

Fall 2007

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AFRICAN AMERICAN CAREGIVERS OF CHILDREN AFFECTED BY HIV/AIDS

by

DORIS COOPER WILBON

(Under the Direction of Nancy Malcom)

ABSTRACT

The Human Immunodeficiency Disease (HIV) and Acquired Immunodeficiency Syndrome (AIDS) have reached an epidemic proportion in many African American communities. There is a significant amount of stigma and denial associated with HIV/AIDS in these communities, leaving people with minimal knowledge about this disease. Caretakers such as grandparents, other relatives, and foster parents take on the role of surrogate parents to these children who have lost one or both of their parents to HIV/AIDS. When family members, especially women, die from this disease leaving their offspring behind these children often experience various emotional and behavioral problems. A few of the children in this study turned to drug use as coping mechanism. Not enough financial support was given to support the orphaned children, and most often the caregivers relied on religion to get them through the rough periods.

The aim of this research was to describe the day-to-day experiences of these caretakers. Findings from this study revealed that when family members assume the responsibility of these children there are a host of significant problems with the children's development, health of the family, financial stability and external resources.

INDEX WORDS: HIV/AIDS, Children, African American caregivers, Affected, Grandparents, Aunts, Uncles, Orphans, Male caregivers, Attention Deficit Hyperactive Disorder, Substance abuse, Emotions, Churches, Schools, Financial Resources, Ryan White Healthcare, Holistic Approach, Stigma, Stress, Coping, Infected

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B. S., Georgia Southern University, 1994

A Thesis Submitted to the Graduate Faculty of Georgia Southern University in Partial
Fulfillment of the Requirements for the Degree

MASTER OF ARTS

STATESBORO, GEORGIA

2007

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DORIS COOPER WILBON

Major Professor: Nancy Malcom

Committee: Elizabeth Brown
Pidi ZhangElectronic Version Approved:
December 2007

DEDICATION

To Wayne, my son, I appreciate your love, encouragement, support and confidence.

ACKNOWLEDGMENTS

First of all I'd like to thank my committee chair Dr. Nancy Malcom, Associate Professor of Sociology for her encouragement, guidance, support and coaching me throughout this entire process. I also would like to thank my co chairs, Dr. Elizabeth Brown, Associate Professor of Sociology and Dr. Pidi Zhang, Associate, Professor of Sociology. I give thanks to my advisor Dr. Peggy Hargis, Professor of Sociology, for her support. I also would like to thank my confidant Lori E Amy, Professor of Writing and Linguistics and Director, Women and Gender Studies.

I would like to thank the State of Georgia's Public Health District's, Southeast Health District, Coastal Health District, and Albany Health Districts for assisting me in locating participants from the Ryan White Health Care program. I would like to thank the nurse practitioner's, Hazel, Susan, Allen, and Ann and social worker's Betty and Chanel for their assistance in helping me to locate the caregivers who participated in my study. In addition I would like to thank my colleagues and friends for their support Melissa, Felecia, Donna, Suzanne, Eric, Essie, and LaDonna for input, support, and encouragement.

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CHAPTER I

INTRODUCTION

The Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) brought a new and different dimension to caretakers of orphaned children. Many families affected by HIV/AIDS live in isolation, leaving them with very little understanding about this disease. A significant amount of stigma and denial associated with HIV/AIDS is found in minority communities because the disease is associated with other social ills such as illicit drugs use and deviant or promiscuous behaviors (Herek & Glunt, 1988; Pryor et al.1990). Furthermore, this denial prevents these caregivers from advocating for their grandchildren who have lost a parent to HIV/AIDS.

The objectives and goals of this research are to understand the day-to-day experiences of these caregivers. What are the complexities of issues these caregivers face while caring for these children? What are the responsibilities, difficulties, and rewards associated with caring for these children? What external resources are available to the caregivers and children?

Children are born into the world with ties to families. In the system of families there are mothers, fathers, sisters, and brothers and extended family members who are all bonded together under one unit. Over time the dynamics of the family structure have changed. Families are not quite the same. There is a diversity of families caring for children today. Children are being raised in single parent homes by grandparents, kinships, adoptive parents, foster parents, and by street people (Reed, 1997). Yet, what we have come to know about the epidemic of HIV/AIDS is that it has infected and

affected families in many ways. Often times these children know that their parents are infected with HIV/AIDS and are traumatized by their parents' illness and death.

Prior to mandatory HIV counseling and testing and the inception of antiretroviral medications for prenatal use a majority of women were indirectly diagnosed when their babies became ill and later diagnosed with HIV (Reid, 1997). Still, today many women don't find out about their HIV status until they become pregnant and seek prenatal care. Often times these women live in denial about HIV/AIDS because they feel stigmatized, and their families live with "the conspiracy of silence" (Reid, 1997 p.2). The family is then isolated from community support.

The fallacies and misconceptions of HIV/AIDS that many families live with are largely due to the historical, cultural and social circumstances surrounding the discovery and span of HIV in the 1980's. What are some of the historical implications of HIV/AIDS for women? How did we get to this point?

History of HIV/AIDS

Twenty-five years ago the Centers for Disease Control and Prevention (CDC) reported a newly discovered infectious disease called *Pneumocystis Carinii Pneumonia* (PCP). These cases were found in five healthy young white men in Los Angeles, California, (MMWR, 2005). All of these men were described as homosexuals. It was later discovered that the case histories suggested a cellular-immune dysfunction related to a common exposure, and a disease acquired through sexual contact. The report prompted additional case reports from San Francisco, New York City, and Miami (June, 2001). Scientists at CDC conducted several studies and reported findings of the disease PCP to be caused by the Human Immunodeficiency Virus (HIV). HIV is the virus that infects the

immune system by decreasing the number of white blood cells needed to fight off infections. Then the body becomes susceptible to opportunistic infections, which causes a person to be diagnosed with the Acquired Immune Deficiency Syndrome (AIDS).

During the 1980s, HIV/AIDS related illness and death began to increase among gay white men, young and old, in California, Florida and New York. The disease then began spreading among the Haitian population in Florida and the intravenous drug users (IDU) population in New York City's shooting galleries. As the country became inundated with HIV positive cases our blood supply became contaminated with HIV. Patients of all ages who needed blood transfusions and individuals with hemophilia needing blood product factors were contaminated with HIV. Prior to 1985, the American Red Cross did not screen blood for HIV, and since that time the HIV disease has become one of the greatest public health challenges both nationally and internationally (MMWR, 2001).

Another challenging aspect of HIV/AIDS disease has been how families were infected and affected by the disease. Many women contracted HIV through heterosexual transmission. Because of their lower socioeconomic status and lack of education about their health care and HIV/AIDS, many African American women were more susceptible to various health problems including HIV/AIDS. For example, when HIV/AIDS education is presented to them their economic condition can sometimes place obstacles to the use of proper behavior regarding safer sex (Tichenor, Donohue, & Olien, 1970). Being unaware of their HIV/AIDS status, these women died suddenly before treatment became available.

The Problem

HIV/AIDS infectious disease claims the lives of 22 million persons worldwide, including more than 500,000 thousand persons in the United States. As of 2006, 1 million persons were living with AIDS in the United States and approximately 40, 000 individuals were infected with HIV (MMWR, 2006). The acquired immunodeficiency syndrome (AIDS) has had an impact on the health and economy of the United States. The number of cases and deaths among persons with AIDS increased significantly in the early 80s. The greatest impact of the epidemic was among white men who had sex with men (MSM) and among racial minorities, with an increasing number of women and of cases attributed to heterosexual transmission. As of December 2000, 774,467 persons had been reported diagnosed with AIDS in the United States; 448,060 of these had died. The number of persons known to be living with AIDS is 322,865. Of these, 79% were men, 61% were black or Hispanic and 41% were infected through male-to-male sex (MMWR, 2001).

Over the past eleven years HIV/AIDS was the leading cause of death for African American women between the ages of 25-44. “Although the pattern of HIV/AIDS in African American communities is well known, this knowledge has not been systematically incorporated in serious efforts to control and manage the epidemic among African Americans at risk” (Okigbo et al. 2002. p 625).

In 2004, women accounted for 27 percent of the estimated 38,730 cases of the diagnosis with HIV/AIDS. Today, women account for more than one quarter of all new HIV/AIDS diagnoses. Women of color are especially affected by HIV/AIDS. HIV/AIDS is the 3rd leading cause of death for African-American women between the ages of 35-44

and the 4th leading cause of death for African-American women between the ages of 45-54 and for Hispanic women between the ages of 35-44 (CDC 2006).

In the same year, HIV infection was the 5th leading cause of death among all women aged 35-44 years, and the 6th leading cause of death among all women age 25-34 years. The only diseases causing more deaths of women were cancer and heart disease (CDC 2006). African American women are disproportionately infected and affected by HIV/AIDS.

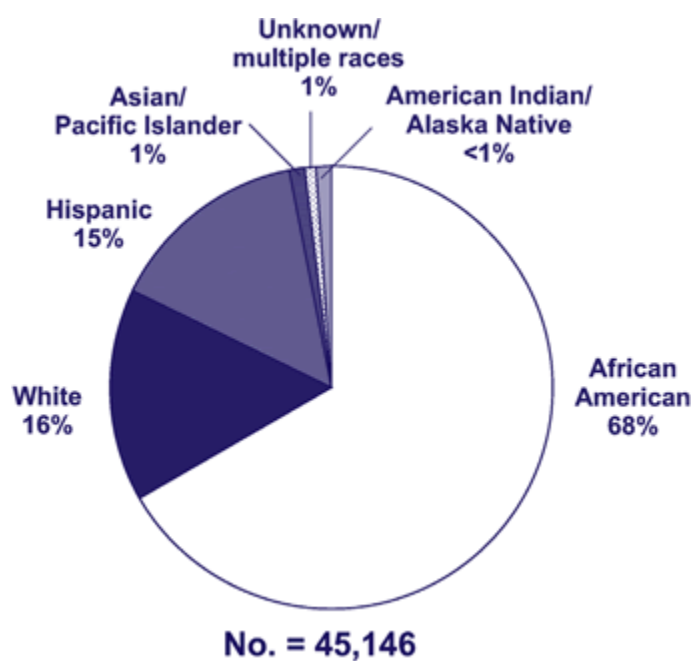


Figure 1.1 *Race/Ethnicity of women with HIV/AIDS 2001-2004*

An accepted fact is that the poorest communities have less access to HIV/AIDS knowledge and health care. The gap in knowledge between the well informed and the ignorant often increases as a result of their socioeconomic status. Thus, in lower social economic communities HIV/AIDS knowledge alone is not sufficient to insure correct

conduct. These communities need talking and teaching activities that instill values that support behavior changes (Okigibo et al, 2002).

HIV/AIDS Stigma

Approximately eighty percent of women who have HIV/AIDS are in their reproductive years, and uncertainty about their future can include who will care for their children should they become incapacitated and die (Reyland et al, 2002). This additional stress can impact their families and children when they must hide their illness. Yet, these women hide their HIV/AIDS for fear of being stigmatized.

These women suffer stress and stigma, because in many marginalized communities HIV diagnoses are associated with sexual promiscuity and drug behaviors (Herek & Glunt, 1998). Many women became infected by husbands or committed partners who had extramarital relationships, intravenous drug uses, or who engaged in sex with male partners (R. A. Ostrom et al, 2006). Thus, for women to disclose to their children their HIV status can be a daunting task.

Many women who are HIV positive will not tell their children about their disease, because they fear that their children may disclose their mother's status to others which will cause these mothers to suffer stigmatization and isolation (Moneyham et al., 1996; Murphy et al., 2006). Once a person is stigmatized by HIV/AIDS and their status becomes evident to others, they are then labeled and made to feel as outsiders. The impact of women being labeled as outsiders contribute to internalized stigma and these feelings affect their relationship with their children and other family members.

There are three specific types of stigma associated with persons who have HIV/AIDS. They are instrumental stigma, symbolic stigma and courtesy stigma.

Instrumental stigma results in fear of HIV and that it is a communicable disease even though it has been scientifically proven that you cannot contract the disease through casual contact (Herek, et al, 1998). The fear of contracting HIV results in avoidance of individuals who are infected with HIV. HIV/AIDS is viewed as an unalterable, degenerative, and ultimately a fatal condition. In the advanced stages the disease is ugly, so ugly that it stigmatizes people. Individuals who are HIV positive become the victims of the negative and unattractive effects of stigma.

Second, the symbolic stigma is the association of HIV/AIDS with negatively viewed groups in society. This stigma type results from the social meaning attached to HIV/AIDS, and using the disease to express attitudes toward the groups associated with it and the behavior that transmits it (Snyder, et al, 1999). For example, symbolic stigma is focused on male homosexuality, injecting drug users, and women who use drugs. This mindset causes individuals to stereotype, discriminate and be homophobic towards people who are different. Moreover, the stigma affects their quality of life and physical well-being. Importantly, stigma is a socially constructed phenomenon that has a profound impact on families and significant others. Symbolic stigma further affects the individual living with the illness (Jones, 1984).

Finally, courtesy stigma refers to the negative attitudes harbored toward partners, family members, and caregivers of those persons infected by HIV, and those perceived to be infected, or at risk of infection (Snyder, et al, 1999). This stigma causes stress for loved ones and health care workers who are sympathetic toward those people who are infected with HIV/AIDS.

Families Dealing with HIV/AIDS

We are now in the third decade of the HIV/AIDS pandemic. HIV/AIDS disease has touched the lives of families in the United States and globally. Millions of children are orphaned by HIV/AIDS worldwide. The capacity of grandparents, extended family members, and foster parents to care for young children is weakening as more and more children are becoming orphaned by the AIDS-affected situations. An increasing number of children are slipping through the extended family network. This leads to an increase in child-headed households, street children and child labor (Safman, 2004). In America and many communities globally, people are still affected by the stigmas associated with HIV/AIDS. Social network organizations and interventions are needed for families to cope and bring about hope.

This situation of mass orphanhood in developing countries is changing the fabric of societies around the globe. For instance, in Thailand there are 300,000 children under 15 years of age affected by AIDS. These orphaned children have lost at least one parent to AIDS (Safman, 2004). The primary concern for orphans is who will care for them. In Thailand the maternal grandparents usually care for the children. However, with orphaned children the decision is based on whether the maternal or paternal grandparents are better qualified as caregivers (Safman, 2004). Some of these grandparents are at home all the time, while other elderly caregivers have had to return to the labor force, because it became costly to raise grandchildren. Then the concern was the availability and cost of daycare centers for AIDS affected children. The cost of placing children in formal daycare such as preschool is often higher than the cost of primary school. In addition to

the cost another concern is that in these daycare-settings grandparents and their grandchildren experience a tremendous amount of stigma.

In Thailand there is a climate of fear among attendants caring for children affected by HIV/AIDS. Parents have threatened to withdraw their children from the daycare for fear that the AIDS disease is contagious. Even more serious, in some daycare settings AIDS affected children are refused admission. Daycare personnel caring for young orphans reported a great deal of resistance from both parents and teachers when caregivers attempted to enroll their children in local preschools or daycare programs. Community members continue to believe that AIDS affected children might be HIV infected until they reach first, or second grade, or as the child's good health dispels the fear (Safman, 2004).

In Africa the AIDS problem is so severe that it has had a tremendous effect on the social and economic stability of the societies. There are 13 million children in Africa who are orphaned as the result of AIDS (Malshalaga, & Powell, et al, 2002). Early interventions to build orphanages have failed, because these children are separated from their families and these children want to be with their families. As a result, authorities in Africa claim that the orphan problem is even more severe. Moreover, in Africa the social consequence of these children growing up in unstable homes without parental love and guidance will have a devastating effect on their society. The lack of family support would breed a new generation of dysfunctional adults, which would increase the likelihood of AIDS cases.

Africa's orphaned children are already traumatized by the illness and loss of their parents, and being separated from their extended family members. The psychosocial

needs of orphans are a growing concern, because “orphans in Africa are affected by the cycles of poverty, malnutrition, stigma, exploitation, and often sexual abuse” (bmj, 2002; p 185). In Africa grandparents are the primary caretakers of grandchildren. The problems of poverty are so great it is amazing that most of Africa’s orphans have been able to be absorbed into extended family network (bmj, 324). Furthermore, as the aging grandparents are dying, there are fewer grandparents available to care for young children affected by HIV/AIDS. Thus, young children must rely on their older siblings to care for them. Many of these siblings are HIV positive and are suffering, as well.

In the United States it has been twenty-five years since the first deaths of AIDS were recorded (MMWR, 2006). Since that time scientists have made great strides in improving the treatment of HIV/AIDS. Our blood supply is safer. Treatment and care is available through the Ryan White Care Act, a federally funded health care program for individuals infected with HIV/AIDS. Patients are living longer and enjoying healthier life styles. Many HIV individuals are returning to work and finding a new lease on life. Yet, the HIV/AIDS epidemic has worsened for African American children who have lost one or both of their parents to HIV/AIDS (Linsk & Mason, 2004).

Historically, African American grandparents have provided cared for their grandchildren while their adult children moved away from their hometowns to seek stable employment in order to provide for their children. Today grandparents are serving as surrogate parents to their grandchildren due to the loss of their parents to HIV/AIDS. The major factor for this new configuration of the family is the multiple social problems of the 1980s, that many young adult parents are struggling with, such as substance abuse, maltreatment of children, maternal incarceration and HIV/AIDS disease (Barnhill, 1996;

Dressel & Barnhill, 1994; Grant, Gordon, & Cohen, 1997; Joslin, 2002). The 2000, Census data estimated that 8.4% of American children live in households headed by non-parental relatives. Grandparents care for about three-quarters of these children. There are between 2.3 million and 2.4 million grandparents serving as primary caregivers for 4.5 million children (Bryson, 2001). This is a lifestyle change for most grandparents. Growth in grandparent headed household has not occurred in a vacuum, rather it has been accompanied by large numbers of other demographic, social, economic, and political changes (AARP, 1998) that potentially have profound implications for the welfare of both the old and the young (Bullock, 2005).

As a group, most of the grandparent caregivers are at a disadvantage. “Fifty-eight percent of these grandparents did not graduate from high school, and another 26% obtained a high school diploma but no further schooling. A result of this lack of education, is that grandparent-headed households are the most impoverished of all types of nontraditional households with a median income half that of traditional households with children, \$18,000 vs \$36,204” (Burnette, 1997). With grandparents having limited resources, they are finding it difficult to manage their income with the additional family members to support.

Overall most grandmother caregivers of children infected and affected by HIV/AIDS have received a lot of attention and recognition in the literature (Bullock, 2005). These women have always been the mainstay of the family. Grandmothers are usually older, suffering chronic health conditions, grieving over the loss of their adult children to HIV/AIDS while they care for, often times, small children. Yet, several studies of grandparents serving as surrogate parents to their grandchildren affected by

HIV/AIDS are “hidden patients,” because they themselves face compromised health conditions. Fifty-five percent rated their own health as ‘fair’ or ‘poor’ and 70% reported having insufficient time to attend to their own health (Joslin & Harrison, 2002). Thus, barriers to self-care for older surrogate caregivers exist, because they fear that calling attention to their own health would give reasons for the authorities to remove their grandchildren from them.

A 2005 study by Karen Bullock focuses on the impact of grandfather’s raising children in rural North Carolina. A number of grandfathers are assuming the responsibility for their grandchildren who have lost their parents to the HIV/AIDS disease. Males, in general, have not traditionally had the responsibilities of providing for the family’s daily hands-on care, unlike mothers and grandmothers. Traditionally men have supported the family by providing the income. Thus, this role transition for grandfathers has been a significant adjustment for them to make. They see themselves in a position of powerlessness, because “they had no choice in the decision to become a parent at such a late stage in life” (Bullock, 2005, p 47). There was no alternative for their grandchildren’s living arrangement. These grandfathers are experiencing life style changes. These men now have to take on the daily responsibilities of cooking, cleaning and attending to the needs of the children such as helping them with their homework. These men report being isolated. They have had to give up spending leisure time with the friends, which caused them psychological stress and loneliness.

Another study by Strug, Rabb, and Nanton in 2002 of male caregivers points out the issues male caregivers face with the social service system. These male caregivers are referred to as the male primary caretaker (MPC) who has primary responsibility for the

care and well being of one or more children regardless of the man's relationship to the children (Strug, Rabb & Nanton, 2002). These men can be the children's biological father, uncle, grandfather, or family friend who are the caretakers of one or more children infected and affected by HIV/AIDS. "The number of such men is substantial, and can be expected to increase as more women become infected with HIV/AIDS and die, and more males assume responsibilities" (Strug, Rabb, & Nanton, 2002, p 303). These men live alone with their children and are in thire thirties and forties.

The most significant problem these caretakers face is that support services are not geared to provide services to men with families. "The Title IV Ryan White Comprehensive Care Act (Public Law 101-38) determines how service providers of these programs view the services needs of MPCs" (Strug, Rabb, & Nanton, 2002, p 304). Yet, there is no information on how to support this population or what their needs are. The Title IV program has provided services to prenatal acquired pediatric HIV/AIDS cases in the United States. The Ryan White HIV/AIDS clinics officially serve the needs of women, children, adolescents, and families, and men are not specifically mentioned except in general terms (Department of health and Human Services Administration, 1999). Furthermore, MPCs need emotional support, because they suffer from anxiety, depression and grief. Yet, many men have not been socialized to provide hands-on care to families. Many of these children who are HIV positive have psychological needs that cause male caretakers a great deal of anxiety. Also, siblings living in these households who are affected by HIV/AIDS also experience a variety of psychosocial problems as a result of growing up in a household where at least one family member has HIV/AIDS (Gruendel, & Andiman, 1995).

Most men don't know how to access the services they need nor are they equipped to know what questions to ask. Also male caretakers need counselors to help them with parenting skills, and communicate with their children, and fathers may face difficulties in terms of custodial rights to their children (Strug, Rabb, & Nanton, 2002). Male caretakers are more likely to work outside the home to provide for their families. In addition, based on statistics, more men will need the social services for themselves and their children. It is estimated that by the year 2000 between 72,000 and 125,000 children and adolescents will have lost their mothers to HIV/AIDS in the United States, and the numbers are beginning to swell (Levine & Stein, 2002).

Stress, Grief, and Emotions

Grandparents function as the surrogate parents to grandchildren affected by HIV/AIDS, and while these grandparents are caring for these children, many of them have had to care for their ill child and the grandchildren in the same environment. These conditions create a tremendous amount of burden and high levels of stress on these caregivers. In addition, most of these caregivers are older women who are struggling with their socioeconomic status, poverty, finances, and health care caused by their reduced levels of physical functioning to physical limitations that may affect their quality of life and care giving capacity (Fuller-Thomson & Minkler; Whitley, Kelly, & Sipe, 2001).

Grandmothers have disclosed that they experience a high level of stress, because they struggle with the stigma of HIV and keeping it a secret. Being silent prevents the healing process and isolates them from traditional forms of support (Fanos & Wiener, 1994; Levine-Perkell, 1996). Moreover, many of these grandmothers have not disclosed

to their grandchildren that their mother and/or father have died from the disease, which causes them to suffer depression, resentment and parenting stress.

Various caregivers have all been supportive of providing care for children who are HIV-affected. These children need to be in stable living environments, because they often times have severe adjustment problems. Children who have lost parents due to HIV have no real-life concept of illness or death. These extreme situations leave children feeling withdrawn from their surroundings, lonely, and they suffer from severe attention problems (Forsyth and colleagues, 1990).

Finally, as some of these children become older their social problems become overwhelming for their caregivers. Their behavioral problems may manifest in such behaviors as being uncooperative, lying, stealing, and being very manipulative. Many older teenagers develop psychological problems, behavior such as overeating, night wandering and suicidal ideations (Linsk, & Mason, 2004). The emotional and stress level of these children is so high many of them, especially males, resort to delinquent behavior.

Conclusion

The literature clearly explains the impact of the Human Immunodeficiency Virus (HIV) and the Acquired Immunodeficiency Syndrome (AIDS) that began twenty-five years ago which inundated many communities in the United States and around the world. This disease has transformed the lives of millions of people of all races, cultures, and ages.

The devastating effects of the disease have affected the most innocent victims, the elderly and children. Elderly caregivers have shouldered parental responsibilities without the benefits of good health and resources to maintain their well-being. Yet, these

caregivers are finding it difficult to care for these children who are affected by the loss of their parents. Despite the burden, grandparents feel rewarded by keeping their grandchildren together. Moreover, the study explains how grandparents globally have provided support for their grandchildren while putting their lives and health on hold. These grandparents are finding ways to cope with the challenges and complexities of their day-to-day experiences of raising young children, adolescents and teenagers in the absence of their parents.

Several issues in the studies mentioned AIDS infected children in the United States but not HIV/AIDS affected orphans. The statistics on orphaned children are aggregated to include not only HIV infected children but also foster children who are affected by other social ills, such as drugs, sexual abuse and homelessness.

The objective of my current research is to explore the understanding of the day-to-day experiences of caregivers who serve as surrogate parents to children who have lost one or both of their parents to the HIV/AIDS disease. My study will be an investigation of all caregivers of children who are affected by the loss of their parent(s) to HIV/AIDS. These caregivers would include grandparents, aunts, uncles, siblings, foster parents, adoptive parents and non-relative friends.

CHAPTER II

RESEARCH METHODS

In 1987, I began my work in the Ryan White Health Care Program in rural Georgia. The patients who used this clinic were primarily gay males. It not until 1990, that I saw my first female patient, a 25 year old African American who recently been diagnosed HIV positive. She had recently been diagnosed HIV positive during her prenatal visit with her obstetrician. After she delivered her baby she was referred to our health care program for treatment. Fortunately she was in good health and did not require extensive medical treatment such as antiretroviral medications. She only needed health check-ups quarterly. However, she needed a good social support system, because HIV was not widely know in the African American community nor was it discussed openly. She and I often times talked about her secret; I provided her the support she needed.

We began to see an increasing number of young African American women infected with HIV in our health clinic. They became HIV positive through heterosexual transmission. Many of these women were substance abusers, trading sex for drugs or money. Also there were women who had relocated to urban cities early in life, and now they are returning home HIV positive to relocate with their families, with their children in tow. Most of these females had accessed health care prior to returning home, and are in good health while other women were in denial about their HIV positive status, refused health care treatment and in poor health.

Around 1998, we were routinely admitting women into our health care program. Women with young children were struggling with their illness. These women's disease was associated with an abundance of denial, stigma and ignorance about HIV/AIDS.

Therefore, some patients refused to keep their appointments and take their medications. A patient said to me, “these pills will make you sick. I don’t trust this medicine.” Thus, many of our women were dying and leaving young children to be cared for by their grandparents and their family members.

I observed many grandparents grieving over the death of their daughter and son. I met with one grandmother who had lost two daughters to the HIV/AIDS disease. This grandmother became the surrogate caregiver of four small children; one child was handicapped. “How are you managing with these children, I asked? Is there any thing I can do for you?” She smiled and said, “I’m okay.” I was perplexed by her answer. I wanted to know more about these caregivers and struggles.

In the spring of 2006, I conducted a pilot research project. My research was to explore and understand the experiences of grandparents who served as surrogate parents to their grandchildren who had lost one or both of their parents to the HIV/AIDS disease. I presented my findings for this research project at the 17th Annual Southeastern Regional Student Mentoring Conference in Gerontology and Geriatrics, in Lexington, Kentucky conference on April 7, 2006.

The eligible participants in the study had to be grandparents whose adult children had died of HIV/AIDS and the grandparents were the caretakers of these children. Also these families had to reside in South Georgia. The study sample included four grandparent headed households who served as surrogate parents to their grandchildren who were affected by the loss one or both of their parents to HIV/AIDS. There were three African American couples and one African American widowed grandmother. Three

families lived in a rural southern community and one African American family lived in a southern urban community. Their ages ranged from 61-65 years old.

The participants for this study were solicited from the Ryan White HIV/AIDS Health Care Organization located in South Georgia. This organization provided health care services to these grandparent adult children who died of AIDS, and prevention care to their children. My pilot study was a semi-structured, face-to-face interview format conducted in the homes of each participant. In the four families the grandmothers were the only participants in the interview. Each interview lasted approximately two hours. An audio tape recorder was used during the interview. No children were allowed to be present during the interview sessions.

There were several research questions for this study. How can the day-to-day experiences be better understood? What are the complexities of issues grandparents face? What are the responsibilities, difficulties, and rewards associated with caring for these children? What are the external resources available to these caretakers? The questions were open-ended and allowed for probing when necessary, such as, my asking the interviewee for clarification or additional information to a question being asked.

The interview began with a collection of demographic information on the grandparents and grandchildren affected by the loss of their parents and also the number of other grandchildren in the household. Information was asked about the grandparent's children who died of HIV/AIDS. Also general questions were asked about the grandchildren's relationship with their parents prior to their death, and if these children had knowledge about their parent's HIV/AIDS status. A series of questions were asked about the grandchildren's coping skills, general health status, school performance, and

general well being. These questions were asked of each child in the home. Questions for the grandparents were centered on the day-to-day experiences as surrogate parents for their grandchildren. For example, I addressed issues such as what their typical day was like, their coping skills, fears, their relationship with their grandchildren, and their health status. I inquired about the external resources, such as their relationship with their community members, their church, and society. Moreover, I asked them if they perceived any rewards and benefits from caring for their grandchildren. Since their grandchildren were young, I asked if they had made arrangements for someone to care for the children in the event they became unable to care for them. Finally, I asked how helpful the state and/or federal government programs were.

The major findings of this pilot study revealed that most grandparents enjoyed having their grandchildren in their lives. The major stressors for these grandparents included the grandchildren's developmental problems. Four of the seven children in the study had Attention Deficient Hyperactive Disorder (ADHD). One of the seven school age children quit school and left home. Other stressors include the stigma associated with the children's parents having HIV/AIDS, financial instability such as denial of social security benefits for the children whose deceased parents had died and never worked. Many of these caregivers had health problems. Most participants relied on social welfare benefits such as Social Security, but they received limited support from their family, community, or government for their caring of grandchildren. Grandparents living in rural communities were significantly worse off in comparison to the one living in an urban setting, especially with regards to the availability of external resources.

Current Project

My current research project will be a continuation study to explore and understand the experiences of all caregivers who serve as surrogate parents to children who have lost one or both parents to HIV/AIDS. To be eligible for this study, participants can be any caregivers who have custody of a child who has lost a parent to HIV/AIDS. I plan to conduct my investigation in both rural and urban communities in Georgia.

I have expanded my research questions in an effort to address the concerns of the expanded caregivers in this study. The additional questions are: (1) Who are the caregivers of orphan children? (2) What are the pitfalls non-family friends have when caring for HIV/AIDS affected children? (3) What concerns do males have accessing social services? (4) What resources are available to non-traditional caregivers? (5) What are the difficulties, responsibilities, and complexities of caring for non-related children?

The area of my current research investigation is broader than my pilot study. I conducted my research in rural and urban communities in Georgia and in other states. I continued to search for participants in the Ryan White HIV/AIDS Health Care and Preventions Services, and Community Based Organization (CBO) who provide services for families and children affected by HIV/AIDS. I made contact with agencies that provide residential services to children affected by HIV/AIDS, foster parent caregivers of children affected by HIV/AIDS, and utilized the snowball affect. The expanded focus of this study included grandparents, kin caregivers, such as older siblings, aunts, uncles, foster parents, and non-relative friends.

Before the interview began, I explained the purpose of the study and gave the participants informed consent letters to sign. Each participant was given an informed consent form making them aware of the purpose of the study. They were required to sign both informed consents. One informed consent is to remain with them and I kept

the other signed informed consent form. An audio tape recorder was used during the interview, with each participant's permission. The interview was a semi-structured and open-ended face-to-face questionnaire. The interviews lasted for approximately two hours. No children were allowed to be present during the interview.

Caregiver Characteristics

Table 2.1: *Caregiver Characteristics*

	Sex	Race	Age	Place	Married	Occupation	No. of Children	Ages
Anderson	F	B	53	Urban	Yes	Textile Worker	1 Female 1 Male	11 17
Crumbly	F	B	51	Rural	No	Cook/Caterer	2 Males	11 14
Evans	F	B	53	Rural	Yes	Nurse Assistant	2 Females 1 Male	11/16 17
Johnson	F	B	43	Rural	Yes	Home Maker	1 Female 1 Male	17 16
Payne	F	B	61	Rural	Yes	Home Maker	1 Male	13
Mason	F	B	67	Urban	Widower	Nurse	1 Male	13
Toliver	F	B	64	Rural	Yes	Cook	1 Female 1 Male	17 16
Robertson	M	B	44	Urban	No	Health Technician	1 Male	11

My sample is made up of eight people. The criteria for participant eligibility included caregivers serving as surrogate parents to children affected by HIV/AIDS. These caregivers were African American grandparents, aunts and uncles. The participants lived in rural and urban communities in Georgia. Each of the participants was assigned pseudonyms. There were five grandparents and one aunt who were selected from the Ryan White Health Care Program. Also one grandparent and one uncle caregiver was recruited through the snowball effect. Their age range was from 44 to 65 years, with incomes from \$19,000 to \$39,000 yearly. Most of the participants completed high school, vocational training skills, and had some college.

Data Collection

Data collection was conducted through semi-structured, face-to-face interviews that featured open-ended questions. These interviews were conducted with participants in their homes or organizations. The interviews took approximately two hours. The interviews were recorded on an audio tape recorder and transcribed. The confidentiality of the audiotape, and informed consents were kept in a locked file at the researchers' home. The participants received a stipend of \$30.00 at the completion of the interview. They were required to sign a receipt stating that they had received the stipend.

I recognized that HIV/AIDS was a sensitive subject and that, for many people, disclosing information to a stranger may be quite difficult. However, I feel confident that because of my twenty years of experience working with HIV/AIDS and other infectious diseases, as a State of Georgia employee, I will be able to discuss this topic with caregivers. I am required by the Georgia Law to maintain patient confidentiality. Also, this Georgia Law applies to the confidentiality of my research project. In my pilot study most of the caregivers seemed excited to care for the children. I recalled one grandmother appeared very eager to talk with me about her struggles with her grandchildren. Another respondent said: "This gives me an opportunity to get a little rest and talk about my feelings. I work all day for my family."

CHAPTER III

BECOMING CAREGIVERS

This chapter discusses the relationships of caregivers, their children, and grandchildren who were affected and infected by the HIV/AIDS disease. Most of the caregivers have welcomed these children into their homes with open arms. Some caregivers had assumed the role of surrogate parents not by choice, but by default, as there was no one else to take care of these children. Some caregivers were ill, the responsibility of caring for these children was more of a burden, they lacked adequate financial support, and/or external resources weren't available to all of them. For most of these caregivers the task of caring for these children was vexing and unexpected.

I asked the participants to describe the circumstances when the children were first brought to their homes:

“My nephew was 8 years old when he came to live with me. This was in 2003. I did not want to care for this child; I have never wanted any children of my own. This child was forced on me. DFACS called me and said if I did not get there [to Savannah] by 5:00 pm, they would take the child away. The system was going to put him in foster care if I did not take this child into my home. I had no choice. There was no one else to care for him. His mother died of AIDS several years ago, and his father was ill with AIDS. My plan was just to keep him until his father died. I was very angry and I refused to spend any time with my nephew. I only did what I needed to do for him; I prepared his meals and made sure he went to school. Our first five months together were the hardest time of my life because there was no income and we lived off the money I had saved. After my brother died, I realized that I was the only family member available to care for my nephew, so I found a job at a hospital, and my financial resources got better.... I began to treat him as if he were my child. I said to Mr. Robertson now that you are getting along better with your nephew find time to spend with him and allow him to make some decisions about the activities that you all can share. You want him to gain some trust in you.” (Mr. Robertson)

She immediately expressed her anger about being a surrogate parent. In a very disturbed manner before taking her grandchildren in, she said:

“I was single and free with no responsibilities. In the beginning, I felt like I was starting over with trying to raise three kids and I became angry, but not with my grandchildren. I had to care for three babies in diapers. I thought to myself, this is my life all over again. My daughter became very ill and I had to take them into my home. I did the best I could. Now one grandson has moved away and I still have the other two teenagers with me. Mrs. Toliver shared with me a mother’s day card that her granddaughter had given her. I said to her your granddaughter is very grateful that you kept them. She mentioned that if it wasn’t for you they would have been in foster care. I said to her be thankful, these children love you. You have been a wonderful grandparent.” (Mrs. Toliver)

“I have always had two of my daughter’s children, a girl and a boy. My youngest granddaughter was born in a prison hospital in Macon, Georgia. After my daughter delivered her baby girl, the Department of Family and Children Services notified me to report to the prison hospital by 2:00 pm, or the baby girl would be placed in foster care. My husband and I went to Macon to pick her up and we brought my grandbaby, which was one-day-old, home to live with my husband and me. When my daughter was released from prison she never came to get her children. She returned to the streets hustling and using drugs and I continued to raise my grandchildren and kept them safe.” (Mrs. Evans)

Mrs. Johnson shared a different story with me about how she and her husband became the surrogate parents to their grandchildren. Mrs. Johnson was elated that she was able to take her grandchildren home to live with her. There were two granddaughters, 9 and 10, and a grandson, 14 years old.

“I watched my daughter and her husband struggling with the care of their children. I would go by and see about them everyday. At the time, they lived down the block from me. One day I just told my daughter, her husband, and her children to get all of their belongings and come to stay with me. They were all very relieved to receive the help from me. It is so wonderful how you have embraced your grandchildren.” (Mrs. Johnson)

Mrs. Mason was another grandparent who was proud to take her grandson into her life and this child had multiple health problems at birth. She was anxious to tell her story about how she found her grandson.

“A social worker told me about my grandson. He was HIV positive and premature. When my daughter delivered my grandson she found out that she was HIV positive. She left the hospital without her baby. I had no idea about him and his conditions. My grandson stayed in the hospital for months. He left the hospital and was sent to Open Arms, a special care residential program for babies who had been abandoned by their mothers. While he was there, he was on a ventilator and

a heart monitor. The caregivers at Open Arms told me that once he turned a year old he would be adopted. I did not want him to get away from me, so I retired from my job at the hospital, and took him into my home when he was 11 months old. My daughter helped me get him. I also took his sister in when she was 4 or 5 years old. I felt like they both needed stability because their mom was in the streets. It's good that you are a nurse and are able to care for your grandson. This is a blessing (smile). I asked, "Where is your granddaughter now?" She is with her father's family and I think they moved away." (Mrs. Mason)

Mrs. Payne and I have known each other for many years. I visited her home on several occasions to provide various health care services. She was happy to sit and talk about how she was able to take her grandson into her home.

"I have my four grandchildren that I care for: a set of twin girls, 14 years old, and their older sister 17 years old. Their mother used drugs. I have had them since they were babies. I have one grandson 13 years old whose father died of AIDS. Also, his mother died of AIDS. Her mother gave my grandson to me. I was happy to be able to take him in my home. I love having my grandchildren. I worry about these children all the time. I suggested to her to get her daughter to help around the house whenever she came over, and now that the grandchildren are older assign them duties." (Mrs. Payne)

Like Mrs. Payne, other caregivers shared stories about how excited they were to be able to take their grandchildren into their home. Mrs. Crumbly said that she felt honored that her sister had wanted her be the caregiver of her sons.

"My sister came to my home with her two children and asked me if they could stay here. She was very ill, she said that she had AIDS and she asked me if I would take care of her children. I said, yes, I was glad she asked me. We are family and we are close. We would never let them go to no foster care. My momma would be turning over in her grave. If my momma would have been living she would not have it like that. I acknowledged to Ms. Crumbly what a wonderful job she was doing with the boys and if she needed me to meet with her and the boys to discuss HIV/AIDS that I would be available and I gave her my locating information." (Mrs. Crumbly)

"I've been caring for my grandson since he was born. His mother was living with me when he was born. When his mother got pregnant again she moved in with her boyfriend and she left her son with me. One day she called me and asked me to meet her at the hospital. She gave me her baby. She was sick. The doctor told me she had AIDS, and two days later she died. I love them I am their only family. My grandson doesn't know his daddy. My granddaughter is HIV positive. Her other

grandparents came to visit her once. They don't do anything for her. I feel responsible for these children because they don't have anybody else. I recognized that Mrs. Anderson appeared forlorn. I asked if she had any concerns about her family. Her reply was that she just doesn't have enough money to take care of her grandchildren. I asked if it was okay with her for me to call the rural health clinic to help get her some assistance. She agreed." (Mrs. Anderson)

Interestingly, there was a recognizable difference in how some of the caregivers who had been involved in their children's personal lives were willing to assume the responsibility of their grandchildren. Mrs. Johnson and Mrs. Payne, for instance, lived close to their children who were ill and their grandchildren. They felt that it was their duty to care for their grandchildren, and nephews. Three other caregivers were already caring for their daughter's children.

On the other hand, the caregivers who were angry their anger was unrelated to the children they took into their home. The anger was related to the children's parents who were substance abusers and infected with HIV/AIDS. In many African American communities it is believed, though not proven, that there is an association between substance abuse and HIV/AIDS. Hence, these caregivers feel that they have put their lives on hold to care for these children. In spite of their feelings, they don't want their children in the social system. Moreover, families will keep children for the purpose of maintaining family structure.

In this study I think most of the caregiver's children who died of AIDS lived in close proximity to their parents and other family members. These living arrangements made it possible for the grandparents to know how their children cared for their grandchildren. Even though some caregivers didn't live close to the children they care for family ties were close enough that distant family members were keep up to date about family matters, especially if a member was ill.

I asked participants to tell me a little bit about their child or relative who died from HIV/AIDS. What was she/he like as a person and what kind of parent was she/he?

“I wasn’t around my brother or his child. I lived up here [in Atlanta]. I hated my brother. My brother used drugs. I just knew that the school system found out that my nephew, 8 years old, was taking care of himself and his sick dad and the school system reported this to DFACS. The child was taken out of the home and placed in foster care until I came to get him.” (Mr. Robertson)

“Oh, he was a good parent and very mature. She smiled. He loved his son and would discipline him.... But his son was spoiled. I recalled Mrs. Payne being very emotional. “I hugged her and said that it’s all right, being emotional is good. We all need to purge sometimes.” (Mrs. Payne)

“She loved her children. She was active with her children, especially, their sports activities. She was involved with the church. She babysat for the family members. Mrs. Crumbly appeared to have a big heart. She smiled when she talked about her sister.” (Mrs. Crumbly)

“She smiled as she often did when she talked about her family. She kept them in church so long as she could go. If she could go to church she was there. She took them to church all the time.” (Mrs. Johnson)

Mrs. Evans had previously told me about her daughter’s substance abuse and I wanted to know if her daughter had spent any time with her children.

“She loved them when she was around them but she did not go out of her way to look for them. She didn’t come around much. She knew that they were always with people that cared about them. She would tell people that she did not have to worry about her children. They were in good hands. She would have them when she had her own home but the sicker she got the shorter her patience got and they would come home to me. I asked, “Do the children appear to be withdrawn at times?” Sometimes, yes they get very quiet and stay to themselves.” I asked, “Would you be interested in them getting some counseling? Our program can assist you with them getting counseling. Think about it and call me if you decide to seek counseling for your grandchildren.” (Mrs. Evans)

“My daughter lived in Florida with her children and I don’t know the relationship she had with her children. When my daughter came home to live with me she was too ill to care for her children.” (Mrs. Toliver)

“I’ve always cared for my grandson. My daughter left home when her son was four months old. I don’t know how she cared for her baby.” (Mrs. Anderson)

“I don’t know if my daughter ever cared for her daughter.” (Mrs. Mason)

Clearly, what stands out for me in the relationship the deceased parents had with their children was similar to the relationship they had with their parents. For example, Mrs. Payne mentioned that her son was a good parent. His parents were also good parents. Likewise, Mrs. Johnson kept her children in church and so did her daughter. As I listened to each of the parents talk about their daughters I am convinced that their children were reared in good homes. Somehow these deceased parents who didn’t care for their children were not available to them because they were preoccupied with their own pain and suffering which made it impossible for them to care for their children.

Oftentimes when children have been separated from their immediate family members, especially their mothers and fathers, they tend to display behaviors associated with stress, emotions, and grief. Even when they come to live with close relatives such as grandparents they feel a sense of loathing. Some of these children have had to watch their parents suffer through their sickness and possibly death. Most young children can’t grasp the full understanding of what sickness and death means, and until recently the subject of death hasn’t been explained to children very well. The respondents were asked what they did to help their children deal with the death of their parents.

“My nephew appears withdrawn at times. He stays to himself and wouldn’t talk very much, and when he did he told me that kids in the neighborhood ask him

about his parents, but he won't say anything about them. He says that he makes up stories about his parents. He wants to know what happened to his mother and dad, but I didn't want to talk about my brother. "Your not talking about your brother may have been the reason your nephew didn't talk to you." I didn't want to bring up any feelings and emotions. My suggestion to Mr. Robertson was that whenever your grandson shares information with you, you should encourage discussion about his feelings. He insisted that he wants his nephew to be strong like him." (Mr. Robertson)

Mrs. Johnson had cared for three teenager grandchildren who lost both of their parents to AIDS. These teenagers suffered significantly from the loss of their parents to AIDS.

"I had all three in counseling. And now I have one in counseling. The 16 year old is nervous. But it came down on her since she lost her momma. Her nerves are bad. It was hard on me when they first died. Children would pick on them. I tried to talk to them. Don't pay them any attention. Just pray and stay strong. My grandson had trouble at school.... They talk about his mom and he didn't like that. They say his mom got AIDS, he doesn't believe them. It used to bother me. I tell him you go pray, it's the Christian way, you know, pray it off. He was up there in the hospital with his ma. It knocked him crazy. It didn't bother him when his dad died. It bothered him when his ma died. I showed all the children their ma and dad's death certificates, and it said that they ma had AIDS. He still didn't believe it. He was happy sometimes. His grades were good. Then he started using drugs, quit school in the eleventh grade, got in trouble and he is up there in the detention center. The girls say something about their mom when they don't feel well. Every once in a while I talk about her. I don't discuss her much. They say grandma she dead she is all right." I said, "It's wonderful that you support your grandchildren, but it's going to take some time for each of you to heal from the loss of your children. Be patient and pray." (Mrs. Johnson)

"He cries a lot. The children at school teased him about his mother who died of AIDS. When the children talk about his momma I would have to calm him down because they would make him cry and I do not let anybody talk about him. They never say anything about his dad who died of AIDS. He was very anxious and he was taking medication to calm him down. He wets the bed. He does not concentrate on his schoolwork. The school says that he had Attention Deficient Hyperactive Disorder (ADHD)." "Mrs. Payne should me the papers from the guidance counselor suggesting that they would be placing her grandson in a special education program." "I asked her if she had spoken with the counselor." "She said, no". "I suggested that she schedule an appointment with the counselor

and ask a family member to come along with her; someone who knew about her grandson's situation. (Mrs. Payne)

"They were frustrated and angry when they lost their mom. The boys were 11 and 13 years old. The oldest was mostly frustrated and had to have some time off from school once she passed away...and he could not deal with the kids and stuff like that. He asked, "How did she get it? Umm how did my mom get sick?" And I told him the best that I could tell him that it was a bug, and "umm", he said. "Did my daddy have it?" What I told him, what was told to me...that was what happened. Both of the boys had to sleep with a night light on all the time." "I suggested to Mrs. Crumbly that I would meet with her again to discuss the HIV/AIDS disease." (Mrs. Crumbly)

"You know there is nothing to say. Her children were never around her. She never went out of her way to see or spend time with her children. Her children wore tee shirts with their mom's picture on it when they celebrated the anniversary of her death this year. It was like a family reunion." (Mrs. Evans)

"My grandson knows why his mother died, but he doesn't believe it. He is sad and very quiet. He stays to himself. I don't know how to talk to him about his mother. My granddaughter is sick and unable to understand anything now." "I discussed with Mrs. Anderson about how to talk with her grandchildren in such a way that they would understand her. Also I sent her pamphlets on HIV/AIDS." (Mrs. Anderson)

"My grandson doesn't know anything about his mother. He is ill and I don't talk to him about his mom having AIDS." I wanted to know from her if she was able to resolve her issues concerning her daughter. I asked, "Will you ever tell him about his mother, because he will want to know how he contracted HIV? I probably will when that time comes. My oldest daughter helps me discuss HIV/AIDS with my grandson. "Do you know anyone who knows your granddaughter's family?" No, but I might be able to find her." (Mrs. Mason)

"I buried my daughter. I don't allow my grandchildren to go to her grave and I will not tell them she had AIDS." (Mrs. Toliver)

It is evident that the children in six of the household whose parents died

understood the meaning of death. They demonstrated their emotions in many ways such as being withdrawn, sad and for some they were in complete denial about their parent's death. Mrs. Johnson grandson, for instance, refused to believe that his mother was

infected with AIDS. I wondered if his drug behavior was a way to forget his pain. Some of the children suffered depression and was counseled. I recognized that a few caregivers were secretive about their children's death because of the stigma that associated with HIV/AIDS. When some of the children being cared for asked their caregivers about their parent's death they refused to discuss the causes of their death.

Most of the participants in this study mentioned that they never expected to outlive their children. Yet, in the 1990s, our country was inundated with the ravages of the HIV/AIDS disease (CDC, 1995) and we began to see large numbers of young adults dying from this disease. Hence, this has been a tragic experience for caregivers and other families to watch their children suffer and die from the HIV/AIDS disease, at such a young age. Many parents have been saddened by this reality. In some families, parents lost more than one child who died from the HIV/AIDS disease.

Many of these caregivers have had to struggle with their own personal issues while dealing with the death of their children or family members. During my interview I asked the participants how did they deal with the loss of their child, and does it matter that they died from HIV/AIDS.

Mrs. Johnson appeared very calm when she spoke about the loss of her daughter.

“My baby doll, she died that Friday. I'm glad I was with her. The Lord helped us to get her with him and away from the children. I did all I could for my daughter and her husband. When I went to her funeral I didn't cry, you know, cause I know I did all I could for her while she was living. Yes, I hurt but I done cried out while she was living. I was doing things for her and I saw how she suffered from that stuff. I done cried out.” (Mrs. Johnson)

“I miss him. I look at his picture all the time and talk to him. I go to his grave a lot. Yes it matters that he died to me, because I wish I had known earlier I would have taken care of him better. Take his medicine on time. I knew he hadn't taken his medication.” (Mrs. Payne)

“I thank God that I was with my daughter when she died. I felt secure with her being here and she died the next day on a Saturday morning September 28, 1996. It was like peace and she looked so peaceful. I cried a few tears. God dried my tears and at the time I realize what people mean when they say God will dry your tears. I was able to be there with my daughter. I wanted a Jesus pinned on her at the funeral home. I’m glad for you that you were finally able to be with your daughter.” (Mrs. Mason)

“I get sad when I think about her. I feel better after I cry. I’m doing well by caring for her children. This helps me to feel okay.” (Mrs. Crumbly)

“I still mourned the loss of my daughter in, because I wasn’t able to care for her. That makes me feel guilty. I was sad when she died and I am still feeling pain when I think of her. I suggested to her that she talk with her pastor, maybe he will pray with you to help relieve your guilt feelings. It isn’t your fault that you weren’t able to care for your daughter.” (Mrs. Anderson)

“I think about when I watch HIV/AIDS discussions on TV. Yes, it matters that she died from HIV/AIDS. I would have loved for her to have taken care of her own children.” (Mrs. Toliver)

“It doesn’t matter that he died from HIV/AIDS. My brother is part of another family member that I had to care for and died. I asked him does it matter that he died of AIDS? No, he had to die from something.” (Mr. Robertson)

“I’m doing fine now. I know where she is. It doesn’t matter that she died of AIDS, using drugs can cause a person to get that disease.” (Mrs. Evans)

In the case where some interviewees spoke negatively about their child or sibling I wondered where the anger was coming from. I’m of the opinion that the caregiver’s angst was focused more on their child or sibling using drugs. It’s more common in some communities to talk about drugs than to discuss the HIV/AIDS disease. Many caregivers mentioned that their child contracted HIV from their partners. Moreover, when family members know their child/sibling contracted HIV from their partners they have someone to else to blame, and this mindset makes it easier for them to talk about HIV/AIDS in closed discussions.

While most of these caregivers had reconciled that they were now responsible for these children, some are happy to be able to take the children into their homes and provide them with love and care. Some expressed conflicting emotions about having to care for these children. Caregivers also expressed pain and sadness after learning that their children and siblings were infected with the HIV/AIDS disease. Many of them have told stories about how they struggled with stigma and disclosure issues around the HIV/AIDS disease. They shared stories about turning to their higher power for strength and guidance as they each cared for their children. I asked them were you taking care of your child or sibling before they died and what was the experience like.

Mr. Payne was with his son when I told him that he was HIV positive. His father became very emotional and took it hard after hearing the news about his son.

“When my son got sick and unable to care for himself he came to live with us, and that’s when I stopped going to church. I didn’t want anyone to ask me questions about my son. My husband is disabled now and he is unable to help me care for our son and grandchildren. My husband cried and told me that he wished he could help me with the children. I would take my son to his doctor’s appointment. I made sure that he was comfortable and warm, he always complained of being cold. He was very quiet and weak. At times he would laugh and talk some. I took care of him for three years before he died.” (Mrs. Payne)

“One night my mom said some lady done called from Florida and you need to go and see about your daughter and I said give me the address. My daughter was by herself in an apartment and her little boy. I called the ambulance my brother and me took her to the hospital in Ft. Pierce. I wanted to see what was wrong with her. God know I did not know my baby had AIDS and that thought never crossed my mind. My daughter had used drugs. I didn’t want to have anything to do with her. I was angry. She told me that she was HIV positive. She claimed that she got it from her dentist that was giving it to everybody, but I knew that she had been doing drugs. I took her home to live with me. I was her nurse when she needed one. The nurse who came to give her medication told me I would have to learn how to give her the medication through the tube. I would tell them I could not do it. That nurse came one day and told me to come on and try giving the medication. I went in there and was shown how to put the medicine in the needle. I was able

to do it and I would go into my room and pray and cry that is how I was able to get passed it. She lived for a year and a half.” (Mrs. Toliver)

“You know I thought something was wrong with my Mae [sister] but none of us knew. She wouldn’t tell us anything. She concealed her illness. She would not come around us much. But when she came to live with me she asked for our family to come together and she told all of us that she had AIDS. She lived with me for four months. I had a lot of hardships but knowing that I was caring for her and her boys I felt good about it. I was working everyday and would come home cook, feed and washed clothes...I did it all. I did it all and felt good showing her that I do love her and the boys. She thought that we would not love her or show her love if we knew she had AIDS. We laughed talked when she had good days. We went shopping and we did lots of fun stuff, but then she had bad days it was hell. The doctor was thinking at one point that she had pneumonia or that it was just a phase of sickness and she get better, you see...They did not know that she was sick and was going to die soon. She died August 26, 2006.” (Mrs. Crumbly)

It was a pleasure interviewing Mrs. Johnson, her spirit felt well. She expressed much love for her daughter and grandchildren.

“When she got sick I went and got her and brought her home to my house. She was so sick I brought her home. She could drive to my house. People were asking me about her. The preacher said you are her mother. Some women wouldn’t even have bothered their children. I said that’s my child I love her. That is mine. I don’t care what she done got. So I went and got her. She got sick and could hardly go. We took her to Jasper hospital she died there. We took her that Wednesday. My baby doll she died that Friday. I’m glad I was with her. The Lord helped us get her with him away from the children. She died August 3, 2001.” (Mrs. Johnson)

“I hated my brother with a passion when we were young, but when my dad died from that day on we became close. I said to him I’m glad the two of you found each other again. He would come up here on weekends. I was raising his son. My brother had been hospitalized. When I went to see him he could not walk and he had lost so much weight. I stayed with him in the hospital everyday. Then when he was able to walk again he was soon released from the hospital. I use to travel back and forth from Atlanta to Savannah to see about my brother. My brother was a drug user. My brother said, life dealt him a bad hand. I took care of him in my home for one year...He thought that I would leave him...He would not discuss his illness. He would mention the Tuskegee study.... Then he went to hospice and died in 2001.” I’m glad you and your brother made peace with each other.” (Mr. Robertson)

Finally, I thought the comments above suggested that there was close relationship between family members, but not all parents had a close relationship with their children who suffered and died from HIV/AIDS. A distant relationship seemed more common, among some of their children. Mrs. Anderson didn't know when her daughter became infected with AIDS. She met her daughter at the hospital and was told by her doctor. She said: "My daughter was sick. She died two days later, June 1996." Mrs. Evans, on the other hand said: "I knew my daughter was on drugs and had AIDS. She was a trouble child. She had been incarcerated at the sheriff's department when she became ill. They notified me that they were transferring her to hospice care in Savannah. They call me to let me know that they were going to cremate her and I had our local funeral home to go get her body." Mrs. Mason didn't talk much about her daughter until I asked specific question about her daughter. I asked her if she saw her daughter before she died and if so what she like was. She said: "My daughter has used drugs for a long time. She didn't come around me much. I found out that my daughter was going to be sent to hospice care and she was brought to my home. When she was brought home to me I felt secure that I could take care of her. My daughter didn't talk about her illness at all. She died September 1996."

The South is known as the Bible belt and the participants admit to being actively involved with their church affairs. Yet, none of them mentioned that their congregation has reached out to them in time of need. One reason why it has been difficult to get the churches to embrace and show compassion for HIV/AIDS is how it was introduced into society. HIV/AIDS was seen as a Gay Man disease and since the church rejects homosexuality some churches have found it difficult to convince members that this is not

the only way to get HIV. Some churches still have an atmosphere of fear and lack of knowledge about HIV. I have asked churches to invite me to speak about HIV/AIDS and they never respond.

I recognized that none of the respondents mentioned anything about their extended family members and the community doesn't seem to want to lend any support to these struggling families as well. However, Ms. Crumbly mentioned that her family is very supportive. Their sister called the family together to announce that she had AIDS. They all supported and took care of her. In fact, her siblings came with her to her clinic appointments. They met each of the staff at the clinic and they would ask questions about HIV/AIDS.

CHAPTER IV

PROBLEMS AND DIFFICULTIES

While most of these caregivers are still mourning the loss of their child or family members they have found a place in their hearts to care for their grandchildren or relatives. Most of these older caregivers had significant health problems, and limited financial resources. More significantly, these caregivers were not prepared to take on the responsibility of caring for young children and adolescents. They were faced with the day-to-day responsibilities of caring for these children, and other complex issues, such as coping, emotions, illnesses, the children's school contexts, stigma, and stressors causing these caregivers additional hardships and worries. Aside from caring for these children they have had the responsibility of juggling multiple household tasks. Another factor involved with the care of these children has been the availability of external resources, benefits and rewards associated with caring for these children.

I found it very rewarding to know that these children were being care for in safe environments. I was delighted to meet the surrogate parents of these children and I wanted to know about the health status of caregivers. In my initial interview with each of the participants I asked them to tell me how healthy they thought they were, if they had had any health problems recently, and did they have any chronic conditions.

“My health is pretty good. I have hypertension. I take medication for it and it is under control. I do suffer with arthritis. I don't have any chronic conditions.”
(Mrs. Mason)

“I am a diabetic and I have arthritis. I take medication for both of my conditions. My husband suffers with scoliosis and he has lots of pain and is unable to hold down a job. He finds odd jobs.” (Mrs. Anderson)

“I suffer with hypertension and I take medication for it. Otherwise my health is good.” (Mrs. Crumbly)

“My health and my husband’s health are very good so far.” (Mrs. Evans)

“My health is very good.”(Mr. Robertson)

“My husband is disabled. He had a heart condition and renal failure. I take him to dialysis three times a week. I have hypertension and I am a diabetic. I take medication for my blood pressure and I take insulin and now my knee is swollen. I had surgery years ago on my knee. She mentioned that she has problems getting her medication for her blood pressure. She is too young for Medicare and unable to purchase health insurance. I told her about the hypertension clinic at the health department. I scheduled an appointment for her. I also told her were to go to get her knee looked. I followed up with her appointments as well.” (Mrs. Payne)

“My husband is disabled he had a heart attack. I am in good health.” (Mrs. Toliver)

“I’m glad that my husband and I don’t have any health problems. I said to her you all are very blessed.” This makes it easy for us to be active and better able for us to take care of our grandchildren.” “I said to her you all are very blessed.” (Mrs. Johnson)

Women were the primary caregivers of the children. I applauded them for provided the children with a safe environment. Most of the women suffered with hypertension but otherwise they were relatively health. I noticed that most of the men suffered chronic health conditions, which prevented them from participating in the care of the children. Those men who could participate in the care of the children had no voice or responsibility. This pattern was typical for some males. Women tended to raise the family members (Bullock, 2005).

Then I asked them to tell me about the overall characteristics and development of the children who were in their care.

“My grandson is HIV positive. He had a bowel obstruction and at first it didn’t look good. But I prayed and he got better where he could use the bathroom. At

one time he could hardly eat. I gave him multiple vitamins and his eating got better. He is very hyper and he takes Ritalin. Also, he takes medications for HIV twice a day. He takes a total of six pills a day. "It's good that you are a nurse and knows how to care for him." He talks with a counselor at school but he can't discuss their conversations with me. "How do you feel about this plan?" It's okay. He attended the Sylvan Learning Center. He does well in school. I am not having any problems with him." (Mrs. Mason)

"My granddaughter is HIV positive. She attended the Rural Health Clinic. There is nothing I can do to make her better. Do the school officials know that she is HIV positive? Yes. My granddaughter is failing in life. "Why do you say that she is failing in life?" She is not healthy and she is in special education at school. "When was the last time you visited her school?" Not in a while, I have to work and I can't take time off from work. "Have you asked your husband or your daughter to visit her school?" Oh I will maybe he can do that. My grandson has some type of failure in his life.... I don't know how to handle it. He is sad all the time. "Try this: go to your grandson tell him that you love him and that you are worried about him. Ask him what he would like for you to do for him. Say to him you look sad all the time. I am here for you anytime you need me. I love you very much. Don't expect any response immediately. Then maybe he will open up to you." I will try. Thanks for your help." (Mrs. Anderson)

"My nephew was a loner and very quiet. He is slowly beginning to open up to me. He does what I ask him to do without complaining." "I hope that you are inviting him interact with you. Plan to watch some of his TV shows with him. You said that he enjoys his play station; play with him sometimes. It will help the two of you to get to know each other." (Mr. Robertson)

"They stayed back in school last year. Are you talking with the school officials to find out what is hindering their progress? Also check with the guidance counselor to see if they offer tutoring. They are kind of loners. They stay back in their room. The oldest is kind of withdrawn. She likes to stay to herself." (Mrs. Johnson)

"I made a promise to my daughter to see about you all, but when you felt like you was at that age and grown I am moving on. My oldest grandson has already left home. The others children have been good. The youngest grandson was diagnosed with Attention Deficient Hyperactive Disorder (ADHD) and he is in the special education program." (Mrs. Toliver)

"My oldest nephew is withdrawn at times. He does mean things. He gets in trouble at school for bothering other students. I have had to go to the school to

talk with his teachers about his behavior. He is mad and angry. Since I am focusing on him he seems to be doing better. His brother is fine.” “That’s great always be supportive of them.” (Ms. Crumbly)

“My grandson wets the bed, and the kids at school tease him about his mother dying from AIDS. He cries a lot and he get angry. I suggested that she check with the school counselor he may need some counseling. The school has him in an education program at the hospital, it similar to a work study program.” (Mrs. Payne)

“My youngest granddaughter has been cloned by her mother. She looks exactly like her mother and her behavior is the same as her mother. She steals just like her mother did. I am worried about her. I suggested that it might be worthwhile to check with the school counselor to see if they can arrange for her to get counseling. I will check around for other resources for her, if you would like for me to. She said, I will check with the school first if nothing happens I will contact you. My other grandchildren are okay.” (Mrs. Evans)

It was clear to me that these caregivers had a tremendous amount of responsibility with these young children. For older caregivers the children’s problems, no doubt, caused them lots of stress and they really didn’t want to talk about it. Much of the problems the children were having seemed to be related to the loss of their parents. Their problems were emotional, such as bed-wetting, crying, sadness and anger. Probably for many of these kids they didn’t know how to express themselves with their grandparents. This research helped me to understand that some of these grandparents were from the old school and some of today’s adolescents don’t relate well to them.

At this point I thought it would be good to know how these families spend their time together. Some of the respondent needed help understanding the children. I asked them to tell me what a typical day was like, and what were some of their day-to-day experience like with the children.

“They have chores such cleaning their rooms, and dishing dishes. They must get their school work done.” (Mrs. Evans)

“I do all the house work when I can. I’m always tired. The children do their homework and take care of their clothes. I make them pick up after themselves.” (Mrs. Payne)

“We have work and school. After work I make dinner, help him with his homework. We go on outing on the weekend.” (Mr. Robertson)

“I make the meals and took care of the house. They wash dishes and do their homework. We go out to eat often.” (Mrs. Johnson)

“I do everything around the house. My granddaughter is not able to help with anything and when my grandson is at home, he stays in his room.” (Mrs. Anderson)

“I work full time and I cook dinner. The grandchildren do the chores around the house.” (Mrs. Toliver)

“I read to my grandson every night. I do all the chores.” (Mrs. Mason)

Some caregivers have multiple difficulties while caring for their grandchildren and their significant others, as well as taking care of themselves. Therefore I asked them to describe the difficulties that they are experiencing.

“I have a full morning taking care of my granddaughter. She has some mental problems. I take her to her clinic appointments and I work a full time job on an assembly line in the evening. I am responsible for everything. I don’t get much help from my husband and my grandson is gone at lot.” (Mrs. Anderson)

“My grandson was diagnosed with ADHD. I had trouble with him adjusting to my being his mother. He is a teenager now. I struggle with getting him to understand that in life you got to do what you are told to do. I wonder if he understands me at times. He wants to do his own thing.” (Mrs. Toliver)

“My grandson had started getting in trouble. His teachers wrote him up because of his behavior. I had to meet with the principle and teachers. Has his behavior gotten better sine you met with the principal. I try not to be hard on him because he is sick. I suggest that you don’t use his disease as a crutch not to punish him. He knows what you are doing.” (Mrs. Mason)

“I have to do everything by myself, taking my husband to his appointments, cooking, cleaning. I need rest. I can’t take time for myself. It’s important that you take some time for yourself. If you spend an hour alone with your self it’s okay. Ask your oldest daughter to look after everybody while you rest. Take a bath and rest.” (Mrs. Payne)

“It’s difficult having to be here for these children. Remember the boys have been close to their mother and it’s going to take some time for them to adjust to their loss. I suggest that you be patient.” (Mrs. Crumbly)

“I’m not having any difficulties at this time.” Mrs. Evans

“Since I know where my grandson is and my granddaughter see the counselor I have few difficulties. I have custody of my granddaughters and I thank the Lord. They are good girls. I’m happy for you and your husband. “Mrs. Johnson”

“I pray and cry when things get difficult.” (Mrs. Toliver)

“I’m not having any difficulties. My nephew is adjusting well. He is a good.” (Mr. Robertson)

Most of these older caregivers don’t know how to remove themselves from their caretaking responsibilities. They seem to think that caring for their families should never end. Mrs. Payne, for instance said to me, “I’m so glad that I can sit and talk with you.” I wonder if they feel guilty when they took time for themselves. The younger caregivers, on the other hand, have allowed other family members to share in the care of the children.

Participants have willingly shared their stories about how they have always turned to their higher power in times of pain, sacrifice, and struggles. For many of these caregivers it has been challenging to care for today youths, especially when some of their

children have learning disabilities, poor self esteem, drug use and participating in other deviant behaviors. I asked the participants what has their challenges and stressors, been like while providing care to these children. How do you manage them?

“I just pray and talk to the Lord and I sit down and cry and I give it to the Lord. I get stressed when children tease him about his mother died from AIDS. I said don’t pay them any attention. I ask the Lord to walk me through this or that. I look to him for guidance and it works for me. I try to get to his school when I can. My brother-in-law helps me with the children in that he gets them off my hands so that I can rest. Also my oldest granddaughter helps me a lot.” (Mrs. Payne)

“My stress sometimes causes me to suffer depression. I still struggle with raising this kid. He has not been problem for me. Sending my nephew to Savannah has been very supportive for me. My cousin lives in Savannah. She works with DFACS and she helps me with him.” (Mr. Robertson)

“I’m dealing with it good. It don’t bother me like it use to. I am stressed because my grandson chose the bad life and is now in prison. Before my grandson went to the detention center he kept me tense and down. My daughter we sit down and talk to one another. We talk it out. It bothers her a lot.” (Mrs. Johnson)

“My grandson will always be with me, because of his illness and his learning disabilities. My stress worries me. I know that God knows about everything so what can I do, I can’t worry because I cannot change anything. I place it all on God’s hands.” (Mrs. Mason)

“The boys are okay now but I worry about the oldest one having sex. I pray all the time. I suggested that she call on me whenever she needs to talk to the boys about sexual issues.” (Mrs. Crumbly)

“Praying and believing helps me. I think it would be good for you to talk with your husband. Lean on him sometimes. Maybe he can help relieve your stress if he talked with your grandson.” (Mrs. Anderson)

“My praying and working through my troubles has given me the strength I need.” (Mrs. Toliver)

“My youngest granddaughter stresses me because of her behavior. I worry about her all the time. I keep her close to me. Since she travels to Jamaica every summer I hope it helps her. This family in Jamaica has adopted her as their child.” How

did she meet this family? My oldest granddaughter dates a guy from Jamaica and she took my baby to Jamaica with her.” (Mrs. Evans)

These surrogate caregivers have relied more on their higher power to help them through their challenges, because this has been, for the most part, how they resolve their issues. But what is important for them to understand is that it’s all right to invite others to help out whenever they can. In many situations people wouldn’t volunteer their support for fear of feeling as if they were intruding. Also caregivers oftentimes were concerned about the stigma and secrecy associated HIV/AIDS. Instead, of reaching out to others who might help them, caregivers continue to turn to their higher power.

CHAPTER V

RESOURCES AND REWARDS

These caregiver's financial hardships and instability has played major a role in how some of these families survived. The elderly caregivers had relied on their Social Security benefit to sustain their livelihood, and for some households these benefits weren't enough to cover their basic necessities. They had health problems and much of their income had to be used to help pay for their medical expenses. Further, when some caregivers sought Social Security for the surviving children they were denied, because many of the deceased parents had not paid enough into Social Security. Moreover, these children did not qualify for the Temporary Aid to Needy Families, (TANF), because family caregivers had custody of the children. Some caregivers who were employed experienced hardships as well. They worked as laborers and their earning power was not substantial enough to care for these children. I asked the respondents to describe to me their family's financial resources.

Mrs. Anderson, for example, was the only person employed person in her home. Throughout the interview she consistently mentioned her inability to care for her family adequately. Her granddaughter receives Social Security Benefit and Medicaid. Her grandson receives Aid to Families with Dependent Children, AFDC. She mentioned to me that sometimes they didn't have any food. Her husband was unable to hold down a job because of his health. She said, "We don't have much money, because I had to file bankruptcy. Sometimes, when I wake up I wonder, you know, what I am going to eat today." I suggested to Mrs. Anderson to discuss her financial hardships with whoever

was handling her bankruptcy case. Perhaps they can counsel her on how to manage her finances.

The other seven participants had financial means to care for their children. Mrs. Mason was a retired nurse, lived in an urban community where there were lots of resources available to her grandson. Mrs. Mason said; “I was awarded temporary custody of my grandson, because there may be another parent alive. Legal Aide said that this is how they always do this.” He receives AFDC and Medicaid because of his illness. Mrs. Mason is a homeowner. She received a pension from her employment and her late husband’s Social Security Benefits. Mrs. Toliver was employed and her husband received Social Security Disability. Her grandchildren received TANF until their eighteenth birthday. Mr. and Mrs. Evans were both employed, and one of the grandchildren received child support benefits. Mrs. Crumbly was employed and her nephews received child support and Social Security benefits. Mr. Robertson was employed and was financially able to care for his nephew. Mr. and Mrs. Johnson both were received Social Security and their grandchildren received were Social Security benefits. However, Mr. and Mrs. Payne received Social Security Disability benefits and their grandson received Social Security benefits. The children who were denied Social Security benefits it was because their parents had not contributed to Social Security.

None of the respondents mentioned that they had access to external resources other than the school system and their church. A few of these families were actively involved in their church fellowship. The church members were similar to an extended family. When families were in need the members supported each other.

The schools were concerned with the children's educational success and counseling these children was a way to help them with their problems as well as to help them to remain focus on their education. Mrs. Mason said, "My grandson was awarded a monetary stipend to send her grandchild for tutoring at a private learning center. My ministry helped him with his homework. The Elders and senior companions work closely with me." Mrs. Payne said, "My grandson's principal was aware that students teased my grandson about his mother and the principal handled the problem. Mrs. Johnson said, "The children talks to the counselor at school and they would call me to discuss their concerns. My pastor would come from Savannah to my house and pray for all of us." Mrs. Crumbly said, "My church members visits us and have pray services." The other caregivers had nothing to say about external resources.

Finally, I asked each interviewee, if they felt that they had benefited or had been rewarded by caring for their grandchildren or nephews.

"When I look back on having to raise this child I benefited. It was one of the best decisions I have ever made." (Mr. Robertson)

"I was rewarded. It really makes me happy, because I at least now know where they are. They are not separated. I have custody of all my grandchildren. I benefited. I wanted them to belong to me so that no one can come and take them away." (Mrs. Payne)

"I was rewarded. She is the sweetest thing. She just wants to make me happy. She is the first one to go to college, because my children did not go to college." (Mrs. Toliver)

"I benefited and I am rewarded, because I am glad that I have my grandchildren. It was God's will to take their mother and father away. It makes me happy to know that I am capable enough to raise these kids for her. She is not here to do it

herself and that is why I do all that I can. I am happy to know that they can depend on me.” (Mrs. Johnson)

“I am rewarded. I have always wanted six children. I have four and now I have two more to rear. I am happy. I tell them just blend in we are one big family.” (Ms. Crumbly)

“I have benefited by being their only parent. I love them. I know how to care for my HIV grandchild.” (Mrs. Anderson)

“I benefited by helping out with my grandchildren.” (Mrs. Evans)

“I benefited and was rewarded by God helping me to find my grandson. He is Mine. I hope I can keep him health and raise him.” (Mrs. Mason)

Fortunately, what I’ve learned from these caregivers is that in spite of their hardships and struggles brought on from taking in their grandchildren and nephews into their homes they did what ever was necessary to keep their families together. Most of all they found ways to utilize their financial resources. Many of these caregivers had external resources to help get through their pain and suffering. Not many of them mentioned that they had other family members to help out with the children. These caregivers seemed to be more connected to their church and the children’s school. These resources were very helpful to them. African Americans have had to endure many hurdles on these shores and this is just one more hurdle to tackle. They believe in something greater than themselves Even when the cards seemed to be stacked against them they come through it. Ultimately, all of the caregivers stated that they benefited and was rewarded by being the surrogate parent to these children.

CHAPTER VI

CONCLUSIONS

This thesis describes many details of the day-to-day experiences of caregivers. Yet several important findings deserve further attention. First caregivers who are affected by the death of HIV/AIDS are in need of more assistance and recognition for the continuance of rearing healthy children for today's society. Many caregivers who are left rearing children whose parents have died of HIV/AIDS may require more assistance from the government than Social Security benefits. The federal and local governments may need to take into account other services such as mental, social, and educational opportunities that may not readily be afforded to these children but will need to be in place for the growing numbers of orphaned children.

Secondly, if more specificity was given to these caregivers they would be more receptive to taking care of the children versus harboring feelings of resentment, bitterness and being overwhelmed due to heavy burdens brought on by the unexpected responsibility of caring for the children. These feelings could possibly be curtailed if the proper support were available to help the caregiver's situation out.

Further, African Americans in rural communities need more educational issues about the effects of HIV/AIDS and how to care for the new addition of children to the family. HIV/AIDS care program should be designed to provide a holistic health care approach; because what I've learned from this study is that the disease of HIV/AIDS involves the entire family system. For instance, some caregivers cared for grandchildren who were HIV positive and these parents weren't adequately trained in how to care for these children. Children who knew their parents had HIV/AIDS didn't understand the

manifestation of the disease. These children suffered mentally from the loss of their parents. Some children were unable to except that their parent had AIDS. Some had behavior problems, ADHD, and drug problems. I recently spoke to the male caregiver in my study, and he said that his nephew has behavior problems. I gave him the names of two AIDS Service Organizations in Atlanta to assist with counseling for his nephew, and he said that the child needs a beating. Some parents were at a loss trying to reconcile their lives and those of the children. The children's schools assisted with providing support for them, but these children need extensive counseling. And although the family's ministry was supportive, these families were still in need of extensive intervention.

My findings revealed that most of the grandparent caregivers were elated to take the children into their homes. Most of them had lived close to their children and grandchildren. These grandparents had played a major role in their grandchildren's lives. Some grandparents had been rearing their grandchildren since birth. Those relatives who weren't excited about rearing these children seemed to be upset with their child or sibling because they had been substance abusers. During the interview sessions the caregivers often mentioned that their child or sibling was involved with drugs. Some of the caregivers felt that their lives had been disrupted because they had to care for their grandchildren, or nephews, these feelings had an effect on the children they care for. Some of the children were sad and angry. Also caregivers mentioned that the child was withdrawn. Another grandparent acknowledged that her granddaughter was a thief, but the parent never mentioned that the child may have low self-esteem and wanted attention. The child needed some intervention to sort out her feelings, possibly a group for children who lost parents to AIDS while going through the process.

Most of the individuals who were infected with HIV/AIDS told their parents. Occasionally, the parents would attend the health clinic with them. Parents who had knowledge about their children's health care were instrumental in helping them keep their appointments, and learned about the HIV/AIDS disease. But HIV/AIDS was never discussed outside the home, because of the stigma associated with it. Also in many rural communities families remained very private when it came to family business.

In the literature review in some communities in Africa everyone in the village would know about families who were infected with HIV/AIDS. Apparently the villages were small and people traveling to their health facilities had to travel in groups (Okigbo, 2002). Most people who attended our clinics came alone, and to avoid contact with other patients they utilized alternate entrances into the facility.

Major stressors for caregivers included grandchildren's physical developmental problems. Two of the children were HIV positive and four children were diagnosed with Attention Deficient Hyperactive Disorder (ADHD). Other stressors included the stigma and denial associated with HIV/AIDS. Also these families were struggling with health problems and financial instability.

Emotional issues of the children who lost their parents were teenagers and they had some understanding about death, but they seemed to be sad, angry and depressed, because they didn't understand the disease. None of the parents talked to the children about HIV/AIDS. One grandparent said to me that she didn't know what to say to her grandson. I talked with the client about how to talk with her grandson. I offered suggestions, and I sent her pamphlets to share with her son.

School support was important to point out that the caregivers informed the schools that the children's parents had died of AIDS. When a child acted out or showed a behavior change the counselor responded to the child. In addition, the children who were HIV positive were monitored at school for their progress, and counseling was provided to them as well. There were four children in the study who has Attention Deficient Hyperactive Disorder (ADHD) and this issue was not addressed well by the caregivers during the interview. They each were placed in special education. It seems to me that the school showed some support around the HIV/AIDS problem and the child's behavior, but not enough when the focus was on ADHD. They each were placed in special education.

Spiritual support was another important point was the church ministry. Support was available to members who came to some churches and discussed their concerns about HIV/AIDS. This ministry made it possible for the families who wanted to turn to their higher power for strength and guidance when they had struggles, emotions and stressors. However, other caregivers reported to me that they had dropped out of church. These caregivers were ashamed and didn't want any in the church to ask them about their children who had died. Many of these caregivers still looked to a higher power for support, but did not find comfort in their churches.

Most participants rely on social welfare benefits such as Social Security, but they received limited support for their family and communities, or government support to help care for their grandchildren. Grandparents living in rural communities were significantly worse off in comparison to the ones living in an urban setting especially with regard to the availability of external resources.

Overall, I applaud the caregivers who were able to juggle both the task of caring for these children and attending to their family health problems. The family's income afforded the caregivers an opportunity to love and provide adequate support to each of the children left in their care. The surrogate parents felt that they benefited greatly by being able to keep these children together and safe.

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APPENDICES

APPENDIX A
PARTICIPANT RECRUITMENT FLYER

Are you the caregiver of a child that
has been orphaned by AIDS?



**A graduate student at Georgia
Southern University is
conducting a research study
detailing the lives of
individuals affected by AIDS.**

Participation in this study includes:

- Financial compensation
- Referrals and resources
- Privacy and confidentiality

For more information contact:

Doris Wilbon, Graduate Student in Sociology

Communicable Disease Specialist

912-489-4975 or via email at dcwilbon@dhr.state.ga.us

If you are interested, please fill out the following information:

Name: _____

Telephone No.: _____

APPENDIX B
INTERVIEW FORM

HIV/AIDS CAREGIVERS

Interview Questions

Background Questions

Sex of the Interviewee

★ ___ Male ___ Female

Where Does the Interviewee Live?

- ★ Name of the Community _____
- ★ Country _____
- ★ State _____
- ★ ___ Within city limits
- ★ ___ Inner city
- ★ ___ Outside city-farm
- ★ ___ Outside city-not farm

Date of Birth

★ _____ (Day/month/year)

Which of the Following Best Describes Your Race/Ethnicity Background?

- ★ ___ Black or African American
- ★ ___ White American
- ★ ___ Asian American
- ★ ___ Mexican American/Chicano
- ★ ___ Puerto Rican American
- ★ ___ Other Latino
- ★ ___ American Indian/Native American
- ★ ___ Native Hawaiian or other Pacific Islander
- ★ ___ Other-Specify: _____

How Many Years of Formal Education Did You Have?

★ ___ Years

What Is Your Highest Level of Formal Education Attained?

- ★ ___ Less than 9th grade
- ★ ___ 9-12 grade, no diploma
- ★ ___ High school graduate/GED

- ★ ___ Some college with no degree
- ★ ___ Associate degree
- ★ ___ Bachelor's degree
- ★ ___ Graduate or professional degree

Your Household Income for Year 2006?

- ★ ___ Less than \$5,000
- ★ ___ \$5,000-9,999
- ★ ___ \$10,000-19,999
- ★ ___ \$20,000-29,999
- ★ ___ \$30,000-39,999
- ★ ___ \$40,000-49,999
- ★ ___ \$50,000-59,999
- ★ ___ \$60,000-74,999
- ★ ___ \$75,000 or more

The Number of People in Your Household?

★ _____

Marital Status

- ★ Married
- ★ Divorced
- ★ Single (never married)
- ★ Widowed

If Married, Tell Me a Little Bit About Your Spouse

- ★ Age _____
- ★ Health status _____
- ★ Employment status _____
- ★ Does he/she also provide care for the grandchildren?

Your Employment Status: Full time job* → In a typical week, how many hours do you work? hours Part time job* → In a typical week, how many hours do you work? hours Don't have a job* → Are you looking for work? Yes No*Religion*

-How important is this religion for you? _____

-The name of the religious organization _____

-How religious do you think you are? _____

What Is the Total Number of People in Your Household Including Yourself?

* _____ Persons

How Many of Them Are Under 18 Years of Age?

* _____ Children

- ★ **Daughters:** _____
- ★ Current age: _____
- ★ Current age: _____
- ★ Current age: _____
- ★ Current age: _____
- ★ Current age: _____
- ★ Current age: _____
- ★ Current age: _____

How Many Children Are Currently Living With You?

Tell Me a Little Bit About the Child That Died From the HIV/AIDS. When Did He/she Die? What Was She/he Like As a Person? For Example, What Kind of a Parent Was She/he?

Were You Taking Care of Him/her Before His/her Death? How Long?

How Are You Dealing With the Death of the Child? How Often Do You Think About Him/her?

Does It Matter That He/she Died of HIV/AIDS? Why? Or, Why Not?

Information About Children:

How Many Children Do You Care for at the Moment? How Long Have You Been a Caregiver for Them?

- ★ **Males:**_____
- ★ Current age:_____
- ★ Current age:_____
- ★ Current age:_____
- ★ Current age:_____
- ★ Current age:_____
- ★ Current age:_____
- ★ Current age:_____

- ★ **Females:**_____
- ★ Current age:_____
- ★ Current age:_____
- ★ Current age:_____
- ★ Current age:_____
- ★ Current age:_____
- ★ Current age:_____
- ★ Current age:_____

*Which of These Children Have Lost Their Parents to the HIV/AIDS?
Child #1, 2, 3, 4, 5:*

- **Overall, how do you think the child is doing?**

- **Health?**

- **How happy or unhappy is the child?**

- **Sleep well?**

- **Anxious?**

- **Depressed?**

What Makes You Happy? Or When Are You Happiest?

What Makes You Sad?

What Comforts You?

What Worries You Most? (What Fears Do You Have?)

Would You Please Describe the Circumstances When The Children were First Brought to Your Home for You to Care for?

-What were they like then?

-And how are they doing now?

Have You Ran Into Any Problems or Difficulty Because You Are a Parent Instead of a Relative (aunt, grandparent, etc.) to the child?

★ Please explain

What Do You Think Has Benefited You As You Raise The Children?

What Is the Most Difficult Thing About Raising The Children?

Do you talk sometimes with other caregivers who are in the same situation?

If so, what kinds of things do you talk about?

What do you do to help you're the children deal with the death of their parent/parents?

Are You Comfortable Talking With The Children About HIV/AIDS and Their Parents?

-If so, how do you bring it up?

-If not, why not?

Have You Made an Arrangement for Someone to Care for These Children If You Lose Your Ability to Do So?

★ If so, who would that be?

What is the most difficult thing in life right now?

How do you cope with difficulties?

What works best as a coping method?

Who provides support?

Emotional support?

Financial support?

O Any other support?

Information About External Resources

Does the School Which The Child(ren) Attend Do Anything to Help Them Deal With the Loss of Their Parent to the HIV/AIDS?

O What kind of assistance is provided?

O If none is provided, what kind of assistance do you want from the school?

What do you think of this neighborhood?

O Do you like living here?

-Why? Why not?

Do Your Neighbors Help You With Anything?

-If so, what do they do?

-If not, what kinds of things would you like your neighbors to do for you and/or the children?

Do Any of Your Relatives Provide Help to You, Especially With Raising The Children?

Financially?

Emotionally?

Any other ways?

Do you get help from your church? If so, what kind of help?

Do you receive any government assistance?

O What kinds (Medicare, Medicaid, Social Security, Food Stamps, etc.)?

O For how long?

How helpful is each of the governmental program?

O Which one is most helpful to you?

May I Ask What Kinds of Family Things (Fun Things) Do You Do With The Children?

O Examples (family reunions, church picnics, etc.)?

★

★

What are the pitfalls non-family friends have caring for children affected by the loss of their parent(s) to HIV/AIDS?

What concerns do male caregivers have accessing social services?

What resources are available to non-traditional caregivers?

Do you care for orphaned children who have lost their Parent(s) to HIV/AIDS?

What are the difficulties, responsibilities, and complexities caring for non-related children?

Is There Anything You Would Like Tell Other Caregivers Who Are in the Same Situation?

○ What are some of the things you would say?

★

Would You Like to Know the Major Findings of This Research Later on?

★__ Yes __ No

APPENDIX C

IRB LETTER

Georgia Southern University
Office of Research Services & Sponsored Programs

Institutional Review Board (IRB)

Phone: 912-681-5465

Administrative Annex

P.O. Box 8005

Statesboro, GA 30460

Fax: 912-681-0719

Ovrsight@GeorgiaSouthern.edu

To: Doris Wilbon
4680 Pulaski Road
Statesboro, GA-30458

cc: Nancy Malcom
P.O. Box-8051

From: Office of Research Services and Sponsored Programs
Administrative Support Office for Research Oversight Committees
(IACUC/IBC/IRB)

Date: May 16, 2007

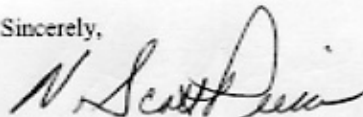
Subject: Status of Extension Request for Approval to Utilize Human Subjects in Research

After a review of your Extension Request for research project numbered: **H06149**, and titled "**Caretakers of Children Affected by HIV/AIDS**", it appears that (1) the research subjects are at minimal risk, (2) appropriate safeguards are planned, and (3) the research activities involve only procedures which are allowable.

Therefore, as authorized in the Federal Policy for the Protection of Human Subjects, I am pleased to notify you that the Institutional Review Board has approved your extension.

This IRB Extension approval is in effect for one year from the date of this letter. If at the end of that time, there have been no changes to the research protocol; you may request an extension of the approval period for an additional year. In the interim, please provide the IRB with any information concerning any significant adverse event, **whether or not it is believed to be related to the study**, within five working days of the event. In addition, if a change or modification of the approved methodology becomes necessary, you must notify the IRB Coordinator **prior** to initiating any such changes or modifications. At that time, an amended application for IRB approval may be submitted. Upon completion of your data collection, you are required to complete a *Research Study Termination* form to notify the IRB Coordinator, so your file may be closed.

Sincerely,



N. Scott Pierce
Director of Research Services and Sponsored Programs

APPENDIX D
INFORMED CONSENT LETTER

**GUIDELINES FOR
MODEL INFORMED CONSENT**

1. I am Doris C. Wilbon, a graduate student in sociology at Georgia Southern University, Statesboro, Georgia. I am also presently employed with public health, working on the Ryan White HIV/AIDS program.
2. Purpose of the Study: I am interested in learning about the responsibilities of caregivers of children who are affected by the loss of one or both of their parents to Human Immunodeficiency Disease (HIV), and Acquired Immunodeficiency Syndrome (AIDS). The purpose of this research is to determine the complexities of issues faced by these caregivers while they care for these children.
3. Procedures to be followed: Participation in this research will have semi-structured face-to-face interviews. The interviews will be audio-recorded. I will ask that children not be present while I am interviewing caregivers.
4. Discomforts and Risks: Although my questions do not focus on the loss of the children's parents, the interview might trigger an emotional response, causing some psychological discomfort and embarrassment because HIV/AIDS is a sensitive subject. If discomfort occurs, you may stop the interview or your participation at any time. We can also suggest options for counselors/psychologist if you experience discomfort and express the need for such assistance during your participation.
5. Benefits: This is an opportunity for you as a participant to reflect on your own role as a caretaker to these children. You may be able to learn about yourself and the situation as a caregiver a little better because of the interview. You will be able to express your concerns for yourself and the children. This may help you to realize how much you have been doing and how valuable you are to the children and your community. You may feel a sense of empowerment as a result. The benefits of this research include helping the public better understand the important and difficult role of a caregiver who raises children who have lost their parents. We as a society may also find ways to provide services to those caregivers.
6. Duration/Time: It will only take two hours to complete the interview.
7. Statement of Confidentiality: Only the investigator involved in the project will know your identity. If this research is published, no information that would identify you will be written.

8. Right to Ask Questions: Participants have the right to ask questions and have those questions answered. If you have questions about this study, please contact the researcher named above or the researcher's faculty advisor, whose contact information is located at the end of the informed consent. For questions concerning your rights as a research participant or the IRB approval process, contact Georgia Southern University Office of Research Services and Sponsored Programs at 912-681-0843.
9. Compensation: There will not be any compensation for participating in this survey.
10. Voluntary Participation: Explain that the subjects don't have to participate in this research; that they may end their participation at any time by telling the person in charge, not returning the instrument or other options; that they do not have to answer any questions they do not want to answer. (For juveniles in classroom settings, add that they may decide to stop working on the project at any time and discuss how they should communicate this to the researcher; also state what alternative activity is available to a juvenile if the research takes place in a classroom setting.
11. Penalty: Advise the subject that there is no penalty for deciding not to participate in the study; that they (or the juvenile) may decide at any time they don't want to participate further and may withdraw without penalty or retribution. (For studies offering incentives and/or compensation, please describe how withdrawal will effect their compensation).

You will be given a copy of this consent form to keep for your records.

Title of Project: Caretaking of Children Affected by HIV/AIDS in the Rural South

Principal Investigator: Doris C. Wilbon
4680 Pulaski Rd.
Statesboro, Georgia 30458
(912) 852-9421
dwilbon@georgiasouthern.edu

Faculty Advisor: Nancy L. Malcom, Ph.D.
P.O. Box 8051
(912) 681-5168
Statesboro, Georgia 30460
nmalcom@georgiasouthern.edu

Participant Signature

Date

I, the undersigned, verify that the above informed consent procedure has been followed.

Investigator Signature

Date