of social support (Vaux, 1988; Zarit, Pearlin & Schaie, 1993). Modes of social support (i.e., the individual, agency, etc. providing the support) may consist of informal and/or formal sources (Zarit et al.). Informal sources of support may include partners, family, friends, neighbors and similar non-professional helping sources. Formal sources include professionally trained individuals such as social workers, nurses, and physicians, as well as larger organizational structures such as homeless shelters, drug treatment programs and respite care. A unique support form which possesses some qualities of each is the Church (or any place of worship). As such, direct interaction with clergy may be categorized within the realm of formal support, as they possess special training and knowledge. However, support from an individual's level of spirituality (i.e., his/her personal relationship with God), or derived from interacting with other members of the congregation would be considered informal.

Although various functions of social support have been identified in the literature, three categories are most consistently highlighted. They are emotional, informational and tangible support functions (see Gottlieb, 1981 or Lin, 1986 for a typological review). It is important to note that these functions are not mutually exclusive, and all can be provided from one individual source (Lazarus & Folkman, 1984). Emotional support is provided to an individual to enhance his/her emotional strengths, and shows that the person is accepted and valued. This has also been called expressive support and esteem support. Informational support is helping the individual to define and understand the problem in order to be better able to cope. It is also known as advice and appraisal support. Tangible support is the provision of financial aid, material resources and other concrete services. This can include respite care type services that contribute to providing the person with additional time to address the stressful event. It is also known as instrumental support.

Social support is an integral component of the Stress-Coping Model, with variations widely used to describe the coping behaviors of persons with a variety of health/mental health circumstances; including, but not limited to – aging (Costa & McCrae, 1993); cancer (Roberts, Cox, Shannon & Wells, 1994); chronic illness (Felton, Revenson, Hinrichsen & Gregory, 1984; Taylor & Aspinwall, 1993); decision-making (Janis, 1993); mental health problems (Billings & Moos, 1984; Farhall & Gehrke, 1997; Rabkin, 1993); substance abuse problems (Moos, 1992); and HIV/AIDS (Hansell et al., 1998; Hansell et al., 1999; Wiener, Theut, Steinberg, Riekert & Pizzo, 1994). It has also been used to help explain the impact of environmental stressors such as – disasters (Weisaeth, 1993); divorce (Nelson, 1989); migration (Shuval, 1993); peer pressure (Wills, Vaccaro & Benson, 1995); stressful jobs (Ramathan, 1995); war (Milgram, 1993); and the daily decisions of very young children (Kliewer, Fearnow & Walton, 1998). Proponents of the model suggest that it can be used to better understand coping under life situations that produce measurable levels of stress (Moos, 1997). However, within the pediatric HIV/AIDS literature there has been little published research that investigates the impact of caring for a child infected/affected by HIV/AIDS (Sherwen & Boland, 1994; Taylor-Brown & Kumetat, 1994; Cohen, F., 1994; Janson & Ammann, 1994).

USE OF THE STRESS-COPING MODEL WITH OTHER POPULATIONS

Social support in one form or another is utilized by individuals of all race and ethnicities in a variety of stress situations. However, cultural differences in social support utilization patterns have been found. The importance of informal support systems among African-Americans, especially familial, is well documented in the literature (W. Hays & Mindel, 1973; Martineau, 1977; Neighbors & Jackson, 1984; Stack, 1974). Extended family members as a means of social support is a more salient structure for Black families than it is for Whites (W. Hays & Mindel; Hunter, 1997). W. Hays and Mindel report that Black families interacted with extended kin more and perceived all kin as more significant in their lives than their White counterparts, except for parents (which were considered equally important by Blacks and Whites). They contend that Black individuals rely more heavily than White individuals on a wider network of relatives as sources of support during times of crisis (W. Hays & Mindel). Other minorities such as Hispanics, Central-American Immigrants and Japanese, who may see the majority-focused external environment as hostile, also turn frequently to this natural helping system to fulfill their emotional and tangible needs (Leslie, 1992; Hanline & Daley, 1992; Koyano, Hashimoto, Fukawa, Shibata & Gunji, 1994).

One of the primary responsibilities of any family is the care and nuturance of its children. As such, there are two main types of stress experienced by primary caregivers of children; those associated with ‘normative’ child-related tasks (i.e., minor daily hassles), and those imposed through a major life event such as a childhood illness or disability (Breslau & Davis, 1986; Breslau, Staruch & Mortimer, 1982; Crnic & Greenberg, 1990; Garner & Thompson, 1978; Kovacs & Feinberg, 1982; Pless & Satterwhite, 1975). Crnic and Greenberg posit that the frustration experienced by parents through daily hassles, although singularly may have little significance, can cumulatively become a meaningful stressor for the parent without appropriate social support. Spousal, friendship and community support acted to moderate the daily hassles of mothers in the study (Crnic & Greenberg). Other situational/environmental stressors that affect the parenting role may also include (but are not limited to): single parenting (Weinraub & Wolf, 1983, as cited in Crnic & Greenberg); poverty/low SES (Werner & Smith, 1982, as cited in Crnic & Greenberg); and number of children in the home (Crnic & Greenberg).

Despite the love and affection felt for a child, caregivers of children with a chronic and/or terminal illnesses continue to face an onerous task. As treatment protocols have advanced, once life-threatening and debilitating illnesses such as cancer and diabetes have resulted in longer life expectancies for afflicted children. Unfortunately, the child’s health improvements may not be complete. Thus, parents may be faced with on-going therapeutic responsibilities, concerns about the child’s future, and the new unknown course of the illness (Avison, Turner, Noh & Speechley, 1993). For children with cancer, perceived social support by parents was an “extremely important predictor of distress” (p. 91), and, although a moderating effect was not found, “these resources do seem to play some role in reducing the effects of the chronic strains associated with giving care” (Avison et al., p. 92).

Although there are important differences, living with cancer has several similarities to an AIDS diagnosis (which many times includes cancer). There are fears of contagion, appearance changes, associated stigma and other stressors (DiMatteo & Hays, 1981; Revenson, Wollman & Felton, 1983). This is especially true for women with breast cancer, with the “emotional trauma that results from the diagnosis and treatment…as potentially damaging as the disease itself” (Roberts et al., 1994, p. 158). Post-operative breast cancer patients with higher levels of perceived support had fewer reported adjustment problems than those with lower levels of support (Northouse, 1988). In addition, Peters-Golden (1982) and Funch and Mettlin (1982) also found that social support was positively related to psychological adjustment in breast cancer survivors.

Another area that has explored the stress-social support relationship is the mental health field. Erickson (1968) explained similarities he found between MMPI profiles of parents of persons with emotional disturbances and parents of persons with mental retardation. This was the first time someone had used a stress-related concept to explain the impact of mental illness on family caregivers. This development was significant, as it demonstrated that the problems that caregivers develop are a direct result of stress caused by the impact of the care recipients’ mental health problems. Research in this vein has gone a long way in reducing stigma and blame for caregivers and in improving services for mental health consumers and their families (Biegel, Farkas & Flint, 1989; Biegel, Milligan, Putnam & Song, 1994; Biegel, Sales & Schulz, 1991; Bulgar, Wandersman & Golman, 1993; Friesen, 1996; Potsazanik & Nelson, 1984).

Although families have been the first line of support for ill members since antiquity, they were often thought of by professionals as part of the problem rather than as part of the solution. For example, the concept of the schizophrenogenic mother (i.e., that a particular pattern of bad mothering causes schizophrenia) has no basis in fact.

Indeed, parents/caregivers may relate to the schizophrenic child differently, but this is probably a reaction to the child's disorder. Parenting style is not a fundamental cause of schizophrenia. However, as a result of the body of research outlined, families are now seen as a source of strength and support for individuals suffering from a variety of maladies rather than as a casual factor in the development or exacerbation of the illness (Solomon, 1994). In addition, as medical budget strains have occurred, the focus has shifted to have caregivers provide care for their family members; however, these duties have brought additional stress and burden on these families members as they provide this care. It is this “caregiver burden” and its impact on the caregiver that is now the focus of study – albeit with the child and caregiver’s HIV status as the stressor.

USE OF THE STRESS-COPING MODEL WITH THE ADULT HIV/AIDS POPULATION

Within this literature base, various permutations of stress-based coping models have been used to conceptualize the impact of becoming HIV positive or receiving an AIDS diagnosis on either the infected individual or other family members, as well as the effects of social support upon the caregiver and/or the afflicted individual. Many phenomenon often associated with burden are incorporated into these studies - issues such as financial problems, increased stress, social stigma, depression, anxiety, and even tobacco use are measured and discussed.

A diagnosis of AIDS can have a devastating effect on an individual’s support system, precisely at the time when stress is greatest. In addition to alterations to one’s life due to medical regimes, bodily changes and potential ostracism, feelings of guilt, loss, fear of death and rejection are a few of the stressor experienced (Macks, 1987). The disclosure of AIDS may serve to destroy previously supportive relationships. Gay individuals may have to ‘come out’ to parents and other family members, and partners/spouses of HIV positive individuals may themselves be positive through exposure by their loved one. Therefore, “the couple must deal with the impact of AIDS on their relationship as well as the uncertainty of the partner’s or spouse’s future health” (Macks, p. 33).

One of the earliest looks at the application of the stress-coping model to the AIDS population was conducted by Zich and Temoshok (1987). They found the diagnosis of AIDS to be a significant stressor. However, all types of social support were inversely correlated to the HIV positive individual’s level of hopelessness and depression, such that the more social support received the less hopeless and depressed the individual may be (Zich & Temoshok). It is reported that study participants found social supports helpful throughout the entire process, with lovers, family and friends critical in maintaining functionality (Zich & Temoshok). Similar results can be found throughout the AIDS literature (Hall, V., 1999; R. Hays, Turner & Coates, 1992; Ingram, Jones, Fass, Neidig & Song, 1999; Leserman et al., 1999; Namir, Wolcott, Fawzy & Alumbaugh, 1987).

It is important to note a significant limitation when reviewing the social support literature on adults infected by HIV/AIDS. Thus far, the emphasis has been on White, middle class, gay males (Barbee, Derlega, Sherburne & Grimshaw, 1998). Barbee and colleagues only found two studies examining Black gay men and one that included women in the sample. This investigator was able to locate two additional articles either focusing solely on Black gay men or comparing them to their White counterparts (Gant & Ostrow, 1995; Ostrow et al., 1991). However, to date, it appears that there are still no articles that have focused solely on women within a stress-coping paradigm outside of their roles as caregiver. Nor is there any research solely focusing on other groups such as Hispanics and straight men. Given the literature citing the importance of family support among African-Americans, Gant and Ostrow were surprised to find only a weak, nonsignificant relationship between family support and mental health. They posit that one explanation may be that traditional measures may not be sensitive to the various dimensions of familial support utilized by African-Americans (Gant & Ostrow). Therefore, it may be found that different stress-social support relationships exist for people of color, people from lower SES, heterosexuals and women.

Although differences exist due to culture, gender, SES, sexual orientation and other factors, there may be challenges that are common to all caregivers. In a recent study of caregivers of persons with AIDS (PWA's), decreases in work performance and economic burden were common stressors that were not unusual for many caregiving experiences (Raveis & Siegel, 1990). Caring for an individual infected with HIV/AIDS also possess several unique characteristics such as uncertainty, multiple premature losses and stigma by association (Brown & Powell-Cope, 1991) that Goffman (as cited in Turner, Pearlin & Mullan, 1998) terms "courtesy stigma" (p. 138). Unfortunately, because of these stressors, both common and unique, the acquisition and use of social support for AIDS caregivers may prove difficult. Indeed, Turner and her colleagues found that close to half of their respondents received no informal assistance with caregiving tasks, and over 14% felt that they had no confidant to turn to when feeling overwhelmed. Interestingly, HIV positive caregivers perceived greater support from family and friends than those caregivers that were HIV negative.

It is clear that HIV positive individuals, as well as their caregivers, are under an enormous burden due the variety of stressors present. As such, within this model, the positive diagnosis and the subsequent care-related behaviors by the caregiver serve to increase the caregiver's stress. This stress, in turn, has an impact on the caregiver - both in the behaviors they use to cope with their loved one's illness and through direct impacts to their own physical and mental health. Social support, encompassing the source and functional range, can assist in alleviating feelings of helplessness, depression and isolation. However, many of these stresses may be heightened when caring for an infected/affected child. Mothers and other caregivers must face challenges parenting children who may lose, in addition to their own life, multiple family members. Family placement decisions must be considered, as well as school issues and developmental milestones. Events such as childhood playdates, which other families take for granted, can be impossible for those families isolated due to societal fear. The next section will review the relevant literature addressing the experiences of those individuals caring for a child infected/affected by HIV/AIDS, as well as their methods of coping with the multitude of stressors present.

USE OF THE STRESS-COPING MODEL WITH THE PEDIATRIC HIV/AIDS POPULATION

Although pediatric HIV/AIDS had been acknowledged as early as 1982, psycho-social research examining the effect upon caregivers of children infected/affected by HIV/AIDS did not emerge in the literature until 1992 – ten years later (Caldwell & Rogers, 1991; Mayers & Spiegel, 1992). Since that time, the literature has averaged one qualitative journal article per year (n=9), and less than one quantitative article (n=6) each year (the first published in 1994).

Given the immensity of this problem for thousands of families, it is difficult to imagine such a lack of attention by the professional community. However, Dr. Phyllis Hansell, Professor and Acting Dean of the College of Nursing has confirmed this paucity of research at Seton Hall University. In a personal communication (December 3, 1999), Dr. Hansell, who has authored or been affiliated with 4 of the 15 published articles, acknowledged the lack of, and further need for, research on this topic area.

Initial research focusing on caregiver’s of children infected/affected by HIV/AIDS followed the logic of the Stress-Coping theory and discussed stress in terms of a reaction to a positive diagnosis, with more recent literature integrating the concept of social support. However, due to the statistical models utilized, only the main effect of social support upon the caregiving relationship has been explored, with none having done so in a moderating capacity. Some critics of the theory’s utilization with the HIV positive population posit that the stressful impact of caregiving is not being caused by the stress of caring for an ill child, but instead uses the concept of race, poverty and other stressors to describe a pre-existing condition that is exacerbated by this disease (Kalichman, 1998). Kalichman highlights studies that have found that a diagnosis of HIV is not listed as the top stressor for infected adults, and that other more pressing needs must first be met such as housing, food, etc. F. Cohen, Nehring, Malm and Harris (1995) posit that, “it is *possible* that the extent of further family disruption caused by HIV disease may not be as readily apparent or is experienced differently because of other concomitant stresses and disruptions due to the conditions and struggles of everyday existence” [italics added] (p. 253). However, they argue that without further research into this area focusing on the mother (caregiver)-child relationship, as well as the entire family system, these questions will go unanswered (Cohen, F. et al.). In an attempt to address the various questions regarding the effect of caring for a child who is infected/affected by HIV/AIDS, the existing qualitative and quantitative studies will be examined, with relevant findings highlighted and the strengths and limitations discussed.

Caregivers of Children Infected and/or Affected by HIV/AIDS - Qualitative Studies

The first article focusing on the stress of caring for a child infected by HIV/AIDS, a qualitative article published in *Health and Social Work*, described a parental support group to prevent social isolation due to the lack of available social support (Mayers & Spiegel, 1992). The authors found isolation from family, friends, and even the medical staff to be a recurrent theme throughout the group meetings. In addition, during those times when support could be found, topics such as death were off-limits “...consequently [the mother] avoided these friends to keep from burdening them” (Mayers & Spiegel, p. 189). This sense of isolation permeates the literature, with the need for social support cited as one of the top concerns of caregivers of children infected/affected by HIV/AIDS (Hackl et al., 1997; Heath & Rodway, 1999; Mayers & Spiegel; Wiener, 1998).

For many HIV negative caregivers, the task of caring for an infected child is a new experience requiring substantial role redefinition and adjustment (Hansell et al., 1999). However, when compared with uninfected caregivers, HIV positive mothers reported higher incidences of isolation, as well as fewer financial and support resources (Hackl et al., 1997; Mellins & Ehrhardt, 1994). Hansell and her colleagues also found that HIV positive mothers presented with multiple and more complex problems than their HIV negative counterparts.

In an examination of the mother-child relationship, S. Andrews, et al. (1993) reported that one-third of the respondents to their qualitative interview relied on their children (16+ years old) as a source of support (Andrews, S. et al.). Eight percent stated that they also relied on their younger children (under 16 years old) (Andrews, S. et al.). As such, children not only take but are also good at offering affection to their caregivers. One mother states, "If I didn't have my kids, I'd be dead by now"…another tells of her son, "If I'm crying, he'll come up to me and ask me 'What's wrong mommy?" (Andrews, S. et al., pp. 195 & 196). Many HIV positive mothers described having a very special relationship with their child, with this special bond acknowledged throughout the literature (Andrews, S. et al.; Caliandro & Hughes, 1998; Cohen, F. et al., 1995). At the same time, several HIV positive mothers viewed the role of motherhood as burdensome, whether or not the child was HIV positive (Andrews, S. et al.).

Illness management was listed as a major stressor, including multiple hospitalizations and juggling outpatient visits (Caliandro & Hughes, 1998; Mellins & Ehrhardt, 1994). This was especially burdensome for children placed with foster families, who, as a group, were much sicker than children still living with their birth mothers (Cohen, F. et al., 1995). Communicating with health care providers and social service agencies proved to be stressful, with "health care providers that are supposed to know about [AIDS] and are in the field giving services…Well, they turn their noses up at us and they're insensitive to our needs and to what the sickness can do" (Mellins & Ehrhardt, p. s56).

Subsequent qualitative articles have identified respite care to be an important source of support for caregivers attempting to juggle medical appointments. In addition, managing multiple medical appointments was identified as “a problem for seropositive mothers, especially when the child is also seropositive” (Andrews, S. et al., 1993, p. 197; Mellins & Ehrhardt, 1994). It was the most frequently cited need, with parents having very little time to meet their own needs (Mellins & Ehrhardt).

Mellins and Ehrhardt (1994), stating that its role within their sample of inner-city families could not be 'overemphasized', highlighted the role of religion as a coping strategy. Many grandmothers expressed a realization to their limits, and found comfort in placing faith that the health of the child was in ‘higher hands’ (Caliandro & Hughes, 1998). Caliandro and Hughes assert that “being strong and able to cope with problems were clearly linked to their strong spirituality” (p. 110). This theme was also present in Heath and Rodway’s (1999) findings, with the issue of spirituality emerging from the qualitative data and two respondents describing a deepening of their beliefs since diagnosis.

It is important to acknowledge the limits of these studies. Several of the samples were quite small, ranging from 3 to 80 people, as listed in Table 3 below. However, the recurrent themes among the articles help lend strength to the overall findings of the articles. The studies profiled illuminate the many challenges faced by caregivers, as well as provide some insight into ways to alleviate some of the stress. The sense of isolation and need for support ties this body of work together in a tapestry that shows the burden perceived by all caregivers, whether foster/adoptive parent, grandparent or birth parent. Despite the rich information provided, none of the studies utilized comparative data to determine if these stresses were truly a result of caring for an HIV positive child, or an artifact due to other factors. Also, the studies as a group did not clearly explain the 'researcher/interviewer as instrument'. As such, the researcher's own reference frame (i.e. gender, race, etc.) should be discussed, as well as any special training received, to explain and reduce the potential influence of personal bias. To that end, there is no mention made regarding the interviewers utilized to conduct the semi-structured interviews in 6 of the 9 studies. Lastly, although several of the studies alluded to the potential moderation of stress through the provision of social support, Hansell and her colleagues (1999) assert from their findings that "stress…for the seropositive caregiver of a child with HIV/AIDS is not significantly buffered by the increased levels of social support" (p. 301). However, this overgeneralization is not warranted from the type of analysis provided.

Table 3: Qualitative Studies – 1992 to Present			
#	***Author(s)***	***Year***	***Methodology***
1	Mayers & Spiegel	1992	Overview of support group for parents and caregivers of HIV infected children. (n=30 families with 35 infected children)
2	Andrews, Williams & Neil	1993	Two semi-structured interviews. HIV positive mothers who have had at least one pregnancy while seropositive. (Interview #1, n=80; Interview #2, n=20)
3	Mellins & Ehrhardt	1994	Semi-structured interviews of caregivers, siblings and HIV infected children. (n=52 participants comprising 25 families)
4	Cohen, F., Nehring, Malm & Harris	1995	Semi-structured interviews of caregivers of an HIV positive child under 3 years of age. (n=8, 4 birth families and 4 foster families)
5	Hackl, Somlai, Kelly & Kalichman	1997	Semi-structured interviews of HIV positive women. (n=8; 7 of the 8 were mothers)
6	Wiener	1998	Overview of telephone support group for mothers whose children have died form AIDS. (n=5)
7	Caliandro & Hughes	1998	Phenomenological interviews of grandmothers caring for an HIV positive grandchild. (n=10)
8	Heath & Rodway	1999	Open-end questionnaire (n=12) and semi-structured interviews (n=6) of HIV positive women. (9 of the 12 were mothers)
9	Hansell, Hughes, Caliandro, Russo, Budin, Hartman & Hernandez	1999	Case examples described to profile social support program. (n=3)

Caregivers of Children Infected and/or Affected by HIV/AIDS - Quantitative Studies

Utilizing a non-random sample, Hardy and her colleagues (as shown in Table 4 below) examined the coping strategies of parents with children who were either HIV positive, diagnosed with cancer, or healthy (Hardy, Armstrong, Routh, Albrecht & Davis, 1994). The researchers used a cross-sectional, comparison/control group design, with 20 children in each group. Social support was found to be non-significant across groups utilizing ANOVA and multiple regression analyses, although the social support variable utilized had no distinction made for the range of potential support sources and functions.

In fact, the only significant finding was that the caregivers of HIV positive children exhibited significantly more wishful thinking then members of the other groups (Hardy et al., 1994). However, it is important to note that the groups contained some significant differences which may have confounded the findings such as ethnicity (more White caregivers in the cancer group), partnered (more married people in the cancer group), SES (higher SES in the cancer group), and foster care status (half of the children in the HIV group were in foster care, while none of the others were) (Hardy et al.). Other potential limitations included a moderate sample size with no mention of statistical power, potential violations of the underlying assumptions of the analysis or the psychometric properties and applicability to this population.

Similar findings were reported by Wiener et al. (1994), with no significant differences found on scores of depression or self-blame in their sample of 101 HIV positive and negative caregivers of HIV positive children. Significant differences were noted for HIV negative caregivers who had higher anticipatory grief scores, and HIV positive caregivers who reported higher anxiety scores. The authors believe that this may be due to the non-infected caregivers accepting the idea of having to live without the child, while the infected parents experience heightened anxiety as they may have to face placing the child due to their own failing health (Wiener et al.). Surprisingly, no relationship was found between parents scores and the child's degree of debilitation, until the child was extremely ill (Wiener et al.). It is hypothesized that this may be due to the illness/recovery pattern experienced by the parents, and the defense mechanism which protects them from this 'emotional roller-coaster' until death is imminent (Wiener et al.). Social support was not examined in this study. The article did not state if the measures utilized were standardized on this population or diagnostic calculations were conducted to determine the appropriateness of the data.

In their first study, Black, Nair and Harrington (1994), compared four groups of caregivers (HIV positive with intervention, HIV negative with intervention, HIV positive with no intervention, and HIV negative with no intervention) and reported no main effects for child abuse potential, stress, support or functioning related to the child's HIV status. The study only identified support as informal or formal, with no descriptions as to specific sources or support tasks needed. In addition, as illustrated in Table 4, the study utilized a relatively small sample and made no mention of potential statistical violations such as homogeneity of variance. Their second study examined social support and maternal HIV status. Support was dichotomized as high/low, with no consideration of source or function, and there were no main or interaction effects noted for the measures. However, utilizing videotaped mother-child interaction sessions, the authors found that HIV positive mothers with higher support were more involved with their infants during feeding (Black et al.). The researchers acknowledge the limitations of their study, stating that they "cannot be sure that the scales were valid measures of the constructs under consideration" (Black et al., p. 610). They further assert that future studies should examine support more carefully (Black et al.).

The theoretical framework utilized by Hughes and Caliandro (1996) was a melding of Lazarus and Folkman's work on stress theory, Vaux's theory of social support, and the theory of caregiver appraisal posited by Lawton, Kleban, Moss, Rovine and Glickman. The study's purpose was to examine the effect of caregiver stress, social support, and level of child illness on the caregiver's appraisal of the situation (Hughes &

Caliandro). No differentiation of social support was made for sources and/or functions, although its global identification was a significant predictor of caregiver appraisal. Surprisingly, the child's level of illness (according to the CDC guidelines) was not significant (Hughes & Caliandro). The authors contend that children, even though classified as asymptomatic, may have a spectrum of health-related difficulties, and, conversely, a child classified as symptomatic may not be perceived to be ill within the caregiver's perception (Hughes & Caliandro). They believe that children identified by the CDC's classification schema are not properly categorized due to these spurious influences that may have skewed the results. Lastly, the researchers make no mention of potential limitations such as the utilization of a small sample, no mention of statistical power, potential violations of the underlying assumptions of the regression analysis, or the potential interaction effects of the variables posited by the theories used.

Utilizing a convenience sample of HIV positive and negative caregivers of infected children, Rose and her colleagues attempted to examine their coping styles within the Lazarus and Folkman framework (Rose, M., & Clark-Alexander, 1998). Social support was measured using a seven question scale with questions such as, "How lonely are you?" (p. 60). These questions were further divided into measures of support from family and friends, with HIV negative caregivers perceiving significantly stronger support from both sources (Rose, M., & Clark-Alexander). In addition, 80% of the sample used prayer as a method of coping with the stress of caring for an HIV positive child (Rose, M., & Clark-Alexander). The authors, citing Lazarus and Folkman's theory, conclude that improved coping skills, including increased social support, will affect healthy outcomes (i.e., buffer the stressful events) (Rose, M., & Clark-Alexander).

However, interactions were not utilized, nor was there evidence of having tested the potential violation of statistical assumptions, such as normality and equality of variance for the ANOVA model used. As a result, it is unknown whether harmful problems were present which may have led to biased findings. Lastly, bivariate analyses can demonstrate significant differences on the measures between groups, yet can not prove the causality inferred (Rose, M., & Clark-Alexander).

A subsequent study also exploring the relationship of social support to caregiver outcomes utilized an intervention to ‘boost’ the availability and utilization of social support. This intervention, which was found to be partially effective, used a modified case management approach to reduce stress by enhancing the social support network (Hansell et al., 1998). Utilizing a four group design (HIV positive with intervention, HIV negative with intervention, HIV positive with no intervention, and HIV negative with no intervention), the researchers examined the effect of the intervention on levels of stress, coping and social support over a 6 month period.

After conducting the appropriate diagnostics tests to ensure the appropriateness of the data, repeated measures MANOVA revealed no statistical differences on levels of stress and coping. However, there was a statistically significant increase over time in the HIV negative experimental group’s scores. Although the stress, coping and social support scores for both HIV positive groups were worse than both HIV negative groups at both time points, the HIV positive experimental group’s social support score dropped to the lowest of all four groups after the intervention (Hansell et al., 1998). This confounding effect has lead to criticism of their conclusions (Eldredge, 1998). Lastly, the authors conclude that the “results are not conceptually congruent with the work of

Lazarus and Folkman (1984) relative to the interactive theory of stress as to the buffering effect of social support on stress by enhancing coping" (Hansell et al., p. 85). Yet, this conclusion is not possible given the lack of testing for possible interactions.

Table 4: Quantitative Studies - 1994 to Present

#	*Author(s)*	*Year*	*Methodology*
1	Hardy, Armstrong, Routh, Albrecht & Davis	1994	Examined parental coping strategies using comparison/control groups. (n=20 HIV positive children; n=20 child with cancer; n=20 healthy children) Analysis: ANOVA, multiple regression (no interactions)
2	Wiener, Theut, Steinberg, Riekert & Pizzo	1994	Psychological adaptation of caregivers of HIV positive children. (n=101) Analysis: t-test, ANOVA
3	Black, Nair & Harrington	1994	Two studies Examining whether support could offset stress of HIV positive mothers (n=43; n=199) Analysis: t-test, MANCOVA, Repeated Measures MANCOVA (with interactions)
4	Hughes & Caliandro	1996	Relationship between social support, stressors and burden for caregivers of children with AIDS (n=49) Analysis: correlations, multiple regression (no interactions)
5	Rose, M., & Clark-Alexander	1998	Coping and quality of life of caregivers of children with HIV/AIDS. (n=79) Analysis: ANOVA
6	Hansell, Hughes, Caliandro, Russo, Budin, Hartman & Hernandez	1998	Effect of social support 'booster' on levels of stress, coping and social support (n=70) Analysis: Repeated Measures MANOVA (no interactions)

Overall, these studies demonstrate the various strains experienced by caregivers of children infected by HIV/AIDS and lay a foundation for further research into this area. However, each possessed numerous flaws which make the findings questionable such as the use of measures not created or standardized for this population, not conducting factor analysis to determine validity of the measures with the samples, small to moderate sample sizes that may impact the power of the statistical analyses and introduce potential bias, findings regarding the value of social support are mixed and differ from those found in the qualitative research, limited utilization of the various sources and functions of support as an independent variable, discussing (or alluding to) the buffering effect of social support without using the appropriate analytical techniques for testing, and, lastly, one-third of the studies only used bivariate statistics in their analyses.

As discussed, there have been several common streams of research within HIV/AIDS and its impact on children and families. However, the available literature lacks well-developed empirical studies regarding the child's infection status and illness management tasks upon the caregiver's stress and coping responses, and the subsequent effect of various social support mechanisms (Sherwen & Boland, 1994; Sherwen & Tross, 1995). The majority of the empirical studies have not adequately tested this theory stream, and many others are based more on anecdotal clinical experience and semi-structured interviews. The Stress-Coping model appears to be relatively elastic and have a multitude of applications. It speaks specifically to the issues of this study, examining the stress factors impinging upon those caring for children infected/affected by HIV/AIDS, and the moderating effects of social support upon those factors. The numerous qualitative and quantitative studies within the literature utilize variants of the Stress-Coping framework to explain the stressful impact of caring for a child infected/affected by HIV/AIDS upon the caregiver. The study proposed will attempt to fill in some of the many gaps remaining in the literature.

USE OF THE STRESS-COPING MODEL IN THIS STUDY

Even though the documented problems of children with HIV/AIDS would appear to have obvious impacts for their caregivers, the specific burden related to the illness management tasks of the child and his/her HIV status, as well as the potential buffering effect of social support, has not been fully researched (Cohen, F., 1994; Sherwen & Boland, 1994; Sherwen & Tross, 1995; Taylor-Brown & Kumetat, 1994a; Taylor-Brown & Kumetat, 1994b). The limited research in this area lacks an appropriate theoretical framework, multivariate analysis, and adequate sample sizes (Cohen, F.; Sherwen & Boland; Sherwen & Tross; Taylor-Brown & Kumetat; Taylor-Brown & Kumetat). This study will build upon the previous body of work by providing a larger more representative sample, investigating additional variables not included in prior studies such as various sources of support, using the Stress-Coping model as a single theoretical explanation, and testing relationships among the variables used through the utilization of a multiplicative interaction regression model.

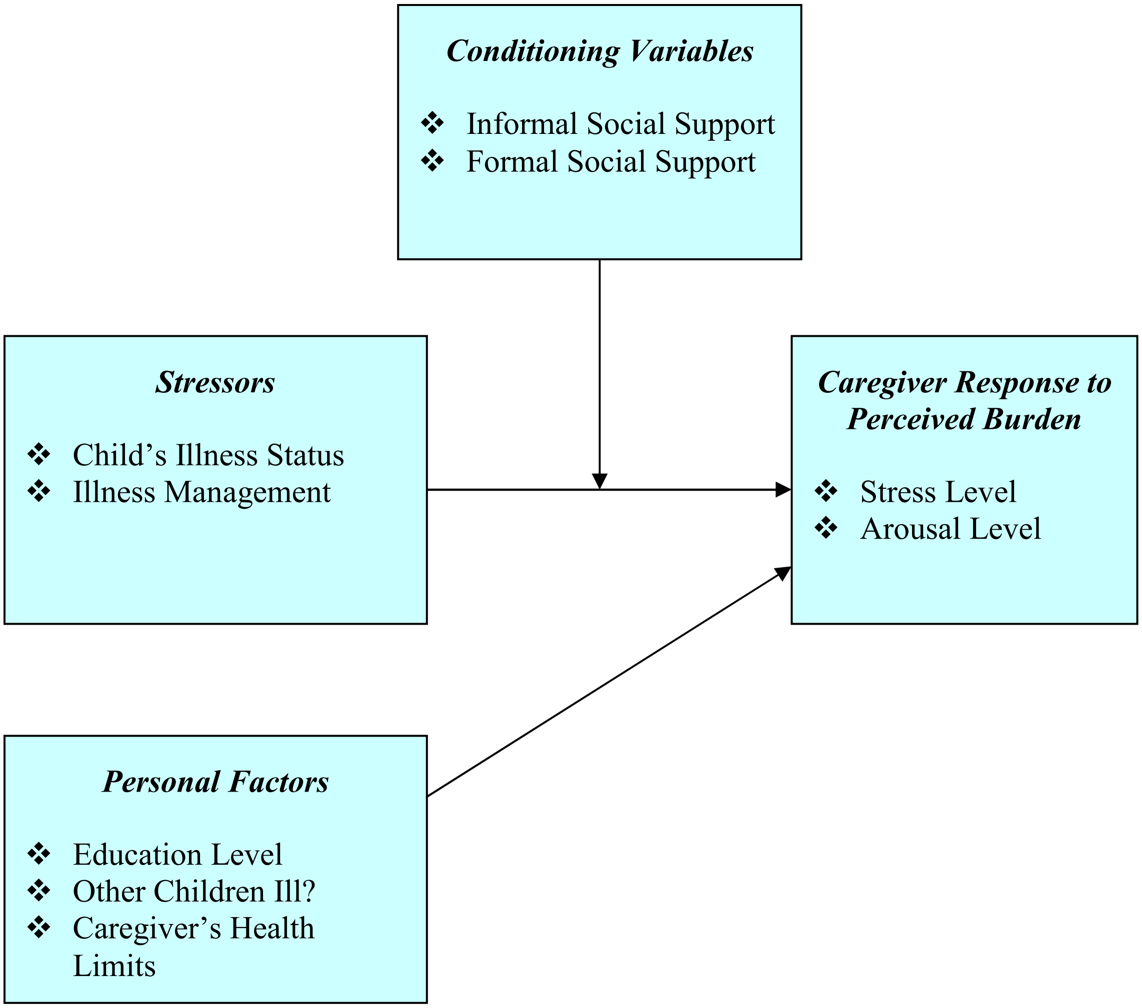
This study will focus on the caregivers of children infected/affected by HIV/AIDS. The purpose of this study is to explore the effects caring for an infected/affected child has on the stress and coping levels of the caregiver. Prior research in this area suggests that these caregivers are subject to burden due to the physical and psychological costs of caring for the infected/affected child. By filling this gap in the literature, this research will lead to a better understanding of caregiver needs and improvements in services to both the families and their ill family members.

The specific Stress-Coping model used in this study is a variation based on the work of Schulz, Tompkins, Wood and Decker (1987). This model is based on their review of the theoretical and empirical literature on caregiving in chronic illness, and encompasses adaptations of this model from the caregiver Stress-Coping models posited by House (1974) and George (1980) (as cited in Schulz et al.). Within the Schulz et al. model, the stressor of the child's illness diagnosis and caregiver illness-related tasks will be used. The impact of the perceived stress will be understood in this study as the level of perceived burden on the family caregiver. This application will also include the conditioning variable of social support, which will buffer the impact of the stressors on the perceived caregiving burden.

Although there are some variants of the Stress-Coping model, due to their common origins there exists consensus regarding the central variables relevant to understanding the phenomenon (Biegel et al., 1991). The central concept of this framework is that the existence of stressors, such as HIV/AIDS in a young child, serves as a source of stress to the caregiver. Within this framework (see Figure A) the independent variables, or stressors, impact the dependent variable of perceived stress. This model also provides for the inclusion of conditioning variables, which can affect the various processes.

Figure 4: Conceptual Model

A variation of the model utilized by Schulz et al. (1987)



Stressors

The underlying assumption of this model is that patient illness and disability represents an objective stressor to the caregiver (Biegel et al., 1991). The illness is typically characterized on any number of dimensions. For example, for caregivers of children infected/affected by HIV/AIDS, it may be on the medical regime and stigma associated with a positive diagnosis. Therefore, the objective factors that evoke the patterned response are referred to as stressors (Selye, 1993). As such, the adaptive response to these objective factors can break down or go wrong because of psychological mismanagement (Selye). The independent variables, or stressors, in this study's model are the child's illness status and amount of illness management tasks. Johnson (1994), examining family's coping, reported that, "There is one common feature [to stress research] the extent and degree of burden appears to be related to the amount of patient dysfunction" (p. 312). Some of the factors that are likely to play a role in creating caregiver stress are the illness prognosis (i.e., terminal) and visibility (i.e., stigma associated with the illness), as well as the level of duties needed to care for the individual (Schulz et al., 1987).

The results of research on the caregivers of HIV positive children, loosely based on the Stress-Coping model, have borne out the tremendous burdens placed on caregivers (Black et al., 1994; Caliandro & Hughes, 1998; Hansell et al., 1998; Hansell et al., 1999; Hughes & Caliandro, 1996; Rose, M., & Clark-Alexander, 1998; Wiener, 1998). Within the Stress-Coping framework, the impact on caregivers is usually conceptualized as a reaction to the stress of caring for the sick child, as well as the additional burden of self-care – as in the case of infected mothers. Further, for many HIV negative caregivers the task of caring for an infected child is a new experience requiring substantial role redefinition and adjustment (Hansell et al.).

In addition, within this framework, the ill child's symptomatology has an effect on the caregiver, which in turn leads to the outcomes of stress and/or coping. These illness management tasks, including multiple hospitalizations and juggling out-patient visits, were listed as a major caregiver stressor (Caliandro & Hughes, 1998; Mellins & Ehrhardt, 1994). This was especially burdensome for children placed with foster families, who, as a group, were much sicker than children still living with their birth mothers (Cohen, F. et al., 1995).

Thus, as discussed above, the association between these two factors and perceived caregiver burden has been documented in the literature - with a clear and strong positive relationship between the stressor and response to the perceived burden. However, it is important to note that, as posited by the theory, conditioning variables can moderate this stress and assist in supporting coping behaviors (Cobb, 1976; Cohen, S., & Wills, 1985).

Conditioning Variables

Conditioning variables are contextual or situational variables that moderate the caregiver response to the perceived burden (Biegel et al., 1991). Social support has always been a part of this equation, having its earliest roots in the work of Durkheim (as cited in Waltz, 1994). As such, social support variables have an indirect effect on caregiver well-being in that they influence the individual's perception of the burden (Schulz et al., 1987). Within this study, social support will be defined as interactions, either emotional, task or informationally oriented, with other individuals and/or groups that provide assistance and validation (Selye, 1993).

The social support variables discussed below will be utilized as buffers to the effects of the stressors on the response to the caregiver's perceived burden. There is some evidence of the power of social support as a conditioning variable for the burden of caring for a child infected/affected by HIV/AIDS (Hackl et al., 1997; Hansell et al., 1998; Hughes & Caliandro, 1996; Mayers & Spiegel, 1992). Social support variables have been found to alleviate some of the burden placed on caregivers, although the buffering effects of these variables may not be as available to birth mother caregivers due to the stigma sometimes placed upon them by traditional sources of support. As such, two social support variable groups in this model will be explored as potential buffers to the effects of the stressor – informal and formal social supports, with the contributions of various sub-sources examined.

The first group of conditioning variables, informal social supports, includes those factors traditionally sought out as the primary line of defense against stressors (Gottlieb, 1988). Sources included are family, friends, children, community connections and church/spirituality.

Family. Emotional support, in particular, is provided primarily by those individuals possessing qualities such as trust and intimacy. Pearlin et al. (1981) posit that this is commonly found in married (or partnered) relationships. Although recognizing that this is not always the case, they argue that "marriage is an institution distinguished by its potential for being a continuous reservoir of emotional support, and, consistent with the findings from other research, we have sought to incorporate [this]…in our measure of support" (Pearlin et al., p. 347). Generally, spousal support for breast cancer patients is positive and beneficial, with the patients husband the most pivotal person in the support network (Funch & Mettlin, 1982; Lichtman, Taylor & Wood, 1987; Roberts et al., 1994). Support from other family members has also been shown to contribute to the adjustment of individual's caring for individuals with HIV (Greif & Porembski, 1988). In addition, Lichtman et al. found high support from family correlated positively with psychological adjustment of cancer patients.

Friends. Social isolation permeates the literature, with the need for social support cited as one of the top concerns of caregivers of children infected/affected by HIV/AIDS (Hackl et al., 1997; Heath & Rodway, 1999; Mayers & Spiegel, 1992; Wiener, 1998). Mayers & Spiegel found isolation from family, friends, and even the medical staff to be a recurrent theme throughout the group meetings. However, when available, Lichtman et al. (1987) found that when provided, high support from friends for breast cancer survivors assisted in improving patient psychological adjustment. In fact, Roberts et al. (1994) found that single women with strong support from friends faired as well as married women with support from husbands. Friends are often the main source of social support for women with HIV, as family relatinships may have been severed (McCarroll, 1988; Namir, Alumbaugh, Fawzy & Wolcott, 1989). Friends can offer empathy and shared values, and have been associated with improved psychological adjustment in individuals with HIV (R. Hays, Catania, McKusick & Coates, 1990).

Child. S. Andrews et al. (1993) reported that many caregivers in their study reported receiving support from their children. Many HIV positive mothers described having a very special relationship with their child, with this special bond acknowledged throughout the literature (Andrews, S. et al.; Caliandro & Hughes, 1998; Cohen, F. et al., 1995). Walker (1998) posits that when the danger of loosing a loved one exists, an intense bond may form. She contends that caregivers grapple with the traumatic nature of the illness through this attachment (Walker). Further, women expected children (8 years old and older) to assist with household tasks, including caring for their younger siblings – some with AIDS (Walker).

Community Connections. There is a small, but growing body of literature demonstrating the therapeutic effects of support group for people caring for children and adults with HIV (Grief & Porembski, 1988; Kelly & Sykes, 1989; Mayers & Spiegel, 1992; Pearlin, Semple & Turner, 1988; Wiener, 1998). One of the earliest articles focusing on the stress of caring for a child infected by HIV/AIDS described a parental support group to prevent social isolation due to the lack of available social support (Mayers & Spiegel). Through the commonality of experiences, meeting with others who are caring for children infected/affected by HIV/AIDS can allow the caregiver the opportunity to reflect, express and reconcile feelings in a support community format. Through the group, caregivers are sustained in fulfilling their roles. In a study of professional caregivers of HIV positive clients, George, Reed, Ballard, Colin & Fielding (1993) found that supportive groups effectively buffered stress and improved the quality of the care provided.

Church/Spirituality. Although HIV infection has been met with opposition by many traditional religious institutions, religion/spirituality have been found to be a positive coping support (Leserman et al., 1992; Warner-Robbins & Christiana, 1989; Weitz, 1989). M. Rose and Clark-Alexander (1998) found that the vast majority of their sample used prayer as a method of coping with the stress of caring for an HIV positive child. Mellins and Ehrhardt (1994), stating that its role within their sample of inner-city families could not be 'overemphasized', have also highlighted the role of religion as a coping strategy. Many grandmothers expressed a realization to their limits, and found comfort in placing faith that the health of the child was in ‘higher hands’ (Caliandro & Hughes, 1998). Caliandro and Hughes assert that “being strong and able to cope with problems were clearly linked to their strong spirituality" (p. 110). This theme was also present in Heath and Rodway's (1999) findings, with the issue of spirituality emerging from the qualitative data and two respondents describing a deepening of their beliefs since diagnosis.

The second conditioning group of variables is formal social support provided by professionals such as doctors, social workers and home health aides, that have also been shown to be important to this process.

Formal Service Support. Although some practitioners still admit to being very fearful and uncomfortable working with PWAs, many caregivers report satisfaction with their relationships with professionals. However, a significant minority has voiced concerns about these relationships (Biegel, Song & Milligan, 1995). Concerns about these relationships are both attitudinal (i.e. caregivers do not want to be stigmatized) and behavioral (caregivers strongly desire a mutual working-partnership with professionals and are dissatisfied when these do not occur) (Solomon, 1994). Some often feel blamed by professionals for their relative's illness – which is an especially sensitive area when working with birth mothers, who *are* the agent of infection for the majority of children. Other caregivers complain about the lack of practical information provided about their relatives' illness and care (Biegel et al.; Francell, Conn & Gray, 1988; Solomon, 1994).

Caregiver Response to Perceived Burden

The most frequent outcome measure utilized in Stress-Coping research is the level of perceived burden by the caregiver in response to the stressors (Biegel et al., 1991). Burden, as defined by Webster's Dictionary (2000), is "that which is borne or carried; a load" (p. 1). Applied to this study, it can be translated to indicate the caregiver response due to the impact of the child's positive HIV diagnosis and the time spent in illness-related tasks. This response can take two co-existing forms: stress – the internal response (positive/negative) to the perceived favorability of the external environment; and, arousal – the active response (positive/negative) to the perceived favorability of the external environment (Cox & Mackay, 1985; King, Burrows & Stanley, 1983; Mackay, 1980; Mackay, Cox, Burrows & Lazzerini, 1978). Thus, the perceived caregiver burden is defined as the cognitive (internal) and behavioral (active) responses caused by caring for a child infected/affected by HIV/AIDS.

The Stress-Coping model suggests that the stressor of child's health status, as well as the level of illness management tasks, will lead to the elevation of stress and arousal levels among caregivers. King et al. (1983) posit that, although distinct factors, stress and arousal tend to be raised in unison. This relationship is both direct and positive (i.e., the higher the level of given stressors, the higher the level of stress among caregivers). It is further posited that as the stressors increase there will be an increase in the caregiver's active coping response, sometimes referred to as their 'fighting spirit', that has been correlated with improved health and self-esteem (Leserman et al., 1992). This active response has also been shown to be strongly associated with perceived satisfaction with social support (Namir et al., 1987). This relationship is also direct and positive (i.e., the higher the level of stressors, the higher the level of arousal among caregivers).

Personal Factors

Figure 1 has an additional feature not directly derived from the Schulz et al.'s (1987) Stress-Coping model. It includes personal factors, or covariates, shown in prior research to impact the caregiving context. These characteristics of caregivers have been recognized as contributing to outcome measures.

Caregiver's Highest Level of Education. Several studies have reported higher education levels among foster parents and other caregivers over birth mothers. F. Cohen et al. (1995) reported that ¾ of the foster parents had attended some college; whereas none of birth mothers had, and only 50% of birth mothers had completed high school. Hansell and her colleagues (1998) found significant differences between HIV negative and HIV positive caregivers' education level. Though not statistically significant, Black et al. (1994) found that HIV negative caregivers in both of their studies had higher levels of education. M. Rose and Clark-Alexander (1998) reported similar findings.

Although there have been mixed results, some studies have demonstrated that education may play a role in medication adherence due to the often complex drug treatment regime (Hecht & Chesney, 1999; Moloney, Damon & Regan, 1998; Singh et al., 1996). Hecht and Chesney, 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. They found one study that indicated a significant relationship between low education levels and lower adherence rates. Mastering the administration of medicines for the child can be a very complex task. The cognitive ability of the caregiver plays an important role in successfully implementing the intervention (Moloney et al.). Missed doses reduce the efficacy of the medication, thereby allowing drug-resistant mutations to develop; this places the infected child at greater risk (Hecht & Chesney).

Another Child Ill? HIV infected mothers are often affected by numerous oppressive factors including poverty, substance abuse and prostitution. An estimated 44% of women in the United States have been infected by intravenous drug usage (CDC, 1999e). The majority of the rest have been infected through heterosexual contact, many through prostitution. As such, these characteristics may negatively affect the growth and development of *all* their children. Thus, in addition to the index child, it is possible that the individual is caring for more than one ill child, this will subsequently add to the caregiver's perceived burden.

Canosa (1991) posits that a new bio-psychosocial entity has emerged: the 'HIV child'. Therefore, even if the child may be HIV negative, he/she may be characterized by many of the same challenges such as low birth weight, delayed psycho-motor development, poor language development, etc. (Canosa). Although half of the children examined by Leeds (1993) were HIV positive by age two (the rest had seroconverted), almost 75% of the 195 children experienced some ailment at least once in any three month period. It is important to control for the potential effects of this additional stressor.

Caregiver's Health Limits. Differences between HIV positive and HIV negative caregivers are prevalent in the literature. Hansell and her colleagues (1999) found that HIV positive mothers presented with multiple and more complex problems than their HIV negative counterparts. However, dichotomous measures of caregiver illness status (i.e., HIV positive vs. HIV negative) have not been found to significantly predict caregiver burden (Hughes & Caliandro, 1996). Conversely, one of the findings in Caliandro and Hughes' (1998) qualitative study of grandmothers who are also caregivers of HIV positive children was that of minimizing their own personal health needs. This is consistent with Walker's (1998) findings on the tendency of birth mother's to attend to their children's needs over their own. In support of the impact of health concerns among both caregiver groups, M. Rose and Clark-Alexander (1998) discovered that HIV positive birth mother caregivers, while differing significantly on a number factors, did not score significantly higher than other caregivers on physical health. Therefore, due to the potential stressors placed on caregivers due to their own potential health limitations, whether HIV positive or not, this variable will also be examined.

SUMMARY AND RESEARCH QUESTIONS

From all of this literature several broad ideas become clear. First, the Stress-Coping Model appears to be an adequate framework to conceptualize the impact of caring for a child infected and/or affected by HIV/AIDS on caregivers. Secondly, this framework provides specific factors whose relationships can be measured.

It is clear that the challenges faced by caregivers of children infected and/or affected by HIV/AIDS are stressful. However, in addition to the familial stress, the pervasiveness of issue is also having adverse effects upon other systems such as child welfare, as well as society-at-large. Further exacerbating these problems are issues related to the inadequacy of service delivery and support systems to meet their needs. Although there has been some exploratory research on the impact of caring for a child infected/affected by HIV/AIDS on the family of these individuals, it has yet to be fully explored.

As discussed, there have been several empirical studies within the HIV/AIDS literature utilizing stress-related theories – with many of the independent, dependent, moderating and control variables chosen for this study having been tested in prior research with various samples of HIV/AIDS infected individuals and/or their family members. However, none of the studies have attempted to examine each of the variables in the same model. As such, there is evidence for the inclusion of each of the individual variables and the model as a whole.

Some initial research in this area has been completed. However, a larger scale evaluation of the impact on caregivers of children infected/affected by HIV/AIDS should be conducted. Caregivers for children either infected or affected by HIV/AIDS are at increased risk of involvement with the child welfare system due to increased levels of stress associated with caregiver tasks such as frequent doctor visits and the associated health needs of the children. These stressors are in addition, in the case of birth mothers, to their own HIV/AIDS status. This study will utilize questions that have been used on similar populations, or based closely on such instruments, thus allowing for some comparisons to other groups of caregivers. This research will attempt to answer the following questions:

1. Are there significant differences between birth mothers and other caregivers in their reports of: personal factors (caregiver’s health limits, educational level, and another sick child in the home); stressors (index child’s reported health status, and level of illness management); informal social supports (family, friends, children, community connections and church/spirituality); formal social support (formal service supports); and perception of caregiver burden (stress and arousal levels)?

2. Controlling for personal factors, are the stressors (index child’s reported health status, and level of illness management) significant predictors of caregiver stress and arousal levels?
3. Does the social support provided [informal social supports (family, friends, children, community connections and church/spirituality); and formal social support (formal service supports)] significantly buffer the effects of the stressor upon the caregiver’s stress and arousal levels?

CHAPTER 3

RESEARCH QUESTIONS AND HYPOTHESES

Three research questions, each with its respective hypotheses, have been developed from the Stress-Coping model to examine the relationships among the variables thought to illuminate the impact upon caregivers of caring for children infected/affected by HIV/AIDS. This chapter will review each question and subsequently provide a supporting rationale for each of the hypotheses presented.

The first research question and supporting twelve hypotheses (as shown in Table 5) investigates the differences between the birth mothers and the other caregivers on the variables within each construct. This is done to examine the comparability of the two groups, as well as illuminate any potential sources of bias. Those variables with statistically significant differences will be highlighted and discussed further. The second question and its two corresponding hypotheses are examining the significance of the two stressor variables, as illustrated in Table 6. A regression equation will be used to examine the relative importance of each predictor variable on the outcome variables. As suggested by the application of the stress-coping framework, the third research question and the remaining six hypotheses (see Table 7) will investigate the buffering effect of each source of social support upon the relationship between the stressor variables and the outcome variables.

RESEARCH QUESTIONS

The study will focus on the following research questions:

1. Are there significant differences between birth mothers and other caregivers in their reports of: personal factors (caregiver's health limits, educational level, and another sick child in the home); stressors (index child's reported health status, and level of illness management); informal social supports (family, friends, children, community connections and church/spirituality); formal social support (formal service supports); and perception of caregiver burden (stress and arousal levels)?

Table 5: Hypothesized Relationships for Research Question #1

Birth mothers as compared to other caregivers	***Relationship***
Personal Factors	
Caregiver's Health Limits	More
Educational Level	Less
Another Child Ill?	More
Stressors	
Index Child's Reported Health Status	Less
Level of Illness Management Tasks	Less
Conditioning Variables	
Family Support	Less
Friends Support	Less
Children Support	More
Community Connections	No Difference
Church/Spirituality Support	No Difference
Formal Service Supports	Less
Perception of Caregiver Burden	
Stress Level	More
Arousal Level	Less

2. Controlling for personal factors, are the stressors (index child's reported health status, and level of illness management) significant predictors of caregiver stress and arousal levels?

Table 6: Hypothesized Relationships for Research Question #2

Dependent Variable	*Independent Variables*	*Relationship*
Stress Level	*Stressors*	
	Index Child's Reported Health Status	+
	Level of Illness Management Tasks	+
Arousal Level	*Stressors*	
	Index Child's Reported Health Status	+
	Level of Illness Management Tasks	+

3. Does the social support provided [informal social supports (family, friends, children, community connections and church/spirituality); and formal social support (formal service supports)] significantly buffer the effects of the stressor upon the caregiver's stress and arousal levels?

Table 7: Hypothesized Relationships for Research Question #3

Dependent Variable	*Conditioning Variables*	*Relationship*
Stress Level	Family Support	-
	Friends Support	-
	Children Support	-
	Community Connections	-
	Religion/Spirituality Support	-
	Formal Service Supports	-
Arousal Level	Family Support	+
	Friends Support	+
	Children Support	+
	Community Connections	+
	Religion/Spirituality Support	+
	Formal Service Supports	+

HYPOTHESES

Hypothesis 1.1: *In comparing birth mothers to other caregivers, birth mothers will have significantly more limits on their daily living due to health concerns..*

Results 1.1: In their qualitative study of grandmothers who are also caregivers of HIV positive children, Caliandro and Hughes' (1998) found that many of the grandmothers minimized their own personal health needs such as high blood pressure, chest pains and asthma. This is consistent with Walker's (1998) findings on the tendency of birth mother's to attend to their children's needs over their own, often to the detriment of their health status. Nevertheless, Hansell and her colleagues (1999) found that HIV positive mothers presented with multiple and more complex problems than their HIV negative counterparts. In addition, M. Rose and Clark-Alexander (1998) discovered that HIV positive birth mother caregivers scored slightly higher than other caregivers on a nine question scale of physical health, although the amount was not significant. Thus, although other (especially older) caregivers may experience health concerns, the evidence indicates that HIV positive birth mothers have more potential health limitations.

Hypothesis 1.2: *In comparing birth mothers to other caregivers, birth mothers will have significantly lower education levels.*

Rationale 1.2: This hypothesis predicts that within the two groups of caregivers, birth mothers will have received a lesser amount of formal education as indicated by the measure. To support this hypothesis, several studies have reported higher education levels among foster parents and other caregivers over birth mothers. F. Cohen et al. (1995) reported that ¾ of the foster parents in their study had attended some college; whereas none of birth mothers had, and only 50% had completed high school. Hansell and her colleagues (1998) found significant differences between HIV negative and HIV positive caregivers' education level. Though not statistically significant, Black et al. (1994) also found that HIV negative caregivers in both of their studies had higher levels of education. M. Rose and Clark-Alexander (1998) reported similar findings. Thus, there appears to be sufficient evidence to support this hypothesis.

Hypothesis 1.3: *In comparing birth mothers to other caregivers, significantly more birth mothers will have another sick child in the home.*

Rationale 1.3: This hypothesis predicts that significantly more birth mothers will also be caring for another ill child in their home (although not necessarily HIV positive). This hypothesis is posited due to the numerous oppressive factors including poverty, substance abuse and prostitution impacting HIV positive women and their children's prenatal care. It is estimated that 44% of HIV positive women in the United States have been infected through intravenous drug usage (CDC, 1999e). The majority of the rest have been infected through heterosexual contact, many through prostitution. As such, these characteristics may negatively affect the growth and development of *all* their children. Thus, in addition to the index child, it is possible that the birth mother is caring for more than one ill child. This will subsequently add to the caregiver's perceived burden. Canosa (1991) posits that a new bio-psychosocial entity has emerged: the 'HIV child'. Therefore, even if the child may be HIV negative, he/she may be characterized by many of the same challenges such as low birth weight, delayed psycho-motor development, poor language development, etc. (Canosa). Although half of the children examined by Leeds (1993) were HIV positive by age two (the rest had seroconverted), almost 75% of the 195 children experienced some ailment at least once in any three month period. Thus, the literature illustrates the increased probability of HIV positive mothers having children with various developmental and health difficulties.

Hypothesis 1.4: *In comparing birth mothers to other caregivers, significantly less birth mothers will have an HIV positive child in the home.*

Rationale 1.4: Due to the nature of the project from which the data were collected, a significantly higher proportion of other caregivers will be caring for HIV positive children. As discussed further in Chapter 4, those families (birth, foster, adoptive and kin) included in the initial project had children infected and/or affected by HIV/AIDS. The birth mothers involved in the project did not necessarily have to have a child with HIV, as their own positive diagnosis met the inclusion criteria. The foster/adoptive parents were all trained by the project staff to specifically care for an HIV positive child. Although some children may have seroconverted after placement, one of the project's goals was to place HIV positive children with appropriately trained and prepared families. Thus, due to the project protocols, it is hypothesized that other caregivers had a significantly higher proportion of HIV positive children in their care.

Hypothesis 1.5: *In comparing birth mothers to other caregivers, birth mothers will have a significantly lower level of illness management tasks.*

Rationale 1.5: HIV positive children may initially grow-up in the care of their birth mother. However, as their mother progresses through the disease process, the child is also progressing through a parallel process. Despite the overall reconceptualization of HIV as a chronic illness, infection eventually results in death. As such, time is an enemy in the fight against the virus, and as the child gets older he/she will inevitably become symptomatic. Thus, those children placed away from the birth mother due to the mother's deteriorating health or death will be further along the illness. As the disease progresses, the responsibility for caring for an ill child becomes more complex due to medication regimes, as well as frequent health appointments and hospitalizations. In support of this hypothesis, F. Cohen et al. (1995) found that the corresponding illness management tasks were significantly more frequent for children placed with foster families (and other caregivers), who, as a group, had much sicker children living with them than those still living with their birth mothers.

Hypothesis 1.6: *In comparing birth mothers to other caregivers, birth mothers will have significantly less support from family.*

Rationale 1.6: Several factors serve to isolate birth mothers from many sources of support, including their families. The stigma associated with HIV, as well as the mode of acquisition for the birth mother and source of transmission to the child, have alienated many families (McCarroll, 1988). Thus, fear of disclosure has prevented many HIV positive mothers from obtaining support from family. Walker (1998) writes that, "for them, the price of disclosure exceeded the benefit of potential support" (p. 83). Stories abound of families rejecting their HIV positive members (Walker). M. Rose (1993) reported that rejection from family was a major concern among women, and that rejection was more common from family members if the member had children, fearing their children may contract the virus.

Although not source specific, Hardy and her colleagues (1994) noted that the parents in their HIV positive group scored lower on social support than either the cancer or control groups. They were also the group with the most single parents and least married parents (Hardy et al.). Black et al. (1994) reported similar findings. Hansell and her co-authors (1998) reported that while 41% of the HIV negative caregivers were partnered, only 29% of HIV positive caregivers were. Hughes and Caliandro (1996) found that their respondents scored at the high end of the low social support range. In addition, Mayers & Spiegel (1992) found isolation from family, as well as friends and the medical staff, to be a recurrent theme for birth mothers. M. Rose and Clark-Alexander (1998) also found that alternative caregivers had significantly more support from family, with birth mothers not reporting support from family. Thankfully, not all birth mothers experience such isolation, as Black et al. found that out of the four study groups, HIV positive mothers receiving the intervention scored highest on informal support, although not statistically significant from other groups. As overwhelmingly demonstrated in the literature, lack of support from family is not uncommon among HIV positive caregivers, who describe being held hostage by the disease (Koehn, as cited by Mayers & Spiegel).

Hypothesis 1.7: *In comparing birth mothers to other caregivers, birth mothers will have significantly less support from friends.*

Rationale 1.7: Lichtman et al. (1987) found that when provided, high support from friends, breast cancer survivors improved in their psychological adjustment. Unfortunately the social isolation of HIV positive birth mothers permeates the literature, with the need for social support cited as one of the top concerns of caregivers of children infected/affected by HIV/AIDS (Hackl et al., 1997; Heath & Rodway, 1999; Mayers & Spiegel, 1992; Wiener, 1998). Mayers & Spiegel found isolation from friends, in addition to other sources, to be an important issue for birth parents in their support group.

Friends are often the main source of social support for women with HIV, as family relationships may have been severed (McCarroll, 1988; Namir et al., 1989).

Friends can offer empathy and shared values, and have been associated with improved psychological adjustment in individuals with HIV (R. Hays et al., 1990). However, M. Rose and Clark-Alexander (1998) found that alternative caregivers had significantly more support from friends; which they described as ‘dramatic’. Indeed, the lack of support from friends is characteristic of AIDS patients and of their caregivers who are often held hostage by the disease (Koehn cited by Mayers & Spiegel, 1992, p185). For example, even though friends may offer support to HIV positive caregivers, almost all of the birth mothers participating in F. Cohen et al.’s (1995) study reported expressing caution and reserve when choosing whom to tell. This indicates a heightened awareness of the potential rejection from this source of social support.

Hypothesis 1.8: *In comparing birth mothers to other caregivers, birth mothers will have significantly more support from children.*

Rationale 1.8: S. Andrews et al. (1993) reported that many birth mothers in their study reported receiving support from their children. Many HIV positive mothers described having a very special relationship with their child, with this special bond acknowledged throughout the literature (Andrews, S. et al.; Caliandro & Hughes, 1998; Cohen, F. et al., 1995). The mothers revealed that the child’s presence decreased their feelings of isolation and gave them a reason to live (Andrews, S. et al.). Walker (1998) posits that when the danger of loosing a loved one exists, an intense bond may form. She contends that caregivers grapple with the traumatic nature of the illness through this attachment (Walker). Birth mothers felt that the anticipated loss of their child, coupled with the fact that they shared the same illness, intensified the bond between them (Walker). Further, women expected children (8 years old and older) to assist with household tasks, including caring for their younger siblings (Walker). Thus, as posited in the literature, due to the bond form by their illness and their isolation, birth mothers rely to a greater degree on the support of their children.

Hypothesis 1.9: *In comparing birth mothers to other caregivers, there will be no difference between birth mothers and other caregivers' level of connection to the community.*

Rationale 1.9: There is a small, but growing body of literature demonstrating the therapeutic effects of support groups for people caring for children and adults with HIV (Grief & Porembski, 1988; Kelly & Sykes, 1989; Mayers & Spiegel, 1992; Pearlin et al., 1988; Wiener, 1998). One of the earliest articles focusing on the stress of caring for a child infected by HIV/AIDS describes a parental support group to prevent social isolation due to the lack of available social support (Mayers & Spiegel). Through the commonality of experiences, meeting with others who are caring for children infected/affected by HIV/AIDS can allow the caregiver the opportunity to reflect, express and reconcile feelings in a supportive community format. Through the group, caregivers are sustained in fulfilling their roles. HIV positive women often report on the benefits of universality and companionship found in support groups to deal with depression, hopeless and anxiety surrounding the disease (Hackl et al., 1997; Wiener). Additionally, in a study of professional caregivers of HIV positive clients, George et al. (1993) found that supportive groups effectively buffered stress and improved the quality of the care provided. It appears that this sources of support is beneficial to both HIV positive and HIV negative caregivers, and, since all participants are affected by HIV, there are minimal barriers to group entry. Thus, it is hypothesized that there will be no difference between birth mothers and other caregivers.

Hypothesis 1.10: *In comparing birth mothers to other caregivers, there will be no difference between birth mothers and other caregivers' level of support from church/spirituality.*

Rationale 1.10: Although individuals infected by HIV met with opposition by many traditional religious institutions during the early stages of the pandemic, church/spirituality have been found to be a positive coping support used by all types of caregivers (Leserman et al., 1992; Warner-Robbins & Christiana, 1989; Weitz, 1989). M. Rose and Clark-Alexander (1998) found that 80% of their sample (70% of who were birth mothers) used prayer as a method of coping with the stress of caring for an HIV positive child. The role of religion as a coping strategy has also been highlighted by Mellins and Ehrhardt (1994), stating that its role within their sample of HIV positive and negative inner-city family caregivers could not be 'overemphasized'. Many grandmothers expressed a realization of their personal limits, and found comfort in placing faith that the health of the child was in 'higher hands' (Caliandro & Hughes, 1998). Caliandro and Hughes assert that "being strong and able to cope with problems were clearly linked to their strong spirituality" (p. 110). This theme was also present in Heath and Rodway's (1999) findings, with the issue of spirituality emerging from the qualitative data and two respondents describing a deepening of their beliefs since diagnosis. Boyle, Ferrell, Hodnicki & Muller (1997) found that among African-American mother-caregivers of adult children with AIDS, two of the greatest sources of support were spiritual beliefs and participation in church. Therefore, it is clear that as a method of coping with the stress produced by caring for a child with AIDS many caregivers turn to their faith and church for support. The literature does not clearly identify which group may derive more support from this source. Thus, it is hypothesized that there is no difference between birth mothers and other caregivers in their level of perceived support from this source.

Hypothesis 1.11: *In comparing birth mothers to other caregivers, birth mothers will have significantly less support from formal service supports.*

Rationale 1.11: In a study of social workers' attitudes toward people with AIDS, it was found that 80% of respondents would refuse the assignment of an AIDS case if they were a hospital social worker, with an additional 9% undecided (Dhooper, Royse & Tran, 1988). Although physicians profess the need to treat all patients, similar findings have been reported (Rose, L., 1994). Even though some practitioners still admit to being very fearful and uncomfortable working with PWAs, many HIV negative caregivers report satisfaction with their relationships with professionals. However, some birth mothers feel blamed by professionals for their child's illness. This is an especially sensitive area since they *are* the agents of infection for the majority of children. Surprisingly, in their first study, Black et al. (1994) found that out of the four groups, HIV positive caregivers in the comparison group scored highest on formal support (although not statistically significant from other groups). Nevertheless, respite and childcare availability is a problem for seropositive mother-caregivers of HIV positive children (Andrews, S. et al., 1993). Communicating with health care providers and social service agencies also proved to be difficult for caregivers, especially for HIV positive birth mothers (Mellins & Ehrhardt, 1994). Foster and adoptive families reported turning to professionals for support more frequently, with birth parents less frequent (Mellins & Ehrhardt). They hypothesize that this may be due to the already existing alliance between foster/adoptive parents and social service agencies (Mellins & Ehrhardt). Lastly, HIV positive women in two studies reported health care professionals to be hostile, fearful and lacking in knowledge (Chung & Magraw, 1992; Florence, Lutzen & Alexius, 1994). Thus, the literature suggests that HIV positive birth mothers will perceive less support from formal support services when compared to other caregivers.

Hypothesis 1.12: *In comparing birth mothers to other caregivers, birth mothers will have significantly higher stress levels.*

Rationale 1.12: It is hypothesized that the combination of factors impacting birth mothers (i.e., poverty, race/gender biases, their own illness status, and the emotions experienced from transmitting the illness to their child) will result in this group having significantly higher stress levels than their HIV negative counterparts. Throughout the literature, HIV positive parents have been shown to experience higher levels of depression, anxiety and anticipatory grief than have foster or adoptive parents or extended family members (Hansell et al., 1998; Hughes & Caliandro, 1996; Wiener et al., 1994). Hughes and Caliandro also reported that their study subjects were less able to relax and find diversion from typical daily routines. In addition, HIV positive mothers also reported above average stress in their family relationships (Hughes & Caliandro). Although not at the highest levels, M. Rose and Clark-Alexander (1998) found mothers to be more depressed than other caregivers. Birth mothers have almost unanimously reported higher levels of stress and stress-related issues; therefore, it is hypothesized that birth mothers in this study will also report higher levels of stress than other caregivers.

Hypothesis 1.13: *In comparing birth mothers to other caregivers, birth mothers will have significantly lower arousal levels.*

Rationale 1.13: Hardy and her colleagues (1994) found that birth mothers of HIV positive children exhibited higher amounts of wishful thinking than caregivers in the other study groups. Hughes and Caliandro (1996) also reported that HIV positive subjects' feelings of mastery were lower than the normative group, although still in the upper half of the possible range. M. Rose and Clark-Alexander (1998) found that alternative HIV negative caregivers used confrontative coping that focuses on constructively handling the stressful situation and directly confronting the problem. The alternative caregivers utilized the more active strategy significantly more than HIV positive birth mother caregivers, who utilized a more passive coping style that is depicted through the modulation of tension by reframing the situation without directly confronting it (Rose, M. & Clark-Alexander). Because of this, alternative caregivers also felt more in control of their lives (Rose, M., & Clark-Alexander).

Lastly, HIV positive birth mothers, in addition to caring for their child, are fighting the illness themselves. Many women experience the extreme physical exhaustion that is characteristic of AIDS (Hansell et al., 1998; Walker, 1998). However, as indicated in the literature, birth mothers will have significantly lower arousal (i.e., active behavioral) levels when compared to the other caregivers.

Hypothesis 2.1: *Controlling for personal factors, the index child's illness status will be a significant predictor of; a) caregiver stress levels, b) caregiver arousal levels.*

Rationale 2.1: After entering the personal factors into the regression equation, the two stressor variables will be entered. This hypothesis predicts that an HIV positive diagnosis for the index child will be a significant predictor of caregiver (a) stress and (b) arousal levels. The qualitative literature clearly illustrates that an HIV positive diagnosis for a child is a stressful event. Women state that they experienced far greater distress when their child was diagnosed with AIDS then when they themselves were diagnosed (Walker, 1998). However, this stressor variable is absent from the empirical literature, as all of the children studied are HIV positive. Nevertheless, the chronic illness literature has long documented the immense stress experienced by the parents upon learning of their child's prognosis (Eisenberg, Sutkin & Jansen, 1984; Love, 1970; Solnit & Stark, 1961). MacKeith (1973) points out that, in addition to the stress caused by the child's illness, there is an accompanying wish to protect and help the child. It is common for caregivers to focus on the needs of the child, even at the expense of their own needs (Walker). Thus, a positive HIV diagnosis will cause significant elevations in both the caregiver's stress and arousal levels.

Hypothesis 2.2: *Controlling for personal factors, the level of illness management will be a significant predictor of; a) caregiver stress levels, b) caregiver arousal levels.*

Rationale 2.2: Within this framework the ill child's symptomatology has an effect on the caregiver, which in turn leads to the outcomes of stress and/or coping. These illness management tasks, including multiple hospitalizations and juggling out-patient visits, were listed as a major caregiver stressor (Caliandro & Hughes, 1998; Mellins & Ehrhardt, 1994). Individuals dealing with caring for a child with a complex medical regime have a great deal of stress with which they need to cope (Rose, M., & Clark-Alexander, 1998). Juggling outpatient visits was identified as especially stressful for caregivers of HIV positive children (Mellins & Ehrhardt). HIV positive caregivers also have to cope with their own illness in addition to managing the child's medical tasks, which is especially stressful when appointments are in different locations (Mellins & Ehrhardt). However, despite the resultant stress caregivers continue to try to find the energy to do the tasks that will benefit their child (Caliandro & Hughes; Walker, 1998). Therefore, it is hypothesized that as the level of illness management tasks increase so will both the caregiver's level of stress and arousal.

Hypothesis 3.1: *Controlling for personal factors, the level of support from family significantly will buffer the effects of the stressor upon; a) caregiver stress levels, b) caregiver arousal levels.*

Rationale 3.1: There is some evidence to support the buffering effect of family support on the effects of the stressors. Roberts et al. (1994) found that spousal support had some buffering effect for breast cancer patients. Additionally, in Black et al.'s (1994) second study it was reported that social support, although not source specific, clearly buffered the amount of stress experienced by all groups – HIV negative, positive and comparison caregivers. The groups were all dichotomized into low and high support segments. The HIV negative and comparison (also HIV negative) low support groups both had reductions in stress, but not to the level of their high support counterparts. In addition, the HIV positive low support group's stress level actually increased, whereas the high support segment reduced stress 76%. It is clear that HIV positive women benefit from support (Black et al.). Lastly, they reported that those HIV positive mothers benefiting from social support exhibited a more positive attitude, decreases in child-related stress, and more positive involvement with their children (Black et al.).

Hughes and Caliandro (1996) reported that high levels of social support contributed significantly to the perception of minimal impact on one's lifestyle. There is also evidence demonstrating that the lack of social support can increase distress within a family (Hughes & Caliandro). Furthermore, M. Rose and Clark-Alexander (1998) found a clear association between social support and the caregiver's level of coping (+) and stress (-). Efforts to boost *all* forms of social support among caregivers of children infected with HIV showed improvement for those individuals who were not HIV positive (Hansell et al., 1999). Thus, it is hypothesized that support from family will significantly reduce the amount of stress perceived, as well as significantly increase the amount of reported arousal.

> Hypothesis 3.2: *Controlling for personal factors, the level of support from friends significantly will buffer the effects of the stressor upon; a) caregiver stress levels, b) caregiver arousal levels.*

Rationale 3.2: Lichtman et al. (1987) reported a moderate correlation between perceived social support from friends and psychological adjustment among cancer patients. Similarly, Roberts et al. (1994) found that the support of friends buffered the stress of breast cancer for single women comparable to that experienced by married women's spouses. Friendship was also consistently seen as a moderator of a mother's experiences of daily parenting hassles (Crnic & Greenberg, 1990). In a sample of male hemophiliacs with HIV, support from friends was related to lowered depression levels (Dew, Ragni & Nimorowicz, 1990). Other study participants noted that the support of friends, as well as family, was crucial in regaining and maintaining equilibrium (Zich & Temoshok, 1987). In another study, contact with friends was cited as the greatest support source (Turner et al., 1998). Friends were a crucial source of support for both foster and birth families caring for an HIV positive child (Cohen, F. et al., 1995). Thus, as indicated in the literature, it is hypothesized that as the perceived support from friends increases, so will caregiver arousal levels. Conversely, caregiver stress levels will decline.

Hypothesis 3.3: *Controlling for personal factors, the level of support from children significantly will buffer the effects of the stressor upon; a) caregiver stress levels, b) caregiver arousal levels.*

Rationale 3.3: Several of the women in Walker's (1998) study identified children as a source of support. This appears to be a surprising, but common, occurrence (Andrews, S. et al., 1993; Walker). S. Andrews and her colleagues reported that many caregivers in their study reported receiving support from their children. They described having a very special relationship with their child, with this special bond acknowledged throughout the literature (Andrews, S. et al.; Caliandro & Hughes, 1998; Cohen, F. et al., 1995). Walker posits that when the danger of loosing a loved one exists, an intense bond may form. She contends that caregivers grapple with the traumatic nature of the illness through this attachment (Walker). Further, women expected children (8 years old and older) to assist with household tasks, including caring for their younger siblings – some with AIDS (Walker). Thus, as the perceived support from the child increases, caregiver perception of the burden (as evidenced by their stress scores) will decrease. Caregiver arousal will significantly increase due to the buffering effect of higher levels of support from children.

Hypothesis 3.4: *Controlling for personal factors, the level of connection to the community significantly will buffer the effects of the stressor upon; a) caregiver stress levels, b) caregiver arousal levels.*

Rationale 3.4: Several women in Heath and Rodway's (1999) study reported attending support groups, and found it helpful for alleviating stress. Crnic and Greenberg (1990) reported that community involvement/support significantly buffered daily parenting hassles. In addition, there is a small body of literature examining the buffering effect of support groups for caregivers of individuals with HIV/AIDS (Greif & Porembski, 1988; Kelly & Sykes, 1989; Mayer & Spiegel, 1992; Pearlin et al., 1988; Wiener, 1998). Groups are especially powerful sources of support in that everyone has the common experience of loss due to HIV (Kreibick, 1995). As such, a solidarity may be established among the caregivers which can assist in augmenting or replacing other damaged sources (Kreibick). McCarroll (1988), describing a support group for caregivers of HIV positive children, explains, "People who have escaped the loneliness of parenting a special child tend to value close times together…[to] face whatever problems emerge: trouble from neighbors or bureaucrats, diaper rashes, the need for a crib or help with housework, lack of sleep" (p. 87). Therefore, the fear of ostracism many caregivers experience can be overcome through this source (Hackl et al., 1997). Thus, it is hypothesized that an increased connection to similar families in the community will reduce caregiver stress and increase one's ability to actively respond to the situation.

Hypothesis 3.5: *Controlling for personal factors, the level of support from church/spirituality significantly will buffer the effects of the stressor upon; a) caregiver stress levels, b) caregiver arousal levels.*

Rationale 3.5: Several of the women in Walker's (1998) study identified God as a source of support. Families dealing with HIV have exhibited a strong sense of spirituality. One grandmother stated, "God never gives you more than you can bear, and I can do all things through God, who strengthens me" (Boyd-Franklin, Alemán, Steiner, Drelich & Norford, 1995, p. 125). When faced with HIV/AIDS, many minority families described how their spirituality buffered the stressful experience and allowed them to cope (Boyd-Franklin, Alemán, Steiner, Drelich & Norford). Although some families may have withdrawn from their 'church families' due to the stigma associated with HIV/AIDS, ministers and other religious leaders can be valuable supports for caregivers (Boyd-Franklin, Alemán, Steiner, Drelich & Norford). Thus, it is hypothesized that one's level of spirituality and involvement in a religious community will reduce the level of stress and increase one's arousal level.

Hypothesis 3.6: *Controlling for personal factors, the level of formal service supports significantly will buffer the effects of the stressor upon; a) caregiver stress levels, b) caregiver arousal levels.*

Rationale 3.6: It is hypothesized that increased support from formal service providers (i.e., case workers, respite care and mental health services) will buffer the effects of the stressor and result in a corresponding decreasing in caregiver stress, as well as an increase in caregiver arousal. This source has only been examined in one empirical study, with no significant findings noted (Black et al., 1994). However, Heath and

Rodway’s (1999) subjects identified counselors, health care workers and social workers as being the most significant social supports (after family and friends). In addition, because of the perceived burden of caring for a child infected/affected by HIV/AIDS, respite care is utilized as a supportive service to reduce the demands placed upon the caregiver (Boyd-Franklin & Boland, 1995). As such , caregivers of children infected/affected by HIV/AIDS have very little time for their own needs; thus, respite care is one of the most frequently cited support services needed (Mellins & Ehrhardt, 1994). Lastly, in support of this hypothesis, mental health services can provide the caregiver the opportunity to address various needs in a safe environment, as well as work with the therapist to identify strengths and other potential sources of support (Boyd-Franklin, Alemán, Steiner, Drelich & Norford, 1995).

CHAPTER 4

METHODOLGY

This chapter will examine the methodology of the proposed study to ensure that its design is appropriate to 1) provide answers to the research questions posed, and 2) to adequately control for variance (Kerlinger, 1992). To that end, the research design of the study will be explained, including the location of the study, the relevance of the location, and the criteria utilized to select study subjects. A power analysis will also be conducted to ascertain the appropriate sample size to address the questions under investigation. The method of data collection and operationalization of the variables will be discussed, with the relevant reliability and validity of the measures examined. Lastly, the proposed plan for data analysis will be put forward, as well as the utilization of specific diagnostic test and missing values analysis to ensure data integrity. Through this examination of the research plan, the two criteria posited by Kerlinger will be met and a higher level of confidence in the findings will result.

RESEARCH DESIGN

Since the early 1980s, child welfare has been impacted by the growing numbers of children infected/affected by HIV/AIDS. In Maryland, this crisis began in the early 1990's with the Pediatric HIV/AIDS Health Care Demonstration Projects reporting 99 children at that time infected with AIDS and growing annually (Groze, Haines-Simeon, & Persse, 1993). This resulted in over 10 children with, or at-risk of, HIV infection entering the foster care system each year in Maryland. To help alleviate this epidemic, a federal demonstration project was initiated in the state of Maryland that was funded by the Abandoned Infants Assistance Act of 1988 (Groza et al., 1997). The Family-

Centered, Community-Based Transagency Model for Children Affected by HIV/AIDS (FaCT Project) was based on a similar program serving HIV infected/affected children in Boston (Groza et al.). This exploratory research project was designed to promote family permanency through the provision of case management and advocacy services (Groze, Haines-Simeon & Persse, 1993).

The project was a statewide initiative administered by the state public child welfare system. Case management services were offered to families to assist them in securing services to maintain the family structure. Services included, but were not limited to, arranging for medical assistance, respite care, family support groups, transportation and financial support (Groza et al., 1997).

Utilizing the data gathered through the FaCT program, this study will conduct an exploratory non-experimental cross-sectional study utilizing a convenience sample of caregivers of children infected and/or affected by HIV/AIDS. Caregivers will be categorized as either birth mothers, or other caregivers (birth fathers, other relatives, and foster or adoptive parents). The responses of these two groups to questions on stressors, sources of social support and stress-arousal levels will be analyzed in both bivariate and multivariate models.

Sample Criteria

FaCT Program Inclusion Criteria. Families could be referred to the FaCT program through public and private social service agencies, as well as being self-referred. The protocol for program participation included meeting any one of the following criteria: having a child who was born drug affected, having a child referred as at-risk due to parental substance abuse, having a child born HIV positive, or having a child referred as at-risk due to the mother's HIV positive diagnosis (Groze, Haines-Simeon & Persse, 1993). Birth, foster, adoptive parents and other caregivers were all eligible to participate, as inclusion was child focused. From the initial family meeting an index child was targeted. For families with only one child, the index child was determined de facto. However, for those families with more than one child meeting the eligibility criteria, the targeted child was the most severely infected/affected, *or*, if two or more children were equally infected/affected, the youngest child, who was considered most at-risk, was chosen.

This selection criteria resulted in 229 birth families (includes mothers, fathers, grandmothers and other relatives) 56 foster families (includes kin and non-kin foster parents) and 7 adoptive families participating in the project from 1991-1997 (Groza et al., 1997).

This Study's Inclusion Criteria. The sample of caregivers for this study will be made up of persons meeting the following criteria:

- The caregiver must have been caring for a child meeting the eligibility requirements for the FaCT program at some point during the years 1991-1997.
- The caregiver must have physical custody of the child at the time of inquiry.
- The caregiver must have been caring specifically for a child who was infected and/or affected by HIV/AIDS. This excludes those caregivers caring for children affected only by substance abuse.
- The child must have been determined to be HIV negative or HIV positive. This excludes those children with an undetermined diagnostic status.

Power Analysis/Sample Size

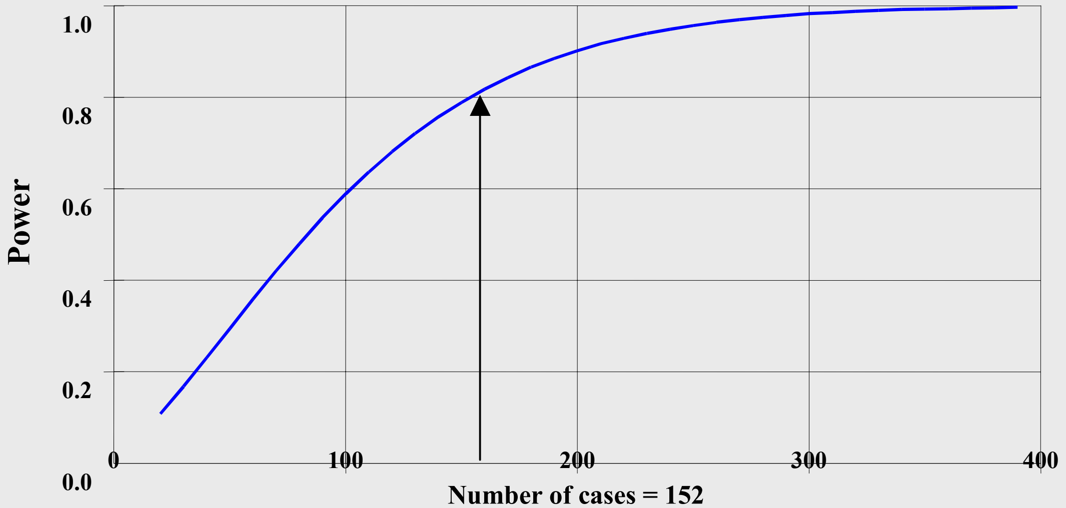
An estimate of sample size was determined through the use of the statistical procedure of a power analysis. This procedure was developed by J. Cohen (1988) to help researchers reduce the risk of a Type II error, the acceptance of a null hypothesis that is actually false. Each of the regression equations calculated in the final model will include 8 independent variables in the set of interest (three personal factors, two stressor variables, one conditioning variable, and two multiplicative interaction variables [for example, see Table 8 below]), which will yield a total R^2 of .25. The adjusted R^2 score used in this calculation is significantly lower than a score of .37 found in a similar sample of caregivers (Hughes & Caliandro, 1996). The lower score was used to determine the most conservative score for a reasonable estimate.

Table 8: Variables used in Regression Equation to Examine the Effect of Formal Support Services on Stress Levels
Personal Factors (3) Educational Level Another Child Ill? Caregiver's Health Limits
Stressors (2) Index Child's Reported Health Status Level of Illness Management Tasks
Conditioning Variables (1) Formal Service Supports
Multiplicative Interaction Variables (2) Index Child's Reported Health Status X Formal Service Supports Level of Illness Management Tasks X Formal Service Supports
Perception of Caregiver Burden (1) Stress Level

Utilizing the statistical program ‘SamplePower 1.0’, the power analysis will focus on the increment for the set of interest over and above any prior variables (i.e., 2 stressor variables yielding an increment of 0.05) (Borenstein, Rothstein & Cohen, 1997). With the given sample size of 152, alpha set at .05, and utilizing an interaction regression equation (such as the one illustrated in Table 8 above - the most rigorous of the calculations proposed), the study will have power of .80, which is generally used as an acceptable level of power (as illustrated in Figure 2). The test is based on controlling for the possibility of a type 2 error, which means that variables entered into the regression will serve to reduce the error term in the significance test and are included in the power analysis. This effect was selected as the smallest effect that would be important to detect, in the sense that any smaller effect would not be of clinical or substantive significance. It is also assumed that this effect size is reasonable, in the sense that an effect of this magnitude could be anticipated in this field of research.

Figure 5: Power as a Function of Sample Size

Multiple Regression with Interactions



Number of cases = 152
Interaction Variables = 2; Total Variables = 8
Total R^2 = .25; Alpha = .05

Data Collection

The data used in this study will be collected from the existing FaCT files. Each file will be examined to determine its acceptability in meeting the sample selection criteria. Data were originally gathered for each family by the FaCT caseworker 30 days after the initial referral (Groze, Haines-Simeon & Persse, 1993). If the caregiver was illiterate or unable to complete the questionnaire, the FaCT caseworker assisted the caregiver to complete the information. After the initial data collection period, data were collected at six-month intervals. However, due to attrition resulting from the caregiver or child's deteriorating health, death or other factors, only the initial interview data are utilized. In addition, although data were collected from 1991 through 1997, information collected over the project duration will be combined to form one dataset. The questions and instruments utilized remained constant over time, thus enabling comparability. Also, HIV/AIDS reconstruction as a chronic (albeit still ultimately terminal) illness had occurred prior to 1991 with the advent of the new medical treatments available for children (Beaudin & Chambre, 1996; FDA, 1996; Meyers & Weitzman, 1991). The FaCT project did not collect specific medical data on the children; thus, it is impossible to know the medical regime of each index child. Therefore, it is assumed that each at least had the availability of drug treatments to prolong life. As such, the cohorts are considered equivalent and will be combined to form the study sample.

Variables – Operationalization and Instrumentation

The instruments used to collect data included a 61item self-administered questionnaire consisting of primarily closed-ended questions. This study will utilize approximately 48% of the questions contained within the questionnaire. The measure contained 29 specific questions on the demographics of the index child, caregiver and family, as well as on the child's health and caregiver sources of support. Of the remainder of the questions, several were considered redundant (i.e., asking for both age and date of birth) and the rest were not considered relevant to this investigation. For example, one question asks, "If this child is not living with you, when do you think he will return" which violates one of the criteria for inclusion on this study (i.e., physical custody). Other non-included questions focus on, for example, various aspects of the birth mother's history that were not also asked of the other caregivers and are therefore non-comparable.

Secondary data utilization contains many unique challenges such as a mismatch between the primary and secondary research objectives (Kiecolt & Nathan, 1985). As such, data may only be available in forms that are not ideal (Kiecolt & Nathan). To that end, the independent variables, as discussed below, are all either single item measures or summated composite scores of two combined questions. As such, the respective validity and reliability of the questions poses specific strengths and limitations that will be addressed. One of the strengths of the measures is that they meet the criteria to be considered to have face and logical validity (i.e., content validity); which is that the test *appears* to be measuring what it purports to measure, and that the question(s) are representative of the content or subject to be examined (Blythe & Tripodi, 1989; Newman & Newman, 1994). The relevance and the representativeness of the variable to the concept are obvious in the basic content of the question and its range of responses (Blythe & Tripodi). Therefore, a measure is valid when it converges with expectations derived from other knowledge about the subject matter (Jacob, 1984).

Sensitivity to the item under investigation is an area of concern. However, Blythe and Tripodi (1989) posit that “a rating scale with 10 levels…is not more sensitive than a rating scale with 3 levels, unless there is evidence that the *client* can reliably discriminate among these 10 levels” [italics added] (p. 42). Yet, given the current study, this can not be known. Another option to ensure the validity of the questions is to check the accuracy by some objective means. However, when people are asked their perceptions and feelings there is no way of validating the answers (Fowler, 1993). Only the person has access to his or her feelings and opinions. As such, other forms of validity (i.e., concurrent or empirical) can only be determined through their correlations with other measures. Unfortunately, other comparable measures were not administered to this sample. Thus, these ‘higher’ forms of validity, although desirable, are not available.

It is impossible to determine the reliability of a single indicant (Zellar & Carmines, 1980). However, questions such as these have been utilized in several other studies (Rosenthal & Groze, 1992). In addition, closed-ended questions such as these have been found to be useful because clients find that they can 1) perform the task of answering the question when response alternatives are provided, and 2) the researcher can more reliably interpret the meanings of the alternatives (Fowler, 1993). Blythe and Tripodi (1989) assert that the tool must be understandable and easy to use. To help increase reliability, the questions were specifically written by the initial investigator to reduce any ambiguity or vagueness, and to have each question's meaning transferable to all caregiver populations (i.e., birth, foster or adoptive) regardless of educational level.

Another method of increasing the reliability of the measures is to form composite or summated scoring of questions (Zellar & Carmines, 1980). A composite score shares more of its variance with the underlying concept than does the single question (Zellar & Carmines). Therefore, the combining of two (or more) questions to form a composite score is a better approximation and is less affected by random error (Zellar & Carmines). Thus, a relatively objective, albeit rudimentary, measure may be a summary score of support (Biegel et al., 1991). Those independent variable measures below indicating subjective states will be composed of the summated score of two objective questions.

The following questions (see Tables 8-12) have been selected for inclusion in the various scales:

Personal Factors

Caregiver's Health Limits. Although it is assumed from the FaCT program criteria that all of the birth mothers are HIV positive and all of the other caregivers are

HIV negative, it is unknown whether the extent to which caregivers from either group have health issues which impact their daily living tasks. As shown in Table 9 below, caregiver health impairment will be obtain by asking the extent to which health problems, if any, impact upon their daily living activity in the home.

Table 9: Variable Questions – *PERSONAL FACTORS*
Caregiver's Health Limits on Daily Living
To what extent do you have any health problems that limit your activity around the house? (0-4) None/Hardly Ever/Sometimes/Often/Almost Always or Always
Education
Primary caregiver's education? (1-3) Did Not Complete HS/Completed HS/Some College+
Another Ill Child?
Can any other child in the home, *other than the index child*, be considered in poor health? (0-1) No/Yes

Educational Level. As shown in Table 9, the level of caregiver education will be determined through a question asking the highest level completed.

Another Ill Child? Similar to Wiener et al. (1994), caregivers were asked whether or not there was another child in the home that could be considered to be ill. The answer will be coded as a dichotomous 'no/yes' variable.

Stressors

HIV Status. All children included in this study will be indicated within their record as either HIV negative or HIV positive as reported by their caregiver (as shown in Table 10). Those children whose status was unknown at the time the instrument was completed will not be included.

Table 10: Variable Questions - *STRESSORS*
HIV Status
Index child's health status? (1-2) HIV-/HIV+
Illness Management (1-11)
Frequency of Dr. visits in the last 6 months? (1-7) Once in 6 months/Once every 2-3 months/Once per month/2-3 times per month/ Once per week/Several times per week/Daily
How many times has this child been hospitalized since birth/last 6 months? (0-4) 0/1/2/3/4+

Illness Management. The number of hospital visits and doctor's appointments on behalf of the child for the previous six months, as reported by the caregiver, will be determined to be the level of illness management tasks, as shown through the summated score of the two questions posed in Table 10.

Informal Social Supports

Family. The combined score of two family-related questions, as shown in Table 11, will be used to demonstrate the perceived level of family support. The first is whether or not the caregiver has a partner, that Cantor (1979) defines a *functional* spouse as "one with whom one lives" (p. 441). The second question asks the level of perceived support from the caregiver's family. The overall questionnaire specifically focuses on the infected/affected child. Therefore, although not specifically stated, this question is considered to ask about support in relation to the child (as are all subsequent support-related questions). In a previous study, Crystal and Kersting (1998) measured HIV positive subject's perception of social support utilizing two questions with three possible responses (very satisfied, somewhat satisfied, and not very satisfied). The answers to both items were combined to form a single index of support (Crystal & Kersting).

Table 11: Variable Questions – *INFORMAL SOCIAL SUPPORT*
Family Support (1-4)
Partnership status? (0-1)
Not partnered/Partnered
Are your relatives supportive of your family? (1-3)
No, not really/Yes, somewhat/Yes, very much
Friend Support (1-7)
Are your friends supportive of your family? (1-3)
No, not really/Yes, somewhat/Yes, very much
How many close friends do you have? (0-4)
0/1/2/3/4+
Child Support (1-9)
How do you and your child get along? (1-4)
Very poorly/Not so well/Fairly well/Very well
How often do you and your child enjoy time together? (0-5)
Less than once per month or not at all/1 per month/2-3 times per month/1 per week/2-3 times per week/Just about every day
Community Connection (1-8)
How often are you (or your spouse/mate) in contact with other families similar to yours? (0-4)
Once per year or less/Every few months/1 per month/1 per week/Daily or almost daily
How active are you in your community? (1-4)
Not active at all/Not very active/Somewhat active/Very active
Church/Spiritual Support (1-6)
How important is religion in your life? (0-2)
Not important/Somewhat important/Very important
How active are you in your church/synagogue? (1-4)
Not active at all/Not very active/Somewhat active/Very active

Friends. To measure perceived support from friends, the scores from the two questions shown in Table 11 will be combined. The number of friends identified, as well as inquiring as to their level of support will be indicident of the caregiver's perceived level of support from this source. Similarly, to add a structural dimension to their measure of support, Crystal & Kersting (1998) asked about the existence of social relationships with friends.

Children. Perceived support from the child is obtained through the summed scores of the questions in Table 11. Satisfaction with the relationship and the amount of time enjoyed together will be used to operationalize this variable.

Community Connection. Self-reported contact with similar families and activity levels within the community will be combined to provide the level of perceived connection to the community.

Church/Spirituality. Asking the respondent how important religion is in his/her life provides a level of perceived support from spirituality. In addition, the frequency in which the caregiver attends services will indicate the level of perceived support from this source.

Formal Social Supports

Formal Service Supports. The receipt of formal services such as respite care and mental health counseling will be measured through a dichotomous 'no/yes' scale. The perceived support from the FaCT care worker will be assessed by the inquiring as to the services provided by the agency worker, as shown in Table 12.

Table 12: Variable Questions - *FORMAL SOCIAL SUPPORT*
Formal Service Support (1-5)
Respite Care received? (0-1) No/Yes
Mental Health services received? (0-1) No/Yes
How would you describe the services provided by the agency worker? (1-3) Not helpful/Adequate/Very helpful

Caregiver Response to Perceived Burden

Stress/Arousal. The majority of studies examining the occurrence of potentially stressful events use some version of a checklist where the stress score is simply the total number of items checked as having occurred (Cohen, S., & Wills, 1985). Similarly, the dependent variables in this study, stress and arousal levels, will be operationalized through the use of the Stress-Arousal Checklist (SACL) developed by Mackay et al. (1978). The 30-item SACL consists of adjectives commonly used to describe one's psychological experience to stress. The SACL was originally tested with a sample of undergraduate students (Mackay et al.). It has since been utilized with a variety of populations; for example - nurses (Hirosawa, Hatta & Yoneda, 1998), computer entry workers (Sharit, Czaja & Nair, 1998), and pilots (Cooper & Sloan, 1987). However, it has never been utilized on caregivers of children infected/affected by HIV/AIDS.

Each respondent utilizing the SACL (see sample instrument in Appendix A) will rate each adjective in terms of the intensity of his/her feelings toward each. Each sub-scale consists of positive and negative adjectives used to describe stress and arousal. For the positive adjectives, the ++ and + ratings are scored 1, and the ? and – are scored 0.

The opposite scoring is used for the negative adjectives (i.e., ++ and + score 0, and ? and – score 1). For the stress sub-scale, the positive adjectives are items 1, 5, 6, 9, 10, 11, 12, 13, 18, 23; and the negative items are 2, 3, 15, 21, 22, 25, 27, 28. The adjectives for the arousal sub-scale are: positive = 4, 7, 14, 19, 20, 29; and negative = 8, 16, 17, 24, 26. Thus, the stress score can range from 0-18 and the arousal score can range from 0-12.

There are no reports on the reliability of the SACL (J. Fischer & Corcoran, 1994). However, the SACL has been subjected to factor analyses by several researchers to determine its internal consistency (D. Fischer & Donatelli, 1987; Mackay et al., 1978). Factor analysis has identified a two-factor structure, subsequently labeled stress and arousal. The SACL has known groups validity showing, for example, that scores increase as a consequence of a stressful situation (Burrows, Cox & Simpson, 1977; King et al., 1983). In addition, the SACL has also been shown to have concurrent validity, with scores correlating with various physiological measures (Burrows et al.; Mackay, 1980).

DATA ANALYSIS PLAN

All quantitative data will be analyzed using SPSS statistical software. Data will be examined for any conflicts against the original surveys. Several types of statistical tests will be utilized to analyze the data and make decisions about the hypotheses: diagnostics and missing values, reliability and validity, as well as descriptive, bivariate, multivariate and interactional analyses.

Diagnostics/Missing Values

First, the data ranges and distributions will be checked to ensure it was appropriately entered. Next, to ensure the appropriateness of the data for analysis, regression diagnostics will be conducted to explore any potential problems that may compromise the assumptions imbedded in the statistical model. Calculations will be conducted to identify any influential data, as well as any violations of multicolinearity or normality. Also, given the sensitive nature of the topic, missing data may occur. However, missing data may reduce the precision of the calculated statistics because of the decrease in available data (Hill, 1997). In addition, many statistical procedures are based upon complete cases, and missing values can complicate the findings (Hill). To correct for this, SPSS Missing Values Analysis will be utilized to impute values for those variables with missing data. To determine if a variable will be kept and missing values imputed, the missing values must be random and less than 20% of the total responses. Little's chi-square test for variables missing completely at random (MCAR) will be utilized (Hill). As such, a non-significant p-value is indicative of randomness (Hill). Conversely, a significant p-value ($p<.05$) illustrates data that is missing non-randomly (Hill). A further analysis of the missing values patterns will be conducted to determine any relevant significance from the missing values, with appropriate tables generated.

Reliability and Validity Issues

All questions used in this study, or variants thereof, have either been found to be reliable in previous research with similar samples or are assumed to be reliable because they are based on scales that have been found to be reliable in previous research. However, statistical tests will be utilized to insure the reliability of the use of all scales with this particular sample. Cronbach's alpha will be used to assess the internal consistency of data generated by measures used in the study.

The SACL has been utilized in numerous previous studies and has acceptable levels of validity, with King et al. (1983) reporting Cronbach's alpha for a modified version at .86 (stress) and .74 (arousal). However, because the scale has not been validated with a primarily African-American, female population factor analysis will be conducted to assess the validity of the scale. Therefore, after factor analyzing the data to discern the patterns, minor revisions of the scale may be done for application to this study.

Descriptive Statistics – Characteristics of the Sample

Descriptive analyses will be used to assess the characteristics of the data both in terms of the overall sample, and in terms of the two caregiver groupings. All collected data will be analyzed in this manner, including the results of the social support questions and SACL, as well as any collected demographic information. Demographic information will include the caregivers relationship to the child, gender, age, race/ethnicity, income, number of other children in the home, employment status and effect of the child. Child demographics (i.e., gender, age and race/ethnicity) will also be highlighted. Statistical tests that will be used in this level of analysis will include frequencies, percentages, distributions, ranges and measures of variability and central tendency. All findings will be summarized in tables.

Analyses – Research Question #1

Once the data has been described and the scales have been found to be reliable, a series of bivariate analyses will be conducted to test the hypotheses associated with the first research question comparing birth mothers and other caregivers. T-tests will be used to compare the means of the variables identified in the associated hypotheses. T-tests will also be utilized to compare the means of the stress/arousal sub-scale measure and applicable demographic categories. The significance or non-significance of these tests will be noted in the descriptive tables.

Analyses – Research Question #2

For the second question a series of regression analyses will be utilized to examine and test the relationships between the independent and dependent variables outlined. The predictive value of each of the two stressors on the caregivers' stress and arousal levels will used to assess the importance on these dependent variables to the model after the personal factors have been included. Thus, the first set of predictors used in the application of this model will include the personal factors. This will be followed by the stressor variables. This will be run for the stress sub-scale, as well as the arousal sub-scale. The subsequent values of the R^2's will be noted with the significance to determine the decision rule in testing the hypotheses.

Analyses – Research Question #3

For question #3, twelve multiplicative regression models with interactions will be conducted. One for each permutation of support source (5 informal, 1 formal) for the two dependent variable sub-scales. Thus, taking the regression equations from question #2 a social support source (for example, family support) will be added, as will the relevant multiplicative terms (family support X child's HIV status, and family support X level of illness management tasks). Therefore, in each regression analysis the personal factors will be entered first, followed by the stressor variables and single conditioning variable, with the multiplicative interaction variable entered last. Main effects from the conditioning variable upon stress and arousal levels will be examined. In addition, the hypothesized moderating effects will be indicated if the added interaction term significantly increases the model's R^2 beyond the main effects, as identified by significant regression coefficients. Lastly, a decomposition analysis will be performed on any significant interaction term to determine the significance of the slope of perceived levels of support on stress at low and high levels.

ETHICAL CONSIDERATIONS

All data will be kept in strict confidence, without any identifying information from the respondents noted in the record. Due to the sensitive nature of the subject, only an identification number will identify caregivers' surveys. Data from the original study was individually coded to ensure the anonymity of the respondents. For example, the code used the following designations – 08H112B [08 = county; H = HIV infected/affected; 112 = client ID number; B = birth family]. This research will utilize the same coding procedure to maintain this level of confidence. In addition, respondents in the original project were not denied treatment, nor given any additional treatment, to participate in the study. For purposes of this study, informed consent can be assumed to have been provided through the completion of the information requested. Those families not wishing to participate will have selected themselves out from the earlier study. There were no known risks to involvement in the original project, nor are any known at this time. Lastly, to ensure that study subjects are protected a Case Western Reserve University Institutional Review Board (IRB) application was submitted, with subsequent approval granted on April 10, 2000 (see Appendix B for a copy of the IRB approval).

CHAPTER 5

DATA ANALYSES

This chapter will discuss the diagnostic actions taken to ensure the integrity and appropriateness of the data. Missing data patterns and the steps taken to impute missing data will also be examined. In addition, descriptive statistics will be utilized to present various sample characteristics from the caregivers, both birth mothers and others, as well as the children under their care. The independent and dependent measures will be subjected to tests of reliability and validity, including subjecting the stress-arousal checklist (SACL) to factor analysis. Also, to support the sampling strategy of combining the subjects from multiple program years, the stress and arousal scores will be compared across the years to analyze any significant variances. Once the previously described steps have been completed, the data will be subjected to bivariate and multivariate statistical procedures, including t-tests, general linear regression, and regression with multiplicative interaction terms, to provide answers to the three research questions posed. In addition, for those interactions shown to be significant, a decomposition analysis will be performed and discussed.

Diagnostics/Missing Values

The first step conducted to ensure the integrity of the data was to check the accuracy of the data coding and entry into the statistical computer program (SPSS). To complete this task, a random sampling of 25% of the original program paper files (n=53) were extracted and compared to the data transcribed onto the specially designed coded data sheets. In addition, the data sheets were subsequently checked against the data entered into the SPSS program file for each matched case. There were no discrepancies identified. Lastly, data ranges were checked for each variable entered (n=59) to ensure that all data were entered within the prescribed ranges. Of the over 12,000 cells ranges examined, slightly over 5% of the cases (n=11) had at least one datum outside the delineated variable ranges. The original files for these cases were pulled and examined for accuracy. In each case, the data had been entered incorrectly (i.e., entering a 7 instead of a 4, etc.). The data were subsequently corrected for each of the cases, and all of the data was found to lie within the necessary parameters.

Once the data had been checked for data entry accuracy, the data was tested for influential cases. As such, an individual subject's data containing extremely high or low values as compared to the remainder of the data may unduly influence the estimation of the regression line (Neter, Kutner, Nachtsheim, & Wasserman, 1996). Therefore, to identify any potentially influential data, Cook's Distance and single fitted values were utilized. Neither produced any influential cases. Examination of tolerance levels and multicollinearity among the independent variables indicated no problems evident – with explanatory variables sufficiently independent of one another.[1]

Although the number of subjects in the study was 212, there were 96 cases that had at least one independent variable item missing. Thus, utilizing a listwise method of data analysis would have resulted in using only the remaining 116 complete cases, reducing the sample size 45%. Therefore, to utilize all available data a method of data

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[1] Multicollinearity was evident within the interaction terms. The centering procedure utilized to correct for this is described under section "Analyses – Research Question #2".

imputation was chosen to estimate the missing data.[2] This was done because the study is explanatory, and the subject matter is such that some extreme attitudes and missing data could be expected. Utilizing the SPSS program *Missing Value Analysis 7.5*, an expectation maximization (EM) technique is used with inferences assumed based on the likelihood under the normal distribution (Hill, 1997). As Hill conveys:

> Each interation consists of an E step and an M step. The E step finds the conditional expectation of the "missing" data, given the observed values and current estimates of the parameters. These expectations are then substituted for the "missing" data. In the M step, maximum likelihood estimates of the parameters are computed as though the missing data had been filled in. "Missing" is enclosed in quotation marks because the missing values are not being directly filled, but, rather, functions of them are used in the log-likelihood (p. 41).

Another assumption is that the missing data is 'missing completely at random' (MCAR). If this assumption is met, "[both] complete cases… [and] EM… methods give consistent and unbiased estimates of correlations and covariances (Hill, 1997, p. 42). The chi-square statistic for testing whether values are MCAR is referred to as 'Little's MCAR test' (Hill). The Little's MCAR test obtained for this study's data resulted in a chi-square = 3277.59 (df = 3393; p<.921), which indicates that the data is indeed missing at random (i.e., no identifiable pattern exists to the missing data). In addition, almost 16% (n=15) of the 96 cases with at least one missing variable were randomly selected and

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[2] Because missing value estimations may fall out of the given data range for categorical variables, imputed data is only utilized when calculating the inferential statistics.

individually examined to discern if individual patterns emerged. However, none was noted. Lastly, the percentage of missing data for each of the variables can be seen in Table 1 in the section 'Descriptive Statistics – Characteristics of the Sample' below. The range of missing data was from 0% -19.8%, with a mean = 6.63% (SD = 6.27%). Thus all missing data percentages fell below the 20% exclusionary score established.

Descriptive Statistics – Characteristics of the Sample

A total of 212 caregiver files met the sample criteria established. This excluded 27 cases due to the child's unknown/undetermined HIV status, yielding an ultimate inclusion rate of 88.7%. The characteristics of the respondents and their children, as shown in Tables 13-18, summarizes the various attributes of the sample utilized for analysis. This section will explore general demographic characteristics of the caregivers and index children, as well as the personal factors, stressor characteristics, and informal and formal social support characteristics.

Although families entered the program each year, as illustrated in Table 13, the majority of the families meeting this study's criteria joined the program in its later years. Over 65% of the sample started the program within its last two years (1995-1996). From the subject families, 67.5% of the caregivers were birth mothers, with the remainder composed of birth fathers, relatives, and foster/adoptive parents. It was also found that the overwhelming majority (93.8%) of caregivers were female. Given the relatively small proportion of men within the sample, data analysis between the two groups was not possible.

Table 13: Caregiver/Household Characteristics (variables not included in regression analyses)

CHARACTERISTICS	*N*	*%*	*Mean*	*S.D.*
Year Started	212			
1991	4	1.9		
1992	31	14.6		
1993	13	6.1		
1994	25	11.8		
1995	85	40.1		
1996	54	25.5		
Relationship	212			
Other Caregiver	69	32.5		
Birth Mother	143	67.5		
Gender	211			
Female	198	93.8		
Male	13	6.2		
Race/Ethnicity	203			
African-American	187	92.1		
White	13	6.4		
Hispanic	2	1.0		
Asian	1	0.5		
Native-American	0	0.0		
Other	0	0.0		
Age	177		34.55 y.	10.38 y.
Number of Children in the Home (including index child)	211		2.44	1.41
Effect of Child on Home	202		4.28	.95
Very Negative (1)	2	1.0		
Mostly Negative (2)	5	2.5		
Mixed (3)	44	21.8		
Mostly Positive (4)	35	17.3		
Very Positive (5)	116	57.4		

The sample was also disproportionately African-American (in relation to the population-at-large), accounting for slightly over 92% of the sample. Once again, due to the small proportion of other races and ethnic groups, further analysis between the groups was not possible. The mean age of caregiver respondents was 34 ½ years old (μ=34.55, sd=10.38), ranging from 15 to 66 years of age. The number of children in each home (including the index child) ranged from 1 to 11, with an average of 2 (µ=2.44, sd=1.41). Lastly, despite any stressors experienced, the caregivers strongly felt that the index child had had a positive effect on the family. However, over 25% of the respondents did feel that the child had either a mixed or negative effect on the home.

As shown in Table 14, the index children were almost evenly split between males and females, with 6.2% more boys. Similar to the race/ethnicity distribution of the caregivers, the children were overwhelmingly African-American. The index children ranged in age from .08 years of age (i.e., 1 month old) to 17 years of age, with an average of approximately 4 ½ years old.

Table 14: Index Child's Characteristics
(variables not included in regression analyses)

CHARACTERISTICS	*N*	*%*	*Mean*	*S.D.*
Gender	209			
Female	98	46.9		
Male	111	53.1		
Race/Ethnicity	203			
African-American	186	91.6		
White	12	5.9		
Hispanic	1	0.5		
Asian	0	0.0		
Native-American	1	0.5		
Other	3	1.5		
Age	204		4.52 y.	3.84 y.

The caregiver's personal factor characteristics can be seen in Table 15. Over half of the caregivers expressed no limits on their daily living tasks due to health issues.

However, 44.5% of the respondents were limited by health difficulties at least some of the time, with over 18% almost always affected. The highest level of education achieved by the primary caregiver was skewed toward the lower end of the measure, with almost 48% of the sample not completing high school. Only 22.7% had attended at least some college. The majority of the families (83.8%) had no other sick children in the home.

Table 15: Personal Factor Characteristics

PERSONAL FACTORS	*N*	*%*	*Mean*	*S.D.*
Caregiver's Health Limits on Daily Living	173		1.37	1.63
None (0)	94	54.3		
Hardly Ever (1)	2	1.2		
Sometimes (2)	28	16.2		
Often (3)	17	9.8		
Almost Always or Always (4)	32	18.5		
Primary caregiver's education?	185		1.75	.80
Did Not Complete HS (1)	88	47.6		
Completed HS (2)	55	29.7		
Some College+ (3)	42	22.7		
Can any other child in the home, other than the index child, be considered in poor health?	204			
No	171	83.8		
Yes	33	16.2		

The HIV status of the index children, as listed in Table 16, was almost evenly split between negative (48.1%) and positive (51.9%). The average child was taken to the doctor's office once every 1 to 3 months, with a mode of once every 6 months (the most infrequent appointment option available). Forty-six children went to the doctor's office more than once per month, with 11 children going once per week or more. The average child had been hospitalized slightly less than one time in the previous six months (or since birth, whichever was shorter). However, nine children had been hospitalized three times, and 15 had been hospitalized 4 or more times.

Table 16: Stressor Characteristics

STRESSORS	***N***	***%***	***Mean***	***S.D.***
HIV Status	212			
HIV-	102	48.1		
HIV+	110	51.9		
Frequency of Dr. visits in the last 6 months?	210		2.5	1.3
Once in 6 months (1)	58	27.6		
Once every 2-3 months (2)	53	25.2		
Once per month (3)	53	25.2		
2-3 times per month (4)	35	16.7		
Once per week (5)	6	2.9		
Several times per week (6)	3	1.4		
Daily (7)	2	1.0		
How many times has this child been hospitalized since birth/last 6 months?	197		.77	1.24
0	124	62.9		
1	33	16.8		
2	16	8.1		
3	9	4.6		
4+	15	7.6		

The majority (60.8%) of the caregiver respondents were not partnered, as shown in Table 17. Almost 85% of the caregivers felt that their relatives were supportive, with only 15% stating that their relatives were not really supportive. There was more variability among caregiver responses to support from friends. Over 27% felt that their friends were not supportive, and another 27% responding only somewhat supportive. The average respondent had 2 close friends, although there was some consistency across the range. Caregivers got along, on average, extremely well with their child, with almost 99% responding that they and their child got along either fairly or very well. Similarly, the vast majority of the caregivers spent time with their child almost every day.

Caregivers were somewhat isolated, with over half (54.5%) interacting with similar families every few months or less. Conversely, slightly more than 20% had almost daily contact with similar families, with the average caregiver in contact slightly more than once per month (although the standard deviation was quite large). Most of the caregivers were not active in their communities, with only 14.3% very active. However, although somewhat isolated from the community, caregivers overwhelmingly responded that religion was somewhat (23.9%) or very (63.3%) important in their lives. Similar to their level of community involvement, caregiver activeness in their place of worship was also low, with half of the respondents not very (25.8%) or not at all (29.7%) active.

Table 17: Informal Social Support Characteristics

INFORMAL SOCIAL SUPPORT	*N*	*%*	*Mean*	*S.D.*
Partnership status?	199			
Not partnered	121	60.8		
Partnered	78	39.2		
Are your relatives supportive of your family?	209		2.41	.74
No, not really (1)	32	15.3		
Yes, somewhat (2)	59	28.2		
Yes, very much (3)	118	56.5		

Are your friends supportive of your family?	210		2.18	.84
No, not really (1)	58	27.6		
Yes, somewhat (2)	56	26.7		
Yes, very much (3)	96	45.7		
How many close friends do you have?	170		2.02	1.48
0	38	22.4		
1	29	17.1		
2	35	20.6		
3	27	15.9		
4+	41	24.1		
How do you and your child get along?	210		3.84	.45
Very poorly (1)	2	1.0		
Not so well (2)	1	0.5		
Fairly well (3)	26	12.4		
Very well (4)	181	86.2		
How often do you and your child enjoy time together?	211		4.45	1.34
Less than once per month or not at all (0)	10	4.7		
1 per month (1)	9	4.3		
2-3 times per month (2)	3	1.4		
1 per week (3)	5	2.4		
2-3 times per week (4)	11	5.2		
Just about every day (5)	173	82.0		
How often are you (or your spouse/mate) in contact with other families similar to yours?	202		1.57	1.58
Once per year or less (0)	80	39.6		
Every few months (1)	30	14.9		
1 per month (2)	31	15.3		
1 per week (3)	19	9.4		
Daily or almost daily (4)	42	20.8		
How active are you in your community?	182		2.16	1.08
Not active at all (1)	68	37.4		
Not very active (2)	43	23.6		
Somewhat active (3)	45	24.7		
Very active (4)	26	14.3		
How important is religion in your life?	180		1.51	.71
Not important (0)	23	12.8		
Somewhat important (1)	43	23.9		
Very important (2)	114	63.3		
How active are you in your church/synagogue?	182		2.32	1.08
Not active at all (1)	54	29.7		
Not very active (2)	47	25.8		
Somewhat active (3)	49	26.9		
Very active (4)	32	17.6		

As shown in Table 18, approximately 80% of caregivers received no support from either respite care or mental health providers. However, all had contact with the FaCT project worker and felt that their support was either adequate (24.5%) or very helpful (70.5%).

Table 18: Formal Social Support Characteristics

FORMAL SOCIAL SUPPORT	*N*	*%*	*Mean*	*S.D.*
Respite Care received?	210			
No	170	81.0		
Yes	40	19.0		
Mental Health services received?	184			
No	142	77.2		
Yes	42	22.8		
How would you describe the services provided by the agency worker?	200		2.66	.57
Not helpful (1)	10	5.0		
Adequate (2)	49	24.5		
Very helpful (3)	141	70.5		

Reliability Issues

Once the missing values analysis had been completed and the results of the EM estimates inserted into the appropriate cases, the measures to be used within the subsequent inferential statistics were created as described in Chapter 4. For example, to create the measure ‘illness management’ a composite score was created through the summing of responses to the questions – ‘Frequency of Dr. visits in the last 6 months?’ and ‘How many times has this child been hospitalized since birth/last 6 months?’. The results of these scale creations can be found in Table 19. It should be noted that since the scales were created through the combination of questions utilizing different scoring matrices, direct interpretation is not possible. For example, a caregiver may score from 1 to 11 on illness management, yet it is not directly known if an individual with a score of 5 took the child to the hospital 3 times and doctor's office once every two months (which is scored as 2). It is not possible to ascertain the direct permutation of tasks undertaken to receive such a score. Rather, the composite score is utilized to demonstrate the relative level of illness management tasks, such that its relation to the mean under the normal curve (i.e., skewness) can be examined.

Earned scores on the illness management scale were low, averaging 3.27 (SD=2.10) with an α of .58. Family support fell almost at the mid-point, with scores averaging 2.80 (SD=0.93) and an α of .22. Support from friends was moderate, averaging 4.30 (SD=1.92) and an α of .51. Support from the index child was quite high, averaging 8.28 out of a possible 9 point scale (α=.35). Connections with the community scored below the mid-point (μ=3.74; SD=2.11), with an α of .44. Church/Spiritual support averaged 3.84 (SD=1.55), with an α of .69. Lastly, formal service support scores averaged 3.04 (SD=0.83), with an α of .10.

The alpha's for the independent variable measures ranged from a low of .10 for formal service support to a moderate .69 for church/spiritual support. Those in the low range (i.e., .10 - .35) include family support, child support and formal service support. The remainder fell within a moderate range of reliability, with alpha's ranging from .44 to .69. These included community connection, friend support, illness management, and church/spiritual support (listed from lowest to highest). None of the measures fell within the more acceptable range of α >.80.

Table 19: Scale Validation

Scales	*Mean*	*S.D.*	*Alpha*
Illness Management (1-11)	3.27	2.10	.58
Family Support (1-4)	2.80	0.93	.22
Friend Support (1-7)	4.30	1.92	.51
Child Support (1-9)	8.28	1.57	.35
Community Connection (1-8)	3.74	2.11	.44
Church/Spiritual Support (1-6)	3.84	1.55	.69
Formal Service Support (1-5)	3.04	0.83	.10
Stress (1-4)	2.06	0.84	.86
Arousal (1-4)	2.94	0.79	.84

Factor Analysis, Scale Development and Reliability for the SACL

Prior to examining potential factor extractions and data reduction, descriptive statistics were run on the individual items to ensure their appropriateness for analysis. With a KMO amount of .89, and a significant chi-square = 3239.5 (p<.001; df=435) on Bartlett's Test of Sphericity, the data appears to be suitable.

In order to determine the appropriate number of factors to best represent the SACL, Johnson and Wichern's (1998) strategies for factor extraction was loosely followed. Utilizing the seven potential factor extraction methods provided by SPSS (PC – Principal Component; ULS - Unweighted Least Squares; ML - Maximum Likelihood; GLS – General Least Squares; PAF - Principal Axis Factoring; ALPHA - Alpha Factoring; and, IMAGE - Image Factoring), reproduced correlations were obtained and the extraction methods with the least number of non-redundant residuals were kept for further use. The non-redundant residual amounts for each extraction method were: PC – 136; ***PAF – 51***; ***ULS – 51***; ML – 54; GLS – 71; IMAGE – 57; ALPHA – 71. Varimax and Oblimin rotations were then conducted utilizing the two extraction methods retained as described above. The factor loadings were obtained after 34 interations, producing 6 total factors with Eigenvalues > 1, explaining approximately 53% of the variance.

Items were only kept if they had a factor loading >.6 and did not cross-load between factors. Thirteen adjectives (tense, relaxed, restful, apprehensive, worried, drowsy, vigorous, peaceful, tired, idle, alert, jittery, and sluggish) did not meet the loading criteria for any factor and were eliminated. There was some consistency between the extraction and rotation methods with only one item (lively) cross-loading onto more than one factor. Another 5 items (active, energetic, sleepy, stimulated, and activated) loaded variously on the other factors. However, they did not appear to form a coherent theme and were deleted as nuisance factors.

After deleting the various adjectives that did not meet the selection criteria, the factor analysis was run again. The resultant scales contain 11 total items split among two factors that explain 52.91% of the variance. The two scales are comprised of the following adjectives: stress – bothered, uneasy, dejected, nervous, distressed, uptight; arousal – cheerful, contented, pleasant, comfortable, calm. Each of the scales have alpha's in the high range, .86 and .84 respectively. The scores on the stress sub-scale reported an average of 2.06 (SD=0.84), with scores ranging along the continuum from 1 to 4. Scores on the arousal sub-scale are higher, averaging 2.94 (SD=0.79); which places it in the affirmative (+) range.

Chronological Bias

To assess the potential bias due to those individuals entering the program at different chronological points a comparison was conducted between the yearly cohorts. An ANOVA was conducted grouping the stress and arousal scores together for the yearly cohorts. Assuming equal variances among the groups (as determined by Levene's test for Equality of Variance, stress = $p<.515$; arousal = $p<.217$), no statistical differences were found between the yearly cohorts on either of the scales (stress, $f(5, 206)=1.345$, $p<.247$; arousal, $f(5, 206)=.312$, $p<.906$). Therefore, it can be assumed that the sample obtained is not skewed due to temporality.

Analyses – Research Question #1

Research question #1 asks if there are significant differences between birth mothers and other caregivers on a variety of personal factors, stressors, and informal and formal social support measures, as well as their respective scores on the stress and arousal sub-scales. To determine if the scores of birth mothers and other caregivers differed significantly, independent sample t-tests were conducted for each of the hypothesized relationships. The results can be seen in Table 20 below.

Hypothesis 1.1: *In comparing birth mothers to other caregivers, birth mothers will have significantly more limits on their daily living due to health concerns..*

Results 1.1: The mean score for birth mothers was 1.51, which is significantly higher than the corresponding score for other caregivers ($\mu=1.05$). As such, birth mothers reported more impact upon their daily living tasks due to health related issues than did their non-HIV positive counterparts. Therefore, the null hypothesis can be rejected. As it appears that birth mothers in this sample have more health related difficulties.

Hypothesis 1.2: *In comparing birth mothers to other caregivers, birth mothers will have significantly lower education levels.*

Results 1.2: The mean score for birth mothers was 1.68, which indicates that the majority of birth mothers did not complete high school. Other caregivers scored significantly higher (μ=2.04), with the average respondent completing high school. As such, birth mothers reported less formal education than did their non-HIV positive counterparts. Therefore, the null hypothesis can be rejected.

Table 20: T-test Results

	Birth Mothers		***Other Caregivers***	
	Mean	***S.D.***	***Mean***	***S.D.***
PERSONAL FACTORS				
Caregiver's Health Limits on Daily Living (0-4)	1.51*	1.56	1.05	1.49
Primary caregiver's education? (1-3)	1.68***	.77	2.04	.76
Can any other child in the home, other than the index child, be considered in poor health? (0-1)	.12*	.32+	.25	.44
STRESSORS				
HIV Status (1-2)	1.44***	.50+	1.68	.47
Illness Management (1-11)	3.12	2.06	3.60	2.16
INFORMAL SOCIAL SUPPORT				
Family Support (1-4)	2.68**	.96+	3.05	.81
Friend Support (1-7)	3.82***	1.79	5.30	1.82
Child Support (1-9)	8.26	1.51	8.32	1.71
Community Connection (1-8)	3.68	2.14	3.86	2.05
Church/Spiritual Support (1-6)	3.59***	1.53	4.34	1.49
FORMAL SOCIAL SUPPORT				
Formal Service Support (1-5)	3.03	.83	3.06	.84
STRESS-AROUSAL CHECKLIST				
Stress (1-4)	2.20***	.79	1.78	.86
Arousal (1-4)	2.86*	.80	3.10	.75

NOTE: *=p<.05; **=p<.01; ***=p<.001; +=Levene's test for equality of variance not assumed

Hypothesis 1.3: *In comparing birth mothers to other caregivers, significantly more birth mothers will have another sick child in the home.*

Results 1.3: There was a significant difference between the amount of birth mothers and other caregivers caring for another sick child. However, contrary to the hypothesis, other caregivers had a mean twice as high as birth mothers. On average, one out of every 4 non-birth mother caregivers also cares for another sick child (in addition to the index child). Slightly more than one out of every 10 birth mother care for an additional sick child. Therefore, the null hypothesis, that birth mothers care for the same amount (or less) of other sick children when compared to other caregivers, cannot be rejected.

Hypothesis 1.4: *In comparing birth mothers to other caregivers, significantly less birth mothers will have an HIV positive child in the home.*

Results 1.4: Birth mothers had significantly less HIV positive children in their care than did their counterparts. Less than half (44%) of the children cared for by the birth mothers in the sample were identified as HIV positive ($\mu=1.44$, SD=.50). Conversely, as shown in Table 20, slightly more than half (68%) of the children cared for by other caregivers were infected. Therefore, the null hypothesis that birth mothers in the sample are caring for the same amount or more HIV positive children can be rejected.

Hypothesis 1.5: *In comparing birth mothers to other caregivers, birth mothers will have a significantly lower level of illness management tasks.*

Results 1.5: Birth mothers made, on average, slightly more than 3 trips to the doctor and/or hospital in the previous six months on the child's behalf. Similarly, other caregivers also made approximately 3 doctor/hospital visits. There was no statistically significant difference between the illness management tasks of the two caregiver groups. Thus, the null hypothesis cannot be rejected.

Hypothesis 1.6: *In comparing birth mothers to other caregivers, birth mothers will have significantly less support from family.*

Results 1.6: Birth mothers had a significantly lower mean composite score on family support, as shown in Table 20, than did other caregivers. Birth mothers scored slightly over the mid-point, while other caregivers scored over the 65th percentile. Thus, birth mothers perceived less support from family than did other caregivers. The null hypothesis can be rejected.

Hypothesis 1.7: *In comparing birth mothers to other caregivers, birth mothers will have significantly less support from friends.*

Results 1.7: The mean composite score for birth mothers (μ=3.82, SD=1.79) fell below the median response range for the category, which indicates that the majority of birth mothers did not perceive adequate support from their friends. In comparison, other caregivers reported significantly higher perceived support from their friends. Therefore, as indicated, the null hypothesis can be rejected.

Hypothesis 1.8: *In comparing birth mothers to other caregivers, birth mothers will have significantly more support from children.*

Results 1.8: Contrary to the hypothesis, other caregivers reported as much of a support relationship with the index child as did birth mothers. As such, there was no significant difference between birth mothers and other caregivers level of perceived support from the index child. However, both caregiver groups reported extremely high scores within this response category, indicating that both groups felt the index child was a support. Each caregiver group scored over 8 out of a possible 9 point range. Therefore, the null hypothesis for child support cannot be rejected.

Hypothesis 1.9: *In comparing birth mothers to other caregivers, there will be no difference between birth mothers and other caregivers' level of connection to the community.*

Results 1.9: Both birth mothers and other caregivers scored below the median response range for connections with the community. This may indicate that both birth mothers and other caregivers are isolated from their communities. There was no statistically significant difference between the two group's scores, as listed in Table 20. Therefore, the null hypothesis can be rejected.

Hypothesis 1.10: *In comparing birth mothers to other caregivers, there will be no difference between birth mothers and other caregivers' level of support from church/spirituality.*

Results 1.10: It was hypothesized that there would be no difference between the two caregiver groups. However, although birth mothers scored above the mid-point, other caregivers reported significantly higher scores of church/spiritual support. Therefore, the null hypothesis cannot be rejected.

Hypothesis 1.11: *In comparing birth mothers to other caregivers, birth mothers will have significantly less support from formal service supports.*

Results 1.11: Birth mothers and other caregivers reported almost exact levels of support from formal sources, with both falling at approximately the median response range for the category. Therefore, contrary to expectations, the null hypothesis cannot be rejected.

Hypothesis 1.12: *In comparing birth mothers to other caregivers, birth mothers will have significantly higher stress levels.*

Results 1.12: The mean score for birth mothers was 2.20 (SD=.79), which indicates that the majority of birth mothers had at least some (+) stress. Other caregivers reported significantly lower (μ=1.78, SD=.86) stress levels than their counterparts. Neither group scored in the high (++) stress range. Therefore, the null hypothesis can be rejected.

Hypothesis 1.13: *In comparing birth mothers to other caregivers, birth mothers will have significantly lower arousal levels.*

Results 1.13: Birth mothers, as hypothesized, reported significantly lower arousal scores than did other caregivers, although both groups had scores in the positive (+) range. Therefore, the null hypothesis can be rejected.

Analyses – Research Question #2

The first step in the process of exploring the moderating effect of social support was to regress the personal factors and stressors on the two dependent variables, stress and arousal. Therefore, an ordinary least squares regression model is utilized to examine the relationships hypothesized below. However, before proceeding with the regression analyses the data were centered (i.e., put in deviation score form) (Aiken & West, 1991). This is done to counteract the harmful effects of multicollinearity between the independent variables and the interaction variable, which is a product term created from the independent variables (Jaccard, Turrisi & Wan, 1990). To eliminate the lack of scale invariance, the scales are transformed by additive constants, the adding or subtracting of a constant (in this case subtracting the mean) from the predictor scores (Aiken & West).

For example, an individual with a raw score of 6.07 on the illness management scale will have the mean (3.27) subtracted from the score, yielding a centered score of 2.80. The new centered scores, each with a mean equal to 0, are thus sufficiently independent of one another. However, according to Aiken and West, the rescaling has no effect on the significance of the linear regression. It is recognized that although the interaction terms are not utilized in the equations in this section, centering was done at this step to ensure continuity between this and the subsequent parts of the analyses.

As shown in Table 21, the personal factors alone predicted a significant, albeit moderate, amount of the variance in the caregiver stress levels reported. All of the personal factors impacted the dependent variable in the hypothesized direction. However, only one of the factors, Caregiver’s Health Limits, was significant. The addition of the stressor variables to the regression equation decreased the adjusted R^2 amount by .2%, although the equation was still a significant predictor model.

Table 21: Main Effects for Personal Factors and Stress upon the Dependent Variable 'Stress'

Dependent Variable - Predictors	*β*	*SE*	*p-value*	*Adj.* R^2
Constant	2.07	.05	.00	14.0***
Personal Factors				
Caregiver's Health Limits	.20	.04	.00	
Educational Level	-.11	.07	.11	
Another Child Ill?	.04	.15	.76	
Constant	2.07	.05	.00	13.8***
Personal Factors				
Caregiver's Health Limits	.20	.04	.00	
Educational Level	-.10	.07	.15	
Another Child Ill?	.03	.15	.82	
Stressors				
HIV Status	-.07	.13	.57	
Illness Management	.04	.03	.23	

NOTE: Model Significance *=p<.05; **=p<.01; ***=p<.001

The personal factors' impact on caregiver arousal levels also explained a significant amount of the variance (19.5%). Two of the three personal factors – Caregiver's Health Limits and Another Child Ill – were significant. All three factors, as illustrated in Table 22, had an impact on the dependent variable, arousal, in the intended direction. The addition of the two variables – HIV status and Illness Management – increased the amount of the adjusted R^2 by .7%. While the overall model remained significant, the *addition* of the stressor variables themselves was not significant.

Table 22: Main Effects for Personal Factors and Stress upon the Dependent Variable 'Arousal'

Dependent Variable - Predictors	*β*	*SE*	*p-value*	*Adj.* R^2
Constant	2.94	.05	.00	19.5***
Personal Factors				
Caregiver's Health Limits	-.23	.03	.00	
Educational Level	.04	.06	.48	
Another Child Ill?	.33	.14	.01	
Constant	2.94	.05	.00	20.2***
Personal Factors				
Caregiver's Health Limits	-.24	.03	.00	
Educational Level	.03	.06	.60	
Another Child Ill?	.37	.14	.01	
Stressors				
HIV Status	-.08	.12	.48	
Illness Management	-.03	.03	.21	

NOTE: Model Significance *=p<.05; **=p<.01; ***=p<.001

Hypothesis 2.1: *Controlling for personal factors, the index child's illness status will be a significant predictor of; a) caregiver stress levels, b) caregiver arousal levels.*

Results 2.1: The HIV status of the index child cared for was not a significant factor in either regression equation. The factor remains non-significant throughout all of the subsequent regression equations as moderator and interaction variables are included. In addition, contrary to expectations, this variable affected the dependent variable, stress, in the opposite direction than hypothesized. However, the variable did influence the caregiver's arousal level in the hypothesized direction. Therefore, the null hypotheses cannot be rejected.

Hypothesis 2.2: *Controlling for personal factors, the level of illness management will be a significant predictor of; a) caregiver stress levels, b) caregiver arousal levels.*

Results 2.2: Similar to the previous hypothesis, illness management was not a significant predictor in either of the initial two regression equations. However, in subsequent regression models which included various moderator and interaction variables this variable did attain statistical significance. The models that Illness Management became significant all contained the arousal dependent variable, and the following moderators with their respective interaction terms; Child Support, Community Connections, and Formal Service Support. In all models, Illness Management impacted the dependent variables in the hypothesized directions. However, within the basic model presented above, the null hypotheses cannot be rejected.

Analyses – Research Question #3

The final step in the exploring the hypothesized moderating relationships of social support upon the stressor variables was to add each social support measure and its corresponding interaction terms to the regression equations utilized above. Once the centering of all the dependent variables had been accomplished, a multiplicative interaction term was created for each social support/stressor combination. For example, to test the main and interaction effects of family support upon the dependent variable (stress) the following equation was created (utilizing centered scores):

Predicted Value (Stress) = b_0 + b_1(Caregiver Health Limits) + b_2(Educational Level) + b_3(Another Child Ill?) + b_4(HIV Status) + b_5(Illness Management) + b_6(Family Support) + b_7(HIV Status * Family Support) + b_8(Illness Management * Family Support)

Similar regression equations were created for each combination of conditioning variable and stressor, with six total regression equations. Each of the six equations were subsequently used to estimate the two dependent variables, stress and arousal, resulting in 12 completed regression calculations. The results from each hypothesis is discussed below.

Hypothesis 3.1a: *Controlling for personal factors, the level of support from family will significantly buffer the effects of the stressor upon caregiver stress levels.*

Results 3.1a: Family support impacted the dependent variable in the hypothesized direction. However, the addition of family support and its corresponding interaction terms, as shown in Table 23, actually decreased the amount of variance explained 1.2%. As such, neither family support nor the interactions were significant predictors of the level of caregiver stress, with coefficients equal to, or almost equal to, zero. The overall model remained significant, although only one variable, Caregiver's Health Limits, was a statistically significant predictor. Therefore, the null hypothesis cannot be rejected.

Table 23: Main and Interaction Effects for Family Support upon the Dependent Variable 'Stress'

Dependent Variable - Predictors	*β*	*SE*	*p-value*	*Adj. R^2*
Constant	2.07	.05	.00	13.4***
Personal Factors				
Caregiver's Health Limits	.20	.04	.00	
Educational Level	-.10	.07	.15	
Another Child Ill?	.04	.15	.82	
Stressors				
HIV Status	-.07	.13	.57	
Illness Management	.03	.03	.23	
Social Support Source				
Family Support	-.00	.06	.99	
Constant	2.07	.05	.00	12.6***
Personal Factors				
Caregiver's Health Limits	.20	.04	.00	
Educational Level	-.10	.07	.17	
Another Child Ill?	.03	.15	.83	
Stressors				
HIV Status	-.07	.13	.99	
Illness Management	.03	.03	.72	
Social Support Source				
Family Support	-.00	.06	.86	
Interaction Effect				
Family Support * HIV Status	-.02	.13	.85	
Family Support * Illness Management	.00	.03	.97	

NOTE: Model Significance *=p<.05; **=p<.01; ***=p<.001

Hypothesis 3.1b: *Controlling for personal factors, the level of support from family will significantly buffer the effects of the stressor upon caregiver arousal levels.*

Results 3.1b: The hypothesized direction of the conditioning variable on the dependent variable was as hypothesized. However, family support was not a significant predictor of caregiver arousal levels, nor were the corresponding interactions. Thus, no buffering effect was found. The final regression had an adjusted R^2 of 19.6% (as listed in

Table 24), which was a reduction of .6% from its previous form. Caregiver Health Limits and Another Child Ill both remained significant within this equation. The null hypothesis cannot be rejected.

Table 24: Main and Interaction Effects for Family Support upon the Dependent Variable 'Arousal'

Dependent Variable - Predictors	*β*	*SE*	*p-value*	*Adj.* R^2
Constant	2.94	.05	.00	20.1***
Personal Factors				
Caregiver's Health Limits	-.24	.03	.00	
Educational Level	.02	.06	.65	
Another Child Ill?	.36	.14	.01	
Stressors				
HIV Status	-.08	.12	.48	
Illness Management	-.03	.03	.22	
Social Support Source				
Family Support	.04	.05	.40	
Constant	2.94	.05	.00	19.6***
Personal Factors				
Caregiver's Health Limits	-.24	.03	.00	
Educational Level	.02	.06	.72	
Another Child Ill?	.35	.14	.01	
Stressors				
HIV Status	-.08	.12	.57	
Illness Management	-.03	.03	.33	
Social Support Source				
Family Support	.05	.05	.66	
Interaction Effect				
Family Support * HIV Status	.04	.12	.71	
Family Support * Illness Management	.02	.03	.52	

NOTE: Model Significance *=p<.05; **=p<.01; ***=p<.001

Hypothesis 3.2a: *Controlling for personal factors, the level of support from friends will significantly buffer the effects of the stressor upon caregiver stress levels.*

Results 3.2a: Within the regression equation, support from friends did not significantly predict caregiver stress levels. Although, as shown in Table 25, support from friends did impact the dependent variable in the hypothesized direction. The addition of the interaction terms reduced the adjusted R^2 .8%, with neither term approaching significance. Lastly, although the overall model remained significant, only Caregiver Health Limits maintained significance. Therefore, the null hypothesis cannot be rejected.

Table 25: Main and Interaction Effects for Friend Support upon the Dependent Variable 'Stress'

Dependent Variable - Predictors	*β*	*SE*	*p-value*	*Adj. R^2*
Constant	2.07	.05	.00	13.8***
Personal Factors				
Caregiver's Health Limits	.20	.04	.00	
Educational Level	-.09	.07	.23	
Another Child Ill?	.04	.15	.80	
Stressors				
HIV Status	-.05	.13	.68	
Illness Management	.03	.03	.25	
Social Support Source				
Friend Support	-.03	.03	.32	
Constant	2.06	.05	.00	13.0***
Personal Factors				
Caregiver's Health Limits	.20	.04	.00	
Educational Level	-.09	.07	.22	
Another Child Ill?	.04	.15	.80	
Stressors				
HIV Status	-.05	.13	.75	
Illness Management	.03	.03	.64	
Social Support Source				
Friend Support	-.03	.03	.63	
Interaction Effect				
Friend Support * HIV Status	.01	.07	.86	
Friend Support * Illness Management	-.07	.02	.96	

NOTE: Model Significance *=p<.05; **=p<.01; ***=p<.001

Hypothesis 3.2b: *Controlling for personal factors, the level of support from friends will significantly buffer the effects of the stressor upon caregiver arousal levels.*

Results 3.2b: Table 26 shows the significant main impact of Friend Support upon the caregiver's level of arousal. In addition, there was a significant change within the overall model as demonstrated in the change in adjusted R^2 from 20.2% to 25.4% (f=13.951; p<.001). Although neither of the multiplicative interaction terms were significant, one, the interaction of Friend Support and HIV Status, was nearing significance with a p-value of .09. Support from friends also impacted the dependent variable in the hypothesized direction. Two other terms remained significant in the regression equation – Caregiver Health Limits and Another Child Ill. Although the main effect was significant, the hypothesized buffering effect was not supported. Therefore, the null hypothesis cannot be rejected.

Table 26: Main and Interaction Effects for Friend Support upon the Dependent Variable 'Arousal'

Dependent Variable - Predictors	*β*	*SE*	*p-value*	*Adj. R^2*
Constant	2.94	.05	.00	24.9***
Personal Factors				
Caregiver's Health Limits	-.23	.03	.00	
Educational Level	-.02	.06	.81	
Another Child Ill?	.36	.13	.01	
Stressors				
HIV Status	-.15	.11	.20	
Illness Management	-.03	.03	.28	
Social Support Source				
Friend Support	.10	.03	.00	
Constant	2.95	.05	.00	25.4***
Personal Factors				
Caregiver's Health Limits	-.24	.03	.00	
Educational Level	-.00	.06	.94	
Another Child Ill?	.37	.13	.01	
Stressors				
HIV Status	-.14	.12	.33	
Illness Management	-.03	.03	.51	
Social Support Source				
Friend Support	.09	.03	.00	
Interaction Effect				
Friend Support * HIV Status	-.10	.06	.09	
Friend Support * Illness Management	.00	.01	.84	

NOTE: Model Significance *=p<.05; **=p<.01; ***=p<.001

Hypothesis 3.3a: *Controlling for personal factors, the level of support from children will significantly buffer the effects of the stressor upon caregiver stress levels.*

Results 3.3a: The addition of the main and interaction effects increased the adjusted R^2 from 13.8% to 14.7%, although the change was not statistically significant. In the final equation, as shown in Table 27, support was close to significant with a p-value of .09. Neither of the interaction terms were significant, although all terms in the regression were affecting the dependent variable in the desired direction. Caregiver Health Limits remained significant for all models. Thus, as no interaction were noted, the null hypothesis cannot be rejected.

Table 27: Main and Interaction Effects for Child Support upon the Dependent Variable 'Stress'

Dependent Variable - Predictors	*β*	*SE*	*p-value*	*Adj. R^2*
Constant	2.07	.05	.00	13.5***
Personal Factors				
Caregiver’s Health Limits	.19	.04	.00	
Educational Level	-.10	.07	.15	
Another Child Ill?	.03	.15	.85	
Stressors				
HIV Status	-.08	.13	.53	
Illness Management	.04	.03	.22	
Social Support Source				
Child Support	-.02	.04	.55	
Constant	2.07	.05	.68	14.7***
Personal Factors				
Caregiver’s Health Limits	.18	.04	.00	
Educational Level	-.08	.07	.24	
Another Child Ill?	.04	.15	.80	
Stressors				
HIV Status	-.09	.13	.24	
Illness Management	.04	.03	.36	
Social Support Source				
Child Support	-.03	.04	.09	
Interaction Effect				
Child Support * HIV Status	-.11	.08	.19	
Child Support * Illness Management	-.02	.02	.47	

NOTE: Model Significance *=p<.05; **=p<.01; ***=p<.001

Hypothesis 3.3b: *Controlling for personal factors, the level of support from children will significantly buffer the effects of the stressor upon caregiver arousal levels.*

Results 3.3b: Table 28 shows the significant impact of several predictor variable upon the caregiver’s level of arousal, including Caregiver Health Limits, Another Child Ill, Illness Management, and the interaction between Illness Management and Child Support. In addition, there was a significant change within the overall model as demonstrated in the change in adjusted R^2 from 20.2% to 22.5% (f=3.879; p<.022). Although one of the multiplicative interaction terms was not significant, the interaction of between Illness Management and Child Support was statistically significance with a p-value of .01. Although the main effect was non-significant, the hypothesized buffering effect was supported for one of the stressor. Therefore, the buffering effect of Child Support on Illness Management and Child Support can be supported and the null hypothesis can be rejected. However, the buffering effect of Child Support on HIV Status was not supported and the null hypothesis for that term cannot be rejected.

Table 28: Main and Interaction Effects for Child Support upon the Dependent Variable 'Arousal'

Dependent Variable – Predictors	β	*SE*	*p-value*	*Adj.* R^2
Constant	2.94	.05	.00	20.3***
Personal Factors				
Caregiver's Health Limits	-.23	.03	.00	
Educational Level	.03	.06	.62	
Another Child Ill?	.38	.14	.01	
Stressors				
HIV Status	-.07	.12	.55	
Illness Management	-.04	.03	.18	
Social Support Source				
Child Support	.04	.03	.24	
Constant	2.93	.05	.00	22.5***
Personal Factors				
Caregiver's Health Limits	-.24	.04	.00	
Educational Level	.03	.06	.58	
Another Child Ill?	.42	.14	.00	
Stressors				
HIV Status	-.06	.11	.24	
Illness Management	-.04	.03	.00	
Social Support Source				
Child Support	.05	.03	.82	
Interaction Effect				
Child Support * HIV Status	-.10	.07	.19	
Child Support * Illness Management	.05	.02	.01	

NOTE: Model Significance *=p<.05; **=p<.01; ***=p<.001

Due to the rejection of the null hypothesis and significance of the interaction term, the interaction between the conditioning variable, Child Support, and the stressor, Illness Management, will be decomposed. This is done to determine the significance of the slope of Child Support on levels of caregiver arousal at low, mid and high levels of Illness Management. Low and high levels of Child Support were obtained, utilizing Cohen and Cohen's (1983, as cited in Aiken & West, 1991) suggestion of amounts one standard deviation below (-1.57) and above (1.57) the mean centered score (with the mean equal to zero). As such, in keeping with Cohen and Cohen's (1983, as cited in Aiken & West) guidelines for decomposing the interaction, the following equation was utilized:[3]

$$\text{Predicted Arousal Level} = ((b_5 + b_8(\text{Child Support})) * \text{Illness Management}) + (b_6(\text{Child Support}) + b_0)$$

Figure 6 below displays the slopes from these three scenarios. The slope of Illness Management on caregiver arousal level was significantly different from zero at low levels of Child Support ($b = -.119$, $SE = .043$, $p<.01$), with a decrease in caregiver arousal levels of 1.18 from low to high levels of Illness Management. However, the slope of Illness Management on caregiver arousal level was not significantly different from zero at either the mean or high levels of Child Support ($b = -.040$, $SE = .026$, $p>.01$; $b = .039$, $SE = .039$, $p>.01$, respectively). Those individuals with no reported Child Support showed a decrease of .47 in their arousal level, while caregivers with high levels of child support increased their arousal levels .39 points across the Illness Management spectrum. Finally, the sign of the significant coefficient indicates that a lower level of arousal is associated with caregivers having a high amount of illness management tasks, yet little to no support from the index child.

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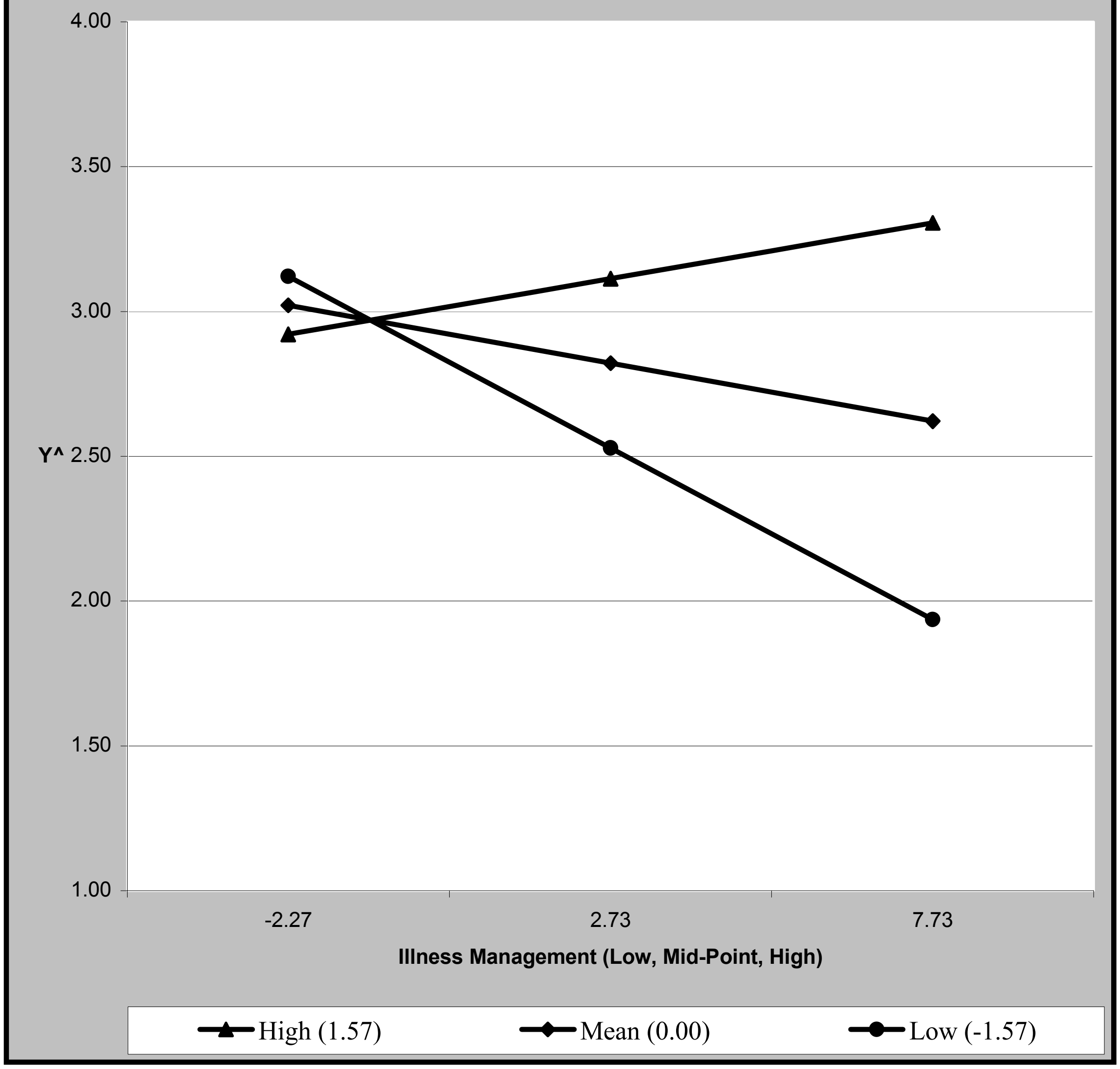
[3] For this analysis the variables not under investigation were removed from the equation, essentially setting them to zero.

Figure 6: Decomposition of the Effect of Illness Management Tasks on Caregiver Arousal at Varying Levels of Support from the Index Child



Hypothesis 3.4a: *Controlling for personal factors, the level of connection to the community will significantly buffer the effects of the stressor upon caregiver stress levels.*

Results 3.4a: Connections within the community did not significantly predict caregiver stress levels. Although, as shown in Table 29, the conditioning variable did impact the dependent variable in the hypothesized direction. However, the addition of the interaction terms reduced the adjusted R^2 .8%, with neither term approaching significance. Lastly, although the overall model remained significant, only Caregiver Health Limits maintained significance. Therefore, the null hypothesis cannot be rejected.

Table 29: Main and Interaction Effects for Community Connections upon the Dependent Variable 'Stress'

Dependent Variable - Predictors	β	*SE*	*p-value*	*Adj.* R^2
Constant	2.07	.05	.00	13.8***
Personal Factors				
Caregiver's Health Limits	.19	.04	.00	
Educational Level	-.10	.07	.15	
Another Child Ill?	.06	.15	.71	
Stressors				
HIV Status	-.09	.13	.49	
Illness Management	.04	.03	.22	
Social Support Source				
Community Connections	-.03	.03	.32	
Constant	2.07	.05	.00	13.0***
Personal Factors				
Caregiver's Health Limits	.20	.04	.00	
Educational Level	-.10	.07	.16	
Another Child Ill?	.05	.15	.73	
Stressors				
HIV Status	-.09	.13	.67	
Illness Management	.04	.03	.64	
Social Support Source				
Community Connections	-.03	.03	.62	
Interaction Effect				
Community Connections * HIV Status	.01	.06	.92	
Community Connections * Illness Management	.00	.01	.90	

NOTE: Model Significance *=p<.05; **=p<.01; ***=p<.001

Hypothesis 3.4b: *Controlling for personal factors, the level of connection to the community will significantly buffer the effects of the stressor upon caregiver arousal levels.*

Results 3.4b: The hypothesized moderator, Community Connections, did not significantly predict caregiver arousal levels, although the conditioning variable did impact the dependent variable in the hypothesized direction. In addition, as shown in

Table 30, the interaction terms increased the adjusted R^2 slightly, yet neither term approached significance. The overall model remained significant, with Caregiver Health Limits, Another Child Ill, and Illness Management reaching statistical significance. Nevertheless, the null hypothesis cannot be rejected.

Table 30: Main and Interaction Effects for Community Connections upon the Dependent Variable 'Arousal'

Dependent Variable - Predictors	β	*SE*	*p-value*	*Adj.* R^2
Constant	2.94	.05	.00	20.0***
Personal Factors				
Caregiver's Health Limits	-.24	.03	.00	
Educational Level	.03	.06	.60	
Another Child Ill?	.39	.14	.01	
Stressors				
HIV Status	-.09	.12	.42	
Illness Management	-.03	.03	.22	
Social Support Source				
Community Connections	-.02	.02	.43	
Constant	2.94	.05	.00	20.6***
Personal Factors				
Caregiver's Health Limits	-.24	.03	.00	
Educational Level	.04	.06	.52	
Another Child Ill?	.37	.14	.01	
Stressors				
HIV Status	-.09	.12	.66	
Illness Management	-.04	.03	.04	
Social Support Source				
Community Connections	-.02	.02	.19	
Interaction Effect				
Community Connections * HIV Status	.01	.05	.88	
Community Connections * Illness Management	.02	.01	.11	

NOTE: Model Significance *=p<.05; **=p<.01; ***=p<.001

Hypothesis 3.5a: *Controlling for personal factors, the level of support from church/spirituality will significantly buffer the effects of the stressor upon caregiver stress levels.*

Results 3.5a: Table 31 shows the addition of Church/Spiritual Support and its corresponding interaction terms to the regression equation. Although there was an .4% increase in the adjusted R^2, the change was not significant. Both of the multiplicative interaction terms, as well as the main effect of the conditioning variable, were not significant. Church/Spiritual Support did impact the dependent variable in the hypothesized direction. Only one item was significant in the regression equation, Caregiver Health Limits; therefore, the null hypothesis cannot be rejected.

Table 31: Main and Interaction Effects for Church/Spiritual Support upon the Dependent Variable 'Stress'

Dependent Variable - Predictors	*β*	*SE*	*p-value*	*Adj. R^2*
Constant	2.07	.05	.00	14.3***
Personal Factors				
Caregiver's Health Limits	.18	.04	.00	
Educational Level	-.08	.07	.26	
Another Child Ill?	.06	.15	.69	
Stressors				
HIV Status	-.11	.13	.41	
Illness Management	.04	.03	.21	
Social Support Source				
Church/Spiritual Support	-.05	.04	.14	
Constant	2.06	.05	.00	14.2***
Personal Factors				
Caregiver's Health Limits	.18	.04	.00	
Educational Level	-.08	.07	.27	
Another Child Ill?	.06	.15	.67	
Stressors				
HIV Status	-.12	.13	.88	
Illness Management	.04	.03	.17	
Social Support Source				
Church/Spiritual Support	-.05	.04	.72	
Interaction Effect				
Church/Spiritual Support * HIV Status	-.02	.08	.83	
Church/Spiritual Support * Illness Management	-.02	.02	.31	

NOTE: Model Significance *=p<.05; **=p<.01; ***=p<.001

Hypothesis 3.5b: *Controlling for personal factors, the level of support from church/spirituality will significantly buffer the effects of the stressor upon caregiver arousal levels.*

Results 3.5b: Church/Spiritual Support, as illustrated in Table 32, shows a significant main impact upon the caregiver's level of arousal prior to the addition of the interaction terms. However, its significance is lost with the inclusion of the multiplicative factors. In addition, there was a significant change within the overall model with the addition of the main effect only, as demonstrated in the change in adjusted R^2 from 20.2% to 23.6% between (f=10.276; p<.002). The adjusted R^2 is reduced .6% with the introduction if the interaction variables. Neither of the multiplicative interaction terms were significant. The conditioning variable impacted the dependent variable in the hypothesized direction. Two other terms remained significant in the regression equation – Caregiver Health Limits and Another Child Ill. Although the main effect was significant, the hypothesized buffering effect was not supported. Therefore, the null hypothesis cannot be rejected.

Table 32: Main and Interaction Effects for Church/Spiritual Support upon the Dependent Variable 'Arousal'

Dependent Variable - Predictors	β	*SE*	*p-value*	*Adj.* R^2
Constant	2.94	.05	.00	23.6***
Personal Factors				
Caregiver's Health Limits	-.21	.03	.00	
Educational Level	-.01	.06	.90	
Another Child Ill?	.32	.13	.02	
Stressors				
HIV Status	-.02	.12	.88	
Illness Management	-.04	.03	.17	
Social Support Source				
Church/Spiritual Support	.11	.03	.00	
Constant	2.93	.05	.00	23.0***
Personal Factors				
Caregiver's Health Limits	-.21	.03	.00	
Educational Level	-.01	.06	.93	
Another Child Ill?	.33	.14	.02	
Stressors				
HIV Status	-.02	.12	.62	
Illness Management	-.04	.03	.52	
Social Support Source				
Church/Spiritual Support	.11	.03	.12	
Interaction Effect				
Church/Spiritual Support * HIV Status	-.04	.07	.55	
Church/Spiritual Support * Illness Management	.00	.02	.84	

NOTE: Model Significance *=p<.05; **=p<.01; ***=p<.001

Hypothesis 3.6a: *Controlling for personal factors, the level of formal service supports will significantly buffer the effects of the stressor upon caregiver stress levels.*

Results 3.6a: The effect of Formal Service Support upon caregiver stress, as listed in Table 33, was not significant. Neither of the multiplicative interaction terms were not significant. In addition, there was an .7% decrease in the adjusted R^2, although the change was not significant. Formal Service Support did not impact the dependent variable in the hypothesized direction; however, the coefficient was almost equal to zero with little impact evident. Only one item was significant in the regression equation, Caregiver Health Limits; therefore, the null hypothesis cannot be rejected.

Table 33: Main and Interaction Effects for Formal Service Support upon the Dependent Variable 'Stress'

Dependent Variable - Predictors	*β*	*SE*	*p-value*	*Adj. R^2*
Constant	2.07	.05	.00	13.4***
Personal Factors				
Caregiver's Health Limits	.20	.04	.00	
Educational Level	-.10	.07	.15	
Another Child Ill?	.03	.15	.82	
Stressors				
HIV Status	-.07	.13	.57	
Illness Management	.04	.03	.23	
Social Support Source				
Formal Service Support	-.00	.07	.95	
Constant	2.06	.05	.09	13.1***
Personal Factors				
Caregiver's Health Limits	.19	.04	.00	
Educational Level	-.09	.07	.19	
Another Child Ill?	.04	.15	.78	
Stressors				
HIV Status	-.08	.13	.37	
Illness Management	.04	.03	.89	
Social Support Source				
Formal Service Support	.01	.07	.28	
Interaction Effect				
Formal Service Support * HIV Status	-.17	.16	.28	
Formal Service Support * Illness Management	.01	.04	.84	

NOTE: Model Significance *=p<.05; **=p<.01; ***=p<.001

Hypothesis 3.6b: *Controlling for personal factors, the level of formal service supports will significantly buffer the effects of the stressor upon caregiver arousal levels.*

Results 3.6b: Formal Service Support, as identified in Table 34, shows a significant main impact upon the caregiver's level of arousal prior to the addition of the interaction terms. However, its significance is lost with the inclusion of the multiplicative factors. In addition, the interaction term, Formal Service Support * Illness Management, is approaching significance. In addition, there was a significant change within the overall model with the addition of the main effect, as demonstrated in the change in adjusted R^2 from 20.2% to 21.3% (f=4.003; p<.047), with an additional .9% added with the insertion of the interaction variables. The conditioning variable also impacted the dependent variable in the hypothesized direction. Three other terms remained significant in the regression equation – Caregiver Health Limits, Another Child Ill, and Illness Management. Although the main effect was significant, the hypothesized buffering effect was not supported. Therefore, the null hypothesis cannot be rejected.

Table 34: Main and Interaction Effects for Formal Service Support upon the Dependent Variable 'Arousal'

Dependent Variable – Predictors	*β*	*SE*	*p-value*	*Adj.* R^2
Constant	2.94	.05	.00	21.3***
Personal Factors				
Caregiver's Health Limits	-.25	.03	.00	
Educational Level	.03	.06	.61	
Another Child Ill?	.38	.14	.01	
Stressors				
HIV Status	-.11	.12	.33	
Illness Management	-.03	.03	.27	
Social Support Source				
Formal Service Support	-.12	.06	.05	
Constant	2.93	.05	.00	22.2***
Personal Factors				
Caregiver's Health Limits	-.25	.03	.00	
Educational Level	.04	.06	.56	
Another Child Ill?	.39	.14	.00	
Stressors				
HIV Status	-.12	.12	.99	
Illness Management	-.04	.03	.04	
Social Support Source				
Formal Service Support	-.12	.06	.20	
Interaction Effect				
Formal Service Support * HIV Status	-.04	.14	.78	
Formal Service Support * Illness Management	.06	.03	.06	

NOTE: Model Significance *=p<.05; **=p<.01; ***=p<.001

Summary of Findings

The data presented in this chapter helps to illuminate many of the characteristics of individuals caring for children infected and/or affected by HIV/AIDS. The answers found to the questions posited also assist in highlighting the impact of various social support sources upon caregivers perceived level or stress and arousal.

Some of the major findings include that the majority of individuals in this study's sample are birth mothers working to maintain their families under difficult situations.

Many caregivers, birth and other, are in poor health, with some also caring for other sick children as well. However, birth mothers, as a group, have more health difficulties that place limits on their activities in the home, lower formal education, less support from their family, friends, and church/spirituality than their counterparts. Yet, it was also found that others provide care for significantly more HIV positive children, as well as more other ill children. There were no statistical differences between birth mothers and other caregivers on a number of factors such as the amount of illness management tasks, amount of support from the index child, connections with the community, and formal service support. Lastly, birth mothers reported more perceived stress and less arousal than did other caregivers.

All of the hypothesized regression model explained a significant amount of the variance, ranging from 12.6% to 25.4%. The models appeared to estimate the caregiver's level of arousal more accurately that their level of stress, with adjusted R^2 from each ranging 19.5% to 25.4% and 12.6% to 14.7%, respectively. The most consistently significant variable in the regression equations was Caregiver Health Limits, with several social support variables also showing significance. However, only one, Child Support, demonstrated a significant interaction effect. These findings will be explored further in Chapter 6, where the results will be scrutinized for their potential influence on theory, practice, policy and research.

CHAPTER 6

DISCUSSION

This final chapter will dissect the results presented in Chapter 5 and discuss the potential of the findings to help families living with HIV/AIDS. Next, to further the development of applicable theory, the findings will be examined within the Stress-Coping model. Significant findings will be placed within the theoretical context and a final model consistent with the findings will be presented. Implications for future practice and program creation will be proposed in light of the findings. To that end, new ways to support families and caregivers through legislation and policy development will be discussed. The limits of the study will also be listed, with their potential influence on the findings examined. Lastly, avenues for future research will be put forth, as well as specific questions posed highlighting the further need to explored the important relationship between social support and caregiver stress throughout the HIV/AIDS illness trajectory.

Discussion of the Findings

A sample of 212 caregivers of children infected and/or affected by HIV/AIDS was obtained to explore the relationship of various sources of social support upon their levels of stress and arousal. This section will place the findings within the context of the existing literature. It will highlight the similarities and differences between this and other studies, as well as suggesting possible reasons for both as indicated by the results. Utilizing this criteria, the sample characteristics will be examined to provide a profile of the caregivers and children. In addition, significant differences found between birth mothers and other caregivers will be illuminated with implications drawn for each. Lastly, the relative influence of the personal factors, stressors, and conditioning and interaction variables upon the dependent variables of stress and arousal will be discussed.

The majority (67.5%) of caregivers in the study were birth mothers, which is consistent with samples found in other studies of caregivers of children with HIV/AIDS (Hughes & Caliandro, 1996; M. Rose & Clark-Alexander, 1998). In addition, the overwhelming majority (93.8%) of the caregivers within both groups were female. In a study of caregivers, Mellins and Ehrhardt's (1994) sample also consisted of primarily (84%) female subjects. This finding permeates the caregiving literature, with M. Rose and Clark-Alexander having an all female sample, and Hughes and Caliandro reporting an 83.7% female sample. The consistency of these findings across studies spanning over a decade illustrate the overwhelming responsibility placed upon women, many (60.8% in this study) of whom are single parents.

Many of the caregivers must also cope with stressors due to their minority status, with 92% of this sample identified as African-American. Although not as high, this majority is consistent with Hansell and her colleagues (1998), who had a sample which included 74% African-Americans. M. Rose and Clark-Alexander (1998) had 68%, Hackl et al. (1997) had 63%, and S. Andrews et al. (1993) also had a majority (56%) of African-Americans in their sample.

This lack of heterogeneity throughout the literature may be attributable to a variety of factors, particularly sampling, yet this study's sample may actually be more representative of its investigative jurisdiction than the other studies. As of July 1999, Maryland had the 6th highest concentration of African-Americans in the United States, accounting for 28.1% of the state's population (U.S. Census Bureau, 2000b). The other studies have taken place in areas that have a much smaller percentage of African-Americans. For example, Hackl et al. (1997) study was conducted in Wisconsin, which ranks 30th with only African-Americans representing only 5.6% of the state's peoples. Similarly, Hansell et al. (1998) conducted their examination in New York and New Jersey which rank 11th and 16th respectively, with an average representation of 16.2% African-Americans. Neither S. Andrews et al. (1993) nor M. Rose and Clark-Alexander (1998) specified their location enough to estimate the representativeness of their samples. Thus, African-Americans in this study were 3.27 times more likely to be included in the sample than individuals of other race/ethnicities.[1] However, African-Americans in Hackl et al.'s study were 11.25 times more likely to be included, and those in Hansell and her colleagues' study were 4.57 times more likely. Therefore, when examining the racial/ethnic dispersion of this study in relation to the others, and also considering the disproportionate amount of HIV positive African-American women found throughout the country, the sample contained herein appears to capture an important and representative segment of affected families.

The mean age of the caregivers was 34 ½ years old. However, birth mothers averaged 31 (SD=6.85) while other caregivers averaged 45 (SD=9.33), which is a significant difference in their respective ages (t=11.105; p<.001). This overall mean age is consistent with Hackl et al. (1997), whose participants had an average age of 35.6 years

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[1] This calculation was obtained by dividing the overall percentage of African-Americans in the sample (92%) by their representation in the population-at-large within the respective state, Maryland (28.1%). For example: 92/28.1=3.27. Similar calculations were made for the other available studies' samples.

old. S. Andrews et al. (1993) reported similar findings, with subjects' having a mean age of 30.3 years and an overall range of 19-43 years old. Respondents in Hansell et al.'s (1998) research had a mean age of 36, with HIV negative caregivers significantly older (mean = 42) than birth parents (mean = 32). M. Rose and Clark-Alexander (1998) also found that alternative caregivers were older than birth mothers, averaging 47.4 years of age (SD=13.0) and 27.4 years old (SD=5.2), respectively. They reported that this was due to many of the alternative caregivers being grandmothers. This was also true for many of the other caregivers within this study. In addition, other caregivers consisted of other female relatives (primarily aunts), as well as foster/adoptive parents who may have waited years to complete their education or attain career goals before choosing to care for a child infected and/or affected by HIV/AIDS.

As hypothesized, other caregivers had more formal education than did the birth mothers. Similarly, S. Andrews et al. (1993) found that 51% of birth mothers had not completed high school, with only 24% graduating high school and another 25% progressing beyond high school. M. Rose and Clark-Alexander (1998) also found that neither group of caregivers in their sample had a mean over the 12th grade (although some had completed high school). Hansell et al. (1998) reported that birth parents had less formal education than others, with half of the birth parents not completing high school. The significantly less formal education found among birth mothers may be a consideration when working on issues such as treatment adherence, understanding complex medical regimes, transportation schedules, program availability and eligibility, and other life sustaining necessities. Social support, if available, must be mobilized to assist in completing these tasks.

Unfortunately, birth mothers had significantly less support from their relatives and friends than did other caregivers. This finding is consistent with the existing literature, with M. Rose and Clark-Alexander (1998) reporting that alternative caregivers in their study had higher family support. They found the same results among support from friends, with alternative caregivers reporting significantly more support (M. Rose & Clark-Alexander). A confounding factor may be that neither caregiver group in this study were asked if their family, friends or other supports were aware of the HIV status of either themselves or their child. Thus, the difference may be due to the perceived or real stigma and fear of rejection associated with telling family and friends about their HIV status. In fact, many women, fearful of losing what support they may have, have not told their family and/or friends about their (and/or their child's) HIV status, resulting in a 'conspiracy of silence' (Walker, 1998).

As hypothesized, birth mothers scored lower than other caregivers on their level of support from family and friends. However, contrary to expectations, there was no difference between caregiver groups in the level of support obtained from the index child. It was thought that birth mothers would have stronger support from the index child due to the strengthening of the mother-child bond through the illness and social isolation process (Andrews, S. et al., 1993; Walker, 1998). Yet, it was found that both caregiver groups in this study had very high levels of support from their child, with three-fourths of all caregivers feeling that the child had had a mostly/very positive effect on the home. This finding is consistent with Hughes and Caliandro (1996), who, in a study of 29 biological parents and 22 other caregivers, reported that caregivers’ satisfaction with their children was very high. The finding of no difference between caregiver groups signals that, regardless of their own HIV status, these caretakers are parents first (Wiener et al., 1994).

Both groups had low levels of connection to their community, which is consistent with the social isolation theme permeating the literature (Hansell et al., 1999; Hughes & Caliandro, 1996; Mayers & Spiegel, 1992; M. Rose & Clark-Alexander, 1998; Wiener, 1998). Caliandro and Hughes (1998) found that grandmothers did not wish to participate in support groups with similar families because they did not want to talk openly with people they did not know. Yet, support groups have demonstrated their effectiveness at helping families cope with the challenges of raising a child infected and/or affected by HIV/AIDS (Mayers & Spiegel; Wiener). However, unlike many of the other sources of support, caregivers must openly admit and face the impact of HIV/AIDS on their family when making connections with similar families in their community. Thus, although beneficial, as shown by Mayers and Spiegel and Wiener, the families in this study may not be ready for this type of support.

Birth mothers found less support from church/spirituality than did the other caregivers. This source has been a strength for many people, although no study has explored this relationship between groups of caregivers of children infected and/or affected by HIV/AIDS. Nevertheless, C. Hall (1986) reported that families who espoused spiritual values were found to live more productively and experience more life satisfaction than families without such values. However, birth mothers may fear condemnation or alienation upon disclosure. For example, African-Americans who may be connected with fundamentalist religions may face real or perceived sanctions for their lifestyles or relationships (Mays, 1989). This very real fear of condemnation was pervasive in the early years of the pandemic, and still exists to a lesser degree today. However, this is not to say that birth mothers found no solace from church/spirituality. In fact, birth mothers scored just over halfway along the scale’s continuum. It may be that self-protective caution has insulated them from pursing this support further. Additional exploration of this support source is warranted to determine the potential benefits of its use.

There was no difference between either caregiver group on level of support from formal sources, with both scoring in the mid-level range. The majority of caregivers did not utilize either respite care or mental health services. However, over 70% of the total sample felt that the FaCT caseworkers were very helpful. An additional 25% felt they were adequate, with only 5% feeling their support was not helpful. It is important to note that the FaCT caseworkers received special training, which may have bolstered their effectiveness in working with the families. Thus, their scores are not easily comparable to the general population of caseworkers. In addition, the instrument itself was provided and collected by the FaCT caseworker, and must therefore be considered with some caution. As such, caregivers may have provided the answers desired in order not to jeopardize their relationship with someone of power (i.e., the ability to secure needed resources, provide reports to child welfare, etc.). This is not to imply any intentional misuse of influence by the caseworkers, but rather as an potentially biasing artifact of the data collection strategy. Despite this limitation, it appears that the overall support provided by the FaCT caseworkers was positive, and future practitioners should avail themselves of similar training.

The majority of birth mothers had at least some (+) stress, with other caregivers reporting significantly lower amounts. Surprisingly, neither group scored in the high (++) stress range. However, this is consistent with the findings of Hughes and Caliandro (1996), who reported that "caregivers did not experience caregiving as having a particularly negative impact on their lifestyle and were more in the middle of the lower range on their reports of burden" (p. 353). Additionally, birth mothers, as hypothesized, reported significantly lower arousal scores than did other caregivers; although both groups scored in the positive (+) range. These higher stress and lower arousal scores may be due to the birth mother’s fear that her own health will deteriorate before that of her child (Wiener et al., 1994). As such, the birth mother's own HIV infection diminishes her ability to maintain a cohesive family structure and cope with the child's needs; thus interfering with her ability to adapt to the caregiving demands.

When examining the independent variables impact upon each of the dependent variable, the surprising significance of the caregiver’s health limits upon their level of stress and arousal, which has been largely overlooked in this literature base, is striking. However, one other study examined the health of birth and alternate caregivers and found no difference in physical quality of life between the groups, with both groups having some health difficulties (M. Rose & Clark-Alexander, 1998). In contrast, Hughes and Caliandro (1996) reported that a dichotomous caregiver illness status variable (i.e., HIV positive vs. HIV negative) did not significantly predict caregiving stress.

Indeed, 44.5% of the caregivers in this study experienced health problems which impinged upon their daily living, with almost 1/5 of them almost always affected. Hackl et al. (1997) reported one mother in their sample stating that "[my son] will be here all alone, and I feel like I've failed him. I don't have anyone in my family responsible enough to take care of my 12-year-old. My biggest challenge is finding some place for my children" (p. 57). In fact, they found that many of the mothers concealed their illness from their younger children. Thus, fatigue and other illness-related problems that affected their ability to continue managing the home resulted in increased guilt. F. Cohen et al. (1995) reported similar findings, with mothers feeling that as their own illness progressed and their health deteriorated they would be much less able to care for their children. Many desperately wanted to give their children as normal a life as possible, and felt that this was not possible if they were ill. Mothers also wanted to be there for their children, and felt that they were abandoning them when their own illness made them incapable of providing daily care.

Caregivers, both birth mothers and others, may be expressing feelings similar to those described by S. Andrews et al. (1993) where HIV positive mothers felt increased anxiety in relation to their children, whether or not the child was HIV positive, due to concerns about the eventual placement of surviving children. This fear is universal and not unique to HIV positive or health compromised caregivers. However, the impending nature of the illness makes the issue forefront in the minds of caregivers.

Although birth mothers reported significantly more health related difficulties, many of the other caregivers also reported health problems. Caliandro and Hughes (1998) reported that grandmothers, which constitute many of the alternative caregivers, tend to minimize their own personal illness such as high blood pressure, ulcers, gastrointestinal bleeding, chest pain and asthma. The grandmothers feared acknowledging the illness and its potential to negatively impact their ability to care for the HIV positive child. Hansell and her colleagues (1998) reported that for an HIV positive birth mother with an HIV positive child, the caregiving situation is both a personal health crisis and a caregiver crisis. It would appear that this is not limited to birth mothers, but that health concerns must be considered among all individuals assuming this taxing role.

Having another child ill was a significant predictor of caregiver arousal level, but not stress level. Of the two stressors variables, only illness management was significant within 3 of the 6 arousal regression equations (Child Support, Community Connections, and Formal Service Support). Thus, it appears that under specific circumstances the amount of burden placed upon the caregiver, as indicated by the having more than one child ill (although it was not specified if the second child's illness was HIV-related), may significantly influence the level of arousal experienced by the caregiver.

Thus, the level/stage of the child's illness may have an impact on the caregiver under certain scenarios. The children in this study averaged 4.5 years of age (SD=3.84). This is similar to Hardy et al. (1994), who reported that the children in their study ranged in age from 4 to 7 years, with a mean of 5.25. Overall, the children in this study appeared to be relatively healthy, with only a slight majority (51.9%) HIV positive. The children were, on average, taken to the hospital less than one time in the previous 6 months, and to the doctors once every 1-3 months. Mellins and Ehrhardt (1994) reported similar findings in that the children in their study, although not severely ill, had been hospitalized at least once, with a small percentage hospitalized more than 10 times. In addition, it was found (falsifying the hypothesis) that there was no difference between caregiver groups on overall illness management tasks conducted on the child's behalf. Birth mothers also had significantly less HIV positive children in their care than did the other caregivers (44% vs. 68%). However, some of this skewness may be due to sampling bias, as other caregivers may have a higher propensity to be known to programs such as this, and thus have a greater chance of being included in the sample. Lastly, contrary to the hypothesis, other caregivers also had more than twice as many other sick children in the home.

There remains some controversy on the importance of the child’s level of illness. Hughes and Caliandro (1996) reported that when considered with other variables it did not significantly predict caregiving burden. However, Wiener et al. (1994) found that scores did not vary according to degree of debilitation until the child was extremely ill. They hypothesize that due to the nature of the disease "parents have encountered the pattern of debilitation and partial recovery so frequently that they deny depression and anxiety in order to participate in the care of the child and avoid experiencing what one parent called the 'emotional roller coaster'" (p. 491). However, when the child finally becomes extremely debilitated, the parent can no longer deny these feelings (Wiener et al.). Findings from these studies help illuminate the mixed findings within this study regarding this variable.

The current study also found mixed results between the various social support sources and either stress or arousal. Support from friends was found to have a significant main effect within the arousal scenario. Thus, support from friends directly impacts the level of caregiver arousal, irrespective of the level of either stressor. As such, a buffering effect was not indicated. However, there was one significant interaction between illness management and child support (although one more, formal*illness management, was approaching significance[2]). Support from the index child significantly buffered the negative effects of illness management upon the caregiver's level of arousal. As such, a lower level of arousal is associated with caregivers having a high amount of illness management tasks, yet little to no support from the index child. This may indicate that caregivers with positive relationships with the infected and/or affected child have sufficient levels of arousal despite increasing amounts of illness management tasks. Yet, those caregivers with negative relationships with the index child have decreasing levels of arousal as illness management-related tasks increase in frequency.

As discussed, the personal factors, especially caregiver health limits, explained the greatest proportion of the variance in each of the regression equations. Illness management was also found to be significant in several of the scenarios. In addition, the impact of social support was mixed, with one exhibiting a main effect and another demonstrating an interaction effect. Theory development, as well as implications for practice, policy and future research, as guided by these findings, will be discussed in the subsequent sections.

Theoretical Implications

The model put forth in Chapter 2 illustrated the moderating relationships hypothesized between the stressors and conditioning variables upon stress and arousal levels, with no direct main effects present. However, several strong effects from the personal factors were demonstrated, with only intermittent significance from the illness

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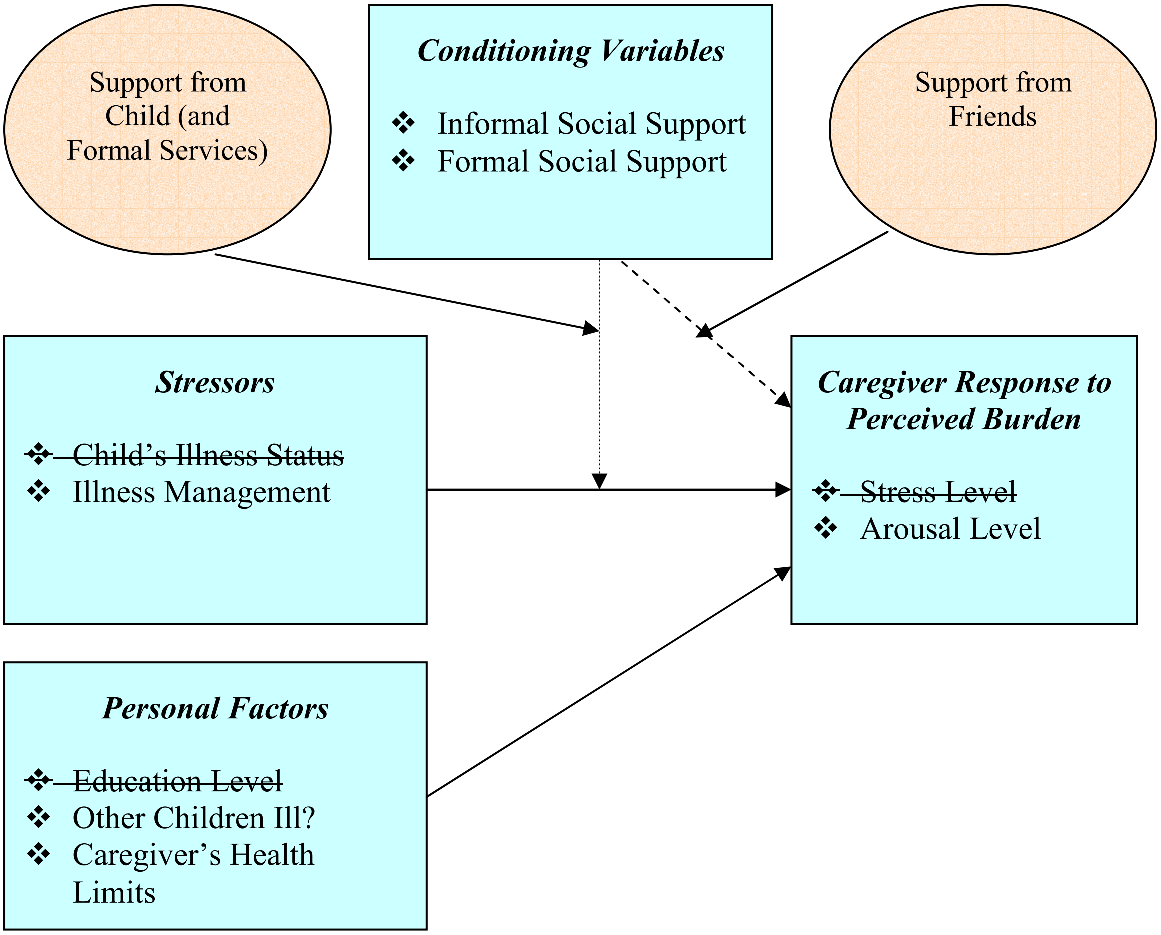
[2] While child support was significant at $p<.01$, formal service support was approaching significance with a p-value of .06.

management stressor. Additionally, only one significant social support main effect and one significant interaction variable were found. Thus, modifications to the model, as presented in Figure 7 below, are warranted.

In general, there are two models which hypothesize the effect of social support upon stress. The first model purports that social resources, such as support, have a beneficial effect on the individual irrespective of whether the person is experiencing stress or not (AKA the main effect) (Cohen, S. & Wills, 1985). As such, there is no interaction between the stressor and social support. Social support acts as a main effect upon the dependent variable (i.e., stress and/or arousal) irrespective of the existence or level of stressor. S. Cohen and Wills posit that "there may be a minimum threshold of social contact required for an effect on mortality to be observed, with little improvement in health outcomes for levels of support above the threshold" (p. 312). For example, an individual with a great deal of support from friends may receive positive regular experiences which may be related to one's overall well-being.

Figure 7: Modified Conceptual Model

A variation of the model utilized by Schulz et al. (1987)



The second model, as proposed in Chapter 2, states that support is related to well-being under varying conditions of stress (AKA the buffering, moderating or conditioning effects). As such, social support protects the individual from the harmful effects of the stressor (S. Cohen & Wills, 1985). S. Cohen and Wills argue that within the buffering model "support may intervene between the stressful event...and a stress reaction by attenuating or preventing a stress appraisal response. That is, the perception that others can and will provide necessary resources may redefine the potential for harm posed by a situation" (p. 312). They contend that there must be a reasonable match between the coping requirements and the available support in order for buffering to occur (S. Cohen & Wills).

There is at least some evidence that not all sources or types of social support are equally effective in reducing distress (Thoits, 1982). Many of the studies exploring the buffering relationship of social support upon stressors have not examined specific supports, and instead utilize a global 'social support' variable encompassing all forms of support (Bass et al., 1996; Blaney et al., 1991; Pearlin et al., 1981). However, it is clear that social support can be provided to individuals by a variety of people, such as a spouse, child, parent, friend, therapist, minister, co-worker, etc. Yet, to obtain a thorough understanding of how much support individuals receive would require an assessment of how much affect, affirmation, and aid they obtained from every person whom they perceive as supportive. To that end, Abbey, Abramis and Caplan (1985) tested the buffering effect of social support from two sources of social support - 'social support from *people*' and 'social support from *some one person*'. The buffering hypothesis was supported for the latter, but not the former. Their study, as well as this, support the need to focus on individual sources of support when studying this phenomenon.

It appears that a mix of the aforementioned influences are at play. For example, as shown in Figure 7, support from friends has a main effect on caregiver arousal level with no interaction effects present. Conversely, child support's interaction with illness management had a significant impact upon caregiver arousal levels, with no main effect present (similar findings are present for formal service support, which is approaching significance). However, it is hypothesized that this may be due to the result of both child support and formal service support being unique to this caregiving scenario. Individuals may have previously existing relationships with family, friends, and their church. However, the special relationship between caregiver and child noted in the literature and support by this study is uniquely different to the typical parent-child relationship due the social isolation and intensity of the illness situation. In addition, families would not be exposed to formal services outside of this scenario. Although it was clear that neither caregiver group was connected with the great HIV community, it is further hypothesized that a buffering effect may be present for those families engaging in these activities. Thus, it may be that some sources of social support exert a buffering effect while others demonstrate a main effect, depending upon the specific crisis at hand. This possibility demands further examination, and could greatly influence future practice and policy development.

Practice Implications

Although this study was exploratory in nature and needs further investigation to confirm the findings, certain implications for practice can be suggested. Given the minority representation among families living with HIV/AIDS, the first suggestion to engage and empower caregivers is that any intervention must be culturally and gender sensitive. To be effective, interventions must include a culturally sensitive approach to assessment and intervention, use key indigenous people, and utilize interdisciplinary collaboration including physicians, nurses, social workers, etc. (Goicoechea-Balbona, 1998). In a qualitative study examining the efficacy of a culturally sensitive intervention with migrant minority families, Goicoechea-Balbona found the Culturally Specific Health

Care Model (CSHCM) to be effective in engaging and empowering families impacted by HIV/AIDS. To engage families and facilitate support, practitioners must consider the person-in-environment, which includes factors such as the client's gender, race/ethnicity, SES, formal education level, and living arrangements, to name a few. It is clear that practitioners working with members of this caregiver group must be considerate of these issues when attempting to build connections.

Practitioners working with families living with HIV/AIDS have suspected the importance of social support upon caregiver levels of stress, arousal, depression, guilt, and other factors for some time. This research lends empirical support to this argument. Thus, it is also recommended that practitioners assist caregivers of both groups in connecting to various supportive sources. Interventions should first be aimed at maintaining and strengthening the integrity of the current social support network. Support from friends and other more traditional sources may assist the caregiver maintain her current living situation, irrespective of the stressor effects. However, it may be that as support network members are made aware of the HIV status of the caregiver and/or child a buffering effect may take place as specific source support is focused on addressing stress resulting from caring for a child infected and/or affected by HIV/AIDS. Of course, given the possible negative consequences, any disclosure by the caregiver to any network member should occur after careful discussion. Practitioners can assist caregivers in talking with support sources through role-plays and other exercises. For example, practitioners can help clients assess the degree of receptivity from support sources to the caregiver and/or child's HIV diagnosis, as well as model caregiver responses to resistance that may be received. These activities may enable caregivers to address concerns, fears and other issues expressed by potential support sources. This process may help to educate support sources on the needs of the child and/or caregiver and assist supports in providing specific helpful relief, whether emotional, informational or tangible.

Practitioners must also recognize the importance of the caregiver-child relationship for families living with HIV/AIDS. The caregiver's satisfaction with this relationship significantly buffers the negative effects resulting from multiple illness management tasks. Thus, practitioners should work with this dyad to support and strengthen this bond through a variety of sources such as the provision of outside activities to allow them to spend time together, teaching the caregiver about methods to engage the child, and the provision of therapeutic services. To assist in preserving the family structure as long as possible, the provision of services by formal sources, such as therapy or respite care, may strengthen the caregiver-child relationship and other aspects of the caregiving role. Similarly, fostering connections with similar families in their community, although not significant in this study, may provide a beneficial support for families (Mayers & Spiegel, 1992; Wiener, 1998). Although it is important to work with families to address potential intrapersonal and environmental barriers to utilizing support-type groups, the families in this study may not have been ready for this type of support. However, supports such as those listed may help caregivers better manage illness-related tasks for the index child, as well as any other ill children in their care. Practitioners should be aware of the potential benefits of this support sources, and assist client in determining their appropriateness for participation.

Lastly, social workers should recognize the important role the caregiver’s own health plays upon her ability to care for a child impacted by this disease. Parenting while ill can be particularly challenging, with children experiencing heightened anxiety and behavior problems (Christ et al., 1993; Siegel et al., 1992). These compounding factors can work to increase stress and decrease arousal, leaving caregivers vulnerable. Assisting caregivers in arranging for permanent child care choices is a significant matter when children will be left without a caregiver. Custody arrangements should be established to provide for the children's long-term care. For example, standby guardians (described further under 'Policy Implications') allows an HIV positive caregiver to designate an individual to become the child's guardian upon the caregiver's incapacitation, yet is revocable when/if the caregiver recuperates. Assurance for these matters may provide some relief to the caregivers. Therefore, it is incumbent upon practitioners to be fluent in the legislative and policy matters such as this that may facilitate or impinge on the caregiver’s ability to plan for the child in her care.

Policy Implications

Current policy does not recognize the important role of social support, especially from informal sources. Other social welfare programs, such as Ohio's Family Stability Incentive Fund that provides ‘flexible’ dollars to allow communities to creatively prevent out-of-home placements, have utilized vouchers to allow clients to 'purchase' support from willing friends, family members, etc (Tracy, Biegel & Johnsen, 1999). Unfortunately, the Ryan White Act, which is the "payor of last resort" (Health Resources and Services Administration, 2000, p. V.3), clearly states that funds cannot be used to pay informal support sources such as a family member or friend. Instead, individuals providing informal support would need to become a home health provider or employed by a contracting agency in order to receive any compensation. Thus attempting to institutionalize informal support by transforming them into formal service agents. Yet this fundamental change may adversely alter the dynamics within the informal support relationship.

Under Ryan White eligible participants may, under very specific circumstances, utilize a voucher system to purchase services from informal providers (Health Resources and Services Administration, 2000). Yet, in such instances, states are also cautioned that such funds should be limited and carefully monitored to assure compliance with all regulations. In addition, such arrangements may also raise liability issues for the funding source, who are once again cautioned that this should be carefully weighed in the decision-making process (Health Resources and Services Administration, 2000). Consequently, if even offered, states impose many qualification requirements which serve as deterrents to interested families (Sheila McCarthy, Health Resources and Services Administration Representative, personal communication, September 18, 2000). On the contrary, Leon (1999) reports that access to sufficient and appropriate resources and services without the imposition of unnecessary ‘red-tape’ is integral to successful service delivery and the empowerment of the families. Thus, these hurdles effectively exclude informal caregivers from accessing funds that may have allowed them to offer additional support.

In a survey of AIDS service organizations that asks directors to list any health and care-related services not covered by Medicaid and Ryan White Titles I and II, Buchanan and Chakravorty (1999) found that respondents reported that these programs did not cover emotional and practical support. In addition, a director responded that the programs did not cover support services for family and friends, stating that "often we encounter family that feels 'left out' because services embrace the HIV infected individual but not the [other] affected person[s]" (Buchanan & Chakravorty, p. 28). This has dire implications for caregivers and other family members (such as siblings) who live in the home with one or more HIV infected individuals.

In addition, family stability services such as permanency planning may also be allowable under Ryan White (Health Resources and Services Administration, 2000). Eighteen states, including Maryland, have enacted legislation that allow parents to appoint standby guardians for their children (Wassermann, 1999). These laws were passed in the latter half of the 1990s to enhance parents' ability to plan for their children. Under the laws, guardians can take authority over the children while the parent is unable to care for them. However, when the parent is able to resume caring for the child they are able to do so (Wassermann). Federal legislation passed in 1997 that encouraged all states to enact such legislation, yet it has yet to be implemented in the other 32 states. This study supports the need for such legislation, as it is clear that mothers are deeply concerned with the permanent plan for their children, and that being in control of this plan would help alleviate stress and bolster arousal levels.

Support for this legislation, curiously, is not unanimous. As Forehand et al. (1999), in a study of 20 children, reported that "even without legal arrangements prior to the mother's death, most children were living with the mother's preference for a caregiver. Thus, policies facilitating legal arrangements prior to the mother's death may not be necessary" (p. 721). Indeed, it may be true that the 20 mother’s in their study did not need this service. However, such sweeping statements based upon such a small sample of the hundreds of thousands of HIV positive parents over generalizes the study's results. Given the stigma and discrimination faced by the numerous mothers described in previous articles, it is felt that recommending against enacting policies which may help protect a caregiver's permanency choice for her children is irresponsible and potentially harmful to mothers.

Public programs, such as Medicaid and Ryan White, are the primary payers for the health and *care-related* services provided to HIV positive individuals. Expanded use of these waiver programs is recommended. Although these programs are intended to provide a safety net to HIV positive individuals, clients are being caught in the confusing web of this net. It is imperative for professionals to familiarize themselves with the available programs, locally and nationally, to better support families' access to available services. In addition, social work professionals should advocate for more flexibility in the program guidelines to have funds dispersed to other members of the HIV positive individual's support network who may otherwise not be able to assist in care-related tasks due to financial concerns and unnecessary red tape.

Study Limitations

This study addresses several of the common concerns listed when examining this population such as adequate sample size and multivariate analytic techniques. However, as with all research, this study also possessed several limitations which should be noted. This section will review those major limitations identified within the conceptual, sampling, data analysis and instrumentation domains.

Conceptual

Most studies, including this one, restrict the ‘primary caregiver’ to those thought to have total care responsibility. However, this focus on a single individual caregiver allows little or no consideration of potentially multiple caregivers within the caregiving situation (Barer & Johnson, 1990). Although a primary caregiver may be indicated, caregiving within families impacted by HIV/AIDS may be shared between many members. In families where both parent and child may be infected, caregiving responsibilities may actually fall upon a grandparent. As such, the grandparent may be reluctant to be identified as the primary caregiver, which may deal a psychological blow to the parent. Thus, this complex constellation of care in which roles may shift according to health status is not adequately addressed within the current research design. The cross-section design does not allow for the shift role patterns which may take place throughout the illness trajectory, nor does the current model allow for multiple caregivers existing at the same time.

Another limitation is the shifting of caregiving over time. The illness progresses through various stages of remission/dormancy and activity along the trajectory, ultimately ending in the caregiver and/or child’s death. This study does not capture where along the illness continuum (i.e., remission or activity) the data were collected, nor does it follow the illness through a longitudinal model. As such, the cross-sectional data obtained from families experiencing illness remission may provide different responses than those families struggling with a severely ill family member. Combining these two populations may serve to confound the findings.

A third limitation is the time since the confirmation of the illness. Families who have known of the illness for several years may have had sufficient time to integrate the information, whereas families that have just learned of the diagnosis may be in a different stage of the anticipatory grief process. This study did not capture this data.

Caring for a child infected and/or affected by HIV/AIDS has special challenges. However, many of the tasks are encompassed by the traditional parenting role. Thus, this and many studies do not adequately discern those tasks which are deemed above and beyond the normal call of duty from the daily hassles of parenting. Crnic and Greenberg (1990) posit that the frustration experienced by parents through daily hassles, although singularly may have little significance, can cumulatively become a meaningful stressor for the parent without appropriate social support. As such, there are two main types of stress experienced by primary caregivers of children; those associated with ‘normative’ child-related tasks (i.e., minor daily hassles), and those imposed through a major life event such as a childhood illness or disability (Breslau & Davis, 1986; Breslau et al., 1982; Crnic & Greenberg; Garner & Thompson, 1978; Kovacs & Feinberg, 1982; Pless & Satterwhite, 1975). For example, taking children to the doctors only once every 1-3 months, as the caregivers in this study reported, may be considered to be within the bounds of normal parenting. This study did not control for the stressors threshold that may be attributed to the normal parenting context as opposed to the illness context.

Stress and coping in caregivers of children with HIV/AIDS presents in a highly complex pattern. In addition, caregivers themselves present with multiple problems in living including transportation, finances, housing, food, schools, employment, clothing, as well as treatment for the child, self and family (Black et al., 1994; Hansell et al., 1998). Mellins and Ehrhardt (1994) further discuss other stressors that can impinge upon families living with HIV/AIDS such as poverty, violence, drug abuse and housing. F. Cohen et al. (1995) posit that, “it is *possible* that the extent of further family disruption caused by HIV disease may not be as readily apparent or is experienced differently because of other concomitant stresses and disruptions due to the conditions and struggles of everyday existence” [italics added] (p. 253). The numerous stressors noted which may impact the caregiver’s ability to cope with the situation were not adequately captured in the current research design.

Just as there are numerous stressors that may impinge upon caregivers, there are a multitude of support sources. R. Hays, Chauncey and Tobey (1990) found that about 1/3 of the HIV positive gay men turned to family for social support. However, within that context, siblings were preferred to parents. This study does not identify individual sources, and only utilizes the more global term 'relative'. In addition, several structural questions (i.e., partnered/non-partnered), as opposed to more functional inquiries of support are asked. Thus the existence of a source is confirmed, but not the quality of the partnership. As such, additional specificity on the relationships and sources of support may be warranted.

In addition, this study did not differentiate between helpful and unhelpful acts from support sources. Barbee et al. (1998) found that of the acts of support provided by friends, 62% were classified as helpful and 38% as unhelpful. Unhelpful acts, while well-meaning, may include statements such as offering advice to get tested again, or to "put yourself into a home because you never know when you might fall sick" (Barbee et al., p. 95). In addition, Ingram et al. (1999) identified four types of unsupportive responses/acts that HIV positive individuals often receive - insensitivity, disconnecting, forced optimism and blaming. Utilizing a hierarchical regression model, they found that unsupportive social support predicted a significant amount of the variance in depression. This study examined the provision (or absence) of positive support, yet did not explore the potential impact of negative influences on caregiver stress and arousal.

Lastly, this study did fully capture the internal coping strengths of the caregiver. The focus of this study was on social support as one mechanism of coping. However, Stress-Coping models may also include the individual caregiver's personal coping resources. Thus, in keeping with the tenets of social work practice, caregivers strengths must be recognized (Saleebey, 1992). It is clear that caregivers of children infected and/or affected by HIV/AIDS posses enormous strengths, yet this is often lacking in the literature. Future research must include this if it to portray an accurate picture of the caregiving situation.

Sampling

The respondents were comprised of a self-selected convenience sample of caregivers and are thus inherently biased (Barer & Johnson, 1990). Nonprobability sampling such as utilized herein increases the risk of producing biased and inefficient estimates of regression coefficients and exaggerated R^2's (Guo & Hussey, 2000). The study would have been strengthened by the utilization of a randomly selected group of caregivers of children infected and/or affected by HIV/AIDS that were subsequently randomly assigned to a treatment (social support exposure) and control group (no social support) (Cook & Campbell, 1979). Other comparison groups could include caregivers of healthy children, as well as caregivers of children stricken with other illnesses. This would have improved the study’s external validity and ability to generalize to the population of caregivers of HIV/AIDS impacted children. Cook and Campbell write that “accidental samples of convenience do not make it easy to infer the target population, nor is it clear what population is actually achieved” (p. 71). Instead, this study utilized a variant of what Cook and Campbell describe as a ‘model of deliberate sampling for heterogeneity’. This model does not require random sampling (thus, no generalizability). However, one can conclude that an effect has or has not been obtained across the particular sample criteria, such as African-American female caregivers.

In addition, the low levels of stress and high levels of reported child support may indicate a strong bias within the obtained sample. Researchers must overcome the dilemma that those caregivers most willing to consent to a study may also be those functioning most successfully in their roles. Presumably, those facing the most overwhelming challenges simply denied consent to participate in the first place. Community outreach must be done in order to ensure a full range of representation within the sample.

Instrumentation

The instruments utilized in this study were created as part of a larger program evaluation, and, as such, were not specifically crafted for research purposes. Thus, one cannot be sure if the scales utilized herein were valid measures of the constructs under consideration. The independent variable measures utilized had low alphas, ranging from a low of .10 for formal service support to a moderate .69 for church/spiritual support. Those in the low range (i.e., .10 - .35) include family support, child support and formal service support. The remainder fell within a moderate range of reliability, with alpha’s ranging from .44 to .69. These included community connection, friend support, illness management, and church/spiritual support (listed from lowest to highest). As described by Cook & Campbell (1979), “measures with low reliability cannot be depended upon to register true changes” (p. 43). A suggested correction for this limitation is to create longer tests with items that have been selected a priori for their representativeness of the construct and their high intercorrelations (Cook & Campbell). Thus, one must question if the scales truly capture the constructs under investigation. One of the difficulties in exploring this type of relationship is that there are no standard, well-validated ‘off-the-shelf’ scales. Typically, each researcher devises his/her own instrument for the specific study depending on the focus (Green, 1993). This difficulty is compounded by SES, culture, race, gender, sexual orientation and other variations.

In addition, 19 of the adjectives on the SACL did not meet the various criteria needed for inclusion and were eliminated. The remaining adjectives comprised the two scales: stress – bothered, uneasy, dejected, nervous, distressed, uptight; and arousal – cheerful, contented, pleasant, comfortable, calm. It appears from the adjectives loading on the arousal factor that a modified form may be at play. M. Rose and Clark-Alexander (1998) discussed a 'confrontative coping' style which focuses on constructively handling the stressful situation and directly confronting the problem, and a 'passive coping' style which depicts the modulation of tension by reframing the situation without directly confronting it (M. Rose & Clark-Alexander). It was hypothesized that the more active form may be present. However, it appears by the adjectives retained that the more passive form of coping may be present in the sample. Due to the study’s sample size, which was inadequate to meet the suggested standards for factor analysis (i.e. 10 subjects per item), it is unclear the exact nature of coping that may actually be utilized by these caregivers (Nunnally & Bernstein, 1994). Consequently, results discussed herein must be viewed as preliminary, and interpreted with caution.

Data Analysis

More robust statistical methods are needed to capture the more complex interactions described above. Structural Equation Modeling (SEM) is a powerful multivariate analysis technique that utilizes cross-sectional data to determine the validity of complex hypothesized models. As such, SEM allows multiple measures to be associated with a single latent construct, taking into account the modeling of interactions and mediating variables, as well as nonlinearities. In addition, the assumptions of the model are more flexible than the traditional OLS regression, and it is able to test the overall model simultaneously rather than individually, as in this study. It also has the ability to test models with multiple dependent variables, as well as controlling for the multiple interactions between the various sources of support. Revenson et al. (1983) found that support may contain elements of both 'true' support and threats to self-worth. They write that social 'support' may be nonsupportive and even insupportable; in fact, it may at the same time constitute a source of stress and a source of support. Through the utilization of SEM and the other recommendations contained above, it will be possible to discern the significant relationships and identify the combination most helpful to various constellations of families.

Design

This study was designed to examine a single data collection point. However, as discussed previously, this fails to consider the temporal effects of the illness trajectory. Therefore, when attempting to conduct future longitudinal studies with this population, a Hierarchical Linear Model (HLM) should be employed to analyze the data. HLM offers several advantages over other longitudinal statistical techniques such as repeated measures MANOVA. This flexibility includes handling the attrition of subjects, as well as data with non-equal spacing of time collection intervals, simultaneous controlling for the effects of potentially confounding independent variables, and correcting for intra-class correlation (Guo & Hussey, 1999).

Research Implications

The results of this study support the National Institutes of Health's (2000) HIV-Related Research goal of "[reducing] the negative impact of HIV on individuals with HIV infection, on their families, on the health care system, and on society" (p. 127). Their priority areas include: 1) the testing of interventions to support formal and informal caregivers and family members of HIV-infected persons in order to prevent depression and burnout; 2) developing instruments for measuring social networks; 3) longitudinal analyses; 4) improved sampling techniques; and 5) innovative theoretical and mathematical models. Each of these areas has also been addressed through this study and its subsequent recommendations. This section will put forth some considerations for future research, as well as pose questions for further exploration into caregiver stress and related topics such as the needs of the infected/affected child and his/her sibling.

As caregivers are examined further under this model, it is also possible that moderation and mediation may be found to exist within the same model and variable (i.e., the stressor 'illness management tasks' may also be mediated by child support in addition to its current buffering effect). In addition, non-recursive relations may also be present, such that the support provided by a friend may directly influence the stressor, as well as the level of the stressor influencing the amount of support given by the friend. As outlined earlier, SEM has been suggested as a statistical model that can incorporate each of these factors (see Hoyle, 1995 for an overview).

One of the major difficulties present in this study was the lack of currently validated and reliable measures that could be utilized with this population. Existing general measures are not sensitive to the special circumstances found among individuals with HIV. For example, when conducting research with HIV positive individuals, current standardized measures may be skewed against the HIV positive individual. According to Kalichman (1998), 7 of the 21 items on the Beck Depression Inventory directly parallel common symptoms of HIV infection, such as problems in concentration, sleep disturbance, fatigue and others. Newly crafted instruments of modifications to existing ones must be validated with families living with HIV/AIDS. In addition, to provide comparability among studies, the instrument must be made available to researchers for inclusion in multiple study situations. Lastly, any measures must be sensitive to, and considerate of, gender, culture and other relevant factors. To ensure that future instruments consider these factors, researchers can employ focus groups as suggested by Zastrow (1992) to obtain input from target populations.

Some questions for further research which emerge from this discussion include: 1) How do different families describe HIV and its impact on their functioning?; 2) What are the usual supports and networks used, and how have these changed since the HIV diagnosis?; 3) Are the members of their support network aware of their (or their child's) HIV diagnosis?; 4) Who was chosen to share this knowledge with and why?; 5) What are the various stressors present in families with multiple family members infected?; 6) What type of support is needed (i.e., emotional, informational and tangible) and when?; 7) How do non-infected children cope after the loss of a parent/sibling?; 8) What is the relationship between the social support and caregiver-child relationship?; 9) To what degree will an individual caregiver's level of stress be moderated by his/her health?; 10) How does the special bond existent within the caregiver-child relationship impact the child along the developmental trajectory?; and lastly, 11) Given the historic role of spirituality within the African-American community (Pinkett, 1992), as well as its sometimes controversial role within the HIV/AIDS community (Kalichman, 1998), in what way can the religious community assist in providing support for caregivers and families infected/affected by HIV/AIDS?. It is clear to see the numerous questions that need further exploration. There is a dearth of studies examining families living with HIV/AIDS in the literature. Indeed, there are commonalties between this and other chronic health conditions. However, there are also significant differences such as its intergenerational impact, and direct transmission between mother and child, that may result in intense feelings of guilt, etc. Answers to these questions will help social workers to create more appropriate interventions to ensure the stability of these families.

Conclusion

This research has opened up new avenues for practitioners and researchers to work with and contribute to the functioning of families living with HIV/AIDS. Social support and its hypothesized buffering effect has enjoyed mixed findings in the literature. However, the healing notion of support continues, as explained by the adage 'we get by with a little help from our friends'. This study lends credence to the efficacy of social support from specific sources with the finding that support from friends does help boost caregiver arousal, and that the support derived from the caregiver-child relationship can help buffer the stressful effects of managing the many illness-related responsibilities.

Indeed, these families are a conundrum of frailty and strength. Due to their HIV diagnosis, infected caregivers and children will eventually become weakened. Yet through the provision of support, especially from friends and children, caregivers can be assisted in maintaining their family structures. It is hoped that the results contained herein can assist families, through improved practice, policy and/or research, to traverse the difficult times a bit easier and enjoy their special children. As Tolbert McCarroll (1988), an adoptive father or several HIV positive children, writes in his book *Morning Glory Babies*, "the fact that you are going to die does not mean you are dying. When death comes, it comes. Up to that moment you are living" (p. 123). We can help these children and families live better.

Appendix A

Stress Checklist

The words shown below describe different feelings and moods. Please use this list to describe your feelings at this moment.

1. If the word *definitely* describes your feelings, circle the double plus (++).
2. If the word *more or less* describes your feelings, circle the plus (+).
3. If you do not understand the word, or you *cannot decide* whether or not it describes how you feel, circle the question mark (?).
4. If the word *does not* describe the way you feel, circle the minus (-).

First reactions are most reliable; therefore do not spend too long thinking about each word. Please be as honest and accurate as possible.

1	Tense	++	+	?	-		16	Tired	++	+	?	-
2	Relaxed	++	+	?	-		17	Idle	++	+	?	-
3	Restful	++	+	?	-		18	Uptight	++	+	?	-
4	Active	++	+	?	-		19	Alert	++	+	?	-
5	Apprehensive	++	+	?	-		20	Lively	++	+	?	-
6	Worried	++	+	?	-		21	Cheerful	++	+	?	-
7	Energetic	++	+	?	-		22	Contented	++	+	?	-
8	Drowsy	++	+	?	-		23	Jittery	++	+	?	-
9	Bothered	++	+	?	-		24	Sluggish	++	+	?	-
10	Uneasy	++	+	?	-		25	Pleasant	++	+	?	-
11	Dejected	++	+	?	-		26	Sleepy	++	+	?	-
12	Nervous	++	+	?	-		27	Comfortable	++	+	?	-
13	Distressed	++	+	?	-		28	Calm	++	+	?	-
14	Vigorous	++	+	?	-		29	Stimulated	++	+	?	-
15	Peaceful	++	+	?	-		30	Activated	++	+	?	-

Appendix B

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