IMPACT OF HIV COMPREHENSIVE CARE FOR GUARDIANS ON THEIR CAPACITY TO MEET THE NEEDS OF AFFECTED CHILDREN, KIBERA, NAIROBI, KENYA

By

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DECLARATION

This thesis is my original work and has not been presented for a degree in any other university or any other award.

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SUPERVISORS APPROVAL

We confirm that the candidate under our supervision carried out the work reported in this thesis.

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DEDICATION

To God for giving me life and hope that it would be completed, to my dad, Mr. Simon Kiarie for all the support and reviews of my work, my mother, Mrs. Lydia Kiarie for all the support during the late nights, and for teaching me the value of hard work, and finally to my siblings Shiku, Nancy and Michael. Thank you all for your love and sacrifice throughout the study. I love you all, may God Bless you.
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LIST OF ABBREVIATIONS

AIDS: Acquired Immune Deficiency Syndrome

AMREF: African Medical and Research Foundation

ART: Anti retroviral therapy

ARV: Antiretroviral Drug

CHW: Community Health Workers

CBO: Community Based Organization

FBO: Faith Based Organization

HAART: Highly Active Antiretroviral Therapy

HIV: Human Immunodeficiency Virus

IMC: International Medical Corps

MSF: Medical sans Frontiers

NGO: Non-Governmental Organization

PLWHA: People Living With HIV/AIDS
OPERATIONAL DEFINITION OF TERMS

Child: persons aged 6-17 years.

**Children with chronically ill caregiver:** children ages 6-17 who are not orphans but have a chronically ill caregiver.

**Control/comparison group:** Parents/guardians identified by the nearest neighbor approach.

**Healthy parents/guardians:** those parents and guardians who are not enrolled in the comprehensive care program and show no signs of illness.

**Orphans:** Children 17 years or younger who have lost either mother or father (single orphan) or both parents (double orphan).

**Well being:** in this study was used to mean parents' perceptions of their children's ability to enjoy medical care, normal life activities overall emotional health, physical, and psychological health.
ABSTRACT

HIV/AIDS impacts on the needs of the affected children on many levels, directly and indirectly, economically and socially. It affects the social and economic status of affected families, leaving the children of the infected parents and guardians vulnerable, increasing the severity and duration of the epidemic. However, with the recent adoption of comprehensive care for HIV/AIDS infected individuals, the quality of life of those infected may improve as the devastating effect of the illness may be reduced. This study was aimed at assessing the impact of comprehensive care for the HIV/AIDS infected parents and guardians on the affected children. The study was a comparative cross-sectional study based in Kibera. The cases were HIV/AIDS infected parents and guardians enrolled in the comprehensive care program for a period of not less than six months, and having children in the age group of 6-17 years. The controls were healthy individuals picked on the nearest neighbour approach, having children in the same age group. The main objective of the study was to establish the social, economic and psychological impacts of HIV/AIDS on affected children living in Kibera. A comparative cross-sectional study design was employed, and data collected using interview schedules, semi structured questionnaires and observation checklist. A total of 700 study subjects were interviewed. The data was analyzed using SPSS Programme: correlation and Chi-square were used to determine association between categorical variables. The results indicated that a total of 73.8% of the HIV/AIDS parents and guardians reported as facing financial constraints as compared to only 53% of the healthy parents and guardians. There was more school absenteeism in the affected children (32.8%) as compared to 24% of the other children. The affected children living with the HIV/AIDS infected parents or guardians were still more susceptible to poor health than their counter parts living with the healthy parents/guardians. The magnitude of the differences between the affected children and the ordinary children was not very large as had been the case previously, generally ranging from 7-15 percent except in a few cases. The impact of the comprehensive care therefore is already being felt in most of the HIV/AIDS affected households. There existed a positive correlation between disclosure of HIV status and duration on ART for 2 years of 0.162 at 0.05 confidence level and 3 years and over 0.183 at 0.01 confidence level. There was also significant correlation between quality of food and duration on comprehensive care of 0.187 at 0.01 confidence level. Various coping mechanisms were adopted by the HIV/AIDS infected parents and guardians that included, getting assistance in schools: school fees wavering, supply of uniforms and stationery for their children, joining various support groups from where they were able to get assistance in the form of food, medication, membership to merry go rounds, and psychological assistance in the form of group therapies. Other coping mechanisms involved seeking assistance from the children. Financially empowering PLWHAs will improve and prolong the capacity to care for the children affected by HIV/AIDS. Most of the comprehensive care programs have made little or no effort on the part of the children. There is therefore need for interventions to reach children affected by AIDS, and also include a package for the parents that will help them make necessary arrangements for their children.
CHAPTER ONE: INTRODUCTION

1.1 Background Information

As the HIV pandemic continues to expand, the impact on children cannot be overstated. Thousands of children become infected through pre-natal or blood-borne transmission each year. Even more children lose one or both parents to HIV and AIDS illness or death. Household incomes decline as parents become sick, forcing children to drop out of school to work or provide care for ill family members. As orphaned children were added to extended families, food and other basic needs are stretched thin, affecting even those children who are not orphaned. However the trend with the epidemic seems to be changing with the annual number of AIDS deaths declining in the past two years from 2.2 million in 2005 to 2.0 million in 2007, in part as a result of the substantial increase in access to HIV treatment in recent years (UNAIDS, 2008).

The needs and status of children affected by AIDS depend on their parents' HIV status, and consequent health condition, whether the parents were healthy, sick, or dead, whether parents disclosed their positive status to their children and other members of the society they live in, the type of family support and the prevailing stigma and discrimination in the community. The issues associated with progressive HIV infection in a parent are particularly complex as each different stage of HIV illness, diagnosis, illness progression; late stage illness, death and family reconfiguration present a different challenge. The recently introduced comprehensive care program for patients put on Antiretroviral Therapy (ART) was aimed at assisting those enrolled lead quality lives through delayed progression of the disease, and more active lives. It encompasses all aspects of holistic
living such as psychosocial and spiritual well-being. It was therefore anticipated that, successful adoption of comprehensive care would serve to improve the quality of lives of the infected people (AMREF, 2005).

As HIV/AIDS impacts on communities, children are often the most adversely affected. Young people suffer in two ways: affected children likely to be orphaned and those infected with HIV/AIDS. The needs of People Living with HIV and AIDS (PLWHA) and their families can be categorized in four interrelated domains: medical needs, such as treatment information and treatment; psychological needs, such as emotional support; socioeconomic needs, such as welfare provisions, help in the household, and orphan support; and human rights and legal needs, including access to care and protection against violence and discrimination (Rugalema, 2000).

The affected children were defined as those living with HIV/AIDS infected parents or relatives, and those who have lost either or both of their parents to AIDS. The latter can be further described as maternal, paternal or double orphans. An unknown number of children live with parents with HIV/AIDS related symptoms: many more live with asymptomatic HIV-infected parents. AIDS directly affects children when they are orphaned. In addition, many more children are affected indirectly when their close or extended family, community and more broadly, the structures and services which exist for their benefit are strained by the consequences of the HIV/AIDS pandemic. It is important to note that, a child by definition refers to a person less than 18 years of age. Data from child health surveys is normally based on children less than 15 years.
Long-term solutions will need to be crafted for these children because the impact of HIV/AIDS will continue to linger for decades after the rates of new cases of infections begin to reduce. For a variety of reasons, little attention has been paid to the situation of these children affected by HIV/AIDS. Greater understanding of the impact of HIV/AIDS on children is important in the design and evaluation of programmes to support children living in difficult circumstances.

1.2 Statement of the Problem

At the time of the KAIS survey was conducted in 2007, only about a third of HIV infected adults age 15-64 in need of ART (35%) were accessing HIV & AIDS treatment nationally. An estimated 250,000 infected adults who were eligible for ART were not on treatment in 2007 (KAIS, 2007). In the Kibera slums, the HIV comprehensive care programs being offered by the health facilities have been designed to improve the quality of life of the HIV infected clients through a range of services. The health facilities offering the comprehensive care include the Amref Kibera Community Based Health Centre, MSF and Kicoshep. These services include provision of ART, early treatment of Opportunistic Infections, nutritional care and Home Based Care of the HIV infected clients. The programs target the HIV infected adults in Kibera who often turn out to be the main providers for the households they live in. Most of these programs have been in operation for approximately five years in the health facilities based in Kibera. Improvements have been reported on the quality of life of the clients enrolled in these programs. However, the impact these programs have had on the children living in the HIV & AIDS affected households where these clients in the comprehensive care
programs live has not been documented. The impact of HIV and AIDS on the HIV infected clients is compounded by the fact that many of their families live in Kibera which is already disadvantaged by poverty, poor infrastructure and limited access to basic services.

1.3 Justification

Most comprehensive care programs are mainly interested in following up the progress of the HIV infected client, and the impact it is having on his/her ability to lead a quality life. The impact the comprehensive care has on the dependants of the client in cases where the infected client is the breadwinner has not been documented. The purpose of this study was to determine the impact comprehensive care for HIV & AIDS infected parents and guardians has had on their capacity to meet the needs of the affected children living in their households. In the study, several issues were looked at to find out the effect of ART in meeting the social, and economic needs of the affected children. The issues included health status of the children, main caregiver’s ability to provide for the child some basic needs, discrimination and stigma due to HIV in the family, family income and resources, living conditions and social needs such as consistency in caregiver. The study also aimed at finding out if the ART has assisted the infected parent/ guardian in coping with the illness, and performing their parenting roles.

1.4 Research Question

What effect does comprehensive care of HIV positive parents and guardians have on their capacity to meet the needs of the affected children?
1.5 Objectives

1.5.1 Broad Objective
To determine the effect of comprehensive care of HIV/AIDS infected parents and/or guardians in meeting the needs of affected children.

1.5.2 Specific Objectives
The specific objectives of this study were:

1. To establish the social and economic impacts of HIV/AIDS on affected children living in Kibera.
2. To determine the contribution made by the comprehensive care on infected parents/guardians in meeting the needs of the affected children.
3. To determine the coping mechanisms adopted by the infected parent/guardian in meeting the needs of the affected children.

1.6 Hypothesis
Comprehensive care of parents or guardians has no impact on their capacity to meet the needs of the affected children.
CHAPTER TWO: LITERATURE REVIEW


Of Kenya’s total population of about 31 million, it is estimated that about 1.1 million adults between 15 and 49 years, and another 60,000 adults aged 50, and approximately 100,000 children are living with HIV/AIDS (KDHS, 2003). Currently about 200,000 People Living with HIV/AIDS (PLWHA) are in need of ART (UNAIDS, 2004). At the time of the KAIS survey was conducted in 2007, only about a third of HIV infected adults age 15-64 in need of ART (35%) were accessing HIV & AIDS treatment nationally. An estimated 250,000 infected adults who were eligible for ART were not on treatment in 2007 (KAIS, 2007). As the epidemic continues to mature, care services are increasingly becoming overburdened. This crisis has led to unprecedented political mobilization, new funding opportunities and a renewed public health response seeking to scale up key interventions including care, treatment and support, in an attempt to meet the needs of those that require them. This is evident in the concerted effort by all care providers involved in the management of the epidemic. This includes the government, Non Governmental Organizations (NGO’s) and Faith Based Organizations (FBO’s).

In the past year, both the government and non –governmental organizations have greatly increased their efforts to combat HIV/AIDS. In December 2003, the government started providing ART in 7 provincial hospitals and 13 large district hospitals in high prevalence areas. Currently over 18,600 patients are on ART countrywide, most of them through the private sector, NGO’S and FBO’s. However, it has come to their realization that a lot more is needed in the care of PLWHA than just the provision of ARVs especially in resource limited settings (UNAIDS, 2008). The people living in these resource-limited
settings have difficulty in meeting even the most basic of their needs such as proper food, clothing and housing.

The main objectives of this comprehensive care program were to reduce HIV related morbidity and mortality, by improving the quality of life of affected people and families, and also through the provision of ARVs. This was to be achieved through home-based care for PLWHA to check on the quality of life the patients lead at home, and also on their adherence to medication. Early treatment of opportunistic infections and provision of ART for free or at reduced prices made them affordable to most infected people and this contributed to the patients leading more productive and active lives.

Psychosocial support was provided through the formation of group therapies where the members met and shared their experiences, and hence were able to accept their status thereby living a full and more fulfilling life. Voluntary counseling and testing (VCT) was also part of the comprehensive care and was provided for members of the community who wished to know their status. It was also encouraged for the partners of those members of the support groups in the aim of reducing the stigma associated with the condition (AMREF, 2005).

Nutritional care and support were also essential elements of the comprehensive approach to HIV, in Kibera, a resource-limited setting where malnutrition and food insecurity are endemic. HIV infection increases energy requirements thereby accelerating the progression of the disease towards AIDS-related death through effects on the immune system and its impact on nutrients intake, absorption and utilization (Piwoz and Preble, 2000). The problem of poor nutritional status on the patient is further confounded by the
influence ARVs have on metabolic processes often leading to food-drug interactions and low nutrient absorption (Poulter C, 1997). Nutritional support began with an assessment of a patient’s specific circumstances, including their nutritional status, diet and the social and other conditions that could prevent the patient from achieving adequate dietary intake. The counseling focused on the need to stay healthy by improving eating habits, management of food and drug interaction, how to overcome the side effects of treatment and the importance of physical activity. Most health care providers have opted for the provision of food and nutritional supplements to the PLWHA living in the resource limited settings. This helps the PLWHA meet their daily nutritional requirements and also cope with the side effects of the medication they are receiving thereby resulting in better nutritional status of the PLWHA receiving care support from these organizations.

2.2 Impact of Parental HIV/AIDS on Affected Children and their Families

Economic impact

In severely affected communities, HIV/AIDS has had an impact on children, families and communities. The continuous attrition rate of deaths in young adults leads to social and economic impacts that increase with the severity and duration of the epidemic. The impact of HIV/AIDS on children and families is compounded by the fact that many families live in communities which are already disadvantaged by poverty, poor infrastructure and limited access to basic services (Steinberg et al., 2002). Strategies for coping with extended families have negative impacts on children in households indirectly affected by HIV/AIDS, thus enlarging the overall impact and number of children affected (Beegle, 2003). For example, children may experience reduction in their quality of life when their mother goes to provide home care for a HIV/AIDS-affected relative or
because of transfers of money to support a sick relative’s household. Children may see their standard of living deteriorate when cousins come to live with them following the death of an aunt or uncle.

When a parent is ill, the children’s school attendance drops because labor is needed to pay medical expenses or because families cannot afford to pay school fees (Sengendo and Nambi, 1997). Adults make decisions that children should drop out of school to provide care for sick relatives or young siblings; the girl child is mainly affected when it comes to providing care for the sick and other siblings in the home. Child caretakers are frequently girls caring for female relatives (Burman, 1996). Children living in HIV affected households and orphans run greater risks of being malnourished than children who have parents to look after them (Ayieko, 1998). This is because the often meager funds are diverted to provide medical care for the HIV infected guardians leaving little to buy food.

Social impact
The vulnerability of AIDS orphans starts well before the death of a parent. Children living with caregivers who have HIV/AIDS will often experience many negative changes in their lives and can start to suffer neglect, including emotional neglect, long before the death of the parent or caregiver. When a caregiver develops HIV related symptoms, children often shoulder new responsibilities; these include domestic chores, income generating activities, childcare and care giving activities such as feeding, giving medication and accompanying sick relatives for treatment (UNAIDS, 2000). Pre-planning for death can ensure that orphans are appropriately cared and provided for after
parental death. Observations show that when a husband dies of AIDS, the mother is also often living with HIV/AIDS and dies shortly thereafter, leaving children as orphans (Nalugoda et al., 1997).

Most parents, even if they are aware of their terminal illness, do not have the capacity to make alternative living arrangements for their children before death. One of the most tragic consequences of HIV/AIDS is its devastating impact on the emotional and physical health and well being of children (Soake, et al., 2000). Frequently, however, these needs are neglected. Often, the children needs are affected in a range of ways, such as: having to cope with sick parents or guardians, which brings both practical and psychological pressures, such as having to cope with the death of parents and other loved ones. The children also deal with the trauma and grief of bereavement, and the resulting psychological problems, such as depression, guilt, anger and fear – often with a lack of support. They are forced to live with neglect and loss of parental care, love and attention - leading to developmental problems, having to adjust to life with guardians/foster parents separation from siblings, and social exclusion (Bochow, 1999).

In addition there is the emotional suffering of the children, which usually begins with their parents' distress and progressive illness. Eventually, the children suffer the death of their caregivers and the emotional trauma that results. They then may have to adjust to a new situation, with little or no support, and they may suffer exploitation and abuse. Children grieving for dying or dead parents are often stigmatized by society through association with HIV/AIDS. The distress and social isolation experienced by these children, both before and after the death of their caregivers, is strongly exacerbated by the
shame, fear, and rejection that often surrounds people affected by HIV/AIDS (Kamali, et al., 2000). Because of this stigma and often-irrational fear surrounding AIDS, children may be denied access to schooling and health care. And once a parent dies, children may also be denied their inheritance and property. Often children who have lost their parents to AIDS are assumed to be HIV infected. This further stigmatizes the children, reduces their opportunities in the future, and they may also not receive the health care they need, and sometimes this is because it is assumed they are infected with HIV an illness known to be untreatable.

These social and economic impacts of HIV/AIDS on orphans have also led to increased vulnerability to HIV infection of the affected children. This is mainly through early onset of sexual activity, commercial sex and sexual abuse. In Uganda, sexual debut occurred earlier in orphans than non-orphans; by age 12, 30% of orphan girls were sexually active rising to 85% by age 18 (Evans and Miguel, 2004). The reasons for becoming sexually active included economic need, peer pressure, discovery, lack of parental supervision and rape by strangers, relatives and teachers (Sharpe, Ssentongo, Ssenyonga, 1993). Although most orphans were aware of the existence of HIV/AIDS, few knew how to protect themselves (Richter and Swart, 1995). When orphaned adolescents or adults become ill, they will have no mothers to consult for home care during terminal illness.
CHAPTER THREE: MATERIALS AND METHODS

3.1 Study Area

Kibera, the second largest informal settlement in Africa is located in Langata Division, southwest of Nairobi province and covers approximately 2.5 square kilometers, 256 hectares, or 630 acres). It is sited approximately 5 km south east of the city centre of Nairobi. It holds more than a quarter of Nairobi’s population. The estimated population density is 300,000/km$^2$. There are a number of villages, including Kianda, Soweto, Gatwekera, Kisumu Ndogo, Lindi, Laini Saba, Siranga/Undugu, Makina and Mashimoni. Its population is estimated between 600,000 and 1.2 million. The region is characterized by high poverty levels, poor infrastructure and low access to basic amenities by the communities living in the area. The health indicators are extremely poor and the HIV prevalence is estimated at 20%, double the HIV prevalence in Nairobi which stands at 9.0% (KAIS 2007). This high prevalence has attracted a lot of attention to the area and hence many government and non-governmental organizations are offering highly subsidized HIV and AIDS prevention services.

3.2 Study Population

The study population comprised of adult men and women above 18 years of age. The case group comprised adults put on antiretroviral therapy, enrolled, and attending one of the organizations for ART and support services with children between the ages of 6-17 years. The infected caregivers who were enrolled in the study were those who were stable enough to be interviewed. Clients who were at the end stage of the condition, who were unresponsive, or who were showing signs of dementia were not enrolled. Community
Health Workers and health personnel at the various health facilities in the area formed the Key informants in the study.

3.2.1 Inclusion Criteria

- Parents and guardians forming the cases were residents of Kibera, enrolled and active in their respective ART and comprehensive care programs.
- Parents and guardian forming the healthy control group were residents of Kibera; healthy individuals who were not enrolled in any ART and comprehensive care programs.
- All parents and guardians enrolled in the study had children between the ages of 6-17 years.

3.2.2 Exclusion Criteria

- Parents and guardians in the ART program without children in the specified age groups.
- Those patients who did not consent to the study and were not Kibera residents.

3.2.3 Ethical Considerations

Feedback to the respondents was confidential, identity was anonymous by ensuring names were not written on questionnaires. Informed oral consent was obtained from the respondents to ensure that participation was voluntary. Clearance was sought from the Ministry of Education, Science and Technology. Permission was also sought from the various health facilities that formed the data collection points.
3.3 Sampling Techniques

The Kibera slum is big and has varied characteristics that make it heterogeneous. It is comprised of 14 villages which were chosen as the key variable of stratification from which the study subjects meeting the inclusion criteria were selected. An equal number of control subjects meeting the inclusion criteria and consenting to the study were enrolled on a nearest-neighbor approach from each of the villages. Patients presenting at these facilities and in the facilities in the catchment area from these selected villages and meeting the inclusion criteria were recruited into the study as they presented at the facilities to form the cases. A stratified random sampling of the cases and hence the controls was therefore used to select respondents from a sampling frame from each of the health facilities in Kibera.

3.3.1 Sample Size

The total population of patients in Kibera enrolled in the comprehensive care program was estimated to be 3,000. To get the required sample size that would represent the division within an acceptable degree of biases, the formula by Fisher et al, 1998 for a population less than 10,000 was used as follows:

\[
n_f = n \times \frac{1}{1 + (n/N)}
\]

where \(n_f\) = the required sample size

\(n\) = the sample size when the population is larger than 10,000

\(N\) = the estimated study population

\[n_f = 384 \times \frac{1}{1 + (384/3000)} = 340\] to be divided equally among the 14 villages.
The sample size for the healthy individuals forming the controls was taken from a population greater than 10,000; hence the formula by *Fisher et al* for a population greater than 10,000. This resulted to a sample size of 384 that was divided equally among the 14 villages of Kibera. A total of 724 (cases and controls) subjects formed the minimum population sample size required for the study.

### 3.3.2 Study Design

The study was a comparative cross-sectional study design where the cases interviewed were the infected parents and guardians living with the affected children, while the controls interviewed were healthy parents and guardians with children in the same age group and residing in the study area. The study design was used to collect both quantitative and qualitative data. Data obtained from the study was analyzed and used to generate information in response to the study objectives. Questionnaires were used for quantitative data whereas review of documents, Key informants interviews and focus group discussions were used for qualitative data. Piloting of the study was carried out in similar situations of the study population and necessary changes on the questionnaires and Key informant schedules adapted before execution in order to ensure data quality control.

### 3.4 Data Management and Utilization

Five research assistants were recruited based on their level of education and experience in research. They underwent two-day training on how to administer the research tools in
both English and Swahili and also in the pre-testing of the tools. Data was collected in two major methods:

3.4.1 Interview Schedules

They were administered to the HIV/AIDS infected attendants of the focus group discussions. Two focus group discussions were held every week of the two months. An average of 15 PLHA attended each of the focus group discussions. The FGD were conducted in Kiswahili. Primary data regarding the impact comprehensive care was having on the caregivers was collected. Key informant interview schedules were also administered to the health and social work personnel at the facilities. This was aimed at gathering key information regarding the progress of the PLWHA from the caregivers.

3.4.2 Semi-Structured Questionnaires

Both open-ended and close-ended questions were formulated to enable every respondent to efficiently give his/her views. This captured mainly quantitative information hence enriching the study further.

3.4.3 Data Analysis and Utilization

Quantitative data was collected from questionnaires, interviews. Qualitative data was collected through the various focus group discussion sessions conducted. Analysis consisted of content analysis, data coding and finally in depth analysis using the Scientific Package for Social Science (SPSS) Programme. The variables analyzed included: health care quality and health status of the children, main caregiver’s ability to
care for an ill child, availability of support for the primary caregiver, basic needs such as, nutrition, education, child care, guardianship, discrimination and stigma due to HIV in the family. Others included family income and resources, living conditions such as housing, psychosocial needs like consistency in caregiver, stimulating daily activities, and problems faced by the children due to the caregivers’ illness, among others. Qualitative data was categorized according to the responses given. Results of this study will be disseminated to stakeholders and non-governmental organizations involved in the provision of comprehensive care to PLWHA, and care of HIV & AIDS affected children.
CHAPTER FOUR: RESULTS

4.1 The Socio-Economic Impacts of HIV/AIDS on Affected Children Living in Kibera.

PLWHA and their families are confronted with additional challenges throughout the course of infection and recurrent episodes of illness. These include psychological needs for the PLWHA and the affected family members, loss of income, medical and transport expenses, funeral costs, and the unmet needs of orphaned children for education, shelter, nutrition, clothing, and other necessities. Some of these socio-economic characteristics assessed in the study included characteristics of households, parents/guardians income, school attendance of the affected children, food quality consumed in the household and the health status of the affected children.

4.1.1 Composition of Households

The results for household characteristics were presented in figure 4.1. Majority of the case and control households interviewed had a fairly equal ratio of males to females. However, some of the parents/guardians were live-in partners as only 56.3% of the infected guardians/parents were married while 59.3% of the control group was married. Only a few of the primary caregivers were youth with only 10.9% and 24.1% of cases and controls respectively interviewed belonging to the 18-27 years age group. Majority of those interviewed fell in the ages between 28-45 years.
Of the cases interviewed, 45.9% had been on comprehensive care for a period of more than six months but less than one year, 14.4% for a period of more than one year, 24% for more than two years while 8.3% had been enrolled and active into the therapy for more than three years. The comprehensive care involved nutritional support, psychosocial support in form of group therapies, counseling and home visiting and also supply of medication: both ARV's and for the treatment of opportunistic infections. The respondents who composed the control group were not enrolled in the comprehensive care therapy and therefore were assumed not infected with HIV/AIDS. Most of the respondents both of the case and control group had a modest level of education with only 2.6% and 3.5% of cases and controls respectively reporting as having received no education at all.
On average, the households that had the infected parents/guardians had more people living with them as compared to those of the ordinary parents and guardians, with 17% of the cases reporting as living with more than five people in their households as compared to only 4.5% of the control group reporting the same. Most of the dependants living in these households were under the age of 18 years with most of the children being female: 82.4% in the case household and 85.6% in the control household.

Data on household structure as presented in figure 4.2 below revealed a high proportion of respondents both infected and uninfected caring for children other than their own in the form of orphans and some taken from relatives. A larger number of children living with the ordinary parents and guardians were either orphans or those of their relatives (45.2%) as compared to 30.3% of the children living with the HIV/AIDS infected caregivers.

![Figure 4.2 Status of children living with the infected parents and guardians.](image-url)
4.1.2 Parents/Guardians Facing Financial Constraints

The parents/guardians facing financial constraints, for the purpose of this study, were assumed to be those earning Kshs 5,000 or less. The results in figure 4.3 below show that a total of 73.8% of the cases reported as facing financial constraints as compared to only 53% of the control group experiencing financial constraints. There was a positive correlation between level of income and remittance from the children of 0.155 at 0.05 confidence levels for both case and control groups. There was also positive correlation observed in the control group between level of income and amount of assistance one received at school of 0.177 at 0.05 confidence levels. There was positive correlation observed between membership to community support group and amount of help received of 0.908 at 0.05 confidence levels for the control group.

![Figure 4.3 Average monthly incomes (%)](image)

Figure 4.3 Average monthly incomes (%)
4.1.3 Health

The population sample of cases had the highest number of respondents (49.8%) who felt the health status of their children was poor compared to 16.6% of the control sample. On the other hand, 59.8% of the control population felt that the health status of their children was good compared to 39.7% of the cases. There was an observed difference in the rate at which the children fell sick between the two groups. More cases (42.8%) than controls (22.6%) reported their children as having fallen sick (Malaria, Diarrhea and vomiting) for more than three consecutive days in the past three months prior to the study suggesting that affected children living with people who are on ART (cases) are more susceptible to poor health than their counter parts living with the healthy parents/guardians.

For all the most common diseases in the area such as diarrhea, and malaria, that affect children, prevalence was highest amongst the case population. The most common diseases observed were malaria (37%), diarrhea and vomiting (15%), while respiratory infections were at 11%, prevalence being highest amongst the case population.

4.1.4 School Related Constraints

All the cases interviewed had children attending school while only 85.4% of the control group had school going children. Differences in the number of school going children were also apparent. A total of 23.1% of cases interviewed reported as having all their school going children in school as compared to 11.1 % of the control group implying that
there is higher enrollment of children in school among the infected parents and guardians than in the ordinary parents and guardians.

A total of 32.8% of HIV & AIDS affected children experienced school absenteeism as compared to 24% of the control group per month. Most common reasons for school absenteeism for Cases were lack of school fees and sickness: while the reasons for the control population was lack school fees and need to assist at home. In the case group, there was a positive correlation observed between rate of absenteeism and level of education of the parents/guardians of 0.191, involvement of children in IGAs of 0.180, number of meals per day in the household of 0.158 and also level of assistance received at school of 0.143, all at 0.05 confidence levels. There was also observed correlation in the control group between the rate of school absenteeism and involvement of children in IGAs of 0.247, average monthly income of the parent/guardian 0.155 at 0.05 confidence levels.

4.1.5 Food

A difference existed between the number of meals consumed per day in the two groups under study with 58% and 77% of cases and controls respectively consuming three meals per day, 34% and 7.5% of cases and controls respectively consuming two meals per day, while 57% of the cases consumed one meal per day. There was a positive correlation between number of meals consumed and the level of income of the parent/guardian of 0.261 at 0.05 confidence levels among the cases. The higher the level of income, the more likely the household was to consuming more meals per day.
Majority of the respondents reported as having balanced diets every time they took their meals (Figure 4.4). This was evident in that 48.9% and 46.9% of the cases and controls respectively reported as consuming a balanced diet each time they consumed in their households. Vitamins (fruits and vegetables) were the least consumed in the households while starchy foods were most consumed in the households.

Figure 4.4 Types of food consumed in the households
4.1.6 Stigma and Disclosure of HIV/AIDS Status of the Parent/Guardian to Children

Survey results showed that 65.5% of the cases (most of who were on ARV’s) had not disclosed their HIV status to their children or any of their relatives. However, there was a positive correlation between disclosure of HIV status of the infected caregivers to their children and level of education of 0.145 at 0.05 confidence levels. It was also observed that the longer one was on ART, the more likely they were to disclose their status to their children.

Reasons given for not disclosing their status included no need to worry the children, the topic was difficult to discuss and the children may not be able to keep a secret. The majority of the parents/guardians felt that it would be a good idea to do so when the children were old enough to handle the truth. According to the parents, they were comfortable disclosing to the older children who would be able to handle the truth. Reasons for disclosure given were, so the children can avoid HIV/AIDS, can prepare emotionally, can prepare practically and so that the children will know what to do when parent/guardians die. According to the infected parents and guardians, 34.5% of the children who knew their parents/guardians HIV status, knew through gossip, and by observing their parents ill health and need for medical services. On the other hand, 9.5% of the control population said they had disclosed their HIV status to their children. The small percentage can be attributed to the fact that most of the respondents of control population are yet to take the initiative to know their HIV status, and also because it’s easier to convey a negative HIV status than a positive one.
Most parents/guardians reported that they had not noticed any difference in the way their children were treated by their peers while out playing or just socializing. An insignificant level of school absenteeism was blamed on discrimination by either the teachers or fellow students due to the parents/guardians illness. The study findings do not suggest a pronounced decline in psychosocial well being of the affected children as compared to the other children.

4.1.7 Social Welfare Impacts of Parental/Guardian HIV/AIDS on the Affected Children

The interview included a number of questions to determine the social welfare impact of parental/ guardian illness on the affected children. These interviews were meant to determine the time the children had for leisure activities such as play, consistency of care giver, source of advice for the children and most common social problems such as stigma. A total of 83% of the case group respondents said they had a regular home for their children, while 73.9% of the control group said they had regular homes for their children. It therefore implied that child's residence was not an issue among the children living with HIV affected parents. The other children had more time for leisure activities as compared to the affected children. Among the affected children 24.5% were reported as having no time at all for leisure activities as compared to 7% other children who did not have any time for the leisure activities.

Most parents/guardians admitted to talking to the children on matters surrounding HIV/AIDS. Some however left this duty to the media, relatives and peers, citing it as too
upsetting to talk about. Only 48.5% of the parents and guardians reported as having talked to their children on matters surrounding HIV/AIDS. There was a positive correlation between duration on comprehensive care and disclosure of status of 0.357 at 0.05 confidence level. The longer the HIV/AIDS infected parent/guardian was on comprehensive care, the more likely it was that they would disclose their status.

Figure 4.5 Knowledge of matters surrounding HIV/AIDS

Figure 4.5 shows knowledge of matters surrounding HIV&AIDS by both affected and ordinary children. Most HIV/AIDS infected guardians and parents (48%) took the initiative to educate the children they were living with on matters surrounding HIV/AIDS (Figure 4.6). Other sources of advice for the children included relatives (25.8%), the
media and peer (4.8%). There was a correlation between duration on comprehensive care and children’s understanding of HIV/AIDS related issues. The longer the parent/guardian had been on comprehensive care, the more likely it was for them to talk to the children living in their household about issues surrounding HIV/AIDS.

![Pie chart showing sources of advice for children]

**Figure 4.6 Source of advice for the children**

### 4.1.8 Overall well-being of the children

Six dimensions were taken to measure the total well-being of children living in the households where the study was carried out. They include material well-being, health and food, education, peer and family relationships, and risks. Almost all the infected parents/guardians expressed worry about their children’s future. Parents expressed the greatest concern about their children’s access to education, food and basic necessities for survival. They also worry about their children being exploited and about the lack of an appropriate guardian. When parents/guardians were asked what they would like to do to ensure the well being of their children, their responses emphasized acquiring productive
resources and improving their economic situations, thereby indicating material needs. Most ordinary parents/guardians interviewed rated their children's well being as generally being better as compared to the rating given by the HIV infected parents and guardians. However, when asked to rate their children's current well being, their responses were as shown in the figure 4.7.

![Figure 4.7 Overall well being of the children](image)

The Chi-square test statistics results arrived at from this study was 35.92. The value exceeds the table $X^2$ (11.07) at 0.05 confidence levels, thus the null hypothesis is rejected in favor of alternative hypothesis. This therefore implies that the variation between the two samples is not explained by randomness. Accordingly, children affected with HIV were still more vulnerable to social, economic and psychological problems than their counterparts.
4.2 Contribution Made by Comprehensive Care in Meeting the Needs of the Affected Children

Correlation analysis was used to determine the contribution made by comprehensive care in meeting the needs of the affected children and was performed on the data from the case group only. It looked at what difference the comprehensive care made in improving the lives of the HIV infected parents and guardians and hence their ability to met the needs of the affected children. Correlation is the degree of relationship to which two measurable variables vary together. The degree of relationship is commonly measured by a correlation coefficient, r which vary between +1 and −1. A positive correlation indicates that the two variables have a tendency to increase as the other increase. Zero correlation indicates absence of relationship. A correlation exceeding 0.5 (or −0.5) is considered in many cases to be perfect. However, more often than not, there are correlations that are usually less than 0.5 but are significant at a specified significant level. In this study, a correlation command, specifically bi-variate, was executed and results presented in the following tables.

4.2.1 Correlation between Disclosure of Status and Duration on Comprehensive Care

Results in table 4.1 show that there exists a significant positive relationship between disclosure of HIV status and duration on ART for 2 years of 0.162 at 0.05 confidence level and 3 years and over of 0.183, at 0.01 confidence level. There was no significant relationship between disclosure of HIV status and ART duration of less than 1 year and 1 year. The results imply that a longer duration on ART is likely to lead to improved
information and attitude, and positive life as a PLWHA. There was also a positive correlation between disclosure of HIV status and level of education of 0.145 at 0.05 confidence levels, which meant that disclosure of status, was greatly influenced by level of education and duration on comprehensive care.

<table>
<thead>
<tr>
<th>Duration on ART</th>
<th>ART- &lt; 1 year</th>
<th>ART- 1 year</th>
<th>ART- 2 years</th>
<th>ART- 3+ years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson correlation</td>
<td>1.000</td>
<td>-.106</td>
<td>-.015</td>
<td>.162*</td>
</tr>
</tbody>
</table>

*Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

Table 4.1 correlations between disclosure of status and duration on ART

4.2.2 Correlation between Health Status of Children and Duration on Comprehensive Care

Despite a majority (51.1%) of respondents saying the health status of children was poor; there was no significant relationship with duration on comprehensive care as seen in table 4.2.

<table>
<thead>
<tr>
<th>Duration on ART</th>
<th>ART &lt;1</th>
<th>ART 1 yr</th>
<th>ART 2 yrs</th>
<th>ART 3+ yrs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Correlation</td>
<td>1.000</td>
<td>-0.131</td>
<td>0.015</td>
<td>-0.068</td>
</tr>
</tbody>
</table>

*Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

Table 4.2 Correlations between health status of children and duration on ART
4.2.3 Correlation between Income and Duration on Comprehensive Care

Table 4.3 shows that no significant correlation was observed between duration on comprehensive care and income.

<table>
<thead>
<tr>
<th>Duration on ART</th>
<th>ART- &lt; 1 year</th>
<th>ART- 1 year</th>
<th>ART- 2 years</th>
<th>ART- 3+ years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Correlation</td>
<td>1.000</td>
<td>.080</td>
<td>.017</td>
<td>-.067</td>
</tr>
</tbody>
</table>

*Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

Table 4.3 correlations between average monthly income and duration on ART

4.2.4 Correlation between School Absenteeism and Duration on Comprehensive Care

No significant correlation between duration on comprehensive care and children school absenteeism was observed (Table 4.4).

<table>
<thead>
<tr>
<th>Duration on ART</th>
<th>ART- &lt; 1 year</th>
<th>ART- 1 year</th>
<th>ART- 2 years</th>
<th>ART- 3+ years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Correlation</td>
<td>1.000</td>
<td>.004</td>
<td>-.013</td>
<td>.016</td>
</tr>
</tbody>
</table>

*Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

Table 4.4 Correlation between school absenteeism and duration on ART

4.2.5 Correlation between Quality of Foods Consumed in the Households and Duration on Comprehensive Care

There is significant correlation observed between type/quality of food and duration on comprehensive care as seen in table 4.5.

<table>
<thead>
<tr>
<th>Duration on ART</th>
<th>ART- &lt; 1 years</th>
<th>ART- 1 year</th>
<th>ART- 2 years</th>
<th>ART- 3+ years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Correlation</td>
<td>1.000</td>
<td>.187**</td>
<td>-.147*</td>
<td>-.083</td>
</tr>
</tbody>
</table>
4.2.6 Correlation between Social Wellbeing of the Children and Duration on Comprehensive Care

Duration on comprehensive care did not result in any change in the social well being of the affected children (Table 4.6)

<table>
<thead>
<tr>
<th>Duration on ART</th>
<th>ART- &lt; 1 year</th>
<th>ART- 1 year</th>
<th>ART- 2 years</th>
<th>ART- 3+ years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Correlation</td>
<td>1.000</td>
<td>-.127</td>
<td>.049</td>
<td>.055</td>
</tr>
</tbody>
</table>

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

Table 4.6 Correlations between regularity of child’s residence and duration on ART

4.3 Coping Mechanisms Adopted by the Surviving Parents/Guardians in Meeting the Needs of the Affected Children

This objective was to determine the coping mechanisms adopted by the surviving parents in meeting the needs of the affected children. The results of where parents turned for assistance in meeting the needs of their households are presented in figure 4.8 below.
Figure 4.8 Sources of Assistance

4.3.1 Membership to community support organizations

The results of this study indicated that majority of the case population were members of CBOs. From the questionnaires and reports given by the key informants, a significant 65.5% of those enrolled in the comprehensive care program were members of various community-based organizations as compared to 45.6% of those who reported as not enrolled in the comprehensive care program.

A corrected Chi-square test was performed to test a significant difference in the membership to community support groups. The critical value using 0.05 significant levels was 3.85 and the adjusted Chi-square value is 5.36, a value that falls outside the rejection region. Consequently, hypothesis of no difference between the sample populations was rejected. Thus, the differences between groups do not occur by random variation. People
who have their status known and are on ART are more likely to seek help or join community support organizations. The key informants reported that the encouragement received from the focus group discussions influenced the HIV infected clients to join the support organizations. The kind of assistance received in the respective Community support organizations are presented in figure 4.9.

![Figure 4.9 Type of CBO assistance (%).](chart)

The results of this test indicated that there were differences in the way the two groups adopted strategies to meet the needs of the affected children. It can therefore be concluded that people who know their HIV/AIDS status are more likely to seek or get assistance from relatives, friends or CBOs than those who haven’t disclosed their status.

### 4.3.2 Children involvement

A number of parents/guardians in both case and control groups required the children to assist in acquiring food for household consumption. From the results, it was evident that
children living in AIDS affected households worked harder to get money that was later used to acquire food and also got more assistance from CBOs than the other children.

Survey results showed that 34.5% (cases) and 35.7% (control) of the households surveyed sometimes require older children of the family to substitute family income in form of remittance. Most of the activities the children were involved in include hawking, and doing manual work for money. There was significant correlation of 0.155 at 0.01 confidence levels between level of income for both the case and control group and remittances from older children. A significant correlation was observed between rates of school absenteeism and remittances from older children for both the cases of 0.180 and controls of 0.247 at 0.05 confidence levels.

A difference existed between children involvement in IGAs with a total of 36.3% of the affected children involved in IGAs such as hawking groundnuts and providing services as compared to 26.2% of the children belonging to healthy parents and guardians. Approximately 20.1% of the affected children were reported as being involved in hawking activities as compared to 18.1% of those belonging to the control group. Parents/guardians needed help with work and chores when they were sick. 80% of cases interviewed received assistance in doing household chores from the children they were living with as compared to only 53.8% of the control group who admitted as receiving assistance from the children they were living with. The most common household chores the children were involved in are represented in the figure 4.10 below. When asked who
cares for them when sick, the HIV/AIDS infected parents/guardians reported spouses or live-in partners, and less often siblings.

![Bar chart showing assistance in household duties for cases and controls.](image)

**Figure 4.10 Assistance in household duties**

### 4.3.3 Assistance in School

In both sample populations 34.5% and 34.7% of parents for Cases and control respectively said they received assistance in form of school fees and supplies. Most parents and guardians admitted to receiving some assistance in schools. Most of the assistance was received from schools themselves or the government through some form of sponsorship program for the affected children. The cases received 14.4% while the control children received 19.1% government sponsorship. Other forms of assistance received came from relatives, CBOs and friends. In both sample populations 34.5% and
34.7% of parents for Cases and control respectively said they receive assistance in form of school fees and supplies

4.3.4 Appointing Guardians.

Most HIV positive parents/guardians believed that there was a need to make explicit arrangements to appoint a guardian in order to ensure future care for their children, to reduce the children’s anxiety, to allow guardians to prepare and to reduce their own worries. A few felt that someone would take care of the children anyway. However, most felt that these arrangements could be postponed since they were still leading an active life, because of the help they were getting from the comprehensive care program and also because they did not want to reveal their Sero-positive status.
4.9 DISCUSSION

The primary focus of these comparisons was between the social and economic status of the HIV & AIDS affected children living with chronically ill parents/guardians, and other ordinary children (those with healthy parents or guardians). The discussion of the results was framed in this manner because the primary objective of this study was to explore whether the social and economic status of affected children were worse off than other children. As programs for orphans and affected children are designed in accordance with the belief that these groups of people were more disadvantaged relative to other children, exploring differences among these groups is critical. For the purpose of this report, quantitative significance was defined as a difference of 6-10 percent between children living with chronically ill caregivers and other children. Differences of approximately 15% or more are considered to be large in this study.

All the parents/guardians forming the case group were enrolled and active on ART for a period of not less than six months. For most categories of study participants, the ratio of males to females was fairly equal. Approximately 50% of all study subjects interviewed were married with 8.3% of the case group being widowed as compared to only 0.5 of the control group reporting the same. The study subjects were both HIV/AIDS infected (case) and healthy parents/guardians (control). Only those who received all the components of ART: Medication, food supplementation, Group Therapy and continued counseling, were enrolled in the study to form the case group. Comparisons were also made between the parents/guardians enrolled in their respective ART programs to be able to assess the impact of the ART depending on how long the patient has been enrolled.
The coping mechanisms for both case and comparison group were also studied. Orphans, vulnerable children and their families were usually confronted with severe threats to their well being including isolation, loss of income, education access, shelter, and nutrition. When families and children are forced to focus on basic daily needs to decrease their suffering, attention is diverted from factors that contribute to long-term health and well-being. While most policy makers assume that orphans and affected children are more likely to live in poorer households than other children, studies examining socio-economic status and HIV/AIDS infected caregivers have had mixed results.

From the study results, 74.2% of the cases interviewed were the main breadwinners in their respective families while 49.7% of the comparison group were the breadwinners responsible for making the financial decisions in the households e.g. how money is spent. 80.3% and 61.4% of infected and healthy parents/guardians respectively in the study earn their income from salaried and self-employment with an average income of 2,000-10,000 Kshs per month. The results indicated that there are more infected parents/guardians facing financial constraints than there were in the control parents/guardians, with a total of 73.8% of the cases reporting as facing financial constraints as compared to only 53%. There was significant correlation for both cases and control, between level of income and remittances from older children of 0.155 at 0.01 confidence levels. Those guardians, who received handouts in form of cash from the older children they were living with, reported as having more income than their counterparts who received none.

Most infected caregivers reported as spending more on food as they aimed to keep up with the advice given during the various counseling sessions, which emphasized on
proper eating habits. Research has shown that on average, AIDS care related expenses can absorb one-third of a household’s monthly household income (Steinberg et al., 2002). An AIDS-affected household’s response depends on the resources it can gather together. When possible, families liquidate savings, borrow money or seek extended-family support (Food and Agriculture Organization, 2003).

Very few HIV/AIDS parents/guardians reported absenteeism from work due to sickness as more lead active lives due to the comprehensive care they receive. It was also observed that there were more infected parents/guardians (65%) joining and seeking assistance from CBOs than healthy parents/guardians (45.6%). Various types of assistance were available from these organizations notably, financial, medical, nutritional and counseling. Most shocking though was the fact that more healthy parents/guardians were able to access financial help by way of soft loans and merry go-rounds than the HIV/AIDS infected caregivers. The reason given for this was that the infected caregivers were on constant migration to the rural areas and only came to town for medication or in the case of females, to see their spouses, hence could not be relied on as members of merry-go-round groups. Often these households had limited savings due to lack of credit or insurance options. This means they must rely solely on their labor power to make up for the lost income (Beegle, 2003).

Both infected and healthy parents/guardians involved their children in income generating activities to make ends meet. There was correlation between level of income and amount of assistance in the form of remittances received from children living in the household. The more the children got involved in IGAs, the more income a household had. However,
there was no notable difference in involvement in the IGAs between affected children and the other children. Children were a vital part of the solution and should be supported in planning and carrying out efforts to lessen the impact of HIV/AIDS in their families and communities provided that these activities do not hamper the well being of these children.

The epidemic’s impact on education has far reaching implications for long-term development. Globally, AIDS is a significant obstacle to children achieving universal access to primary education by 2015—a key target of both the Education for All Initiative (UNESCO, 2000) and the Millennium Development Goals (United Nations, 2001). In three South African provinces, a survey of 771 AIDS affected households reported that more than 40% of primary caregivers took time off work or school to take care of an ill HIV infected family member. Out of this, almost 10% of households removed a girl from school compared with 5% for boys (Steinberg et al., 2002). There was however a different trend observed in this study where, 23.1% of cases interviewed reported as having all their school going children attending school, as compared to 11.1% of the control group. This means that the infected parents/guardians had more of their school going children enrolled in school as compared to the non-affected parents and guardians.

While it was hypothesized that the affected children are less likely to be in school than those not affected, the results did not support this assumption. This can be attributed to the fact that there were many NGO’s in the region that were willing to support the HIV/AIDS infected parents/guardians in giving their children free or subsidized education as they attract donor attention. A significant number of cases reported as
receiving help in form of school fees. The result of this has seen more HIV/AIDS infected parents/guardians enrolling their children in such schools thereby having more children in school as compared to the other children. The infected caregiver had accommodated orphans and children from relatives who were hence able to benefit from this free or subsidized education. This was evident in the fact that most of the children (58.8%) living with the affected parents/guardians were orphans or belonged to their relatives as compared to only 38.9% orphans and relative’s children living with the comparison group.

Many AIDS–affected households may withdraw children from school to compensate for labor losses, increased care activities and competing expenses. If the mother was dying or has died, children particularly girls, are needed for household duties (Steinberg et al., 2002). As relating to school absenteeism in the study, a significant difference was observed between case and control children with affected children reporting 32.4% school absenteeism as compared to 24% of the control group, suggesting that adult illness may be taking a toll on the education of the older children.

There was no significant difference in absenteeism between the sexes as males were as likely as girls to be absent from school. Most common reasons for school absenteeism for Cases were lack of school fees (15.3%) and sickness on the part of the child (9.2%): while the reasons for the control population was lack of school fees (13.1%) and need to assist at home especially taking care of the younger children (13.1%). School fees pose a significant problem for AIDS–affected households; families simply cannot afford them. It
was the primary reason children were withdrawn from school (Mutangadura, 2000). It was observed from the study that, the amount of income received from older children in the case household significantly affected the rate of absenteeism. A correlation of 0.247 was also observed in the control household depicting that the more income in the household brought in by the older children, the less likely the school going children were likely to be absent.

Young girls may drop out of school to tend to ailing parents, look after ailing parents, and look after household duties or younger siblings. Day to day attendance was lower but not significantly different for both the affected and the other children. Keeping children in school is crucial for their future. It can provide education that can act as a safety net in the child’s life when the parents or guardians are not there anymore to provide. Schooling can also help to break the cycle of poverty (Mutangadura, 2000).

Adult heads of households face enormous problems caring for their own health and that of their own children and dependants when they cannot afford to pay for formal health center treatment and medicines (Steinberg et al., 2002)). To cover increased AIDS-related medical costs, households often reduce spending on food, housing, clothing and toiletries (World Bank, 1999). Fortunately ART has come to ease the difficulty with which the infected caregivers can be able to access health care facilities and medication. It is within the main components of ART to have medication provided at a subsidized cost to enable even those from poor backgrounds like Kibera have access to both the ARV’s and the medication needed in the treatment of opportunistic infections. This was
available for the HIV/AIDS members enrolled in the respective ART centers. This was evident in the reasons given as being the cause for financial constraints as only a negligible number of both the HIV/AIDS infected caregivers and the ordinary caregivers gave medication as the reason for financial constraints in the households. AIDS causes household expenditures to rise as a result of medical and related costs, as well as funeral and memorial costs (Food and Agricultural Organization, 2003).

On the part of the children, the sample of the cases had a higher number of respondents (49.8%) who felt that the health status of their children was poor compared to 16.6% of the control sample. This was further confirmed by 59.8% of the control population who reported that the health status of their children was good compared to 39.7% of the cases. This was in agreement with the actual health status of the children as when asked if the children they live with have been sick for the past 3 months; respondents in the category of cases had the highest number (42.8%) reporting that their children had fallen sick in the past three months prior to the data collection.

There was a discrepancy in the percentage of children falling sick (22.6%) in the period three months prior to data collection and what the percentage of ordinary parents (16.6%) who felt that the health status of their children was poor. Comparing the two groups of children, the health status of the affected children is much poorer than that of the ordinary children even after ART intervention. Despite a majority (49.8%) of HIV/AIDS infected respondents saying the health status of children was poor; there was no correlation with duration on ART. For all the common diseases such as diarrhea and
malaria that affected both the ordinary and children living with infected caregivers, prevalence was highest amongst the Case population. These results therefore suggest that children living with people who are on ART (cases) are more susceptible to poor health. For the maximum well-being of orphans and other vulnerable children, they and their guardians need to have access to complete, relevant information and appropriate health care including clinical and preventive health care services, nutritional support, palliative and home based care. For most common diseases that affect children such as malaria and diarrhea, prevalence was highest amongst the case population.

AIDS-affected households and families experience famine or food shortages differently. Normally there is ample forewarning before an impending food shortage but even with the forewarning, the AIDS affected households had reduced coping capacity given the confounding factors brought about by HIV. For instance AIDS tends to cluster in households, generally striking individuals in their working and nurturing prime. Then children and partners become infected, and are unable to compensate for the illness of the prime breadwinner or caregivers (Baylies, 2002).

This study examined the differences in food intake among the children living in AIDS affected households and those in the comparison group. A significant 58% of the affected parents/guardians households were reported as consuming three meals per day as compared to 77% in the comparison group. From the results, 34.1% of the infected parents/guardians reported as consuming 2 meals per day as compared to only 7.5% of the comparison group. Unfortunately, no parent/guardian in the comparison group
reported as consuming one meal per day as compared to 5.7% of the infected parents/guardians. Thus findings suggest that orphans and children with infected parents/guardians have lower food intake than other children. This can be attributed to the fact that due to a family’s illness, the household may result to reduced spending on food due to increased medical costs and reduced income.

On analysis of the study data, a statistical significance of 0.155 was observed in the case group at 0.01 confidence levels, between number of meals consumed per day and the level of income, whereby the higher the income, the more likely it was for the household to consume three meals per day. On average AIDS care related expenses can absorb one third of a household’s monthly income (Steinberg *et al*, 2002). In a certain South African study, more than 5% of AIDS affected households were forced to spend less on food to cover these increased costs. Some studies indicate families may partially recover their earlier consumption levels. This was found to be the case in this study as there was a great improvement in quality of food consumed the longer a parent or guardian was enrolled on ART. Parents/guardians who had been on ART for more than one year consumed more balanced meals than those who had just been recently introduced to the therapy, mainly due to the nutritional advice they received during the various group therapy sessions they received as part of the comprehensive care services.

Encouraging though, was the fact that an almost equal percentage of both infected parents/guardians (48.9%) and comparison group (46.2%) reported as consuming balanced meals each time they ate food in their households irrespective of the number of
meals. However, it was worth noting that a higher number of infected caregivers (21.8%) reported as consuming starchy foods every time they ate in their households as compared to only 14.1% of the comparison group.

AIDS undercuts the resilience, which households and communities draw upon to cope during periods of difficulty. In the face of an external shock, poor households respond with a variety of strategies, including altering income generating activities and consumption patterns as well as calling upon family and community support (UNAIDS, 2003). This was clearly evident when 24% of infected parents/guardians admitted to involving their children in income generating activities for the purpose of obtaining food as compared to 17.1% of the comparison group. A further 33% of children living with the infected caregivers received assistance from CBOs in form of food as compared to only 15% of the comparison group. From the findings therefore, it can be concluded that a significant number of HIV/AIDS affected children living with the infected caregivers were more involved in methods of obtaining the food than their counterparts living with the healthy parents/guardians.

The stigma surrounding HIV/AIDS prevents both adults and children from talking honestly about HIV prevention and cure. This also prevents them from talking about the other topics associated with it such as illness, death and sexuality. This was evident in this study, as only a mere 35.5% of the HIV/AIDS infected parents/guardians had disclosed their status to their children. However a positive correlation was observed
between disclosure of status and duration on ART. Parents who had been on ART longer were therefore more likely to disclose their status.

There was positive correlation of 0.145 at 0.01 confidence levels in the cases between level of education and disclosure of status. Most of these parents were afraid of the stigma that may follow them and their children should they disclose their status to their children. Most studies in Africa have shown that orphans are often stigmatized against, both within foster households and in the larger community. Typically these studies show poorer nutrition and lower school enrolment among orphans (Kamali, *et al.*, 1996; Nalugoda 1997). These researchers questioned the study participants for their views on these issues. More than a quarter of adults reported that children of PLWHA and orphans are sometimes treated differently and experience a lot of stigma because of having an HIV infected persons in the households.

In this study, a negligible number of the infected parent/guardian interviewed reported stigma and discrimination as the reason for school absenteeism. This meant that their children did not experience stigma and discrimination either from the teachers or fellow students. This can be partly because only a few of the infected parents/guardians had disclosed their status to their children or other people so there was little chance of the children disclosing it to the other children as they played or the teachers getting to know of their status. Survey results show that 65.5% of the cases that were on ART had not disclosed their HIV status to their children or any of their relatives. There was however a
positive correlation between disclosure of HIV status and level of education of 0.145 at 0.05 confidence levels.

Approximately 9.5% of the control population reported that they had not disclosed their HIV status to their children. The small percentage by the control population can be attributed to the fact that most of the respondents of control population were yet to take the initiative to know their HIV status and hence did not have any thing to report on. Consequently, more HIV/AIDS infected caregivers than the comparison group took the initiative to educate their children on matters surrounding HIV/AIDS. Other sources of advice for both the affected children and the other children were the media, peers and relatives. Both groups of children were fairly informed on matters surrounding HIV/AIDS. It’s hopeful to note that the older children whose parents felt they were reasonably informed about HIV transmission and prevention have come across sexual health education messages often in conjunction with HIV/AIDS awareness messages through the media and special awareness messages.

HIV/AIDS has a wide range of psychosocial effects on children and young children that place a great emphasis on the children’s psychological and emotional needs. The psychological needs of children continue to be one of the most neglected areas of support. But the AIDS pandemic has increased the urgency to address the psychological problems of children on a par with other interventions (Donohue J, 1996). Affected children often have many physical needs such as nutrition and health care, and these can often appear to be most urgent. But they will have significant emotional needs as well as
the sickness and death of a parent is clearly a major trauma for any child. The emotional needs of the children must not be forgotten. The study findings do not suggest pronounced decline in psychosocial well being of the affected children as both affected and those children in the comparison group had time for leisure activity such as play. However, there were a higher percentage of affected children (24.5%) who had no time at all for leisure activities as compared to the children in the control group. Reasons given for this were that the children were mostly involved in income generating activities during playtime.

Studies have shown that poor households are particularly in danger of losing their economic and social viability, and eventually being forced to dissolve, with children migrating elsewhere (Rugalema, 2000). Aids affected households also appear more likely to suffer severe poverty than non-affected households (Rugalema, 2000). This was observed in the study where 15% of the infected parents/guardians reported as giving up their children to live with their relatives as compared to 9% of the ordinary parents/guardians. This difference is worth noting because it implied that a child’s residence is a major issue among the children living with HIV affected parents. Reasons given for this were the financial and food constraints experienced in the AIDS affected households.

AIDS strikes at productive adults, the asset most likely to help during a crisis (UNAIDS, 2003). AIDS affected households rely heavily on relatives and community support systems to counter the economic impact of the epidemic. These networks lend money,
provide food and assist with labor and childcare. Community support structures include savings clubs, burial societies, grain-saving schemes, loans clubs and labor exchanging schemes (Mutangadura, 2000). An AIDS affected household’s response depends on the resources it can gather together. When possible, families liquidate savings, borrow money or seek extended-family support (Food and Agriculture Organization, 2003). The membership in the various community-based organizations was higher (65.5%) for infected parents than the healthy ones (45.6%). The differences between the two groups do not occur by random variation, as people enrolled on ART were more likely to join the CBOs than healthy individuals. Through assistance from various CBOs, the members interviewed were able to get financial assistance in form of soft loans from these groups and also become members of merry go-rounds where the members contributed money on weekly basis, and take turns in receiving it.

A notable difference existed between the two groups in the form of financial assistance they received from these CBOs. More healthy individuals (12.6%) than infected (0.4%) were able to get financial assistance in the form of soft loans from the CBOs. On the other hand, ART clients were able to participate in merry go-rounds formed by the members themselves. Many felt that were it not for the fact that these merry go rounds were formed by fellow ART members, they would otherwise not be able to join. Reason given for this was discrimination from other community members who felt that HIV/AIDS positive people would die anytime hence would not be able to repay borrowed money. It is worth noting that those who were able to access and receive assistance from these welfare groups reported less financial constraints than their counter parts. Welfare
programs can help, and should be specifically targeted towards the most deprived and vulnerable households in the communities. Local institutions, such as health clinics, could identify and obtain help for impoverished households struggling with serious illness. Special care should include home visits, food and nutritional support, waiving of school fees, etc (Sauerborn, et al, 1996). Other necessary targeted initiatives include community-based programmes to provide families with direct financial assistance so that they don’t have to sell productive assets to cope with AIDS costs.

The household impact of AIDS can be especially severe when the infected individual is an adult woman. In all low and middle-income households, women and girls perform the lion’s share of social reproduction work. They raise and nurture children, perform domestic labor and take care of the sick. Households cope with epidemic’s devastation in various ways (Beegle, 2003). In Kagera, Tanzania, households that experienced a death added at least one member, perhaps because extended family members stepped in to help out (World Bank, 1999). Elsewhere, in Rakai, Uganda, households become relatively smaller, possibly because children were sent to relatives, or adults left to search for employment (World Bank, 1999). In this study, the children were greatly involved by both the HIV/AIDS infected and healthy parents. Their involvement was mainly in substituting family income through participation in IGAs, contribution in methods of obtaining the food; seeking assistance in various CBOs, parents received assistance in school mainly through subsidized education. Both the case and control parents and guardians equally involved their children in IGAs, the main activities being hawking and providing their services for a pay that they would later give to their parents/guardians to
add to the household income. Notably was the fact that the children living with the infected parents (33%) were able to access CBO assistance more than the other children (15%). The type of assistance received was mainly in the form of food. In this study also, there was no discrimination observed between the sexes for both affected and ordinary children. Both boys and girls were equally involved in household duties that included taking care of their siblings, washing, and cooking. The older children were more involved in these activities than the younger ones, which in turn left the younger ones with more time for leisure.
6.1 Conclusions

- HIV/AIDS infected parents and guardians in Kibera were leading more active lives than they would normally, a fact that can be attributed to the comprehensive care they are receiving from the various health facilities in their localities. Most of the comprehensive care clients felt that the ARV’s and the group therapies were the main components of comprehensive care they had benefited greatly from.

- The children living in the HIV/AIDS affected households in Kibera slums were still more prone to financial constraints, more susceptible to poor health, and experience more school absenteeism. However, an improvement was reported in the quality of meals consumed in the household and overall well-being of the HIV affected children.

- Various coping mechanisms were adopted by the HIV/AIDS infected parents and guardians that included, getting assistance in schools, joining various support groups from where they were able to get assistance in the form of food, medication, membership to merry go rounds, and psychological assistance in the form of group therapies. Other coping mechanisms involved seeking assistance from the children living in their households in the areas of daily household chores, and methods of obtaining food. Children involvement was not significantly different for both the affected children and the ordinary children. This suggested a shift from the ordinary where HIV/AIDS affected children had to actively participate in ways of substituting family income and in taking care of ailing parents and guardians.
• The magnitude of the differences between the affected and ordinary children in Kibera slums was not very large, generally ranging from 7-15 percent except in a few cases. The impact of the comprehensive care therefore was already being felt in most of the HIV/AIDS affected households. However a lot more still needs to be done to ensure the impact of HIV is still further reduced in the affected children.

6.2 Recommendations

• Most of the comprehensive care programs have made little or no effort on the part of the children. There is therefore need to change the comprehensive care package policies for interventions to include children affected by HIV/AIDS. One way to reach children early is to link programs for children affected by AIDS with care and support programs for PLWHA. This link will strengthen the responsiveness of care and support programs by addressing a top concern expressed by PLWHA: the future welfare of their children.

• Many HIV/AIDS guardians were poor and constantly faced financial constraints. Financially empowering this group of people will improve/prolong the capacity to care for the children affected by HIV/AIDS. Those offering the comprehensive care programs should therefore consider including material support whether in the form of income generating projects or a money-lending scheme in the form of soft loans they can use to start up projects or otherwise which will greatly assist the clients and hence the HIV/AIDS affected households.

• The comprehensive care programs should also include a package for the parents that will help them make necessary arrangements for their children to assist them cope in
times of illness and death. This includes issues like education, how to survive in their absence, preparation of Wills, and in choosing guardians to take care of their children.

6.3 Areas for Further Research

7. REFERENCES


UNAIDS Central Executive Board, CEB/2003/HCLP/CRP.27. (2003). Organizing the UN Response to the Triple Threat of Food Security, Weakened Capacity for Governance and AIDS.


# 7.1 Work Plan

## May 2005 - Jan 2008

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7.2 Budget

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I am a student at Kenyatta University from the school of Pure and Applied Sciences. I am carrying out a research on; The Impact of Comprehensive Care for HIV/AIDS Infected Parents/Guardians on the Affected Children. You have been Chosen as one of the participants of the study.

Please assist me by answering the questions as accurately as possible. There will be confidentiality of the information given. It will be used for academic purposes only.

Thank you for your cooperation.

KEY INFORMANT NUMBER..............................
INTERVIEWER...........................................
DATE.....................................................

General information

1. What is your Gender?
   a. Male
   b. Female

2. What is your date of birth? Day /Month /Year

3. What is the highest level of education you received?
   a. None at all
   b. Primary school
   c. Secondary school
   d. Tertiary

4. What is your marital status?
   a. Single
   b. Separated
   c. Married
   d. Divorced
   e. Other

5. What religion are you?
   a. Christian
   b. Muslim
I am a student at Kenyatta University from the school of Pure and Applied Sciences. I am carrying out a research on; The Impact of Comprehensive Care for HIV/AIDS Infected Parents/Guardians on the Affected Children. You have been chosen as one of the participants of the study.

Please assist me by answering the questions as accurately as possible. There will be confidentiality of the information given. It will be used for academic purposes only.

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KEY INFORMANT NUMBER.................................
INTERVIEWER....................................................
DATE..............................................................

General information

1. What is your gender?
   a. Male
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2. What is your date of birth? Day /Month /Year

3. What is the highest level of education you received?
   a. None at all
   b. Primary school
   c. Secondary school
   d. Tertiary

4. What is your marital status?
   a. Single
   b. Separated
   c. Married
   d. Divorced
   e. Other

5. What religion are you?
   a. Christian
   b. Muslim
c. Hindu
d. Other
6. How many People are you living with in your household?
   a. one
   b. Two
   c. Three
   d. Four
   e. Five
   f. Other (Specify)
7. How many children below the age of 18 are you living with in your household?
   (Please indicate their age, sex and status.)
   a. Child Sex Age Status own/relative/orphan
   b. Child Sex Age Status own/relative/orphan
   c. Child Sex Age Status own/relative/orphan
   d. Child Sex Age Status own/relative/orphan
   e. Child Sex Age Status own/relative/orphan
   f. Other

This section asks questions regarding the socio-economic status of your household
8. Are you the main breadwinner of your household?
   a. Yes
   b. No
9. If not, what is your relationship with the main breadwinner? (Specify)
   a. Spouse
   b. Relative
   c. Live-in partner
   d. Friend
   e. Other
10. Are you a member of any support group in this community?
    a. Yes
    b. No
11. Do you get any help from the group?
   a. Yes
   b. No

12. If Yes, which one? (More than one answer is allowed?)
   a. None
   b. Medication
   c. Nutritional support
   d. Counseling (Group Therapy?)
   e. Other

13. What is your Occupation?
   a. Work at home
   b. Salaried employment
   c. Self employment
   d. Other

14. For how long have you been on Antiretroviral Therapy?
   (Specify) ........................................

15. What kind of assistance do you receive from the respective ART groups
   a. Drugs
   b. Counseling
   c. Home Visiting
   d. Food supplementation
   e. Other

16. What is the main source of income in the household?
   a. Self-employment
   b. Salaried employment
   c. None
   d. Other

17. What is your average monthly income?
   a. Less than 2000
   b. 2000-5000Ksh
   c. 7500-10000Ksh
18. Do the children you live with assist in housework?
   a. Yes
   b. No
   c. Don’t Know

19. If Yes, how? (Please tick appropriately)
   a. Cooking
   b. Washing
   c. Caring for the sick family members
   d. Taking care of younger children
   e. Others (Specify)

20. Do the older children in the household substitute family income?
   a. Yes
   b. No

21. If yes, what activities are they mostly engaged in?
   a. Hawking goods such as groundnuts
   b. Providing their services
   c. Other (Specify)

22. What do you do to cope with the difficulties you are experiencing in meeting the needs of your household?
   a. Looked for support from community organizations
   b. Asked for help from relatives
   c. Asked for assistance from able members of the household
   d. Other (Specify)

This section asks questions regarding food intake in your household

23. How many meals are you able to afford for your household per day?
   a. One
   b. Two
   c. Three
   d. None
24. If none, explain why
   a. Can't afford
   b. Scarcity of food
   c. Out of habit
   d. Other

25. What are the most common foods consumed in your household?
   a. Ugali, porridge, matoke, yams, cassava rice
   b. Spinach, saget, sukumawiki, bananas, avocado
   c. Eggs, beans, kunde, liver, milk
   d. Others (specify)

26. How do the children you are living with get food and methods of obtaining the food?
   a. Grow the food
   b. Borrowing from friends and relatives
   c. Work to obtain money to buy the food
   d. Are given by charitable organizations
   e. Other

This section asks questions regarding your children's school attendance

27. How many of the children you are living with are enrolled in school?
   a. One
   b. Two
   c. Three
   d. All
   e. None

28. Are they usually absent from school?
   a. Yes
   b. No

29. If yes, how often are they absent from school?
   a. One day per week
   b. Two days per week
   c. Three days per week
d. Four days per week  
e. Don’t go to school

30. What is their reason for their being absent from school?  
a. Needed to assist at home  
b. Has been sick  
c. Parent/guardian was sick or had died  
d. Lack of school fees  
e. Teachers/students/school not welcoming  
f. Other

31. Do you receive any assistance for school fees and supplies?  
a. Yes  
b. No

32. If yes, what type of assistance was provided?  
a. Payment of school fees  
b. Reduction of school fees  
c. Waived off school fees  
d. Provision of stationery and uniforms  
e. Other

33. Who provided the assistance?  
a. Partner  
b. Parent/guardian of the child  
c. School authorities  
d. Relatives  
e. Other

34. Do the children you are living with have opportunities for leisure activities like sports?  
a. Not at all  
b. A little  
c. Moderately
This section asks questions regarding the health status of your children

35. How would you rate your children’s health status?
   a. Very good
   b. Good
   c. Poor
   d. Don’t know

36. In the past three months, have any of your children been sick for more than three consecutive days?
   a. Yes
   b. No
   c. I don’t know

37. If yes, how many children?
   a. One
   b. Two
   c. Three
   d. Other
   e. All

38. What were they suffering from?
   a. Malaria
   b. Diarrhea and vomiting
   c. Respiratory infections
   d. Other (specify)
   e. Don’t know

This section asks questions regarding your children’s psychosocial wellbeing

39. What particular problems do you think the children may be facing (more than one answer is allowed)
   a. Lack of financial support
b. Poor school attendance  
c. Lack of quality food  
d. Poor health care  
e. Lack of skills training  
f. Stigma from the community  
g. Adjustment to a new home  

40. Do the children you are living with have a regular place to live?  
   a. Yes  
   b. No  
   c. I don’t know  

41. if no, what is the reason?  
   a. Frequently taken up by relatives for care  
   b. Long distance to school hence don’t always come home  
   c. Have been taken up by charitable organizations  
   d. Other(specify)  

42. Have you disclosed your status to your children?  
   a. Yes  
   b. No  

43. What is the main source of advice for your children?  
   a. Self  
   b. Marital partner  
   c. Relative  
   d. Peers  
   e. Other  

44. How well do the children you are living with understand the knowledge and awareness of HIV/AIDS?  
   a. Very poor  
   b. Poor  
   c. Good  
   d. Very good  
   e. Don’t know
45. How would you rate the quality of life of your children?
   a. Very poor
   b. Poor
   c. Neither poor nor good
   d. Good
   e. Very good

46. Do you have any comments about this assessment?

........................................................................................................................................................................................................................................................................................................
........................................................................................................................................................................................................................................................................................................
........................................................................................................................................................................................................................................................................................................

Thank you
7.5 Chi Square test result table

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NB. * Statistical chi-square value for each sample
I am a student at Kenyatta University from the school of Pure and Applied Sciences. I am carrying out a research on; The Impact of Comprehensive Care for HIV/AIDS Infected Parents/Guardians on the Affected Children. You have been Chosen as one of the participants of the study.

Please assist me by answering the questions as accurately as possible. There will be confidentiality of the information given. It will be used for academic purposes only.

Thank you for your cooperation.

1. What are the main problems experienced in the households where there re PLWHA?

2. How have the parents or guardians living with these children tried to adapt to be able to meet the needs of the affected children?

3. According to you, do you think the comprehensive care received by these parents or guardians has assisted them in meeting the needs of the affected children?

Thank you for your cooperation.
7.7 Case Population Correlations

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** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).
### Case Group Correlations Continued

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**Correlation is significant at the 0.01 level (2-tailed).**
**Correlation is significant at the 0.05 level (2-tailed).**
## Control Group Correlations

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* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).
Control Group Correlations continued

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<th></th>
<th>membership to support group</th>
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<th>Any assistance for school fees/supplies?</th>
<th>rating of children's quality of life</th>
<th>have you disclosed status to children?</th>
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