NAIROBI EVANGELICAL GRADUATE SCHOOL OF THEOLOGY

An Assessment of the Strengths and Challenges of a Residential Approach and a Community Based Approach to Caring for HIV Positive Orphans: A Case Study of Grace Children's Center and the Lea Toto Program

BY
VALERIE ROGERS

A Thesis Submitted to the Graduate School in Partial Fulfillment of the Requirements for the Degree of Master of Arts in Missions

JULY, 2007

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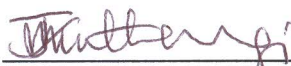
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July, 2007

STUDENT'S DECLARATION

AN ASSESSMENT OF THE STRENGTHS AND CHALLENGES OF A
RESIDENTIAL APPROACH AND A COMMUNITY BASED
APPROACH TO CARING FOR HIV POSITIVE ORPHANS:
A CASE STUDY OF GRACE CHILDREN'S CENTER
AND THE LEA TOTO PROGRAM

I declare that this is my original work and has not been submitted to any other College or
University for academic credit.

The views presented herein are not necessarily those of the Nairobi Evangelical Graduate
School of Theology or the Examiners.

(Signed) _____

Valerie Rogers

July, 2007

To

The children in Grace Children's Center and the Lea Toto Program: May you know the love and the hope of our Lord Jesus Christ.

ACKNOWLEDGEMENTS

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LIST OF ABBREVIATIONS

ADHD – Attention Deficit Hyperactivity Disorder

AIDS – Acquired Immune Deficiency Syndrome

ARVs – Antiretroviral drugs

GCC – Grace Children's Center

HIV – Human Immunodeficiency Virus

ISS – International Social Service

NEGST – Nairobi Evangelical Graduate School of Theology

NGO – Non governmental organization

UNICEF – United Nations International Children's Education Fund

WHO – World Health Organization

CHAPTER ONE

INTRODUCTION

There are currently about 2.4 million children in sub-Saharan Africa who are living with HIV/AIDS, and 1600 children die every day from AIDS – related illnesses (O'Hare et al 2005, 443). Because the majority of these children have acquired HIV from an infected mother, many of these children are orphans, and those whose parents are still alive are at great risk of becoming orphaned. There are already more than 11 million orphans in sub Saharan Africa, and experts predict that there will be 20 million by the year 2010 (UNICEF 2003, 6,10). A significant number of these 20 million orphans will be infected with HIV themselves.

As governments and organizations develop programs to address the needs of these orphans, there is an ongoing discussion regarding the best model of care for orphaned children. In the past few decades, many residential homes have been built for orphaned children. However, residential care has been widely criticized, and community based care is often advocated as a better alternative for orphans. Although there has been a significant amount of research done regarding the different models of care, the vast majority of this research focuses almost exclusively on HIV negative orphans, and the special needs of HIV positive orphans are not taken into consideration.

This research studied both a residential model and a community based model of care for HIV positive orphans to attempt to determine the strengths and challenges of both models of care in meeting the needs of the children. The residential model used in

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this research is Grace Children's Center, a children's home in Karen (Nairobi, Kenya) and the community based model is the Lea Toto Program in Nairobi, Kenya.

These two ministries were chosen because they are comparable in terms of the quality of care provided, the geographical area in which they operate, and their access to resources. Both ministries are known to offer excellent care to the children in their programs, and both ministries operate in Nairobi. In addition, both ministries receive the majority of their funding from Western countries.

Grace Children's Center

David and Jennifer Hatley began Grace Children's Center (GCC) in 1995 to cater for orphaned children who were HIV negative. After receiving three HIV positive children, they decided to expand their residential home and opened an extension home for HIV positive children in 2002. GCC currently has nineteen children who are HIV positive. The children range in age from three to thirteen years old. The residential home is on a five acre compound that also contains a home for about forty HIV negative orphans, a pre-school, a primary school, and a church.

Grace Children's Center provides all of the basic necessities for the children, such as adequate clothing, bedding, shelter, and a balanced diet. The children are cared for by several house moms who work at the home. In terms of medical support, all of the children are currently receiving ARVs and go for a check up and drug monitoring once a month. All of the children receive full pediatric care in addition to the specific care for HIV. They are all fully immunized and receive nutritional supplements.

In terms of psychological support, the social worker and house moms are available to talk with the children about any problems or concerns they have. In addition, the children receive spiritual support from the pastors and church community. The children receive full educational support and are all enrolled in either the pre school or primary school on the compound. Their uniforms, books, and other school necessities are provided by the home.

Lea Toto Program

In 1992, Father Angelo D'Agostino began a residential home for HIV positive children called Nyumbani. In 1999, the management of Nyumbani decided to introduce a new program that would reach out to HIV positive children in their communities, and the Lea Toto program was launched. Since 1999, over 3500 children have received support from Lea Toto, and there are currently over 2000 children enrolled in their program. Out of those 2000 children, approximately 400 children are orphaned. The children in the program range in age from infants to 18 years old.

Lea Toto has clinics and offices in eight different slum areas in Nairobi: Kangemi, Waithaka, Kibera, Kawangware, Riruta, Mutuini, Ruthimitu, and Kariobangi. In terms of psychosocial support, Lea Toto provides free HIV testing and counseling for children and adults. They provide counseling to affected families, child counseling, and disclosure counseling/trainings for caregivers. In terms of social support, Lea Toto provides food or direct financial support to families based on a needs assessment conducted by a social worker. In order to ensure that the children are able to access education, Lea Toto

provides various means of educational support including school fees, uniforms, books, and shoes for children whose caretakers cannot afford such items.

Lea Toto also offers extensive medical support to the children in their program. They provide drugs to manage opportunistic infections as well as free ARVs for children who qualify for them. To date, over 700 children have received ARVs from Lea Toto. If a child needs additional medical assistance, Lea Toto provides transportation to the hospital as well as payment of hospital bills for families who cannot afford to pay these charges.

Finally, Lea Toto is also involved in empowering and educating the community. After encountering a lot of stigma in the early years, Lea Toto launched a massive educational campaign in all program areas to engage the community and provide information about HIV/AIDS. In addition, Lea Toto trains community health workers, volunteers who provide extra care by visiting families, giving nutritional and medical advice, and referring children to the clinic for further care.

Problem Statement

This study is an assessment of a residential and a community based care program that attempts to evaluate the areas in which these different models of care are able to meet the physical and psychological needs of orphaned children infected with HIV/AIDS.

Significance of this Study

HIV/AIDS has already created 11 million orphans in sub-Saharan Africa, and experts predict that the situation will only worsen in the future. By the year 2010, it is estimated that there will be 20 million orphans in Sub Saharan Africa (UNICEF 2003, 6, 10). In addition, there are currently 2.4 million children who are living with HIV in sub-Saharan Africa, and the majority of them were infected by mother-to-child transmission (O'Hare et al 2005, 443). Because the majority of HIV positive children acquire the disease from infected mothers, all of these children are at risk of becoming orphaned if they have not already lost their parents.

Oftentimes, HIV positive children are overlooked in support programs for orphaned and vulnerable children. These children are overlooked both because of stigma associated with HIV and also because of the high levels of support and care that these children require. Many relatives are unwilling to take in sick orphans, and oftentimes these children are neglected, leading to a premature death. In other cases, caregivers have neither the resources nor the knowledge to effectively care for HIV positive children. If programs can effectively address the needs of these children, both the quality of their lives and their longevity can be greatly improved.

As both the number of orphaned children and the number of HIV positive children continue to increase, it is important for churches and organizations to develop models of care for such children that can effectively meet their needs. There is an ongoing discussion about the strengths and weaknesses of both residential care and community based care for orphaned children. However, this discussion focuses almost exclusively on HIV negative orphans. The researcher was not able to find any research

that has been done on the strengths and weaknesses of these models of care for HIV positive children. This research project will focus on the different models of care as they relate specifically to HIV positive children.

Purpose of this Study

The purpose of this study is to determine the strengths and challenges of caring for HIV positive orphans in both Grace Children's Center, a residential approach, and the Lea Toto program, a community based approach.

Research Questions

This study attempts to answer the following research questions:

1. What strengths does the Lea Toto program have in its ability to meet the physical and psychological needs of the HIV positive orphans in its program?

2. What challenges does the Lea Toto program face in meeting the physical and psychological needs of the HIV positive orphans in their program?

3. What strengths does Grace Children's Center have in terms of its ability to meet the physical and psychological needs of the HIV positive orphans in their home?

4. What challenges does Grace Children's Center face in meeting the physical and psychological needs of the HIV positive orphans in their home?

Limitations

Although the researcher has a good relationship with the children and staff at Grace Children's Center, the researcher does not know the children or caregivers in the Lea Toto program. Because AIDS is a stigmatized disease, they may be reluctant to offer information to a stranger. In addition, because the researcher is a foreigner, they might offer inaccurate information in hopes of receiving additional assistance. The effects of this limitation were reduced by conducting interviews with the assistance of a Lea Toto social worker who has a relationship with the interviewees and knowledge of their situation. Another limitation is that there was a language barrier because the interviewer does not speak fluent Swahili, and four of the people interviewed did not speak English. To address this limitation, a translator was used in all four of the interviews where the interviewee spoke Kiswahili.

Delimitation

This study was limited to one residential program and one community based program. Therefore, it is not wide enough to fully address the strengths and challenges of residential care and community care on a broad level. In addition, this research focuses mainly on the ability of residential and community based programs to meet the needs of HIV positive orphans and not the financial viability of residential or community based programs.

Definition of Terms

Residential care – also referred to as children's homes or institutions. It refers to a model of care where several unrelated orphaned children are cared for by staff members who are usually not related to the children. The home is responsible for meeting all of the needs of the children.

Community based care – also called foster-family care, this refers to a model of care where orphaned children are cared for by extended family members or unrelated foster parents. The community and caregivers are primarily responsible for the care of the children. Community based programs aim to expand the capacity of the caregivers and support them in various ways to enable them to effectively meet the needs of the children.

HIV – stands for Human Immunodeficiency Virus and is the virus that causes AIDS. HIV causes a slow breakdown of a person's immune system by destroying white blood cells (also called CD4 cells).

AIDS – stands for Acquired Immune Deficiency Syndrome – AIDS is the name for the condition when HIV has destroyed most of the CD4 cells in the body, leading to many opportunistic infections. Many people can live with the HIV virus for many years before it develops into full blown AIDS.

HIV positive orphans – refers to children who have the HIV virus and have lost one or both parents through death or abandonment. This includes both children who are asymptomatic and those who have symptoms of full blown AIDS.

Physical needs – refers to the basic requirements of children to achieve physical health, including adequate food, housing, medical care, and education.

Psychological needs – refers to the basic requirements of children to achieve mental health, including love, a sense of belonging, and counseling or support to deal with issues of loss and stigma.

Secondary caregiver – refers to a person who is the main caretaker for a child and is not that child's biological parent. For example, a secondary caregiver may be an aunt, uncle, grandmother, or a neighbor (this list is not exhaustive).

House mom – a woman who works as one of the caregivers for orphaned children in a residential home.

ARVs – stands for Antiretroviral and refers to the medication that has proven most effective against HIV/AIDS. These drugs are often very expensive and the majority of people cannot afford them without assistance from a hospital or program.

CHAPTER TWO

LITERATURE REVIEW

Introduction

Over the past twenty years, HIV/AIDS has caused considerable devastation in sub-Saharan Africa, claiming the lives of parents while leaving millions of orphans behind. In 1990, there were less than 1 million orphans who had lost one or both parents to AIDS in sub-Saharan Africa. Just eleven years later, by the end of 2001, there were 11 million orphans as a result of AIDS (UNICEF 2003, 6). Although these statistics are already overwhelming, the orphan crisis will get worse before it gets better. Even in areas where the prevalence rates of HIV/AIDS have stabilized or decreased, the number of orphans will continue to increase over the next several years because of the long time period between infection with HIV and death (Ibid. 10).

Although the majority of these orphaned children are HIV negative, there are a significant number of orphaned children who are infected with HIV. As cited earlier, there are currently 2.4 million children in sub-Saharan Africa who are HIV positive (O'Hare et al 2005, 443). In addition, almost 1800 children under the age of 15 are infected with HIV every day. Over 90% of HIV positive children have acquired the virus either at birth or from their mother's breast milk (UNAIDS/WHO 1999, 829). Because these children acquire HIV from their infected mothers, they face a very high risk of becoming orphans in their lifetime.

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Needs of HIV Positive Orphans

HIV positive orphans have numerous physical and psychological needs that must be addressed by any organizations or programs that are seeking to provide care and support for these children. Their most immediate needs are a place to stay and someone to take care of them. They need basic necessities such as adequate food and clothing. In addition, they need access to education and medical services. Finally, they need physical security from abuse and exploitation. In terms of psychological needs, HIV positive orphans need psychological support to help them deal with the implications of their illness and the multiple losses they have suffered. They also need psychological support to deal with stigma from their peers, community, and family members. The following sections are a reflection of the research dealing with each of these key areas of need.

Shelter and Caregivers

The most obvious and pressing physical needs of orphaned children are a place to live and a caregiver. African tradition and culture dictate that orphans should be taken in by extended family members. However, these extended family structures are becoming increasingly burdened as the number of orphans continues to rise (Blair et al 1996, 46). The burden of raising these orphans often falls to elderly grandparents who do not have adequate resources or capacity to care for them. As a result, some children remain in their homes even after their parents have died and children as young as 10 or 12 years old assume the responsibilities of head of the family (Onyancha and Shorter 1998, 87).

The Western concept of adoption does not exist in most Kenyan communities. Because kinship is very important in Kenyan culture, orphans are often fostered by

extended family members to prevent the complete termination of their father's household. However, sometimes the extended family is unable or unwilling to care for the orphans (Blair et al. 1996, 55). This reluctance is especially strong when the orphans are HIV positive, since they are often stigmatized and require a greater amount of money and effort than healthy children.

Orphaned children typically live in one of five categories of households. The first category is foster families, which are extended family networks where the children are raised by an uncle or aunt. The second category of households is third generation caretakers, where children are raised by grandparents. The third category is orphan headed households, where the children continue to live in their house without any adult caregivers. The fourth category is households employing orphans. Orphaned girls are often employed as house girls, and sometimes relatives will even receive remunerations for these girls (Ibid.). The fifth category is orphans who live in residential homes, also called children's homes or orphanages.

<center>Basic Necessities</center>

Because orphaned children are usually cared for by already impoverished relatives, many orphans struggle simply to have their basic needs met (UNICEF 2003, 20). In a 1994 study conducted of 128 orphans and 32 of their caretakers in various parts of Kenya, the researchers discovered that the most immediate problem for many orphans was a lack of basic necessities. Orphans were very vulnerable to malnutrition due to scarcity of resources. Child-headed households often struggled to obtain enough money to buy sufficient food. In most cases, foster families were already poor; therefore, taking

in orphans meant extra mouths to feed when resources were already insufficient. In addition, orphans often occupied a low position in their foster families and received less food than other members of the family (Blair et al. 1996, 46, 56).

Many of the children in this study also lacked adequate clothing. For some children, one school uniform was their only article of clothing. Others did not even have a complete school uniform. For example, one boy was unable to attend school because he did not have a complete uniform even though the school agreed not to charge him school fees. Many of the children in this study lacked proper bedding, and some slept on cartons or their parents' old clothing. Blankets were inadequate, and in one circumstance three orphans shared one thin blanket (Ibid. 56).

Education

Education is an important need that most orphaned children struggle to obtain regardless of their HIV status. In a study of orphans in Korogosho slums, 72% of the orphans identified education as their most important need (Onyancha and Shorter 1998, 87). A Ugandan study of orphans in 15 villages showed that orphans and non-orphans had similar rates of school attendance at around 7 or 8 years of age. However, among older children, orphans had lower rates of school attendance than non-orphans (Kamali et al 1996). Due to inadequate resources and greater household responsibilities, many orphans are not able to complete primary education and very few are able to receive secondary or higher education. Young orphaned girls are especially at risk for dropping out of school. Oftentimes they are drafted into sex work or forced into early marriage in order to raise funds for the other siblings (Blair et al 1996, 46). Although some HIV

positive orphans do not live long enough to reach school age, those who do reach school age often face an even greater challenge of obtaining education than HIV negative orphans due to stigma, discrimination, and frequent illness.

Protection and Security

Orphaned children are at an extremely high risk of abuse and exploitation. Children who have been orphaned are more likely than other children to be forced into domestic work and commercial sex (UNICEF 2003, 30). Orphaned children are also at high risk for abuse, mistreatment, and exploitation by their foster families. Orphans often eat less than other members of the family and may be forced to work in the house or outside of the house to earn extra income (Blair et al 1996, 51).

Andrews et al. (2006, 271) demonstrated that orphaned children are significantly more vulnerable than non-orphaned children in a variety of ways. Orphans are more likely to live in female headed households, to live in impoverished households, and to have limited or no access to proper nutrition, health services, education, and social services. In addition, a Zimbabwean study of teenagers showed that orphans were more vulnerable to sexually transmitted infections, HIV, and teenage pregnancy than their non-orphaned peers (Gregson et al 2005, 792). Because orphaned children are so vulnerable, they have a great need for protection and security.

Medical Care

Medical care is essential for HIV positive children. Without medical care, the life expectancy of children born with HIV is very low. About 25% of HIV positive infants will succumb to AIDS related illnesses and die before their first birthday. More than 50% of children born with HIV will develop AIDS and die before their second birthday. Without medication, only a minority of these children will live to celebrate their fifth birthday (Baltazar et al 1996, 22).

Psychological Support

In addition to physical challenges, HIV positive orphans also face great psychological challenges. However, care and support for such children has tended to focus on their material rather than social or psychological needs (UNICEF 2005, 16). Studies show that HIV-infected children have high rates of ADHD, anxiety, and depression (Scharko 2006, 442). As medical advances are making it possible for HIV positive children to survive into teenage years, they also must deal with the implications of their illness. At some point, a child must be given an appropriate understanding of HIV so that they can make good choices regarding sexual activity and planning for the future. As the child comes to terms with his or her terminal illness, it is important for that child to have social support and open communication. HIV positive children will most likely deal with complex emotions including loneliness, guilt, fear, confusion, anger, and depression. These children need support in order to handle the psychological distress that will accompany their illness (Domek 2006, 1367-1368).

A Zimbabwean study of psychosocial support for youth found that orphans have lower levels of psychosocial well-being than non-orphaned youth. Orphans had little access to supportive adults with whom they could discuss problems, greater levels of stress, and less social support as compared to their non-orphaned peers. Orphans were also more likely to report feeling worried, overwhelmed, irritable, and alone in the world (Gilborn et al. 2006, 24-25). Having adult support and guidance is especially imperative in adolescent years, when children begin to make important decisions that can have life-threatening consequences (Jareg 2005, 43).

Support to Deal with Loss

HIV positive orphans also require psychological support to deal with the multiple losses they have experienced. The greatest loss that HIV positive orphans face is the loss of their parents. Along with such a loss comes not only a loss of parental love and attention, but also a loss of physical and social security (Blair et al. 1996, 46). Orphaned children suffer many psychological effects as a result of losing their parents. They often suffer from depression, guilt, and fear, which may eventually develop into mental health problems that can remain into adulthood (Foster 2006, 700). Many orphans also suffer from low self esteem and self pity. Especially in cultures where outward grieving is not acceptable, children often grieve secretly and may have socialization problems as a result (Blair et al. 1996, 59). A case study in Uganda showed that orphaned children tended to be sad, quiet, and kept to themselves when compared to non-orphaned children (World Vision 2005). In addition, orphaned children are often forced to take on many household and economic responsibilities following the death of their parents (Marcus 1999, 18).

Loss of parents can be very confusing and distressing to young children who do not have an accurate understanding of death. Because most HIV positive children do not live very long, most of the children are very young when they lose their parents. They often cannot understand the finality and irreversibility of death. Young children tend to have magical thinking and may even believe that their words or actions caused the death in some way (Webb 2002, 4-5).

In addition to the loss of their parents, HIV positive orphans face many other significant losses. Following the death of their parents, children are often removed from their home to live with relatives or in a residential home. Therefore, they suffer loss of home, community, friends, security and familiarity. Because of the nature of HIV, many children also suffer from the death of several loved ones. They may lose not only their mom and dad, but siblings as well. HIV positive children also experience the loss of their own health and must face the challenges of understanding their own illness and facing their own death. It is essential that HIV positive children receive psychological support in order to deal with these issues of death and loss.

Support to Deal with Stigma and Discrimination

Stigma and resultant discrimination is one of the biggest and most psychologically damaging challenges that HIV positive children face apart from the loss of their parents. AIDS is still highly stigmatized in most African communities, and children often experience discrimination from relatives, orphanages, schools, peers, and community members (Smart 2000, 24). A study in rural Zimbabwe showed that 40% of the respondents would not permit their child to play with a child who is HIV positive

(Howard et al. 2006, 6). Ministries serving HIV positive orphans must have a way to address stigma and its negative affects on the children.

Meeting the Needs: the Ongoing Discussion

There has been an ongoing discussion concerning the best way to meet the needs of orphaned children. Residential homes have often been built in order to care for orphans when competent or willing relatives were not available. However, many Western countries have already moved away from residential care over the past century in favor of foster care. One factor in this shift was Freud's psychological research which demonstrated the importance of the parent-child relationship, especially in a child's early years. Consequent studies demonstrated that maternal deprivation and residential care could have a negative impact on a young child's physical and emotional development. As a result, Western countries adopted a foster care system, where children were placed with relatives or non-related families rather than being placed in institutions (Lewis 1964, 34). A recent study demonstrated that a similar shift is occurring in Europe and Eurasia as organizations are attempting to adopt family-focused, community care models in place of the government run institutions that have existed for decades (Davis 2006, 5).

Despite the shift that has occurred in the West, there are still many residential homes for orphans in sub-Saharan Africa. Many organizations and individuals are advocating a worldwide shift from residential care to community based approaches. Although many people concede that residential care is necessary in some cases, other organizations do not think residential care is appropriate in any circumstance.

For example, the International HIV/AIDS Alliance argues that residential care is inappropriate in any situation. They think that residential care should not even be considered as a last resort because it will allow institutions to remain which will continue to attract resources and children. Instead, they promote an exclusively community based approach to caring for orphans. This organization suggests that no new residential care facilities should be built, and existing ones should stop expanding their facilities (http://www.ovcsupport.net/sw3336.asp).

What is Community Based Care?

The major idea behind community based care is for the child to be able to remain with his or her own extended family members, and to remain in his or her own community (Tolfree 2003, 10). An estimated 90% of orphans in sub-Saharan Africa live with relatives. This arrangement is culturally accepted and it is often assumed that the community will also offer support for the orphaned child. However, the reality is that communities often provide little or no support, and the family must carry the full burden of raising additional children (Miller et al. 2006, 1429).

Unfortunately, many families encounter incredible financial difficulties from taking in orphaned children. A study in Botswana examined the financial difficulties of households caring for orphans where at least one adult in the household was working. The results demonstrated that nearly half of working households struggled to obtain enough resources to provide even basic necessities for the orphans. Some of the most common challenges that these households faced were caring for multiple orphans and receiving no outside assistance from the community or NGOs. Only 2% of working

households received any help from friends or community members, and less than 1% received any type of support from community volunteers (Ibid., 1429, 1431).

Because caring for orphans causes great financial strain on families, community based approaches seek to support families who are caring for orphans with financial or material assistance. According to Russell and Schneider (2000, 4), there are four major arrangements in South Africa for community based care. The first arrangement is for the child to live with a relative, who is most often a grandmother. The organization provides support or assistance to the caregiver of the orphaned child. The second arrangement is for an organization to help support a sibling over the age of 15 who has assumed primary responsibility for the younger siblings. A third arrangement is a cluster foster care model, where a woman is hired to care for six orphans. She raises the children in a home provided by the organization, and receives foster care grants to pay for school fees. Finally, the fourth arrangement is foster care by older women. In this arrangement, older women in the community are placed in the homes of orphaned children to be their primary caregivers.

The support given to such families by community based organizations varies greatly from one organization to the next and includes many different aspects of support. For example, an organization may provide a family with material support, micro-enterprise loans, vocational training, or finances to set up work cooperatives. In order to encourage child development and allow parents to work, organizations may also provide a day care center for the orphaned children. They may build facilities to provide cultural, educational, recreational, and social opportunities. In an attempt to educate children, reduce unwanted pregnancies, and prevent HIV transmission, organizations

may also provide sexual health education programs. Many organizations provide advocacy and legal support for families with orphans. These organizations seek not only to empower families, but to empower entire communities. To achieve that objective, they also may provide community awareness programs and education. Finally, they may provide material support to special needs families, such as single mothers or families raising a disabled child (Tolfree 2003, 10).

Strengths of Community Based Programs

Community based care is beneficial because it enables orphans to continue to be cared for by familiar adults while staying in their own communities. This arrangement provides children with a sense of identity and belonging. In addition, the children benefit from the continuous support of different networks that exist in their own communities (Tolfree 2003, 14). According to UNICEF (2003, 38), "Extended family relationships are the first and most vital source of support for households affected by HIV/AIDS, including those with orphaned children." According to Tolfree (2003, 14), community based programs are more likely than residential care to support the developmental needs of children and to equip them to live independently once they reach adulthood.

A study of elderly caregivers in rural Kenya found that many elderly caregivers derive a sense of satisfaction from caring for orphans or ill children. These caregivers are determined to provide care for their grandchildren in order to continue their lineage. The major challenges that these caregivers face are poverty, poor health, and lack of access to health care (Juma et al. 2004, 2-4). As one elderly caregiver in the study commented, "Our hearts are willing but we are incapacitated due to a lack of resources," (Ibid., 4).

Community based care can help such caregivers attain the resources that are needed to raise their orphaned grandchildren. Therefore, community based care can empower willing relatives to assume the role of caregivers, enabling children to remain in their families and communities.

In addition, community based programs are often much less expensive than residential programs. As a result, the community based programs are more sustainable and can impact more children. For example, a study done by the World Bank in Tanzania found that community based care was six times less expensive as compared to residential care. Other studies have reported similar findings, and some studies even estimate community based care to be twenty or even one hundred times less expensive than residential care (UNICEF 2003, 38).

Challenges of Community Based Programs

Although many people insist that the best place for orphans is with relatives, it is becoming harder to find relatives that are healthy and willing to take care of orphaned children. As a Kenyan widow in her fifties said, "In the past, people used to care for the orphans and loved them, but these days they are so many, and many people have died who could have assisted them, and therefore orphanhood is a common phenomenon, not strange. The few who are alive cannot support them," (UNICEF 2003, 2). Many orphaned children end up being raised by their elderly grandparents. A study in South Africa showed that 39% of orphans were living with grandparents (Vermaak et al. 2004, 2). Another study in South Africa showed that these elderly caregivers have their own health problems including arthritis, high blood pressure, diabetes, and vision, hearing,

and mobility problems. These health issues can make care giving extremely challenging. The grandparents are also dealing with the emotional stress and grief of losing their children (Reddy, P. et al 2005, 5). The burden on elderly caregivers is even more when the child is HIV positive, requiring even more care, attention, and resources.

Although many African societies have a cultural value of mutual community assistance, this community assistance is diminishing as more and more families are becoming affected by HIV/AIDS (Schachinger 2005, 12). Pervasive illness, endless funerals, and economic and social strains felt by the majority of households have resulted in a limited capacity for community response (Marcus 1999, 60). In many cases, guardians who take on the responsibility of caring for orphans may even be HIV positive themselves. In a Ugandan study, researchers found that one-third of the guardians of orphans were HIV positive (Gilborn et al 2000, 1). Another Ugandan study showed that 21.5% of households in a rural area had at least one adult who was infected with HIV (Nalugoda et al 2004, 112). These statistics demonstrate that AIDS is not only producing many orphans but is also reducing the number of potential caregivers.

Abuse and exploitation are very common in foster families. Orphaned children often eat less than other family members, and can be forced to work in the house or outside of the house to earn extra money (Blair et al. 1996, 51). In fact, many people living with AIDS have great fears about their children being raised by relatives. They fear that their children will be turned into "slaves," that they will not be given enough food, and that they will not be allowed to continue with school (Russel and Schneider 2000, 22).

A study in Mozambique confirmed that orphans often face discrimination when they are raised by relatives. This study found significant discrimination against orphaned children in poor households in that they received a smaller allocation of household resources than the caregiver's biological children. The researchers discovered that this discrimination was more significant for children below ten years of age in rural households, and more significant for children between 11 and 15 years of age in urban households (Nhate et al 2005, 1, 13).

Other caregivers may simply refuse to care for orphans. Studies have shown that in some communities, extended families are more reluctant to take in orphans whose parents have died from AIDS than those who have been orphaned by other causes (UNICEF 2003, 21). Another challenge with locating caregivers is that the nature of the family is changing rapidly in many parts of Africa. Due to modernization, labor migration, and the extension of cash economies, ties within extended families have been weakened or broken. Especially in urban areas, many Africans live in nuclear family units without strong connections to extended family members. This dynamic can make it very difficult to find and identify relatives who are willing to care for orphans (Ibid.).

Some programs are attempting to place orphans into foster families with caregivers who are not related to the children. However, in some cultures, it is neither common nor accepted for children to be raised by strangers. In other cultures, unrelated children may be accepted but in exchange for some kind of labor. Other cultures promote discrimination and exploitation by condoning less favorable treatment for foster children (Tolfree 2003, 11-12). In addition, foster children are at a heightened risk of abuse.

Even in Western countries, where foster care arrangements are typical and culturally accepted, it is well known that foster children have an elevated risk of abuse (Ibid.).

Even if community based programs identify competent caretakers for orphans, there are other challenges to overcome. Many community based programs are dependant on community volunteers, who can be difficult to recruit and retain. Generating resources for the program and maximizing the community's own resources are constant struggles. In addition, the programs constantly struggle to manage the growing numbers of orphaned children, which often exhausts family and community resources (Russel and Schneider 2000, 4).

Another limitation is the poverty within the communities. Even if the community members are willing to assist the orphans, they may lack the necessary resources or skills to be effective. Many of these communities are limited in the extent to which they can be 'self-reliant' without the help of outside assistance (Ibid., 17). A study in rural Zimbabwe showed that 98% of people would be willing to foster orphans, but poverty prevented them from doing so (Howard et al. 2006, 1). Therefore, if financial assistance could be available to foster families, more people would be willing to take care of orphans.

What is Residential Care?

According to Miles and Stephenson (2001, 9), residential care can be defined as "A group living arrangement for children in which care is remunerated by adults who would not be regarded as traditional carers within the wider society." In simpler terms, residential care can be defined as a group of children who are not related and are cared

for by adults who are not their biological parents (Ibid.). Alternative terms to describe residential care are children's homes and orphanages.

The size of residential homes varies considerably. A residential home may contain less than ten children, or it may contain up to hundreds or even thousands of children. The quality of care in residential homes also varies considerably. While there are some residential homes which make the rights and well being of the children a top priority, other residential homes ignore the rights of the children and may even directly abuse them, significantly decreasing their quality of life (Dunn et al. 2002, 3).

There are many different situations where children may be placed in residential homes. For example, some types of children in residential care are disabled children, street children, orphaned children, children whose parents are in prison, and children with socially unacceptable behavior. In some cases, residential homes also accept children whose parents feel that they are not able to provide for them adequately due to poverty (Miles and Stephenson 2001, 10-11)

Strengths of Residential Care

While there are very few experts who would suggest that residential care is the best option for all orphaned children, most people recognize that in some cases, it is the preferable or only option (Tolfree 2003, 15). Because exploitation, abuse, and neglect are common when children are raised by non-parental relatives (UNICEF/ISS 2004, 4), residential care may be the best way to protect children from abuse. In cases where children come from an abusive or destructive family environment, they may experience psychological and even physical trauma as a result. It such cases, it may be in the best

interest of the children to remove them from their families and place them into residential care (Miles and Stephenson 2001, 8-9).

In some cases, relatives are not able to handle the burden of caring for an HIV positive child because of poverty, lack of access to healthcare, or illness among the caregivers. In communities that are highly affected by HIV/AIDS, there simply are not enough caregivers or resources to handle the increasing numbers of orphaned children (UNICEF/ISS 2004, 3). A community which has been greatly affected by poverty in addition to HIV/AIDS may not have the capacity to care for HIV positive children. Commenting on the fact that community based care is often promoted as the best option for orphaned children, Marcus (1999, 62) observes:

> In reality, this (community based care) may neither be possible nor preferred, given that the welfare of children raised in a community greatly depends on the socio-economic welfare of the whole community. The more general well-being has been compromised by AIDS, the less well are children likely to fare.

Challenges of Residential Care

There has been a lot of criticism of residential care in recent literature, and almost all of the literature suggests that community based care is the preferable option of care for orphaned children. Many of the challenges faced by orphaned children in residential care are unique to residential care; however, some of the challenges faced by children in residential care are also faced by orphaned children in community based care programs. Some of these problems can be limited or reduced in residential care through proper guidelines and monitoring.

Residential care tends to segregate children from others in their families and communities. Oftentimes, when children enter residential homes, they lose contact not only with their families but also with their sociocultural background (Dunn et al. 2002, 9) Segregation from the surrounding community may result in discrimination and stigma against the orphaned children, which can lead to a decrease in their self esteem (Tolfree 2003, 9).

Although children in residential homes often face stigma and discrimination, the problem of stigma and discrimination is not limited to residential care. Many HIV positive orphans who are not in residential care also face significant stigma and discrimination from their extended family members, peers, schools, and community members (Smart 2000, 24). Due to stigma against those affected by HIV/AIDS, orphaned children taken in by extended family members are at risk for poorer treatment than non-orphaned children in the household. In addition, they are often less fully integrated into the family and household than non-orphaned children (UNICEF/ISS 2004, 4).

The decision to place a child in residential care is often driven by the desires of the relatives, rather than a concern for the best interest of the child. As a result, the child may experience feelings of abandonment or rejection by his or her family. Although some relatives may visit the child, these visits tend to become less frequent over time. Lack of interaction and connection with family may cause a child to experience a loss of identity. Children in a residential home often have little sense of connection or belonging to their family or community, and they have few if any familial support networks (Tolfree 2003, 9).

Another challenge is that residential care often does not provide orphaned children with enough individual care, attention, and affection. As a result, children in residential care do not have many opportunities for attachment and continuous relationships with parental figures. As one child who grew up in residential care explained, "We never had any affection; we had all the material things-a bed, food, clothing-but we never had love," (Ibid.). However, there are exceptions, and some residential homes do provide the children with adequate attention, affection, and significant adult relationship. These exceptions tend to be smaller residential homes that have a commitment to foster unconditional relationships between every child and at least one adult (Miles and Stephenson 2001, 12).

It is not only children in residential homes that face these challenges; orphaned children living with relatives may also be denied appropriate attention and affection. The average dependency ratio in families caring for orphaned children is 1:8 as opposed to 1:5 for families who are not caring for orphans. This dependency ratio means that in households with orphans, there is one member of the family aged 18-59 years old for every 8 members of the family below 18 or above 60 years of age. In families who are not caring for orphans, there is one member of the family aged 18-59 for every five members of the family. This high dependency ratio for families caring for orphans results in less time for the caregivers to spend with each child and less attention and affection given to each child (UNICEF/ISS 2004, 3).

Residential homes often have high staff to child ratios as well as high staff turnover rates. These factors result in a lack of stable and supportive adult relationships, which can have a negative impact on the mental and physical development of young

children. These factors can also make it very difficult for children raised in residential homes to form meaningful and long lasting relationships (UNICEF 2006, 18).

A study done in the United States confirmed these findings. This study compared nineteen primary school aged children who were living in a residential home to nineteen primary school aged children who were living with a foster family. The researchers discovered that one fifth of the children living in residential care demonstrated a significant lack of selective attachment relationships with caregivers. One fifth of the children living in residential care also demonstrated a lack of selectivity in peer friendships. None of the children living in foster families demonstrated either of those traits (Roy et al. 2004, 866).

In an earlier study of children between the ages of 5 and 8, the same researchers discovered that children who were being raised in a residential home had higher levels of emotional and behavioral difficulties than other children. The most common problems were inattention and overactivity (Roy et al. 2000). This study confirmed the results of a previous study which also demonstrated that children who had spent their early years in a residential home had problems with overactivity and inattention (Hodges and Tizard 1989.)

Another challenge of residential care is that children may not have an opportunity to learn about the roles and functions of adult members of their society. This lack of knowledge and experience can make it very difficult for a child to make the transition from the residential home to the community as an adult. In addition, in some residential homes, children may have little or no interaction with children and adults from outside of the residential home (Tolfree 2003, 9). According to Save the Children fieldworkers,

many children who are currently living in residential homes or who had previously lived in residential homes reported that they were deprived of the life skills they would have learned growing up in a family. Their lack of life skills made it harder for them to cope with life outside of the home (Dunn et al. 2002, 9).

A study of Russian orphans who had been raised in a government residential home found that their greatest challenge was inclusion into society. Many of these orphans encountered difficulties in their careers, marriages, and in establishing friendships and professional relationships. The researcher in this Russian study discovered that some of these difficulties are not only related to the orphan's own experiences, but also to the society's perception of orphans. There were strong negative stereotypes that many people attached to orphans, making it difficult for them to be accepted by the society (Kuznetsova 2005, 20,29).

Child abuse is a common but often hidden reality in some residential homes, which can be devastating to the development and well being of a child (Ibid.). Some evidence suggests that children in residential care may have more difficulties in reporting abuse, escaping from the abusive situation, and getting help from outside of the home (Dunn et al. 2002, 9). However, abuse is not something that is limited to orphans in residential care; exploitation, abuse, and neglect are also common for orphaned children who are raised by extended family members (UNICEF/ISS 2004, 4).

In a Ugandan study, orphans who were being raised by relatives reported abuse from both the caregivers as well as abuse from the caregiver's biological children. The orphans attributed the caregiver's abuse to their anger and frustration with the increased burden of caring for additional children with extremely limited resources. The orphans

attributed the abuse from the other children to anger and jealousy as a result of sharing their parent's attention (World Vision 2005). Because abuse is so common in orphans raised by relatives, with the proper guidelines and monitoring, a residential home can offer security and protection to a child who has been abused or threatened by relatives.

Summary

Regardless of whether HIV positive orphans are placed in residential homes or with relatives, they are very vulnerable and have many challenges in getting their needs met. The basic needs that should be addressed by any program are shelter, caregivers, basic necessities, education, medical care, security, psychological support, and support against stigma and discrimination. In this study, a significant amount of literature has been reviewed about the strengths and weaknesses of both community based care and residential care. Almost all of the literature favors community based care over residential care. However, the majority of the research, as well as the majority of programs, focuses almost exclusively on orphaned children who are not HIV positive. HIV positive orphans require more effort and resources in order to meet their needs. This research will focus on the strengths and weakness of both community based care and residential care specifically for HIV positive orphans, which is not covered in the current literature.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

Research Design

This research is a qualitative study concerning the strengths and challenges of both a community based program and a residential program for HIV positive orphans. According to Creswell (1994, 1-2), a qualitative study is "an inquiry process of understanding a social or human problem, based on building a complex, holistic picture, formed with words, reporting detailed views of informants, and conducted in a natural setting." There are many reasons why a researcher would choose to do a qualitative study. Qualitative research is often chosen when an area of study is immature due to lack of prior research (Ibid., 146). In addition, qualitative research is chosen when the researcher is seeking to understand people's experiences (Patton 2002, 33). Therefore, the researcher chose a qualitative research design because she was not able to find any previous studies that focused on HIV positive orphans. Additionally, the researcher was seeking to understand the experiences of the caregivers and staff members in meeting the needs of HIV positive orphans. Therefore, a qualitative approach was most appropriate for this research.

The major methodology used was ethnographic interview. An ethnographic interview can be compared to a friendly conversation, where the interviewer engages in conversation with the informants in order to learn from them and to attempt to understand

their viewpoints (Spradley 1979, 58). The researcher chose to use ethnographic interviews in order to hear about the experiences of the informants in their own voices. Two questionnaires were also used in order to obtain some background information about each of the programs studied. The research design included developing a questionnaire for the directors of each program, developing interview questions for ethnographic interviews, selecting the study sample, collecting data, and analyzing the data collected.

Research Approach

In this study, data was collected by two means; a questionnaire and ethnographic interviews. A questionnaire was given to the assistant manager of Lea Toto and the directors of Grace Children's Center in order to obtain general information about each program and the children involved in the program. Each questionnaire was accompanied by an ethnographic interview. The interview questions for the assistant manager of Lea Toto were designed to be parallel to the ethnographic questions for the directors of GCC. Ethnographic interviews were also done with five secondary caregivers from each project. For the Lea Toto caregivers, background questions were asked in order to understand the composition of their households. The main interview questions for each set of caregivers were designed so that the questions for the Lea Toto caregivers would be parallel to the questions for the GCC caregivers. All of the interviews were conducted by the researcher.

The Researcher's Role

As Creswell (1994, 163) explains, "The role of the researcher as the primary data collection instrument necessitates the identification of personal values, assumptions, and biases at the outset of the study." The researcher's perception of care for HIV positive orphans has been shaped by her personal experiences. The researcher assisted a couple who were beginning a home for orphaned and abandoned infants in Johannesburg, South Africa from September 2003 to April 2004. The researcher also worked at a community based program for women and children affected by HIV/AIDS in a slum area in Nairobi, Kenya from January to September 2005. The researcher has visited and volunteered at several community based and residential programs in Johannesburg and Nairobi from 2003 to the present. Finally, the researcher has had a personal relationship with the children and staff at GCC on a non-professional basis since January 2005.

The researcher's experience with different programs enhances her awareness, sensitivity, and knowledge regarding the strengths and challenges of both models of care. The researcher has had both positive and negative experiences with both models of care. Based on her experiences, the researcher began this study with an appreciation for both models of care and an understanding that both models can be effective in providing care for HIV positive orphans.

Ethical Considerations

In ethnographic research, the researcher has a responsibility to safeguard the rights, interests, and sensitivities of the informants (Spradley 1979, 36). Before each interview, the researcher described the nature and the purpose of the research to all of the

interviewees. Then each interviewee was asked if he or she would be willing to participate in the interview, and if he/she would be willing to have his/her interview recorded. All of the interviewees were willing participants; none of them were forced or given any kind of monetary reward. All of the informants willingly agreed to have their interview tape recorded. The names of the respondents have not been used in this report to protect their privacy and anonymity.

Population of the Study

The population of this study is the directors and secondary caregivers in the Lea Toto program and Grace Children's Center in Nairobi, Kenya. There is one director at Lea Toto, and two directors at GCC. Out of the 2000 children in the Lea Toto program, approximately 200 of them are orphans. Although the exact numbers were not available, it can be estimated that there are approximately 200 secondary caregivers in the program. The secondary caregivers at Lea Toto include both men and women. There are five house moms at GCC, and all of them are women.

Study Sample

For the study sample, five secondary caregivers were chosen from each program. Because there are only five full time house moms at GCC, the study sample could not exceed five caregivers from each program. The researcher chose the largest study sample possible in order to gather the widest variety of experiences. Three of the GCC house moms interviewed were daytime workers, who are at the home from 8am until 5pm. The

other two house moms interviewed were overnight house moms, who are at the home from 5pm until 8am the following morning. These five women were chosen for the study sample because they are the only full time house moms at GCC.

There were several elements taken into consideration in choosing the study sample from the Lea Toto program. Lea Toto has clinics in several different areas of Nairobi. The researcher wanted to get feedback from more than one program area. Due to time and financial limitations, the researcher was limited to visiting two of the program areas, Kangemi and Kibera. Three of the informants were from the Kangemi program, and two of the informants were from the Kibera program. Each day, several of the participants in each program visit the clinic. The study sample was selected based on the secondary caregivers who visited the clinic on the day that the researcher was there.

The directors of each program were also included in the study sample in order to understand the experiences of caring for HIV positive children from a managerial viewpoint. In addition, each director has years of experience in addressing the needs of HIV positive children and therefore has valuable insight into the strengths and challenges of the different models of care. Because the director of Lea Toto was not available to be interviewed, the assistant program manager was interviewed instead. Both of the directors of GCC were included in the study sample.

Entry

According to Patton, entry into a field of research involves negotiation with the gatekeepers about the nature of the research in order to gain permission to carry out the desired research (2002, 310). The researcher gained entry to GCC through the directors

of the program. The researcher has had a personal relationship with the directors, staff, and children at Grace Children's Center since 2005. To request permission to carry out research at GCC, the researcher sent an email to the directors explaining the purpose and background of the study. The directors responded positively and granted permission to the researcher to conduct the research at GCC.

To gain entry at Lea Toto, the researcher visited the Nyumbani offices in Karen and was given the contact information for the assistant program manager of Lea Toto. The researcher went to his office in Kangemi and presented to him a letter from the head of the missions department at NEGST describing the nature of the research. In addition, the researcher presented to him a cover letter, an explanation of the research project and design, and the interview questions. The researcher met with the assistant manager three times to explain and discuss the research design and procedures. Following these meetings, the assistant manager consulted with the director of the program, and they granted permission to the researcher to conduct the research at Lea Toto.

Pilot Testing

The researcher conducted a test of the ethnographic interviews with two secondary caregivers from the Lea Toto Kangemi program to ensure that the questions and the language were clear. Patton emphasizes the importance of clarity when he states, "The interviewer bears the responsibility to pose questions that make it clear to the interviewee what is asked...Unclear questions can make the person being interviewed feel uncomfortable, ignorant, confused, or hostile," (Ibid., 361). Following the test

interviews, the researcher was able to make necessary adjustments to enhance the clarity of the interview questions.

Collection of the Data

In order to collect data, interviews were conducted with the assistant manager of Lea Toto, the directors of Grace Children's Center, and five caregivers from each program. The questionnaires were completed during the interviews with the assistant manager and directors. All of the interviews were conducted by the researcher as one-on-one interviews, with the exception of the two directors of GCC, who were interviewed together. Four out of the five interviews with secondary caregivers at Lea Toto were conducted in Kiswahili, and a translator was used. The other interviews were conducted in English. A tape recorder was used to record all of the interviews, and the interviews were transcribed by the researcher.

Analyzing the Data

For data analysis, the researcher sought to answer the four research questions presented in chapter one. The method of data analysis was adapted from Creswell (1994) and Patton (2002). Creswell suggests coding the data as a primary step in data analysis. He says, "It is clear, however, that one forms categories of information and attaches codes to these categories. These categories and codes form the basis for the emerging story to be told by the qualitative researcher," (154). To begin the process of analysis,

the researcher went through the interview transcripts and questionnaires and coded

responses that addressed any of the following four categories:

- Strengths of Lea Toto

- Challenges of Lea Toto

- Strengths of GCC

- Challenges of GCC

Once the responses were organized into the above four categories, the researcher

performed a pattern, theme, and content analysis. This method of analysis involves

making sense of qualitative data by looking for themes, patterns, and concepts which

emerge from the data (Patton 2002, 452-453). The researcher examined the data in each

of the four categories and grouped the data into more specific categories according to the

nature of the strength or challenge being described. These specific categories were

derived from the strengths and challenges of both models of care which were discussed in

the literature review. Once the data had been divided into these specific categories, the

researcher looked for patterns and themes in the data by examining the frequency of

responses as well as agreement or disagreement among the respondents. Attention was

also given to whether the data collected for HIV positive orphans in this study was in

agreement with the strengths and challenges discussed in the literature review. The

findings of the data analysis are presented in chapter four.

Validity

In order to test the validity of the findings, the researcher e-mailed the findings

and conclusions to the assistant manager of Lea Toto and the directors of GCC to inquire

if their opinions and programs were accurately and fairly represented in the research findings and conclusions. The directors of GCC confirmed the accuracy of the findings via email. Their email stated, "A very accurate and balanced paper. We see no need for changes, additions, or omissions... Well done!" (12-4-07). This email is printed in Appendix C. Although the research made several attempts to contact the assistant manager of Lea Toto via phone and email, she was unsuccessful in following up with him.

Weaknesses

One weakness of this study is that the researcher did not have a personal relationship with the informants from the Lea Toto program. Therefore, the researcher was not able to develop the same level of rapport and trust as with the informants from GCC. This weakness was addressed by working with a social worker from the Lea Toto program who has a personal relationship with the caregivers interviewed.

A second weakness is that the caregivers for Lea Toto were interviewed on the program compound in the presence of a Lea Toto social worker. Since they are receiving benefits from the program, they may have been hesitant to mention any negative opinions for fear that it would affect their standing with the program. In the same way, the house moms from GCC were interviewed at their place of work. They may have also been hesitant to offer any negative opinions regarding GCC for fear of that it would affect their jobs. This weakness was addressed by trying to focus questions on their personal experiences in caring for the children rather than focusing the questions on the programs themselves.

A third weakness is that there was a language barrier for four of the interviews which were conducted in Kiswahili. This weakness was addressed by using translators; however, rather than translate word for word, the translators often summarized the responses of the interviewees. This summarization compromised the depth and richness of understanding the responses of the informants in their own words. A final weakness is that the researcher was not able to contact the Lea Toto program to validate the findings.

CHAPTER FOUR

RESEARCH FINDINGS

In this chapter, the data collected was analyzed in accordance with the researcher's four research questions. These questions are:

1. What strengths does the Lea Toto program have in its ability to meet the physical and psychological needs of the HIV positive orphans in its program?

2. What challenges does the Lea Toto program face in meeting the physical and psychological needs of the HIV positive orphans in their program?

3. What strengths does Grace Children's Center have in terms of its ability to meet the physical and psychological needs of the HIV positive orphans in their home?

4. What challenges does Grace Children's Center face in meeting the physical and psychological needs of the HIV positive orphans in their home?

In the following sections, a brief summary of the respondents will be given, and then the data will be analyzed in respect to each of the four research questions.

Respondents

There were thirteen respondents in total. A description of and general information about the respondents are provided in tables 1 and 2 below.

Table 1: Respondents from Grace Children's Center

Code	Title	Gender	Years in Program	Nationality
GCC1	Director/ Founder	Male	5*	American
GCC2	Director/ Founder	Female	5*	American
GCC3	Social worker/ House Mom	Female	4	Kenyan
GCC4	Daytime House Mom	Female	4	Kenyan
GCC5	Daytime House Mom	Female	1	Kenyan
GCC6	Night House Mom	Female	3	Kenyan
GCC7	Night House Mom	Female	1 ½	Kenyan

* the directors founded GCC in 1995 so they have been at GCC for 12 years. However, the 5 years in this table refers specifically to the HIV extensive home which was started in 2002.

As shown in Table 1 above, six out of the seven respondents from GCC are female and one is male. Both directors are American, and all five of the house moms are Kenyan. All of the house moms have been working at the home for at least one year, and the two house moms who have been there the longest have both been there for four years. In order to quote and refer to these respondents throughout this chapter, each respondent has been assigned a code number.

Table 2: Respondents from the Lea Toto program

Code	Title	Gender	Years in Program	Nationality
LT1	Assistant Program Manager	Male	2	Kenyan
LT2	Secondary Caregiver	Female	1	Kenyan
LT3	Secondary Caregiver	Female	4	Kenyan
LT4	Secondary Caregiver	Male	2	Kenyan
LT5	Secondary Caregiver	Female	2	Kenyan
LT6	Secondary Caregiver	Male	1	Kenyan

Table 2 summarizes the respondents from the Lea Toto program. Out of the five secondary caregivers interviewed, two are male and three are female. All six of the respondents are Kenyan. The majority of the respondents have been involved in the

program for one or two years, and the secondary caregiver who has been in the program the longest has been involved for four years. Each of the respondents from Lea Toto has been assigned a code number for reference throughout this chapter.

Data Analysis

As described in chapter three, the researcher went through the interview transcripts and coded the information based on the four research questions. Once the information had been coded, the researcher looked for patterns of agreement and disagreement, and grouped the data into further categories based on the specific strength or challenge being described by the informants, i.e. stigma, poverty, etc. These categories were chosen in light of the strengths and challenges discussed in the literature review. The researcher then examined the responses of the informants in order to determine the extent and the nature of the strength or challenge.

After performing this analysis, several strengths and challenges of each program emerged from the responses of the informants. The researcher also considered whether the strengths and challenges which emerged in this research were in agreement with the strengths and challenges of community based care and residential care discussed in the literature review. The strengths and challenges that emerged from each program are described in detail in the following sections.

Research Question 1: Strengths of Lea Toto

Empowering Willing Caregivers

One the greatest strengths of Lea Toto is that they are able to empower willing relatives to care for HIV positive orphans. As described in the literature review, the goal of programs that assist orphans should be to enable them to remain with familiar relatives whenever possible (Tolfree 2003, UNICEF 2003). Without assistance from Lea Toto, most of these caregivers would not be able to handle the burden of an HIV positive child. For example, one grandmother (LT2) said that in an average month, she earns only 2000 shillings (about $28). Medical costs alone for an HIV positive child can easily exceed 2000 shillings a month. However, because she receives medical, food, and educational assistance from Lea Toto, she is able to care for her grandson despite her small income. The different types of assistance that the caregivers receive from Lea Toto are shown in table 3.

Table 3: Types of assistance provided to the secondary caregivers in Lea Toto

Type of assistance given	Number of secondary caregivers interviewed who receive that type of assistance	Percentage of caregivers interviewed who receive that type of assistance
General medical assistance	5	100%
Antiretroviral drugs	5	100%
Food support	4	80%
Educational support	4	80%

As demonstrated in this table, 100% of the caregivers interviewed are receiving medical assistance and antiretroviral drugs, and 80% of those interviewed are also receiving food support and educational support. This support empowers the caregivers to address the needs of the HIV positive orphans.

Because of the frequency of illness with HIV positive children, medical costs alone can easily overwhelm a family which is already struggling financially. By providing full medical care for these children, Lea Toto is able to remove a significant burden for the secondary caregivers. In addition, the caregivers are able to access antiretroviral drugs, which would otherwise be too expensive for them to afford.

In order to assess the importance that the caregivers place on each of the different types of assistance provided, all of the caregivers were asked what the greatest benefits of the Lea Toto program are. Their responses are summarized in the following table.

Table 4: Assistance that caregivers viewed as the greatest benefits of the Lea Toto Program (each respondent listed more than one)

Type of assistance given	Number of caregivers interviewed who identified that type of assistance as a great benefit	Percentage of caregivers interviewed who identified that type of assistance as a great benefit
General medical assistance	4	80%
Antiretroviral drugs	4	80%
Food support	4	80%
Educational support	1	20%
Training	1	20%

It is evident that medical assistance is very important to the caregivers. 80% of the caregivers listed medical care and antiretroviral drugs as some of the greatest benefits that they have received from Lea Toto. In addition, three of the caregivers noted a very significant improvement in the child's health since starting ARVs. One caregiver (LT4) explained, "Since he [the HIV positive child] starting taking ARVs, I can say that he has improved a lot. He has added a lot of weight. So many symptoms which were there before, now I don't see them."

Food and educational support from Lea Toto also helps to ease the burden on the secondary caregiver. Table 4 shows that all four caregivers who are receiving food support listed food support as one of the greatest benefits of the program. The educational support from Lea Toto also ensures that all of the children in the program will have access to education. One grandmother (LT5) listed the educational support as one of the greatest benefits of the program. Because Lea Toto is assisting her with school fees, she was just recently able to send her 8 year old grandson to begin nursery school.

Caregivers are Familiar Adults

Table 5: Relationship of Secondary Caregivers to the orphaned children in Lea Toto

Secondary Caregivers	Relationship to HIV positive child	Number of child's siblings also cared for by this caregiver
LT2	Grandmother	0
LT3	Aunt	1
LT4	Uncle	0
LT5	Grandmother	1
LT6	Uncle	0

As demonstrated in table 5, all five of the orphans are being cared for by familiar relatives; two caregivers are grandmothers, two are uncles, and one is an aunt. Two of the caregivers are also caring for siblings of the HIV positive child. Therefore, the children are being raised by members of their own family, giving them a sense of family, tribal, and community identity.

Impact Extends to the Entire Community

Because Lea Toto works with the entire community, they are able to educate and empower the entire community. They not only cater for the needs of the children, but they also run trainings and educational programs for the community. When asked about

the strengths of community based programs, the assistant manager of Lea Toto (LT1) responded, "When you involve the entire community and identify other stakeholders who should be in the service delivery system, you enhance the capacity of the community." He explained that Lea Toto engages the entire family by teaching them about HIV and how to care for an HIV positive child. By giving them proper knowledge and training in these areas, they hope to generate love towards the child rather than discrimination.

As shown in table 4, one of the caregivers (LT5) listed the trainings as one of the greatest benefits he has received from Lea Toto. He said that he has attended five different trainings focused on issues such as general information about HIV/AIDS and caring for adults and children affected with AIDS. He explained that he is very knowledgeable about HIV/AIDS and is open with his neighbors about the HIV status of the child. By training this caregiver, Lea Toto has empowered him to educate his neighbors and others in the community.

Capacity to Combat Stigma

Stigma against HIV positive children and their families was one of the challenges of community based care identified in the literature review (Nhate et al. 2005, Smart 2004, UNICEF/ISS 2004). Although Lea Toto has faced challenges with HIV/AIDS stigma, they have been able to overcome stigma in the community to a significant degree. Therefore, one of the strengths of Lea Toto is its capacity to address the issue of stigma in the community.

The assistant manager (LT1) identified combating stigma as one of the greatest achievements of the Lea Toto program. In the early years of the program, stigma was one of the biggest challenges to overcome. He explained that in the first years of the

program, "they [those in the program] could not be very comfortable for the neighbors to see a social worker entering their homes because they know these social workers are from Lea Toto and Lea Toto caters for HIV positive children. They did not even want to hear our program vehicle which normally goes to the field to come to their house."

In order to combat stigma, Lea Toto launched a massive educational campaign to educate the communities about HIV/AIDS in all the program areas. They also provided trainings for community members and caregivers in order to combat ignorance about HIV/AIDS. The assistant manager (LT1) described the impact of this educational campaign on the community by explaining, "But nowadays, because of that massive educational campaign, people are not afraid to get associated with the program; they are not afraid to send their children to the program."

In order to assess the secondary caregivers' experiences with stigma, each of them was asked about how the community treats the HIV positive child and whether they had experienced stigma or discrimination. The following table summarizes the caregivers' assessments of the level of stigma against the HIV positive child in their communities.

Table 6: Levels of stigma as reported by the secondary caregivers in Lea Toto

Level of stigma reported	Number of caregivers interviewed who reported that level of stigma	Percentage of caregivers interviewed who reported that level of stigma
No stigma at all against the child	3	60%
Some indirect talk/gossip but no direct discrimination against the child	1	20%
Direct stigma and discrimination against the child	1	20%

Based on the interviews with the secondary caregivers, Lea Toto has been fairly successful in combating stigma. Three of the caregivers reported no stigma or discrimination at all against the child. One caregiver (LT6), who is very open with his neighbors about the status of the child, said, "I wanted it (the HIV status of the child) to be something open so that people can see that although you are positive, you can still survive and be like any other normal person."

One of the caregivers (LT4) reported that there is some talk in his neighborhood regarding the HIV status of the child. However, this talk is limited to the rumor mill, and nobody has said anything to him or the child directly. In addition, he has not experienced any direct confrontation, and the other children play with the child and treat him like a normal child. He explained, "He's just a normal kid in a normal society."

There was only one caregiver (LT2) who reported direct stigma and discrimination against her HIV positive grandson. She explained that some of the adults in her community will not allow their children to play with her grandson because he is HIV positive. She has tried to explain that children cannot get infected just by playing, but it still brings her many problems. Therefore, although Lea Toto has been successful in addressing the issue of stigma, there is still some stigma remaining.

Research Question 2: Challenges of Lea Toto

Poverty

One of the biggest challenges for Lea Toto is overcoming the poverty in the community. Table 7 summarizes the composition of the caregivers' households.

Table 7: Composition of households of secondary caregivers in Lea Toto

	Caregiver's marital status	Number of people in household	Number of children in household	How family is supported	Number of wage earners in household
LT2	Single	3	1	Casual work	1
LT3	Single	9	7	Casual work	2
LT4	Married	6	4	Dairy cows	1
LT5	Widow	5	4	Casual work	1
LT6	Widower	5	3	Casual work	2

In the respondents' households, the average number of people per household is 5.6. In 4 out of 5 households, the secondary caregiver is either single or has lost his/her spouse. In 3 out of the 5 households, the secondary caregiver is the only one providing an income for the entire household. In the other two households, there is one other adult who is also bringing in some income. However, out of the 5 households, only one caregiver (LT4) has a steady income. The other four caregivers are dependant on casual work to provide an income for their families. All four of the secondary caregivers who are dependant on casual work identified money as a major challenge in caring for an HIV positive child.

For example, one respondent (LT3) is a single woman who lives with her sister and seven children, including two orphans. She and her sister both try to find casual work, but paying rent and caring for seven children is a major challenge. She said that one of the biggest challenges of caring for an HIV positive child is that when the child falls sick, she must stay home to care for him and is unable to look for work. Therefore, caring for an HIV positive child increases her challenge of providing for the household.

Another respondent (LT6), a widower, commented that it is very challenging for him to provide the child with a balanced diet. He said that he knows a balanced diet is important for the child, especially since the child is taking ARVs. However, he does not

have a steady income, and therefore he admitted that he cannot always afford to provide a balanced diet for the child.

The assistant manager of Lea Toto (LT1) also described the poverty in the community as one of the challenges that Lea Toto is facing. He said, "When you consider the level of livelihoods of these beneficiaries, many of them come from the slum area where there is a lot of unemployment and lack of family businesses to sustain them. The level of poverty is extremely high." He explained that Lea Toto is currently attempting to overcome this challenge by developing a micro-finance program to equip caregivers with business skills and income generating activities. However, this program is still in the beginning stages and many caregivers have not yet benefited from it. The assistant manager commented, "…even though we are trying to set up micro-finance program to equip [caregivers] with business skills and create IGAs [income generating activities], we have not been able to encompass everyone."

Regulating ARVs

In order to maximize the effectiveness of ARVs, the drugs must be taken faithfully and consistently. The assistant manager of Lea Toto (LT1) identified compliance to the treatment as one of the challenges in community based programs. He explained that the caregivers are the ones who must give the drugs to the children and ensure that the drugs are given at the right time and in the right dosage. He said that this can be a challenge because, "Across the program at times we might hear a caregiver telling you I forget yesterday evening to give that dose to my child. So if there is no constant link between the program and caregiver, the effectiveness of the drugs might be compromised." In response to this challenge, the assistant manager said that Lea Toto

social workers make regular home visits to the families. In addition, they liaise with caregivers to determine if they are having any problems with the medication.

Summary of Lea Toto's Strengths and Challenges

Based on the interviews with the assistant manager and secondary caregivers at Lea Toto, several strengths and challenges emerged from the data. The major strengths discussed and identified by the respondents were the ability to empower willing relatives to care for HIV positive orphans, to enable the orphans to be raised by familiar relatives, to impact the entire community, and to have the capacity to combat stigma against HIV positive children in the community. The major challenges of Lea Toto discussed and identified by the respondents were overcoming the poverty of the caregivers and ensuring that the antiretroviral drugs are administered correctly.

Research Question 3: Strengths of Grace Children's Center

Providing Care for Abused or Neglected Children

One of the strengths of residential care identified in the literature review is that it is able to provide care for children who have no known relatives or who have been neglected, threatened, or abused by relatives (Tolfree 2005, UNICEF/ISS 2004, Marcus 1999). Based on the interviews in this study, this strength is one that is demonstrated by GCC. According to the directors (GCC1, GCC2), at least half of the nineteen children at GCC were abused, neglected, or threatened before they came to the home. Two of the girls in the home were infected with HIV through sexual abuse (the other seventeen

children were born with the virus). One of the house moms (GCC6) responded that one of the greatest benefits for the children at GCC is that they have protection from abuse.

During the interview with the directors, they illustrated this strength by giving the specific example of a six year old girl who was brought to the home by a social worker from a community based program. The program had been giving the grandfather a check each month to care for the child, but he was taking the money for himself and starving the child. Every time the social worker visited, the grandfather bundled the girl in many blankets so that the abuse was not evident. Once the social worker realized what was happening, she referred the girl to GCC. When the girl arrived, she was dangerously emaciated. The directors pointed out that this is an example of a child who was not able to receive adequate support from the community and benefited from residential care. Unfortunately, the girl was already very sick and in the advanced stages of AIDS when she arrived at GCC, and she passed away after eight months.

A Family Not an Institution

One of the challenges of residential care cited in the literature review is that it does not provide enough individual care, attention, and affection (Tolfree 2003, UNICEF 2006, Roy et al 2004). However, in this research it was discovered that this challenge is not a significant one for GCC. In fact, one of the strengths of the program is that there is a lot of affection between the children and the house moms in the home, and they function as a family rather than as an institution. The following table summarizes the frequency of some key words that the house moms used to describe the relationships in the home.

Table 8: Words used by house moms to describe the relationships in GCC

Words used	Number who used those words to describe the house mom/child relationship	Percentage who used those words to describe the house mom/child relationship	Number who used those words to describe the relationships among the children	Percentage who used those words to describe the relationships among the children
Love	4	80%	2	40%
Familial terms	2	40%	2	40%

When asked about how the children interact with the house moms, four out of five respondents used the word "love" to describe their relationship with the children. One house mom (GCC5) explained, "They love us so much and we love them." Two of the house moms also used familial terms in describing their relationship to the children; one described the house moms as aunties and the other described the house moms as mothers. Referring to herself as a mother to the children, one house mom (GCC7) explained, "We show them that we love them, and then they show you their love. You have to discipline them. You have to be their mother to show them that discipline."

When questioned about the children's interactions with each other, all of the house moms reported that the children get along well with each other. Two of the house moms used the word love in describing the relationship between the children. In addition, two of the house moms used familial terms in describing their relationships with each other, explaining that the children see each other as brothers and sisters. One house mom (GCC5) said, "They love each other. Even they think they are brothers and sisters." Another (GCC6) responded, "When one comes here, they tell him, this is your brother, this is your sister." Describing the way that the children encourage each other, one house mom (GCC7) explained, "If one of them is sick, the other children encourage them.

'You take this medicine and you will get well. You eat so that you will get well.' They encourage one another."

In fact, the directors of GCC identified the sense of family as one of the greatest accomplishments of the home. They explained that their goal from the beginning was to make GCC a family and not an institution. One of the directors (GCC1) said, "…we wanted it to be a family environment where there is a mom on duty, the men in the church…would be the fatherly uncle influence and have some involvement in their lives, so that they would as much as possible live a normal existence in life." One of the house moms (GCC7) confirmed that GCC is more of a home than an institution when she explained that one of the greatest benefits for the children at GCC is that "they feel as if they are at home."

Table 9: Adult to child ratios in GCC and households of secondary caregivers in Lea Toto

Household	Number of adults	Number of children	Adult to child ratio
GCC	5	19	1:3.8
Household of secondary caregiver	2	1	2:1
Household of secondary caregiver	2	7	1:3.5
Household of secondary caregiver	2	4	1:2
Household of secondary caregiver	1	4	1:4
Household of secondary caregiver	2	3	1:1.5

Table 9 compares the adult to child ratio in GCC to the adult to child ratio in the households researched in Lea Toto. Based on a comparison of the ratios, the researcher would hypothesize that the family environment of GCC can be attributed to its small size and its relatively small adult to child ratio, which is about 1:4. This adult to child ratio is

comparable to households studied in the Lea Toto program; the adult to child ratio in GCC is not larger than the adult to child ratio in typical households in the community. More research should be done to examine the link between the size of a residential home and the quality of relationships within the home.

Providing Total Care

According to the directors of GCC, the primary strength of residential care is the ability to give the children full care. Because GCC takes full guardianship of the children, they are able to ensure that each child is receiving education, food, and spiritual care. In addition, they are able to closely regulate their health, medicine, and hygiene and make sure that all the children are receiving a balanced diet. One of the directors (GCC2) explained that they are able to provide extra care to enhance the health of the children. She said, "We also provide supplements that are very costly that the normal family will not be able to do. We buy a lot of supplements, we buy a special porridge, and those are the little extras that really boost the health of the kids." These elements of diet and health care are especially important for HIV positive children who have a greater need than uninfected children for medical care, a clean environment, and a balanced diet.

Because the home is responsible for all aspects of the children's care, the children receive many benefits from the home. When asked about the greatest benefits for the children, the house moms listed several different benefits. Table 10 lists the house moms' responses to this question and the frequency of each response. The wide variety of responses suggests that the home provides many different kinds of support for the children and confirms the idea that the home is able to provide total care to the children.

Table 10: Greatest benefits to the children at GCC as reported by the house moms

Benefit to the child	Frequency of response	Percentage of house moms who listed this benefit
Medical care	2	40%
Spiritual care	2	40%
Psychological support	2	40%
Access to education	1	20%
Antiretroviral drugs	1	20%
Protection	1	20%
Place to live	1	20%
Decreased stigma	1	20%

Research Question 4: Challenges of Residential Care

Stigma

One of the challenges of residential homes discussed in the literature review is that children in residential homes often face stigma and discrimination (Tolfree 2003). Table 11 summarizes the amount of stigma at GCC as reported by the house moms.

Table 11: Stigma reported by the house moms at GCC

Type of stigma	Number of house moms who reported stigma	Percentage of house moms who reported stigma
Direct stigma towards a child	1	20%
Indirect stigma towards a child	1	20%
Stigma towards house moms	3	60%

As demonstrated in table 11 above, only one house mom (GCC3) reported a case of direct stigma towards a child. The researcher would hypothesize that the fact that all of the children attend school on the compound is most likely a significant factor in limiting the amount of stigma against the children. This arrangement has limited the

amount of stigma because the school is able to educate the parents, teachers, and other students about HIV/AIDS. The one incident of direct stigma reported occurred several years ago when some children at the school refused to play with one of the HIV positive girls. The house mom explained that some of the children at the school made insulting comments to the girl such as, "Go away, you're HIV positive." This discriminatory treatment had a negative effect on the child. However, the house mom reported that this problem has been resolved and the child is now accepted and treated well. This case is the only case of direct stigma against a child that was reported by the house moms.

One of the house moms (GCC6) reported indirect stigma towards the children. She said that some of the parents whose children attend the school tell their children not to go into the house where the children live; however, many kids just come anyway because they enjoy playing with the children. As she explained, "In fact, many kids like playing with our children. They really like them. Because also they see it's not a big deal. They are kids like us, it's just that they have the virus."

Although there were very few cases of stigma towards the children, three of the house moms (GCC3, GCC5, GCC6) reported that they had experienced stigma against themselves because of their job working with HIV positive children. These three house moms reported that they have received comments from others about the fact that they are staying with HIV positive children. They have received questions such as why are they risking their lives by staying with HIV positive children. One of the house moms (GCC6) reported a recent incident where one of the workers from the compound refused to use or even to touch gloves that had been used to wash clothes for the HIV positive children.

The house moms explained that most of the comments are just outside talk, and the comments are made to the house moms and not the children. The researcher found it very interesting that the majority of the stigma is directed towards the house moms and not the children. However, the stigma didn't seem to affect the way the house moms viewed their work. As one house mom (GCC6) commented, "The challenge is only that some people don't like it, but us, we love our jobs."

It was interesting that one of the house moms (GCC3) even identified decreased stigma as one of the benefits of the residential home. She said that many of the children experienced a lot of stigma in their communities before coming to GCC. For example, after one child lost her parents, her relatives refused to accept her because she was HIV positive and chased her away from the house. The child lived on the streets for a few months before a social worker brought her to GCC. The house mom explained that once the children come to GCC, they see that there are other kids who are going through the same thing and they are just normal kids. Psychologically they feel that they are all there together and are going through the same thing together.

Limited Travel Outside of the Home

One challenge of residential homes identified in the literature review is that the children have few opportunities to interact with children and adults from outside of the residential home (Tolfree 2003). Because the children at GCC attend school and church on the residential compound, the children do not have many opportunities to travel outside of the compound. One of the house moms (GCC3) estimated that when school is in session, each child leaves the compound about once every month (not including their monthly medical check up). The house moms identified circumstances that enable the

children to travel outside of the compound. Table 12 lists the different reasons given by the house moms for the children to leave the compound and the frequency of these responses.

Table 12: Reasons for the children at GCC to travel outside of the compound

Reason for children to travel outside of the compound	Frequency of response	Percentage of house moms who gave this reason
Accompanying a house mom to do errands	2	40%
School trips	2	40%
Visit relatives	1	20%
Visit homes of the house moms	1	20%
Taking a walk	1	20%

The directors commented that they are addressing this challenge by providing many opportunities for the children to interact with children and adults from outside of the home. The pointed out that both the pre-school and primary school on the compound include children and teachers from the surrounding community, and the membership of the church is primarily people from outside of the compound. In addition, the home gets both local and international visitors who spend time with the children. When asked about how the children interact with the other children at school from the surrounding community, all of the house moms responded that the interactions are positive and the kids interact well with children from the surrounding community.

<div align="center">Summary of GCC's Strengths and Challenges</div>

Based on the interviews with the directors and house moms at GCC, several strengths and challenges of the residential home emerged. The major strengths that were identified and discussed by the respondents were the ability to take care of abused or

neglected children, the capacity to provide total care, and the ability to maintain a family environment and positive relationships within the home. The major challenges identified and discussed by the respondents were the issue of stigma against the house moms and children and the limited opportunities for the children to travel outside of the compound.

Need for Cooperation

One other element that emerged from the interviews was the necessity of residential homes and community based programs to work in cooperation with each other. Both the directors of GCC (GCC1, GCC2) and the assistant manager of Lea Toto (LT1) emphasized the importance of community based programs and residential homes working together. The assistant manager of Lea Toto explained that there are cases of children who are being abused or who are total orphans without willing or competent relatives to care for them. Although community based care is able to assist many children, he suggested that residential care is still relevant and necessary for these extreme cases. He said that Lea Toto has linked with residential homes and has had cases where they have referred children to residential care.

The directors of GCC were in agreement that both models of care should work in cooperation to provide care for HIV positive children. They said that the community based care programs are on the ground and are able to work with the families of the children. Because these programs have sometimes been working with the families for years, they are able to know and understand the situation of the children. They are also able to get a better picture of the capacity of the extended family. Therefore, the community based programs are able to identify and recommend those children who truly

have no other options besides residential care. One of the directors (GCC2) concluded by saying "We need each other."

In fact, it was interesting to discover that GCC and Lea Toto are already working in cooperation. The researcher was unaware of this cooperation when the two programs were selected for the study. Lea Toto has referred a few children to GCC, and the children at GCC are currently enrolled in the medical program at Lea Toto. The children at GCC receive free ARVs and monthly monitoring through the Lea Toto program.

CHAPTER FIVE

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Summary

The purpose of this research was to assess the strengths and challenges of two different models of care for HIV positive orphans. In order to answer the four research questions listed in chapter one, the researcher interviewed the assistant manager of Lea Toto, the directors of GCC, and five secondary caregivers from each program. The data was analyzed by coding the information given and dividing the information into groups. Patterns of agreement and disagreement were taken into consideration.

Conclusions

In conclusion, this research demonstrated that both Lea Toto and GCC are able to effectively meet the physical and psychological needs of the HIV positive children in their care. Although both programs face challenges in caring for the children, they are taking steps to address and overcome these challenges. This research reached the following conclusions regarding the research questions:

1. What strengths does the Lea Toto program have in its ability to meet the physical and psychological needs of the HIV positive orphans in its program?

One of the greatest strengths is that Lea Toto is able to empower willing caregivers to take care of HIV positive orphans. They are able to provide for the needs of the children while enabling them to remain with their families and in their communities. Because

they address the entire community and not just the children, they are also able to empower and educate others in the community. Therefore, they are well positioned to combat stigma and ignorance about AIDS in the wider community. Their education and training programs initiate the "ripple effect," where those who have been educated are able to educate others, who are then able to educate others, and so on. This ripple effect can disseminate accurate information about HIV/AIDS throughout the entire community.

Although stigma is still a problem for some of the caregivers, Lea Toto has made significant progress in combating stigma in the community over the past several years. Enabling HIV positive children to remain in their communities and educating the communities about HIV/AIDS have shown to be effective ways of addressing and combating stigma.

2. What challenges does the Lea Toto program face in meeting the physical and psychological needs of the HIV positive orphans in their program?

One of the challenges that Lea Toto faces is the poverty of the caregivers. Most of the caregivers interviewed were unemployed and struggled to provide even the basic necessities for the children. They had to depend on food support from Lea Toto in order to provide enough food for their families. However, Lea Toto is addressing this challenge by introducing microfinance and income generating activities to economically empower the caregivers. Another challenge is making sure that the caregivers are administering the ARVs properly. Lea Toto is addressing this challenge by providing follow up and monitoring of the caregivers.

3. What strengths does Grace Children's Center have in terms of its ability to meet the physical and psychological needs of the HIV positive orphans in their home?

One of the strengths of GCC is that they are able to provide quality care for children whose needs cannot be adequately met by their families or community based programs. Such children may not have any living or competent relatives, or they may be neglected or abused by their relatives. Most of the children in GCC came from such situations and were referred to GCC by community based programs because the children did not have any options for adequate care within the community. A second strength is that GCC is able to offer full care to the children, ensuring that all of their needs are met while monitoring their health and diet daily. A third strength of GCC is that they are able to maintain a family environment with affectionate relationships between the children and the house moms and a low adult to child ratio.

4. What challenges does Grace Children's Center face in meeting the physical and psychological needs of the HIV positive orphans in their home?

One of the challenges faced by GCC is stigma and ignorance of the surrounding community. This stigma was mostly directed towards the house moms; there was only one incident a few years ago when a child was affected by stigma. GCC is able to address this challenge by having a school on the compound which enrolls both the GCC children and other children from the community. Because all of the children attend that school, the directors can easily monitor their education and ensure that the children are not experiencing any stigma or discrimination in school. In addition, the school also gives them an opportunity to educate other children, parents, and teachers from the community about HIV/AIDS.

Another challenge faced by GCC is that the children do not have many opportunities to travel outside of the compound. GCC is addressing this challenge by creating

opportunities to take the children outside, and also by ensuring that they have significant and frequent interaction with children and adults from outside of the home through the school, church, and visitors.

In conclusion, this research suggests that both community based care and residential care can be effective in meeting the needs of HIV positive orphans. "Arguably, institutional and family or community based care need not be juxtaposed as alternatives to one another. Rather, they should be developed as potential routes of choice or necessity in a range of care options," (Marcus 1999, 62). When dealing with an individual orphan, it is important to understand the strengths and challenges of both models of care to determine which kind of care would be in the best interest of that child. Community based programs and residential homes should work in cooperation in order to provide different options of quality care for HIV positive children.

Recommendations

In light of what was found in this research, the following suggestions regarding care for HIV positive orphans would be made:

1. Because of its capability to empower relatives and keep children in their families and communities, community based programs should be the first and most common response in caring for HIV positive orphans. If a child has relatives who are willing to care for that child, every effort should be made to empower the relatives so the child can remain in his or her family.

2. Community based programs should include programs to economically empower caregivers and enable them to earn an income so that they can provide for the

basic necessities of the child without becoming dependant on the program. If a program is not able to offer such training, they should network with other organizations in the community which offer economic training and empowerment.

3. Community based programs should seek to engage, educate and empower the entire community. Because the children in these programs are part of a family and part of a community, community based programs have a great opportunity to impact not only orphans but also families and communities as well.

4. Residential homes are necessary and relevant in cases where children cannot receive adequate care from their family or community. Residential homes are capable of providing quality care for HIV positive children when all options of remaining in their families have been exhausted.

5. Residential homes should remain small and should maintain a low adult to child ratio in order to foster a family environment and encourage positive relationships within the home.

6. Residential homes should make every effort to integrate the children into the normal life of the surrounding community. Children should have significant interactions with people from outside of the home, and opportunities should be created for children to frequently travel outside of the home. By creating numerous opportunities for interactions with the surrounding communities, the children can develop friendship networks outside of the home and can learn how to function effectively in the wider society.

7. Residential homes and community based programs should work in cooperation in order to effectively meet the needs of HIV positive orphans.

Suggestions for Further Research

Only one residential home and one community based program were considered in this research. More research should be done to look at the strengths and challenges of a larger number of programs. In addition, a wider variety of programs should be studied. Lea Toto and GCC were chosen for this research because of their excellent reputation and their adequate funding. Other programs might demonstrate significant challenges that are not faced by either Lea Toto or GCC because of their excellent capacity to meet the needs of HIV positive children. Therefore, research should be done to determine if the strengths and challenges identified in this research are applicable to a wider variety of programs, or if they are unique to the two programs studied. Finally, this research only focused on the ability of the two programs to meet the needs of the children, and did not address financial issues. A study should be done to compare the financial costs of care for HIV positive orphans in both community based programs and residential homes.

REFERENCE LIST

Andrews, Gail, Donald Skinner, and Khangelani Zuma. 2006. Epidemiology of Health and Vulnerability among Children Orphaned and made Vulnerable by HIV/AIDS in sub-Saharan Africa. *AIDS Care* 18, no 3 (April): 269-276.

Baltazar, Godfrey, Helen Odido, John Stover, Alan Johnston, and Tom Mboya Okeyo. 1996. Epidemiological Aspects of HIV/AIDS in Kenya. In *AIDS in Kenya: Socioeconomic Impact and Policy Implications*, eds. Steven Forsythe and Bill Rau, 11-26. US: Family Health International/AIDSCAP.

Blair, Caroline, Roselyn Mutemi, and Paul Saoke. 1996. Another Song Begins: Children Orphaned by AIDS. In *AIDS in Kenya: Socioeconomic Impact and Policy Implications*, eds. Steven Forsythe and Bill Rau, 45-64. US: Family Health International/AIDSCAP.

Creswell, John W. 1994. *Research design: Qualitative and quantitative approaches.* California: SAGE Publications.

Davis, Rebecca T. 2006. *Emerging practices in community-based services for vulnerable groups: A study of social service delivery systems in Europe and Eurasia.* US: USAID.

Domek, Gretchen J. 2006. Social Consequences of Antiretroviral Therapy: Preparing for the Unexpected Futures of HIV Positive Children. *Lancet,* 22 April, 1367-1369.

Dunn, Andrew, Elizabeth Jareg and Douglas Webb. 2002. *A last resort: The growing concern about children in residential care.* UK: Save the Children.

Foster, Geoff. 2006. Children who live in communities affected by AIDS. *Lancet,* 25 February, 700-701.

Gilborn, Laelia, Lou Apicella, Jonathan Brakarch, Linda Dube, Kyle Jemison, Mark Kluckow, Tricia Smith, and Leslie Snider. 2006. Orphans and Vulnerable Youth in Bulawayo, Zimbabwe: An Exploratory Study of Psychosocial Well-being and Psychosocial support programs. *Horizons Final Report.* Washington DC: Population Council.

Gilborn, Laelia Zoe, Rebecca Nyonyintono, Robert Kabumbuli, and Gabriel Jagwe-Wadda. 2001. Making a Difference for Children Affected by AIDS: Baseline Findings from OR in Uganda. *Horizons Baseline Report.* Washington DC: Population Council.

Gregson, S., C.A. Nyamukapa, G.P. Garnett, M. Wambe, J.J.C. Lewis, P.R. Mason, S.K. Chandiwana, and R.M. Anderson. 2005. HIV Infection and Reproductive Health in Teenage Women Orphaned and made Vulnerable by AIDS in Zimbabwe. *AIDS Care* 17, no. 7 (October): 785-794.

Hodges, J. and B. Tizard. 1989. Social and Family Relationship of ex-institutional Adolescents. *Journal of Child Psychology and Psychiatry* 30: 77-97.

Howard, Brian H, Carl V. Phillips, Nelia Matinhure, Karen J. Goodman, Sheryl A. McCurdy and Cary A Johnson. 2006. Barriers and Incentives to Orphan Care in a Time of AIDS and Economic Crisis: a Cross-Sectional Survey of Caregivers in Rural Zimbabwe. BioMed Central Ltd.

International HIV/AIDS Alliance. *Residential care.* Available from http://www.ovcsupport.net/sw3336.asp

Jareg, Elizabeth. 2005. *Community-based foster homes in Ethiopia: An account of a follow-up experience ten years after phase out.* Oslo: Save the Children Norway.

Juma, M., T. Okeyo, and G. Kidenda. 2004. Our Hearts are Willing, but…Challenges of Elderly Caregivers in Rural Kenya. *Horizons Research Update.* Nairobi: Population Council.

Kamali, A. J.A. Seeley, A.J. Nunn, J.F. Kengeya-Kayondo, A. Ruberantwari, and D.W. Mulder. 1996. The Orphan Problem: Experience of a sub-Saharan Africa Rural Population in the AIDS Epidemic. *AIDS Care* 8, no. 5 (October): 509-516.

Kuznetsova, T.I. 2005. Social Stereoptypes of the Perception of Graduates of Children's Homes. *Russian Education and Society* 47, no. 2 (February): 19-30.

Lewis, Mary. 1964. Foster-Family Care: Has It Fulfilled Its Promise? *Annals of the American Academy of Political and Social Science* 355 (September): 31-41.

Marcus, Tessa. 1999. *Wo! Zaphela Izingane (It is Destroying the Children): Living and Dying with AIDS.* Pietermaritzburg, South Africa: The CINDI Network.

Miles, Glenn and Paul Stephenson. 2001. *Children in Residential Care and Alternatives.* UK: Tearfund. Available from http://tilz.tearfund.org/webdocs/ Tilz/Topics/CareENG_full%20doc(1).pdf

Miller, Candace M., Sofia Gruskin, S.V. Subramanian, Divya Rajaraman, and S. Jody Heymann. 2006. Orphan Care in Botswana's Working Households: Growing Responsibilities in the Absence of Adequate Support. *American Journal of Public Health* 96, no. 8 (November): 1429-1435.

Nalugoda, F., R.H. Gray, D. Serwadda, N.K. Sewankambo, F. Wabwire-Mangen, N. Kiwanuka, T. Lutalo, G. Kigozi, C. Li, F. Makumbi, M. Kiddugavu, L. Paxton, S. Zawedde, and M. Wawer. 2004. Burden of Infection among Heads and Non-head of Rural Households in Rakai, Uganda. *AIDS Care* 16, no. 1 (January): 107-115.

Nhate, V., C. Arndt, M. Barslund, and K. Van den Broeck. 2005. *Orphans and Discrimination in Mozambique: An Outlay Equivalence Analysis.* Available from http://www.crin.org/bcn/details.asp?id=9522&themeID=1001&topicID=1006.

O'Hare, B.A.M, J. Venables, J.F. Nalubeg, M. Nakakeeto, M. Kibirige, and D.P. Southall. 2005. Home Based Care for Orphaned Children Infected with HIV/AIDS in Uganda. *AIDS Care* 17, no. 4 (May): 443-450.

Onyancha, Edwin and Aylward Shorter. 1998. *The Church and AIDS in Africa: A case study: Nairobi city.* Nairobi, Kenya: Paulines Publications Africa.

Patton, Michael Quinn. 2002. *Qualitative research and evaluation methods.* Thousand Oaks, California: Sage Publications.

Reddy, P., Shegs James, Eka Esu-Williams, and Andrew Fisher. 2005. Inkala ixinge etyeni: Trapped in a Difficult Situation: The burden of care on the elderly in the Eastern Cape, South Africa. *Horizons Research Update.* Johannesburg: Population Council.

Roy, Penny, Michael Rutter, and Andrew Pickles. 2004. Institutional Care: Associations between Overactivity and lack of Selectivity in Social Relationships. *Journal of Child Psychology and Psychiatry* 45, no. 4 (2004): 866-873.

_____. 2000. Institutional Care: Risk from Family Background or Pattern of Rearing? *Journal of Child Psychology and Psychiatry* 41: 139-149.

Russel, Michele and Helen Schneider. 2000. A Rapid Appraisal of Community-based HIV/AIDS Care and Support Programs in South Africa. Johannesburg: University of Witswatersrand.

Schachinger, Claudia. 2005. *A child's right to a family: The experience, learning and vision of SOS children's villages.* Vienna, Austria: SOS-Kinderdorf International.

Scharko, A.M. 2006. DSM Psychiatric Disorders in the Context of Pediatric HIV/AIDS. *AIDS Care* 18, no. 5 (July): 441-445.

Smart, R. 2000. *Children living with AIDS: A rapid appraisal in South Africa.* South Africa: International AIDS Society.

Spradley, James P. 1979. *The ethnographic interview.* Belmont, CA: Wadsworth Group.

Tolfree, David K. 2003. *Community based care for separated children.* Stockholm, Sweden: Save the Children Sweden.

UNAIDS/WHO. 1999. The HIV/AIDS Epidemic at the End of 1999. *Population and Development Review* 25, no. 4 (December): 827-829.

UNICEF. 2003. *Africa's orphaned generations.* New York: UNICEF.

_____. 2005. *Children: The missing face of AIDS.* New York: UNICEF.

_____. 2006. Protection and Children Affected by AIDS. A Companion Paper to *The Framework for the Protection, Care, and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS.* New York: UNICEF.

UNICEF /International Social Service. 2004. *Care for Children Affected by HIV/AIDS: the Urgent Need for International Standards.* New York:UNICEF. Available from http://www.unicef.org/protection/files/HIV_NOTE_FINAL.pdf

Vermack, Kerry, Nqobile Mavimbela, Jane Chege, and Eka Esu-Williams. 2004. Challenges Faced by Households in Caring for Orphans and Vulnerable Children. *Horizons Research Update.* Washington, DC: Population Council.

Webb, Nancy Boyd. 2002. *Helping bereaved children.* New York: Guilford Press.

World Vision. 2005. *Violence against children affected by HIV/AIDS: A case study of Uganda.* Nairobi: World Vision International.

APPENDIX A

ETHNOGRAPHIC INTERVIEW QUESTIONS

Caretakers in Lea Toto

Background questions:

Besides you and this child, who else lives in your house with you?

Are you married?

How is your household supported financially?

Main interview questions:

What is your relation to the child in the program?

How long have you been involved in the Lea Toto program?

Describe your biggest challenges in caring for this child.

What are your greatest concerns for the future of this child?

How does the child interact with other members of the family?

How does the community respond to you and to this child?

Describe how the child interacts with other children and community members.

How does this child behave at home? At school?

Describe what support you give this child when he/she is scared or sad.

How is the child's general health?

    What access to medical services do you have?

    How many times has the child been admitted in hospital in the past two years?

What has been the greatest benefit of the Lea Toto program?

Caretakers in Grace Children's Center

Describe your relationship to the children in the home.

How long have you been working at Grace Children Center?

Describe your biggest challenges in caring for these children.

What are your greatest concerns for the future of these children?

How do the children interact with one another? With the house moms?

How does the community respond to these children?

> How often do the children travel outside of the compound?

> How do they interact with the other children at school?

How do the children behave at home? At school?

Describe what support you give them when they are feeling sad or scared.

How is the children's general health?

> What access to medical services do you have?

> How many of the children been hospitalized in the past two years?

What do you think is the greatest benefit for children in this home?

Assistant Manager of Lea Toto

Why did you decided to begin a community program instead of expanding your residential home?

What do see as the strengths and weaknesses of community based care?

What do you see as the strengths and weaknesses of residential care?

What are the greatest challenges you face in this program?

What do you think are the greatest achievements of this program?

Director of Grace Children's Center

Why did you decide to open a residential home instead of supporting children in their community?

What do see as the strengths and weaknesses of community based care?

What do you see as the strengths and weaknesses of residential care?

What are the greatest challenges you face in this program?

What do you think are the greatest achievements of this program?

APPENDIX B

Questionnaire for Lea Toto Program

How many children are in this program? _____ What is the age range?_____

How many children are living with a non parental relative?_____

A non related adult?_____ An older sibling? _____

Do you have access to ARVs?_____ How many children are on ARVs? _____

What is the average cost to support one child for a month?_____

What are your criteria for determining who receives ARVs?_____

_____

What other medical support do you provide?_____

_____

What support do you provide of basic necessities such as food and clothing?

_____

What educational support do you provide?_____

_____

What psychological support do you provide?_____

_____

What other support do you provide?_____

Have you had any cases where a child was being abused or neglected? _____

How did you respond?_____

Questionnaire for Grace Children's Center

How many children are in this home? _____ What is the age range?_____

How many children have known relatives?_____ How many children were abused,

neglected, or threatened by non-parental relatives before coming to the home?_____

Do you have access to ARVs?_____ How many children are on ARVs? _____

What is the average cost to support one child for a month?_____

What are your criteria for determining who receives ARVs?_____

_____

What other medical support do you provide?_____

_____

What support do you provide of basic necessities such as food and clothing?

_____

What educational support do you provide?_____

_____

What psychological support do you provide?_____

_____

What other support do you provide?_____

_____

What is your entry criteria to accept children into your program?_____

_____

How much interaction do the children have with people outside the compound?

_____

APPENDIX C

Email From The Directors Of GCC

Valerie Rogers

From:	cmiacotr@wanachi.com
Sent:	Thursday, April 12, 2007 9:03 PM
To:	Valerie.Rogers@negst.edu
Subject:	Re: My thesis

A very accurate and balanced paper, Valerie. We see no need for changes, additions, or omissions... Well done!... Jennifer H

> Hello David and Jennifer,
>
> Thank you very much for assisting me with my thesis research! I am
> working on editing and the final thesis is due at the end of this
> month. In order to test the validity of my findings, I am sending a
> copy of my findings and conclusions to you and the assistant manager
> of Lea Toto to make sure that I have represented each organization
> accurately and that my findings are consistent with your experiences.
> If you have time, will you please read over the attached document and
> let me know if I have misrepresented you or GCC, or if you disagree
> with any of my findings or conclusions. If possible, please email me
> your comments by Friday 20th April.
>
> Thanks again!
>
> Valerie

CURRICULUM VITAE

PERSONAL DETAILS

Name:	Valerie Rogers
Mobile Phone:	0725281502
Email Address:	rogers_valerie@hotmail.com
Nationality:	American

EDUCATIONAL BACKGROUND

2005-2007	Nairobi Evangelical Graduate School of Theology	Master of Arts (Missions)
1999-2003	University of North Carolina–Chapel Hill	Bachelor of Science (Biology/Chemistry)
1995-1999	Somerville High School	US High School Diploma

WORK EXPERIENCE

Jan–Sept 2005	Beacon of Hope	Nairobi, Kenya
Sept. 2003-April 2004	Baby Haven	Johannesburg, South Africa

MINISTRY EXPERIENCE

Jan 2006 to date	Karen Community Church Lay leader for youth	Nairobi, Kenya
Jan 2007 to date	Watoto Wetu Bible Club leader	Nairobi, Kenya
Aug 2004-Dec 2004	Chapel Hill Bible Church Children's ministries	Chapel Hill, NC
Sept 2003-Apr 2004	Khanysweni Children's Home Bible study leader	Johannesburg, South Africa
Sept 2002-May 2003	Victory Campus Ministries Student/Bible study leader	Chapel Hill, NC
Sept 2002-May 2003	King's Park International Church Various children's ministries	Chapel Hill, NC