

**A STUDY ON THE CHALLENGES FACED BY CHILDREN INFECTED  
WITH HIV: THE CASE OF CHILDREN ON THE SOS CHILDREN'S  
VILLAGES COMMUNITY OUTREACH PROGRAMME (GLEN VIEW,  
GLEN NORA AND BUDIRIO)**

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## **ABSTRACT**

The aim of the study was to establish the challenges faced by HIV infected children. The objectives of the study were to ascertain health, education and psychosocial needs and problems of children infected with HIV, to establish how children infected with HIV are benefiting and helped to cope through the SOS Children's Villages outreach community program and to find out the challenges faced by SOS Children's Villages in providing services to HIV infected children. The study was carried out in three high density suburbs in Harare. Thirty four children infected with HIV and seven key informants formed the respondents. The responses generally show that the needs of HIV children infected include access to basic food, health fees assistance, and school fees assistance, access to counselling and support group services and clothing. The major problems that the child participants noted included continued ill health, drug shortages, limited access to psychosocial support services such as counselling services, stigma and discrimination and anxiety about what will happen in the future. It was recommended that collaborative efforts be strengthened between relevant government ministries, and non state actors to ensure increased availability of basic food and other services such as drugs, school fees and psychosocial support services so as to meet fully the needs of HIV infected children and promote their growth. Other recommendations include improved linkages and networking of all partners in HIV/AIDS service provision so as to ensure complimentary service provision thereby avoiding duplication of activities to the same target population. These among many other issues are discussed in the dissertation.

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## **DEDICATION**

I dedicate this study to my daughter Darleen Tanatswa Mupfanchiya , my husband Augustine Mupfanochiya , my father Mr BT Rugaranganda , my father in law Mr M Mupfanochiya, my mother Mrs J. Rugaranganda, my two sisters Chata and Beaula. Your love and support shall always be cherished forever more. You are the pillars of my strength and the anchor of my life.

## KEY DEFINITIONS

- **Acquired Immune Deficiency Syndrome (AIDS)** is defined as means that the body loses the ability to fight infections because the immune system is weakened by the HIV virus.
- **Antiretroviral Drugs (ARVs)** are medicines that can be given to prolong the quality of life for people living with HIV/AIDS. They improve the immune system and slow the progression of HIV to AIDS and reduce opportunistic infections.
- **Antiretroviral Therapy (ART)** refers to the correct provision of ARVs with adherence support and all the appropriate care that includes several components such as nutrition, counselling, treatment of opportunistic infections and infection control.
- **Child** is defined as any person below the age of 18.
- **Children Living with HIV/AIDS (CLWHA)** are persons below the age of eighteen who have been diagnosed to be having the HIV and AIDS virus; these can be in any of the HIV staging either stage one to five.
- **Epidemic** refers to an outbreak of disease on a scale not normally seen in a given population.
- **Human Immune Deficiency Virus (HIV)** is the virus that causes AIDS (Jackson, 2000).
- **Informed Consent** is defined as the agreement with or permission from a person, e.g. for a procedure, after they have understood clearly what the decision means.
- **Orphan** refers to a child both of whose parents have died.

- **People living with HIV and AIDS (PLWHA)** are persons who have been diagnosed to be having the HIV and AIDS virus; these can be in any of the HIV staging either stage one to five.
- **Multidisciplinary** is an approach actively involving different disciplines (e.g. medicine, demography, social work, psychology etc).
- **Multisectoral** is an approach that actively involves different sectors e.g. agriculture, health and includes Government, Private Enterprises, NGOs and other players.
- **Support Group** refer to a group of people with the same problem coming together to provide each other with psychological, social, emotional, spiritual, material or other support.

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## **CHAPTER ONE**

### **1.0 INTRODUCTION**

This chapter discusses the background of the problem, the problem statement, significance of the study and a definition of terms.

### **1.1 BACKGROUND INFORMATION OF THE STUDY**

Human Immuno Virus (HIV) which leads to AIDS (Acquired Immuno Deficiency Virus) has been the worst chronic disease of the twenty-first century .The first case of AIDS in Zimbabwe was identified in 1985 (Zimbabwe HIV/AIDS Policy, 1999).

Since then, the problem of AIDS has continued to grow at alarming rates. The chronic condition has no cure and continues to threaten human life (UNAIDS, 2010). Vast numbers of children across the world have become and are still being infected by the virus every year. Methods of HIV infection include; through sexual contact, blood transfusion, sharing of sharp objects and from mother to child during birth or through breastfeeding. Mother to child transmission (perinatal transmission) is the most common cause of paediatric HIV infection accounting for more than 90% of the infections (Jackson, 2002).Children and young people may also acquire HIV horizontally through unprotected sexual intercourse with an infected person or during sexual abuse. In 2007 reports show that 2 million children were infected with HIV and of these two thirds lived in Sub-Saharan Africa with 120 000 living in Zimbabwe (UNICEF, 2007).

In the past children infected with HIV were thought not to survive longer than five years, especially if treatment was absent. Recent research has proved this theory wrong.

Researchers based at Counnaught Clinic in Harare released results reflecting that children infected by HIV could survive into adulthood even in the absence of medical care and therapy (SAfAIDS, 2006).

Failure to acknowledge that children infected with HIV at birth could live into adulthood has led to a gap in HIV infected child based intervention activities. Service provision has been biased towards adults and the under fives. More, so there are issues to do with the appropriateness of ART to these young children if one is to consider that treatment plan has been drawn from adult treatment plan. Paediatric ARV formula remains few. Hence, to date child friendly medication is still lacking (SAfAIDS, 2009).

A closer analysis of the trends in opportunistic infections clinics (OI) shows much less children visiting the centers compared the estimated number of children infected with HIV. More so, Zimbabwe continues to have a few state funded pediatric OI clinics. This poses a challenge to the management of pediatric infections.

HIV is a reality faced by children (Plan International, 2006). Like any other adults who are HIV positive they too suffer directly through continued ill health, stunted growth and delayed puberty for some. This breeds psychological trauma resulting in feelings of anxiety, depression and distress.

Children infected with HIV are not spared the stigma and discrimination that adults face. Society, especially other children may shun them, laugh or give them nicknames due to their distorted physical appearance. For example children on ART may have thin legs, a bellied stomach and fat around the cheeks. Such distortion of physical appearance is at times a result of the complicated dynamics of the HIV or the side effects of anti-retro viral treatment tablets.

Late diagnosis and disclosure among children infected by HIV is also of great concern. Guardians are usually reluctant to take their children for Voluntary Counseling and Testing (VCT) and even when they do, disclosing to their children may be delayed. Children therefore have to live in anxiety and psychological stress suspecting they may be infected by HIV. When they get to know it still makes it no better. Children continue to feel isolated and unable to talk about their problems outside the home because of the shame associated with being infected by HIV and AIDS.

Participation in development activities and other mainstream activities can be a challenge for HIV positive children. Mainstreaming of such children into community activities designed for the orphaned and vulnerable children needs to be taken with caution. Ill health, fatigue and disabilities (loss of sight, hearing etc) due to the virus can inhibit the children's ability to take part in age appropriate activities (SAFAIDS, 2006). Despite lack of school fees they may fail to attend school classes due to ill health. This makes them a special group among the orphaned and vulnerable category that needs safeguarding and protection against social exclusion in societal developmental activities. Hence, well thought out and designed participatory techniques should be used to maximize HIV infected children's involvement in community activities.

Overall progression of HIV is more rapid in children because of their weak immune system yet issues of HIV cure remains elusive to date (UNICEF, 2007). Currently Antiretroviral drugs are the scientifically proven method of treatment. Antiretroviral Treatment (ART) is the administration of Antiretroviral drugs which suppress further multiplication of the HIV virus, thereby prolonging the ability of the body's immune system to resist and fight against opportunistic infections (OIs).

Accessibility and affordability of ART treatment remains another challenge faced by children living positively in sub-Saharan Africa (SAfAIDS, 2009). The Church World services reports that only 5% of people in the developing world who need lifesaving AIDS medications have access to them. Reasons for limited access vary from treatment being expensive, prevalence of non favorable trade laws to inadequate resources and or unavailability of resources. For a country like Zimbabwe currently characterized by poor economic performance, a low level of donor funding and limited access to international borrowing the extent of the problem is worse. This surely complicates the life of any person living with the virus children included.

Accessibility to ART is also limited due to constrained human and financial resources. Health system continues to suffer brain drain of qualified professionals. This makes the life of an HIV positive person in sub –Saharan Africa complicated and what more for a child whose life depends on the adult caregiver who themselves (adult) may also be struggling to survive as they may also be infected by the disease and or without means of earning a living. This is best described by Safman (2004) when he states that children are typically more vulnerable than adults in times of family crisis as they lack the resources to distance themselves from problems in the home.

Children infected by the virus also suffer the effects of loosing either one or both of their parents leaving them orphaned and vulnerable to the economic, psychological and emotional trauma that comes with being orphaned (UNICEF, 2007). For some they are subjected to experience living in child, sibling headed or grandparent headed households. In such households hunger, lack of parental control, guidance, clothing, medication and school fees to mention but a few, characterize their pattern of daily living. In Africa over eleven million children have lost at least one parent to the disease, hence the sprouting of such type of households (Church World Services, 2008). They also become susceptible to

child abuse and exploitation as they are forced to do anything to earn a living and bring food on the table.

As the cure of HIV/AIDS remains elusive, there is need for continued integrated effective intervention strategies. The political and civic leadership need to advocate for policy review and change, speak out against HIV based stigma and discrimination, encouraging HIV testing that is voluntary and confidential, devising comprehensive health care systems backed by home based care educational programs, improved nutrition and economic security, and accessibility to life-extending antiretroviral medication. Panjabi (2005) stresses the importance of advocating for a human rights approach which includes social and economic rights as opposed to political and civil rights in the fight against AIDS.

Some community stakeholders are coming up with strategies to intervene through the formation of support groups , provision of free access to ART, nutrition and herbal gardens projects among many others for HIV affected households .However issues to do with the effectiveness of such activities to the infected children, still needs to be looked at. This paper will therefore look into the challenges faced by children infected by HIV.

## **1.2 STATEMENT OF THE PROBLEM**

Zimbabwe is faced by a growing number of HIV infected children. The HIV infected children are more likely to be orphaned, in care of grandparents and or chronically ill parents with limited financial resource (Plan International, 2006). This weakens the guardian's ability to fully provide for the needs of HIV infected children thereby exposing them to problems such as lack of basic food, clothing, school fees, medication fees among others. The HIV condition further complicates the plight of HIV infected children in a number of ways among which includes susceptibility to opportunistic infections such as pneumonia and tuberculosis (TB) as the virus progresses and continues to weaken the immune system and also the need to depend on ARV drugs as no cure has been found to date. The government of Zimbabwe has over the years come up with a number of strategies to help meet the complicated needs of HIV infected children. However, the governments' ability to fully respond to the plight of HIV infected persons has been jeopardised by limited human and financial resources, a situation that has been perpetuated by the current economic melt down. The private sector and various other NGOs have joined the government in helping alleviate the problems faced by HIV infected children. However, due to the magnitude and extent of the problem; and economic challenges faced in the last 10 years, the private sector and NGOs have also been unable to fully respond to the problem. One such NGO is SOS Children's Villages which offers school fees assistance, food and health fees assistance to HIV infected children. This study therefore seeks' to establish the challenges faced by HIV infected children, how the children are benefiting from SOS Children's Villages community outreach program and the challenges that SOS Children's Villages face as an organisation in helping infected children meet their needs.

### **1.3 JUSTIFICATION**

The number of HIV infected children in Zimbabwe is expected to continue to increase despite a decrease in the HIV prevalence rate. This is because of strengthened immune system as a result of ARV leading to extended life expectancy and decreased mortality (UNAIDS, 2010). The experience of coping with a life threatening disease is one of the most distressing life events that a child has to face. It therefore becomes imperative to undertake a study on the challenges faced by HIV infected children so as to understand their experiences of living with HIV. A number of studies have already been carried out and this study aims to complement data already gathered. The study also seeks to discover if there are new psychosocial, health and educational emerging issues. Literature built through the study will help SOS Children's Villages and other organizations better understand conditions of children infected with HIV which will help them strengthen the support mechanisms targeted at their clients. More so the findings of the research will build on what is already known about the health, educational and psychosocial wellbeing of children infected with HIV. It will also help the government and policy makers in shaping current support mechanisms.

#### **1.4 AIM:**

To establish challenges faced by children infected with HIV.

##### **1.4.1 OBJECTIVES:**

- To ascertain health, education and psychosocial needs of children infected with HIV.
- To establish health, education and psychosocial challenges faced by HIV infected children in the quest to manage their sickness.
- To establish how the children infected with HIV are benefiting and helped to cope through the SOS Children's Village Community Outreach program.
- To establish the challenges SOS Children's Village faces as an organization in assisting children infected with HIV.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.0 INTRODUCTION**

This Chapter focuses on literature review of various theories and studies on the challenges faced by HIV infected children.

#### **2.1 THEORETICAL FRAMEWORK**

HIV and AIDS are complex issues causing an array of challenges which can not be comprehensively explained by lone factors. Consequently a number of theories biomedical, psychosocial, social and structural in nature have been put across to explain factors influencing or underlying how people respond to HIV/AIDS and likewise, challenges that they face as a result of their HIV status.

##### **2.1.1 The Contagionism Theory**

A number of ideological perspectives have been put forward with regards to prevalence and incidence of diseases. The type of ideology adopted by a particular society affects how communities perceive and respond to the health needs and challenges faced by a particular group of people. It also influences the design and implementation of health related policies. Agere (in Mandaza, 1986) identified two ideological perspectives which can influence health policies. These he termed the “contagionism and anti-contagionism” theory. The contagionism theory is also known as the biomedical model (Giddens, 2009). Contagionism ideology postulates that disease is caused by germs and spread by movement of populations. According to this theory the diseased individual can only get better by receiving treatment in the form

of drugs. Emphasis of the model is on the physical component of health and curative medicine i.e. ARVs for HIV/AIDS patients.

Contagionism theory can have negative or positive effects on the lives of the sick.

One of its major strengths is recognition of the importance of medical treatment services for the sick. It also stimulates the need by the sick to seek medical treatment in the hope to get better. When viewed in the context of HIV, contagionism theory has the ability to influence government to come up with favourable policies for the treatment of HIV infected individuals. This includes drawing up financing plans for HIV treatment, therapy and prevention services. More so, adoption of contagionism theory by communities opens room for increased adherence to HIV treatment and increased need for voluntary counselling and testing services in the hope to get early treatment and prolong life.

The negative effects of adopting the contagionism theory can be seen in its weaknesses. Gumbo in (Hall and Mupedziwa, 1995) outlines the weaknesses of the contagionism model as follows:

- a) It assumes that the individual is solely responsible for getting ill-health. In a way the theory has some elements of placing blame on the sick. This can result in the creation of an environment that stigmatises and discriminates the sick. (Giddens, 2009) reports that links between particular lifestyles and risks of HIV infection have led to stigmatisation of various HIV infected groups in the society such as the gay men; and women with a background of prostitution and their children.
- b) It is also argued that the contagionism theory promotes dominance of doctors in the medical profession on management of ill-health at the expense of other

professionals such as social workers and other social scientists who can also contribute to the well being of patients. The theory lacks acknowledgement of behavioural science in contributing to the physical, social and mental well being of the sick. For the HIV infected individual, contagionism theory limits therapy to purely medical profession and ignores other factors such as the social, political and economic issues that can also affect the overall well being of the sick.

- c) Application of the contagionism theory has proved difficult in third world countries due to lack of adequate highly trained manpower, modern technology and prohibitive costs of medical care as a whole. Considering the high cost of HIV medical treatment and therapy, the contagionism approach falls short as the sole lone model that can be used to fully understand and respond to the needs and challenges faced by HIV infected persons. Mancoske and Smith (2004) state that HIV treatment costs remain high the world over. Most third world countries continue to face financial and human resources constraints. This has affected their ability to fully respond to the ART needs of HIV infected people.

### **2.1.2 The Anti-Contagionism Theory**

The anti –contagionism theory tries to address the deficiencies of the contagionism theory. Proponents of the theory go beyond the individual and look at how other external environmental factors that may perpetuate ill health. According to Gumbo (1995) anti-contagionism theory puts emphasis on how the social, political and economic environment can affect one's health. The theory states that ill health can be caused by a host of inter-related factors, such as poverty which may result in overcrowding, poor environmental hygiene, lack of health education and malnutrition.

Its strength lies in recognising the importance of addressing wider social, political and economic issues such as oppression, social classes and economic classes in helping individuals or crippling them to attain full health. In order to achieve full health, this model advocates for the revamping of social and political systems that lead to oppression of people, mass health education to conscientise people on causes of ill health and an attack of the social environment that causes illness.

The theory provides a relevant approach to understand the dynamic needs and challenges of HIV infected children. The theory helps in understanding how the environment can influence lives of the sick (HIV infected persons) as they battle to cope with their illness. For example, the effects that socio economic status has in influencing access to basic goods and services such as drugs and food. In a way anti-contagionism theory can influence adoption of health policies that address various environmental factors that impact positively or negatively on the lives of HIV infected persons. This may include policies on increasing accessibility of health services through provision of medication subsidies for the chronically ill, supplementary feeding programs for the chronically ill, policies against stigma and discriminations among many others. Thus the anti –contagionism model is another pragmatic model that can be used to understand needs and problems of HIV infected persons especially children.

### **2.1.3 The Ecological Systems Theory**

The theory is founded on the continuous interaction between the person and the environment. Proponents of the ecological systems theory argue that to study any component of the environmental system i.e. a child, there is need to look beyond the

child and consider the interactions between the child's immediate family environment and wider community. Proponents of this theory argue that interactions between factors in a child's maturing biology, immediate family or community and the societal landscape fuels and steers how the child develops. The environment is seen as comprising of layers which are interrelated and is divided into four categories namely the microsystem, mesosystem, exosystem, and the macrosystem. Changes in any of the environmental layers (family, community, and society) will thus have a rippling effect on other layers.

The *micro system* is defined as the layer closest to the child and containing the structures with which any individual i.e. the child has direct contact. Structures in the micro system include family, school, neighbourhood, or childcare environments e.t.c. At this level, interactions between a child and his immediate surroundings have two directions - away from the child and toward the child (Berk, 2000). For example, a child's parents may affect his/her beliefs and behaviour; likewise, the child may also affect the behaviour and beliefs of the parents. Bronfenbrenner (1990) termed these *bi-directional influences*, and stated that these occurred at all levels of the environment. At the micro system level, bi-directional influences are strongest and have the greatest impact in shaping the behaviour and growth of a child.

The *mesosystem* is defined as the layer that provides the connection between the structures of the child's micro system (Berk, 2000). Examples include the connection between the child's teacher and his parents, between his church and his neighbourhood, etc. While the exosystem is the layer that defines the larger social system in which the child does not function directly. The structures in this layer impact the child's development by interacting with some structures in the child's

micro system (Berk, 2000). Parent workplace schedules or community-based family resources are examples. The child may not be directly involved at this level, but he does feel the positive or negative forces involved with the interaction with his own system. Thus loss of employment by parents may affect access to basic needs and services for HIV infected children which may include food, education and health services. The *macrosystem* is the layer that may be considered the outermost layer in the child's environment. While not being a specific framework, this layer comprises of cultural values, customs, and laws (Berk, 2000). The effects of larger principles defined by the macro system have a cascading influence throughout the interactions of all other layers. For example, if it is the belief of the culture that parents should be solely responsible for raising their children, that culture is less likely to provide resources to help parents. In such cases HIV positive children and or orphaned children in care of non biological guardians may receive less attention and care as the guardian may feel it is the parent's responsibility to care for their children. This in turn, affects the structures in which the parents function. The *chronosystem* encompasses the dimension of time as it relates to a child's environments. Elements within this system can be either internal or external such as the physiological changes that occur with the aging of a child, or the timing of a parent's death. As children get older, they may react differently to environmental changes and may be more able to determine how that change will influence them. For example as HIV positive children mature into adolescent stage their needs and concerns may differ from those of younger children.

The ecological systems bi-directional relationships are important in helping one understand the needs and challenges faced by HIV infected children. Bi-directional relationships between an HIV positive child and their environment can impact

negatively or positively on their lives. For example, continued ill health due to HIV infection may lead to missing school and participation in social and sporting games. Lack of love and experiences of stigma at household and community level can result in the development of low self esteem among children. Other effects can be access to financial resources at household and national level which may affect how HIV positive children may access basic services such as food and health; lack of adequate psychosocial support services which may also leave children with unresolved grief over loss of good health. Positive effects of environmental interactions may include increased child specific interventions as a reaction to growing needs and demands of children i.e. increased provision of psychosocial support services such as counselling and support groups which in a way help HIV positive children cope and understand their terminal illness and provision of child supplementary feeding schemes thereby helping HIV infected children meet their dietary requirements for quick and speedy recovery. Thus the ecological systems theory helps in the understanding of how interactions between the environment and the individual can negatively or positively influence the lives and development of HIV infected children there by aiding or complicating their ability to meet their needs.

#### **2.1.4 Structural Functionalism theory**

According to structural functionalism theory the society functions as a system with interrelated parts which are dependent on each other to achieve maximum function (Haralambos and Holborn, 1995). To understand any part of the society such as the family or religion that part must be seen in relation to society as whole. This therefore involves examination of the relationship between the different parts of the structure and the society as a whole. The society is defined as made up of different structures

such as the family, economy, political and educational systems. The different structures have different functions i.e. the family has an important role in socialising the society, while the educational structure or institution is responsible for providing formal education, and the health institutions have a role to play in provision of health services. All these structures and institutions have complimentary roles which help maintain a balance in the way society functions. A breakdown in any part of the system affects the overall function of the whole societal system. According to the functionalism theory if a society is to survive its various parts must have some certain degree of compatibility. If one part does not fit the overall function of the whole system is affected.

The functionalism theory can help in understanding how a breakdown in family systems due to increased deaths of parents' can affect socialisation of children and impact negatively on other structures in contact with children i.e. education and health system. Structural functionalism also helps in understanding the various response strategies that a society can come up with in adjustment to the negative effects of HIV so as to ensure the whole systems maintains equilibrium and continues to function in a compatible and sustainable way. The Zimbabwean Government's National Orphan Care Policy was one of government response policies to the growing numbers of orphans due to HIV/AIDS.

### **2.1.5 Maslow's Hierarchy of Needs**

Maslow's theory on hierarchy of needs forms part of the theories that can be used to understand the needs and challenges faced by children infected with HIV and AIDS. The Hierarchy of needs is a pyramid depicting the levels of human needs that is, psychological and physical. At the bottom of the pyramid are the "Basic needs or Physiological needs" of a human being, food and water and sex. The next level is "Safety Needs", which encompasses the need for security, order, and stability Maslow states that these two steps are important to the physical survival of a person. Once individuals have basic nutrition, shelter and safety, they attempt to accomplish more. The third level of need is "Love and Belonging," which are psychological needs; when individuals have taken care of their physical needs, they are ready to share themselves with others. The fourth level is achieved when individuals feel comfortable with what they have accomplished. This is the "Esteem" level, the level of success and status (from self and others). The top of the pyramid, "Need for Self-actualization," occurs when individuals reach a state of harmony and understanding (Simmons, Irwin and Drinnien, 1987). Failure to meet requirements of any of the above mentioned levels results in a crisis among human beings thereby compromising growth into the next level. When looked at in the context of children infected with HIV, Maslow's hierarchy of needs help us understand the priority needs of HIV infected children.

### **2.1.6 Attitude and Behaviour Theories**

Goffman (1963) defined stigma as the process by which the reaction of others spoils normal identity. His theory on stigma states that stigma is an attribute, behaviour or reputation which is socially discrediting in a particular way causing individuals to be

mentally classified by others in an undesirable, rejected stereotype rather than in an accepted normal way. Falk (2001) describes stigma as based on two categories namely existential stigma and achieved stigma. He defines “existential stigma” as stigma derived from a condition which the target of stigma did not cause or over which he has little control. This qualifies the type of stigma faced by children infected with HIV as they have limited control towards prevention of such infection. On the other hand achieved stigma is defined as stigma that is earned because of conduct or because one contributed heavily to attain the stigma in question.

In a way stigma results in labelling of particular groups of the society. Once people identify and label ones’ differences, others will assume that it is just how things are and the person will remain stigmatised until stigmatising attribute is undetected. Stigma is a form of labelling and labelled persons are therefore subjected to status loss and discrimination .For those infected with HIV this may take the form of nicknames, isolation, denial of ones rights and lack of friends .The result being psychological distress of the stigmatised group and or persons. In children, experiences of stigma may take toll on ones self esteem, academic achievement and can result in one being withdrawn from mainstream society. In environments where people are likely to experience stigma individuals may devise various methods to avoid stigmatisation which may include non disclosure of HIV status to others. Reece, Tanner, Karpiak and Coffey (2007 ) research findings reflected that social stigma prevented people living with HIV from revealing their status to others causing serious health concerns to both the stigmatised and stigmatiser which included poor drug adherence, delayed disclosure and unsafe sexual practice. Garanganga (2009) in a focus group discussion with children infected with HIV, the child respondents reported fear of stigmatisation as one of the reasons for non disclosure of HIV status

to friends. However, it is equally important to note that the stigmatised will always seek various ways to cope with the stigma.

### **2.1.7 Social Labelling theory**

The theory is concerned with how the self-identity and behaviour of individuals may be determined or influenced by the terms used to describe or classify them, and is associated with the concept of a self-fulfilling prophecy and stereotyping. The social labelling theory states that when individuals are labelled by society they seek ways to cope, and one way is to accept this label as a part of them (Becker, 1963). According to this theory labelling can influence affected persons to start thinking of themselves as the labelled behaviour, leading to the highly likelihood of acting as labelled. In a way this can be a coping strategy for the affected individuals. For individuals infected with HIV, social withdrawal and self exclusion from participating in social activities can be as a result of being labelled non productive.

Over and above it still remains clear that an array of theories can be used to understand the dynamic needs and problems faced by HIV infected children.

## **2.2 NEEDS AND PROBLEMS FACED BY HIV INFECTED CHILDREN**

Children infected with HIV are faced by a number of needs and challenges. The challenges can be analysed at micro and macro level. Micro level issues focus on the individuals themselves while macro level includes issues beyond the individual and this incorporates community and national levels.

### **2.2.1 Health Needs and Problems**

HIV and nutrition are intimately linked. HIV infection can lead to malnutrition, while poor diet can in turn speed the infection's progress. Hence, a good nutritional diet is one of the major requirements of HIV infected persons as it helps in the recovery and maintenance of a healthy status. If one is taking medication such as ARVs or TB treatment food intake demands become high so as to help the medication effectively function and strengthen the body. AVERT (2008) states that HIV infected children food uptake should be higher than that of other children to enable them gain weight and grow like any other child.

Current research in a number of third world countries (South Africa, Zambia, Zimbabwe and Uganda) continues to reflect limited access to food as one challenge faced by HIV infected persons in third world countries. Maruva, Keatinge, Miller, Foster and Bwakura (2010) in a study on the clinical and community provision of care and treatment for children infected with HIV in Zimbabwe note poor nutrition as one of the challenges faced by HIV infected children. Caregivers cite inability to secure adequate food for children infected with HIV as one major challenge that they face on a day to day basis (Vambe, 1997). In a similar study in Uganda caretakers noted difficulties in feeding HIV infected children to grow like other children (Rujumba and Ndeezi, 2006).

According to Maslows' hierarchy of needs food is among the basic needs for survival. When such basic needs are not met a crisis is developed (Simons et al, 1987). In this case it includes malnourishment, stunted growth and delayed recovery from opportunistic infections for HIV infected children. Hunger can also be a major barrier for consistent uptake of ARVs leading to failed adherence which has the effect of creating drug resistance on the patient. In other cases households may even go as far as opting to selling ARVs so as to access basic food.

A number of barriers inhibit access to basic food in households with HIV infected children. Households in which the breadwinner becomes bed ridden or home bound due to chronic illness face loss of income. At the same time other adult caregivers in the same household may spend less time in productive or income generating activities in order to care for sick family members who also have the effect of decreasing overall household income and access to basics such as food. It is also important to note that when a household has a sick member most of the resources will be directed towards the cure of that member depriving other needs such as food, school fees e.t.c.

Qualitative studies in India also show that households with people living with HIV/AIDS are more likely to suffer a decrease in agricultural activities leading to a decrease in household income and subsistence food (India HIV Alliance: 2009).

According to Kwaramba (1997) studies in Zimbabwe show 61% reduction in maize production as a result of HIV/AIDS related deaths. Reports from similar studies in Swaziland also reflect a 52.4% decrease in maize production as a result of HIV/AIDS related deaths (UNAIDS, 2002).

The above discussion shows that reasons for limited access to food at household level are linked to household financial problems. From a residual concept of welfare when an individual and his family fail to meet their needs it is the states responsibility to intervene (Hardiman and Midgley, 1982). In this case it would be expected that the government provide supplementary feeding mechanisms to help those faced with basic food problems. However, due to limited financial resources most third world countries have been unable to fully provide food needs of households in hunger. Garanganga (2009), in her study notes that by year 2009 the government of Zimbabwe had no provision for supplementary feeding while coverage of food aid by non-governmental organisations also remained low.

However, it is equally important to note that poor appetite due to continued ill health may develop among children infected with HIV limiting their capacity to feed adequately.

HIV/AIDS threatens the very survival of children and young people. According to UNAIDS (2010) HIV has no known cure to date and ART is the only scientifically proven method of treatment. For children, the course of HIV is particularly aggressive. The virus multiplies rapidly, destroying their defences against infection and opening the way for pneumonia and other opportunistic infections (UNICEF, 2006). ARV treatment therefore becomes an essential need in their lives.

Current research findings continue to reflect limited access to ART medication as one of the major problems faced by children infected with HIV in developing countries.

UNICEF (2007) reports that although the number of children with access to treatment has increased significantly over the last few years, notably in Africa .This has been from a very low base hence overall coverage remains low. For instance of the 2.3 million HIV infected children in 2006 about 780,000 needed ARVs and only 15% were receiving it.

It is also important to note that child ART coverage continues to be reported low in comparison to adult ART coverage in most Sub-Saharan African countries. For example in Mozambique child ART coverage was pegged at 12% while adult ART coverage was pegged at 32% in 2009. Zimbabwe's ART coverage for children was at 30% while that of adults was 52%.In the same year only two countries Botswana and South Africa had greater ART coverage for children than that of adults (UNAIDS, 2010).

A number of factors can be cited for limited access to ART services however, financial constraints, is the most crucial factor in the failure to provide ARVs to persons living with HIV in the third world countries. Hardiman and Midgley (1982) observes that most third world countries have limited financial resources. This therefore makes it difficult for them to afford ART medication for the huge HIV infected population, at the same time due to rising unemployment levels in these countries, families fail to afford private medical assistance.

Moyo, Mubaira and Tholana (2009) in one study report financial constraints as the main crippling factor to limited access to ART and other related health delivery services in Zimbabwe. At macro level this has led to frequent stock-out of drugs in

public health institutions with clients having to buy drugs which could have been offered for free. Ferrand, Lowe, Whande, Munaiwa, Langhaug, Cowan, Mugurungi , Gibb, Munyati, Williams and Corbett (2010) in a similar study on children accessing HIV services in Zimbabwe also noted unavailability of drugs as one of the major challenges faced by HIV infected children with a total 40% of the health key informants interviewed reporting this as their major challenge.

Despite free ART services clients have to incur substantial expenditure in travelling, accessing testing facilities and treatment of opportunistic infections which can also be a barrier to accessing ART services in poor households (India HIV/AIDS Alliance, 2009).

### **2.2.2 Psychosocial Needs and Problems**

Current literature reflects limited access to psychosocial support services as one of the other challenges that face children infected with HIV. Children infected with HIV face multiple psychosocial problems which require various psychosocial support services such as counselling and support group services to help them cope with their circumstances.

Psychosocial problems include grief over loss of good health, stigma and discrimination, and feelings of anxiety about what will happen in the future. Loss for children infected with HIV can include death of parent(s) or guardian(s). Among teenagers dating, relationships and safe sex issues also become of importance. Children experiencing stunted growth may develop feelings of shame for their condition hence limiting interaction and participation in social activities with other children.

Stigma and discrimination is also one of the most commonly cited psychosocial problems faced by HIV infected persons. UNAIDS (2010) reports that results from 9 countries (Bangladesh, Paraguay, Rwanda, United Kingdom, Scotland, China, Dominica Republic, Fiji, Myanmar) provides rich evidence of multi layered ways in which stigma and discrimination manifests it self in the lives of people with HIV. Studies in India also show that children infected with HIV are susceptible to stigma and discrimination at school by other children. Stigma was reported to take the form of ridicule, ostracism and isolation (India HIV/AIDS Alliance: 2009). Cloete, Strebel, Simbay, Wyk, Henda and Ngeketo (2006) in a study in South Africa report HIV/AIDS related stigma as still prevalent in local communities. In Zimbabwe evidence from research studies also continue to reflect the presence of HIV /AIDS related stigma despite reports that due to continued openness stigma is decreasing.

HIV continues to be one of the life threatening diseases of the 21<sup>ST</sup> century .This is because it still has no cure and is life threatening. Individuals upon learning that they are infected with HIV, experience personal trauma as they grieve over anticipated loss of good health and battle to understand and accept their condition. Grief feelings may include denial, acceptance, bargaining, and blame and anger (Kubler-Ross, 1969).

Roberts (2006) defines personal trauma as an individuals' experiences of a situation in which she or he perceives to have exhausted his coping skills, self esteem, social support and power resulting in a state of crisis. Proponents of the crisis intervention theory state that personal trauma can result in self blame, disorientation, confusion, poor concentration, feelings of uncertainty and poor trouble shooting. Poor eating habits and withdrawal from social situations also form some of the signs of emotional distress. Individuals who learn that they are HIV positive are more likely to get into a crisis and suffer emotional and or physical distress. Thus, HIV infected children are at

risk of suffering physical and emotional abuse which produces stress in their lives as opposed to other children. Proponents of the crisis intervention theory state counselling as one of the ways to help persons experiencing personal trauma. The aim being to help individuals realise their potential and deal with the situation in a positive way. Zimbabwe like most third world countries faces limited availability of psychosocial support services (i.e. counselling) to help people going through traumatising experiences. Research findings by Garanganga (2009) and Mhaka-Mutepfa (2010) reflect limited availability of psychosocial support services as one challenge faced by HIV infected persons in Zimbabwe. Hence, children are faced with the challenge of not having adequate professional support to help them deal with feelings of anxiety, depression, blame and anger when they learn about their HIV status.

It is of importance to note that needs and challenges faced by HIV infected children cannot be generalised across all age groups. Adolescents may face other challenges that are unique to their needs. Ferrand, Lowe, Whande, Munaiwa, Langhaug, Cowan, Mugurungi, Gibb, Munyati, Williams and Corbett (2010) research findings show that among adolescents, the most common issues are psychosocial problems, which includes lack of resources to seek help for these issues; erratic drug taking and lack of disclosure of HIV status. Respondents described the main psychosocial stressors for adolescents as stigma, difficulty in identifying with HIV-negative peers, anxiety about sexual relationships and future planning, and low self-esteem and feelings of hopelessness. These stressors are compounded by having to care for ill relatives and siblings and by assuming the head of the household status prematurely.

Issues to do with dating and puberty are of similar concern to HIV infected children as with any other children of their age group. The situation of HIV infected adolescents may be complicated by other factors such as disclosure of status to partner and delayed puberty due to poor growth rates. All this brings feelings of worry as the HIV positive children may not be psychologically prepared to handle the resultant consequences such as rejection.

### **2.2.3 Educational Needs and Problems**

HIV has altered the lives of children in a number of ways. HIV infected children face the threat of limited access to education. In some cases HIV infected children fall within the orphaned and other vulnerable categories due to a number of reasons such as death of one or both parents and being under the guardianship of other children, grandparents and or chronically ill parents with limited ability to engage in economic activities. In the event of the guardian or parent getting sick children's lives are altered in a number of ways depending on age and sex of the child. For example while HIV infected younger children risk losing adequate care and supervision, older children especially the girl child also risk dropping out of school to take up premature responsibilities such as housework and care for the sick and other younger children in the household. They may also drop out of school and start working outside the home where they risk exploitative labour practices and child sexual abuse (UNICEF, 2007).

In other words when parents become sick, or when children are orphaned and in the care of other children or elderly, households become poor due to decreased income from the breadwinner. The children in turn fail to get school fees and uniforms limiting their ability to access education. In a study in India lack of school fees is

cited as one of the challenges faced by HIV infected children (India HIV/AIDS Alliance, 2009).

According to UNICEF (2006) HIV/AIDS has eroded many of the hard earned gains in reducing infant and child morbidity and mortality. Thus children infected with HIV are at greater risk of continued ill health and premature death due to weakened immune system. Ill health can affect participation in school activities. Children may miss class while sick and miss participating in other non academic school and sporting activities as they have to nurse their ill health.

In the broader spectrum the same children risk poor quality of education due to frequent absenteeism of academic staff as they attend to the HIV/AIDS related issues such as funerals, care for the sick and tending to their own HIV related health needs.

In conclusion, needs and challenges faced by HIV infected children are varied ranging from access to medication, stigma, missing school and discrimination, to lack of access to adequate health care as evidenced by data from current research. A number of theories can therefore be used to understand the dynamics behind the complicated needs and challenges faced by HIV infected and these range from social structural theories, social psychology to biomedical theories.

### **2.3 ZIMBABWE'S RESPONSE STRATEGIES TO THE AIDS PANDEMIC**

The first HIV case in Zimbabwe was reported in 1985 (Jackson, 2002). Since then the government of Zimbabwe, international and local institutions have over the years come up with a number of measures and strategies to mitigate against the plight of HIV infected people. These include formation of the National AIDS Council (NAC) in 1999, the National AIDS Council ACT of 1999, The Zimbabwe National HIV/AIDS Policy (1999), The National Orphan Care Policy , The Zimbabwe HIV/AIDS Strategic Plan (2005 -2010) , the HIV /AIDS Levy among many others. The National AIDS council is responsible for coordinating government and non state actors HIV /AIDS treatment and support services in the community. Its' duties are guided by the National AIDS ACT (1999). On the other hand Zimbabwe HIV/AIDS policy provides guidelines on present and future responses to AIDS in Zimbabwe. Guiding principle 16, 25, 27, 28 and 29 contain issues to do with the protection and safeguarding of the rights and needs of HIV infected children. These include provision of counseling services to all persons infected with HIV, promotion of the rights of CHLWHA, right to access information for protection against HIV and other sexually transmitted diseases among many other issues.

In the year 2000 the government of Zimbabwe introduced the 3% national AIDS Levy on all employees. The fund is administered through NAC and meant to subsidise ART treatment and other needed services in the fight against HIV and AIDS. In 2002 the Ministry of Health and Child Welfare declared HIV a national disaster and called upon the international community for assistance resulting in Zimbabwe being given the license to produce generic HIV drugs so as to make them more affordable. To date Varichem is one of the companies producing generic HIV drugs in Zimbabwe. In the same year that the Zimbabwe National HIV/AIDS Strategic Plan (ZNASP) was put in

place –a policy document meant to guide HIV/AIDS activities (National AIDS Council 2006). One of ZNASP strategies for treatment was to accelerate enrolment of patients at registered sites; basic laboratory services; affordability of AIDS treatment, and regular supply of ARVs including paediatric formulations and drugs for Opportunistic Infections. Its overall objective included ensuring access and utilisation of treatment and care services for a minimum of 75%. For children, the national target by 2010 was set at 100% (Moyo et al, 2007).

Elizabeth Glaser Foundation and the Clinton Foundation are among the major private institutions providing Paediatric ART technical and financial support to the government of Zimbabwe. SOS Children’s Village, Mashambanzou and Child Protection also form part of the NGOs offering educational, health, social and food assistance support to households with children infected with HIV. Thus over the years a number of non governmental organizations and other private institutions have set up interventions to help meet the complex needs of HIV infected persons.

## **2.4 SOCIAL WORK CONTRIBUTION TOWARDS HELPING CHLWHA MEET THEIR NEEDS AND PROBLEMS.**

Social work can be defined as an art, science; a profession that helps people solve personal, group and community problems. It also seeks to help people attain satisfying personal, group and community relationships through social work methods which include group work, casework, community work, administration and research (Skidmore, Thackeray and Farley, 1994). Its activities can be grouped in three categories namely restoration of impaired capacity, provision of individual and social resources and prevention of social dysfunction. Social work borrows theories from other social science fields such as psychology and sociology to enhance understanding of human beings and better respond to help them cope with their situations and environments. Such theories include the psychodynamic theories (how past childhood experiences can have an effect on adult behaviours), attachment theories, social learning theories, systems theory among others (Beckett, 2006).

Mupedziswa (1998), states that social workers have an important role in helping HIV infected person understand their conditions, cope and prevent any future disabling possibilities. Their roles include advocacy, direct change agent and executive roles. Direct agent roles include provision of therapy and counseling services, mediation and education to CHLWHA, family members and community as a whole. Executive roles include design and management of legislation, policies and programs of CHLWHA.

Conclusively it can be noted that children infected with HIV are at risk of experiencing a number of problems which range from drug shortages, to dropping out of school and being victims of stigma and discrimination. Current research evidence continue to show that the majority of children are at great risk of experiencing these

challenges are in third world countries. A number of theoretical frameworks can be used to analyse the diverse needs and problems faced by these children. Thus this study remains relevant in trying to establish the challenges and needs of HIV infected children.

## **CHAPTER 3**

### **METHODOLOGY**

#### **3.0 INTRODUCTION**

This Chapter will focus on the research methodology used which include target population interviewed, the sampling method, and data gathering method used, data analysis method used, limitation or problems of the study. The study was carried out in Glen Nora, Glen View and Budiriro high density suburbs in Harare.

This research was descriptive. Descriptive research according to Babbie (1989) is a research which describes records and reports phenomena as objectively as possible. The research also sought to discover facts surrounding phenomena. In this case the research sought to describe the needs of children infected with the HIV virus, the challenges that they face, their needs, type of services that they are currently receiving from SOS Children's Villages, challenges faced by SOS Children's Villages in providing assistance to HIV infected children and possible suggestions to ease them.

#### **3.1 DATA COLLECTION PROCESS**

##### **3.1.1 Target Population**

Target population consists of 68 HIV infected children aged 11 years to 17 years currently enrolled as beneficiaries on the SOS outreach program. Key informants were drawn from the 20 Mashambanzou Health Volunteers (Home based care facilitators), the SOS Children's Villages Coordinator, the 2 National AIDS Council (NAC) co-coordinators for the Glen Norah and Glen View Districts, and 16 School Heads (11 primary, 5 Secondary) in Glen View, Glen Nora and Budiriro.

### **3.1.2 Sampling Method**

Availability sampling was used to identify 34 respondents from a total of 68 Children (aged 11 years to 17 years) on the SOS Outreach Program in Glen View, Glen Nora, and Budiriro.

Purposive sampling was used to sample 2 of the 20 Mashambanzou home based care facilitators, the SOS Children's Villages Coordinator and the National AIDS Council (NAC) co-coordinator for the Glen View District. Random sampling method was used to sample 2 of the 16 school heads in Glen View, Glen Norah and Budiriro.

### **3.1.3 Research Instrument**

Data from children was collected using an interview schedule. Face to face interviews with the aid of a schedule were used to ensure accurate interpretation of questions .Both open and closed ended questions were used in the data gathering exercise. Interview guides were used for the key informant respondents.

### **3.1.4 Data Collection**

The researcher was responsible for collecting data. The researcher administered interview questionnaires to HIV infected children on the SOS Children's Villages Community outreach program in Glen View, Budiriro and Glen Norah. A 100% response rate was achieved as most of the children had not gone on holiday. Also the children and parents were willing to take part in the study. Although the interview schedule was in English all interviews were conducted in vernacular language (Shona) to ensure maximized expression of feelings, thoughts, experiences, needs and challenges of the HIV infected children. Structured, in depth interviews were conducted with key informants who included NAC Coordinator for Glen View and Glen Nora, the Coordinator of SOS

Children's Villages, the Field Officers of SOS Children's Villages, the two School Heads and two Mashambanzou Volunteers.

### **3.1.5 Data Analysis**

Data entry, and analysis was done using the Statistical Package for Social Sciences (SPSS). The SPSS has the advantages of scientifically computing analysis thereby minimizing errors as compared to manual analysis.

### **3.1.6 Ethical Considerations**

The study participants comprise children age between 11 years and 17 years who already knew of their HIV positive status. The children could not provide consent therefore assent was sought from their guardians to enable them to take part in the research study. The researcher also explained fully to each respondent and their guardians on the objectives and purposes of the study. Confidentiality was assured to each participant. Interviews were carried out in privacy and no names were captured on the respondent forms, instead codes were used.

### **3.1.7 Limitations**

The target population comprised children from households that are currently recipients of various NGO social welfare assistance programs. This posed some challenges with some of respondents being tempted to over state their problems in anticipation of aid and also as a way of defending and protecting their current position as beneficiaries of various social transfer programs. The researcher made it clear that information collected was for academic purposes and would not earn or disqualify children's current enrollment status in various NGO interventions.

## CHAPTER 4

### PRESENTATION AND DISCUSSION OF FINDINGS

#### 4.0 INTRODUCTION

This chapter presents and discusses the findings from the study.

#### 4.1 SECTION A: DEMOGRAPHIC DATA

The study was carried out with a total of 34 children (14 boys and 20 girls) out of the 68 children who are HIV infected and are knowledgeable of their HIV status. The age of children interviewed ranged from 11 years to 17 years as shown in the table 1 below. The mean age was 14 years while the modal age was 15 years recording a total 21 % (7) of the child respondents.

**Table 1: Age and Sex of Child Respondents**

Age of Child	Sex of Child		Total
	Male	Female	
11 years	1	3	4
12 years	1	5	6
13 years	1	4	5
14 years	2	1	3
15 years	3	4	7
16 years	2	1	3
17 years	4	2	6
<b>Total</b>	<b>14</b>	<b>20</b>	<b>34</b>

**Table 2: Household Size, Number of Children and Adults in the Household**

<b>Total Household size</b>	<b>Adults in the Household</b>	<b>Children in the household</b>	<b>Total Household members</b>
<b>Mean</b>	3	3	6
<b>Mode</b>	3	2	4
<b>Range</b>	1 to 8	1 to 6	2 to 12

Table 2 above, shows an analysis of household sizes, indicating household members indicating household members ranged from 2 to 12. The modal household size was 4 while the mean household size was 6. The number of children in the household ranged from 1 to 6 with 3 being the mean and modal number of children number of children. It can be observed that large household sizes are a characteristic feature of children infected with HIV. This could be due to a number of factors which include absorption of HIV/AIDS orphaned children in the extended family. Inability of other adult household member to move out of guardians home due to high unemployment rates which results in adults failing to secure employment and become independent and self reliant. Rujumba and Ndeezi (2006), in a similar study in Uganda reports large family sizes as characteristic feature of HIV/AIDS affected households.

**Table 3: Orphan Status of Child and Relationship of Caregiver**

<b>Orphan Status/Relationship of Caregiver</b>	<b>Single Orphan</b>	<b>Double Orphan</b>	<b>None Orphaned</b>	<b>Total</b>
<b>Biological Parent</b>	8	0	4	12
<b>Sibling</b>	0	1	0	1
<b>Other Relative</b>	5	7	0	12
<b>Grandparents</b>	1	8	0	9
<b>Total</b>	14	16	4	34

Table 3 indicates that only 12 (35%) of the children are under the guardianship of biological parents while 22 (65%) are under the guardianship of grandparents, relatives, and or siblings. The table also indicates that orphaned children to a total of 30 (88%) form the bulk of HIV infected child respondents. Of these 16 (47%) are double orphans, while 14 (41%) are single orphans (double orphans are defined as children who have lost both parents while single orphans are children who have lost at least one of their parents). Child respondents who were in the care of biological parents and not orphaned formed the minority recording a total 12% (4).

The findings differ from those by Dijk et al (2009) who in a similar study reported 74% of HIV infected children in rural Zambia to be in the care of their biological parents. However, the findings of this research concur with most Sub-Saharan Africa research findings in which other extended family members such as grandparents and

aunts are reported to be the major caregiver of children infected with HIV/AIDS due to high HIV/AIDS related deaths (Mupedziswa, 1998).

**Figure 1: Age Categories of Caregivers**

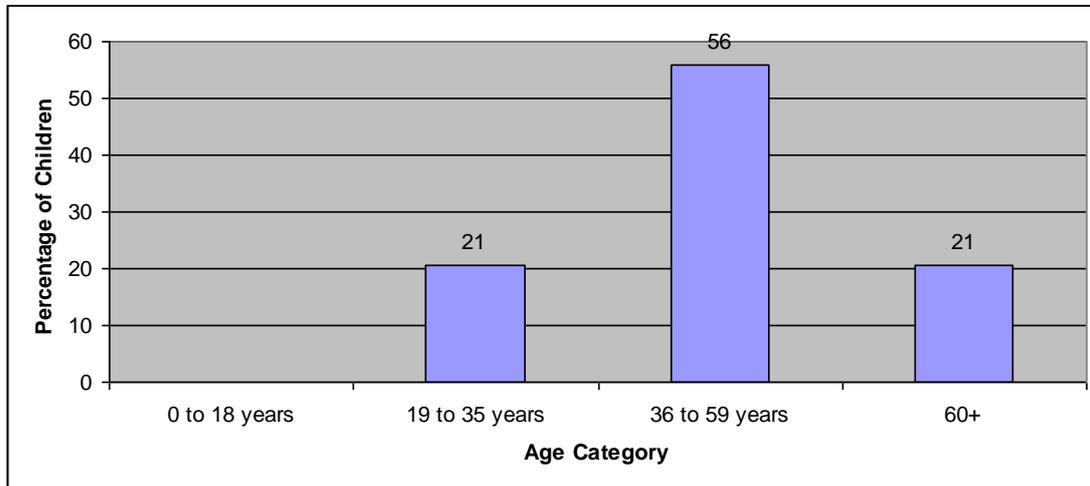


Figure 1, shows the age of caregivers as ranging from 19 years to 71 years. The most common age category was in the 36 years to 59 years age group recording a total of 19 (56%) of the caregivers. This finding concurs with those by Djick et al (2006) who reported the median age of caregivers of HIV /AIDS infected children as 35.8 years. During the study no child headed households were recorded despite high orphan prevalence. Structural functionalism theory can be used to explain low prevalence of child headed households in a region characterized by high adult death rate due to HIV/AIDS. The structural functionalism theory states that society functions as system with interrelated parts (Giddens, 2009). Each part has a different but complimentary role to the others. In the event of one part being subject to shock societies will look for alternative ways to ensure compatibility of the affected part with other systems of the whole. In the African culture one way to cope with shock of death of guardian in the household has been to transfer affected children to other households within the extended family members and or to provide affected household with an a mature adult

from other households in the extended family. This is meant to ensure continued role of supervision and guidance by a mature adult member to the affected children.

The major sources of household income for respondents included self employment, petty trade and casual labor. Table 4 indicates self employment and petty trade as the most commonly reported recording a total 15(44%) and 11(32%) respectively and a combined total of 26 (76%). Self employment activities included carpentry, dressmaking, candle making, peanut butter making, welding and subletting. Petty trade included vegetable sales, freezit and sweet selling. Formal employment remained low recording a total 2(6%) of the households. Remittances, pension and formal employment remained low as major sources of household income. This could be due to a number of factors which included the prevalence of high unemployment rates in third world countries, Zimbabwe included, high death rates within the economically active age groups who would form source of social security for the aged by way of sending remittances (Midgley, 1982). Other factors include guardians' inability to seek formal employment due to chronic illness (i.e. AIDS) which may confine him or her to bedridden and home bound status. The findings concur with those by Rujumba and Ndeezi (2006) who reported the majority of HIV infected children's guardians in Uganda as relying on informal employment activities such as petty trade and casual labor at major sources of household income.

**Table 4: Major Sources of Household Income and Income Ranges**

<b>Source of Income</b>	<b>Frequency</b>	<b>Percentage</b>	<b>Income Ranges</b>
Casual Labor	2	6%	US\$20 - US\$100
Self Employment	15	44%	US\$50 -US\$200
Formal Employment	2	6%	US\$100-US\$150
Remittances	1	3%	US\$90
Petty Trade	11	32%	US\$20 -US\$100
Pension	3	9%	US\$20 -US\$50

Table 4 above, shows household incomes as ranging from US\$20 to US\$200 per month depending on source of income. The average household income was US\$108.57 while the modal income was pegged at US\$50. These findings concur with those by Dijk et al (2009) who reported households of children infected with HIV as having a low socio economic status. It is important to note that guardians were used as proxy to provide details on household's average income.

## 4.2 SECTION B: HEALTH CONDITION AND OTHER HEALTH MATTERS

### 4.2.1 A Look at the Health Background of the Child Respondents Living With HIV

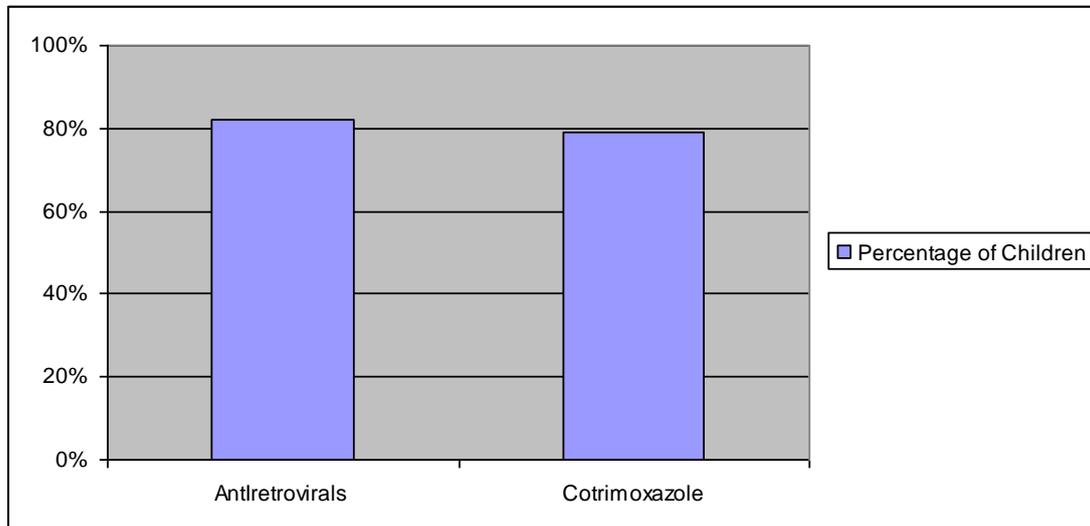
**Table 5: Percentage Distribution of Child Respondents by Health Condition**

Condition	Frequency	% number of clients
HIV	27	79%
HIV and Tuberculosis	6	18%
HIV and Meningitis	1	3%
Total	34	100%

Table 5 above, shows that 6 (18%) of the child respondents were suffering from Tuberculosis (TB) while only 1(3%) had Meningitis. Tuberculosis and Meningitis are among the most common opportunistic infections that HIV infected persons can suffer from. The findings reflect a decrease in the prevalence of opportunistic infections (OI) among HIV infected children. This can be attributed to a number of factors which include increased accessibility of opportunistic infections treatment services following the government's decentralization of OI clinics in Zimbabwe. The move was meant to make OI services accessible as guided by the Zimbabwe HIV /AIDS policy and the ZNASP 2006- 2010 framework.

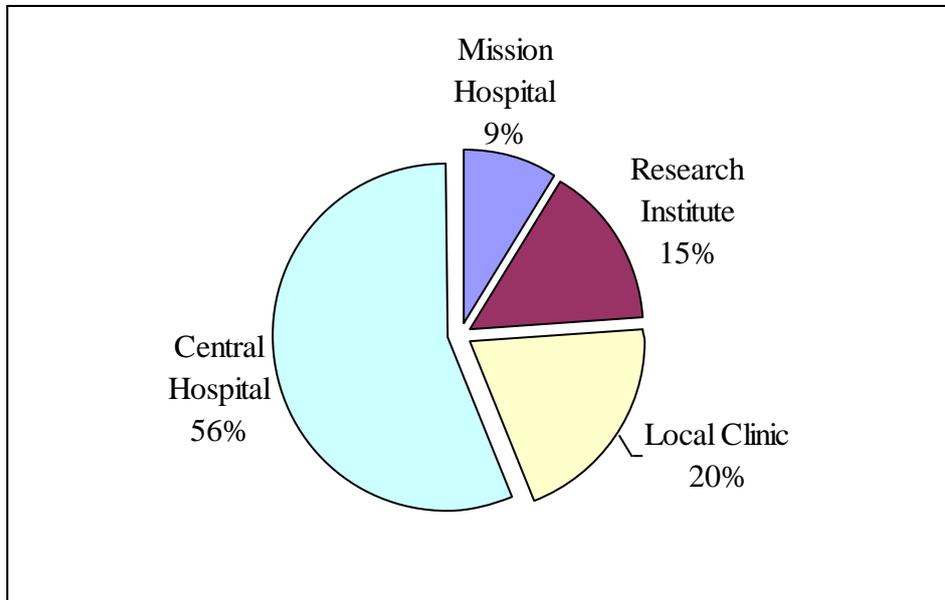
## 4.2.2 Access to Anti-Retro Viral Treatment

**Figure 2: Type of ART Medication**



All child participants reported being on some form of HIV treatment and also knowledgeable about the type of treatment and name of medication they were taking. Child respondents on Antiretroviral drugs recorded a total 82 percent while those on antibiotics (Cotrimoxazole) recorded a total 79 percent as shown in figure 2 above. The findings match UNAIDS (2010) global epidemic report that the number of children with access to Antiretroviral therapy treatment has increased over the last few years, notably in Africa. A number of factors could be given for increased access to ART among HIV infected children and these include the ability of Zimbabwe to produce generic HIV drugs beginning in 2002 which has made them relatively cheaper. One of the ZNASP (2006-2010) strategic framework target for 2010 was to increase accessibility of ART services by 100% to HIV infected children thus, a number of organizations in the past referenced period have come up with a number of services to meet the specified target.

**Figure 3: Percentage Distribution of Children Accessing ART Medication by Type of Health Institution**

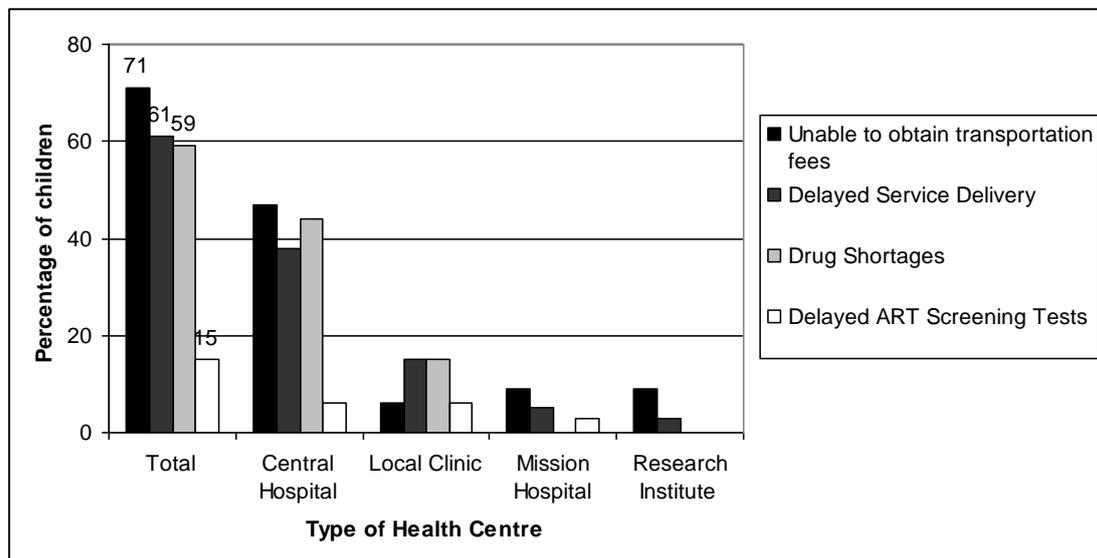


Children infected with HIV may access HIV medication and treatment from various institutions. Figure 3, above shows various types of health institutions were CHLWHA reported to be accessing HIV treatment and medication and these include government institutions, mission hospitals and research institutes. Fifty percent of the child respondents reported accessing direct ART and other related medication such as cotrimoxazole from central hospitals such as Parirenyatwa Central Hospitals and Harare Central Hospital. On the other hand twenty percent cited local clinics, fifteen percent accessed ART from research institutes and nine percent from Mission Hospitals. Research institutes included UZ-UCSF Pediatric HIV/AIDS Research Project while Mission hospitals included Howard and Nyadire located approximately 100km and 280km from Harare respectively. An analysis of the above figures show an increase in the type of institutions offering direct ART treatment and the zeal among the HIV infected children to seek ART treatment services from various types of health centers. Adoption of the contagionism theory in Zimbabwean health delivery

systems have influenced treatment and care services for HIV infected persons in a number of ways. Gumbo (1995), states that according to the contagionism theory the diseased person can only get better by receiving treatment and that it is the individuals' responsibility to seek treatment. At macro-level various institutions have taken government's call in 2002 that HIV was a state of emergency. This saw various organizations taking centre stage in ensuring HIV infected persons have increased access to ART services. Also affected individuals have continued to show understanding that it is their responsibility to get better by participating in research studies and traveling long distances to seek treatment.

#### 4.2.2 Challenges faced by CHLWHA in accessing direct ART treatment services

**Figure 4: Challenges Faced by Child Respondents in Accessing Direct ART Treatment Services**



When asked if they were experiencing any challenges in accessing direct ART treatment 74 % of the children responded in the affirmative. Figure 4, shows the type of challenges child respondents face in accessing direct ART treatment services. The challenges singled out by the child respondents included inability to obtain

transportation fees, delayed service delivery, drug shortages during medical review periods and delayed processing of ART screening tests recording 71%, 62%, 59% and 15% respectively. Inability to obtain transportation fees is as a result of some of the children accessing direct ART services outside their places of residence. This implies the need for bus fares. The respondents disclosed that the amount of money required for transport differed by distance to be travelled. Children accessing direct ART services from central hospitals in Harare required a minimum US\$2 per visit while those accessing outside Harare required a minimum of between US\$10 and US\$20 per visit. In terms of drug shortages children mentioned paediatric cotrimoxazole formula as the most commonly out of stock drug.

The key informant on health issues also gave what she felt were the most common challenges faced by children in accessing direct ART services. She mentioned drug shortages due to clinic erratic supplies, delayed service delivery due to shortage of adequate health staff, and delays in processing of ART prescreening tests i.e. CD4 count services. She also cited paediatric cotrimoxazole as one of the most common drugs that usually run out of stock in pharmacies. ARVs were reported to be in stock at all times. The key informant also explained that access to CD4 count services remained a challenge due to limited availability of screening machinery i.e. CD4 count machinery. Thus priority to CD4 count services was given to certain groups of people which included all persons in the AIDS stage including children. She also noted that once the first test has been performed having repeat test was a challenge yet this is an essential procedure for monitoring progression of HIV disease in the human body. The findings are similar to Ferrand et al (2009) who reported unavailability of drugs as one of the challenge faced by HIV infected children and Dijk et al (2009) who reported lack of transportation fees as one of the challenges faced by HIV

infected children. The findings are also similar to Moyo et al (2009) who in a study on ART delivery services reported inadequate health staff, machinery and drug shortages as some of the challenges crippling Zimbabwe’s health delivery system.

The findings in the broader perspective are also similar to India HIV/AIDS Alliance Report (2009) and UNAID (2010) AIDS Global Report which states that access to CD4 count services remains limited in most third world countries.

#### **4.2.3 Challenges Faced By CHLWHA in Accessing Health Services When Sick**

**Table 6: Percentage Distribution of the Number of Child Respondents Who Fell Sick by Type of Ailment**

<b>Type of Ailment</b>	<b>Frequency/Number of Children</b>	<b>Percentage</b>
Persistent Headaches	12	35%
Cough , Cold , Flue	10	30%
Diarrhoea	4	12%
Stomach Pains	3	9%
Skin Rash	2	6%
General body pains	5	15%
Chest Infections	2	6%
Ear Infections	2	6%
Eye Problems	3	9%

The respondents in the category of children were asked if they had fallen sick during past three months. A total of 85 percent reported having fallen sick and the type of ailments they suffered included persistent headaches, persistent cough, skin rashes, sore eyes and persistent diarrhoea. Table 6, above shows persistent headaches and cough as the most commonly reported type of ailment with 35 percent and 29 percent prevalence respectively.

**Figure 5: Type of Treatment Service Sought By Number of Children**

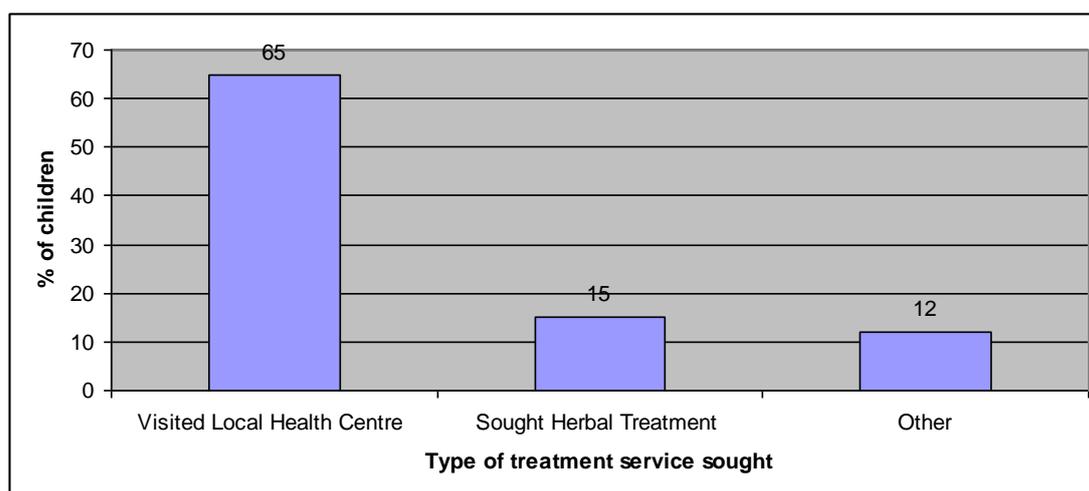


Figure 5 above, shows how the HIV infected child respondents manage sickness. The HIV infected child respondents reported managing sickness in a number of ways which included visiting health institutions and use of herbal treatment recording 65 percent and 15 percent respectively. Other types of treatment included preparation of oral sugar and salt solution, drinking lots of water and purchase of over the counter stop pains such as panado. The child respondents noted that herbal treatment was cheaper as no consultation fees are involved. The child respondents went on to say in situations when they could not afford clinic costs or would fail to secure drugs at health centers they would opt using herbal therapy.

**Table 7: Percentage Distribution of Child Respondents by type of Challenges Faced In Seeking Health Services When Sick**

<b>Type of problem</b>	<b>Non ART Health Services</b>
Drug shortages	52%
Lack of consultation fees	38%
Delayed service delivery	27 %
Inability to obtain prescribed medical test fees	14%
Inability to obtain transport fees	10%

The child participants reported a number of challenges faced in seeking health services when the children fell sick. Table 7, above shows drug shortages in health centers and inability to obtain consultation fees as being the most commonly reported problems recording at total 52 percent and 38 percent of the child respondents respectively. Clinic consultation fees for children below 12 years were said to be USD\$3 while for children 13 years and older were USD\$5. ART treatment services are offered free of charge whereas when one falls sick with any other ailment they are expected to pay for health services. A total 10 percent of the children reported inability to obtain transport fees. The children expressed that they opted visiting local clinic for treatment when they fall sick as they are located within walking distance thereby cutting on transportation costs. These research findings confirm the observations by India HIV/AIDS Alliance (2009) that inability to afford medical treatment was one of the challenges faced by children infected with HIV. India HIV Alliance noted that despite free ART services, HIV infected children from poor

households faced problems in obtaining or raising consultation fees and other medical test fees for treatment of opportunistic infections.

#### 4.2.4 Overall Management of HIV Status

**Figure 6: Percentage Distribution of the Number Of Children Reporting Challenges In Managing Their HIV Status**

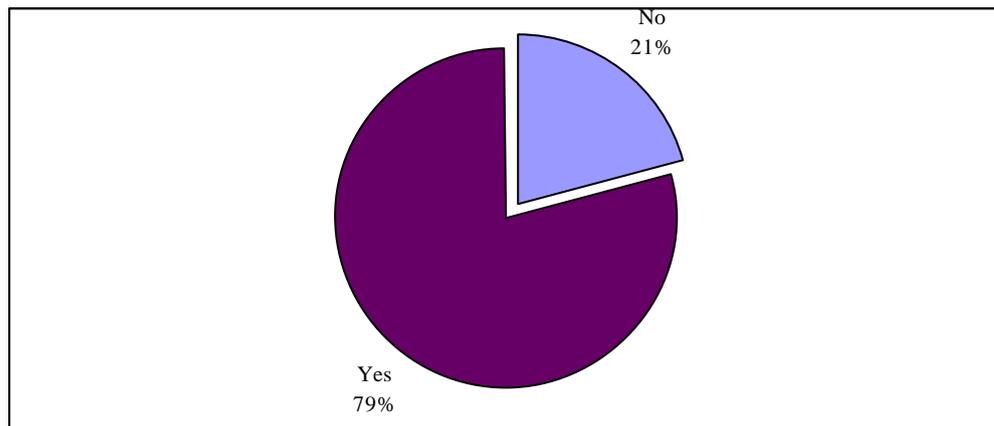


Figure 6 above, shows the number of children who reported experiencing challenges in managing their HIV condition. Seventy nine percent of the children acknowledged experiencing problems in managing their HIV status. Management of HIV status includes issues to do with access to the right food, treatment services and ability to handle other psychosocial problems such stigma and discrimination.

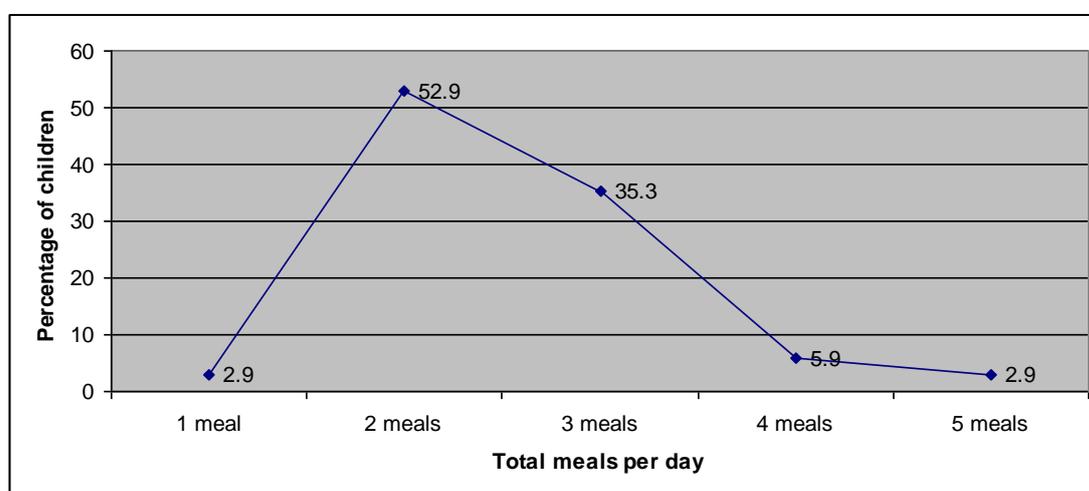
**Table 8: Percentage Distribution of the Child Respondents By Type Of Challenges Faced In Managing Overall HIV Status**

<b>Type of problem</b>	<b>Frequency</b>	<b>%</b>
Inadequate basic food	28	82%
Failure to obtain clinic transport fees	24	71%
Drug Shortages	21	62%
Inadequate supplementary diet	20	59%
Failure to obtain consultation fees	16	48%
Continued ill health	11	32%
Delayed health service deliveries	8	24%
Delayed ART screening tests	4	12%
Unable to obtain fees for non ART prescribed tests	2	6%

The child respondents cited a number of challenges in managing the overall HIV condition and these include failure to obtain hospital consultation fees, inadequate basic food and supplementary diet, failure to obtain transportation fees and continued ill health as shown in table 8 above. Transport fees were considered critical especially in cases where the respondent was ill and bedridden. Inadequate basic food, inability to obtain clinic consultation fees, drug shortages and lack of supplementary diet, were the most commonly noted challenges recording a total 82% (28), 71% (24), 62% (21), 59% (20) respectively of the child respondents. The findings confirm the findings

by Vambe (1997), Rujumba et al (2006) and Garanganga (2009) who all reported that children infected with HIV/AIDS often lacked sufficient food and medical care. The findings are also similar to Kwaramba (1997) who reported that HIV infected persons faced challenges in accessing basic food due to a number of reasons which included decreased maize production in the home as caregivers spend more time nursing the sick and loss of household income due to death or illness of parents.

**Figure 7: Number of Meals Consumed by Child Respondents on Daily Basis**



The figure above shows the reported number of meals consumed on a daily basis. Children reported consuming meals ranging from 1 to 5 the average number of meals most commonly reported being 2 and average number of meals consumed in a day being 2. During discussions a proportion of not less than 80% of the child respondents cited that the meals they consumed were not adequate and failed to meet dietary requirements of HIV infected persons as most meals comprised starch with limited protein and vitamin content.

### **4.3 SECTION C: EDUCATIONAL AND OTHER RELATED ISSUES**

#### **4.3.1. Academic Background**

A total 85% (29) of the child respondents reported being currently enrolled in school. The remaining 15% (5) were post Ordinary Level students who are now out of school. Of the child respondents currently enrolled in school 97% (28) reported being beneficiaries of the SOS Children's Villages school fees assistance program. The key informant reported that SOS Children's Villages school fees assistance intervention program to children infected with HIV was a contributory factor to increased number of children enrolled in school. Another factor to increased enrolment in school of the HIV infected child respondents as noted by the key informants was the increased access to ARV medication among the child respondents. According to UNAIDS (2010) ARVs strengthen the immune system reducing susceptibility to illnesses that may cause advanced stages of the disease. When HIV infected children's immune system is strengthened they are better able to attend school like any other children due to decreased incidence of ill health. These findings reiterate reports by UNICEF (2007) that over the past few years the number of children from HIV affected households attending school has increased owing to various mitigation strategies by governments and NGOs in facilitating provision of school fees to deserving households.

### 4.3.2 Challenges Faced In Accessing Education

**Figure 8: Percentage Distribution of the Number of Child Respondents'**

**Reporting Regular School Attendance.**

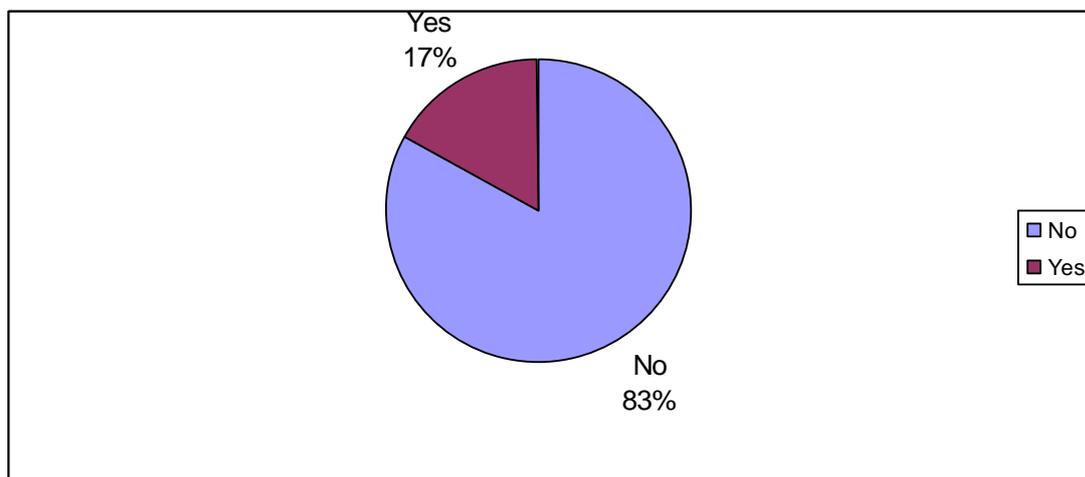


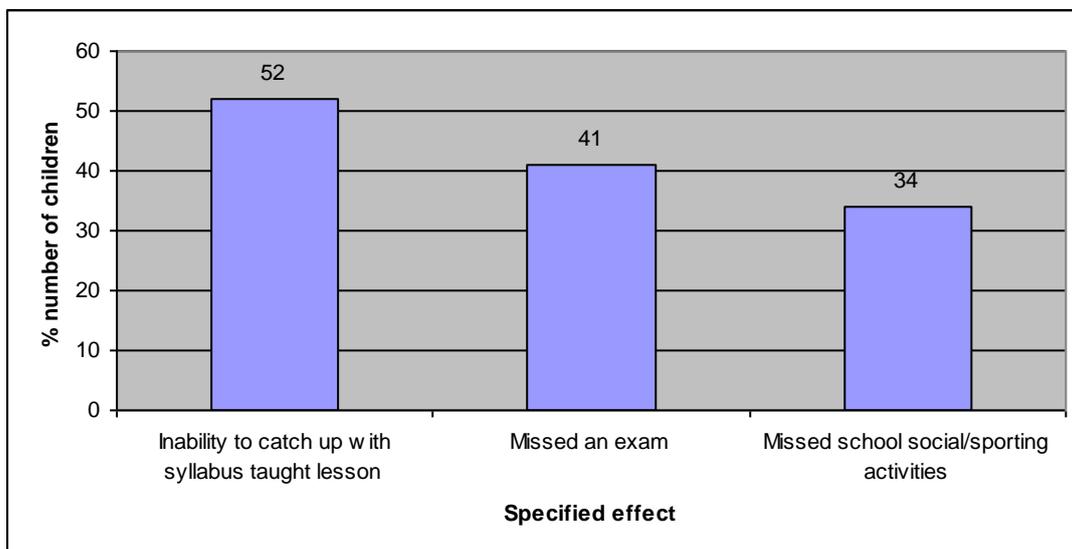
Figure 8, above shows child respondents' response to the question on whether they attended school regularly in the past term. The number of child respondents who reported regular school attendance totalled 17 percent while 83 percent of the child respondents reported irregular school attendance.

**Table 9: Percentage Distribution of the Child Respondents Who Missed School by Reason For Missing School**

Reason for missing school	Frequency	%
Collection of medication	17	59%
Non payment of school fees	1	3%
Was sick	13	45%
Other	3	10%

The child respondents reported a number of reasons for not attending school regularly. The reasons given for not attending school regularly included need to collect monthly allocation of medication, being sick and lack of school fees. Collecting monthly medication and being sick were the most commonly cited reasons for missing school recording at total 59% (17) and 45% (13) of the children respectively. Only 3% or one child reported school fees as reason for missing school. The other category includes reasons such as to collect food packs and taking care of some other sick member of the household. Table 9 above, provides an outline of the reasons for failure to attend school regularly in the previous academic term between January 2011 and April 2011.

**Figure 9: Percentage Distribution Of Child Respondents Reporting Various Negative Effects Of Missing School By Type Of Negative Effect**



The child respondents who reported missing school were further asked to state the effects of missing school and a number of negative effects were outlined. Figure 9 above, shows percentage distribution of the number of child respondents' reporting various types of negative of missing school. Three main negative effects were

outlined and these included missing class tests or exams, inability to catch up with the syllabus which was taught during days of absenteeism and inability to participate in other school sporting and social activities recording a total 52% (15), 41%(12) and 34% (10) respectively .

The respondents also revealed that when they missed an exam they were not afforded the opportunity to sit for that exam upon their return for lessons. This was reported to be disadvantageous to the children as some teachers would score a zero on their academic reports affecting the overall grade of a particular subject.

#### **4.3.3 Other Challenges Faced In Accessing Education**

**Table 10: Other School Related Problems Faced By Children**

	<b>Other school related problems</b>	<b>Frequency</b>	<b>Percentage of Children</b>
1	Inadequate school stationery	15	52%
2	Lack of school uniform	11	38%
3	Continued ill health	9	31%
4	Other (Lack of extra lesson fees)	15	28%

CHLWHA noted a number of other school related problems apart from irregular school attendance. Table 10 above, shows a number of challenges cited by the children and these include lack of complete school uniform, lack of adequate school stationary (exercise books, pens, and covers), continued ill health and other related issues cited on number 4 in the same table. The majority of the children recording a

total 52% reported lack of adequate school stationery. One child responded and I quote:

*“My grandmother has no money to buy me plastic covers the teachers refuse to mark my work as she says my book is not properly covered”*

Lack of school uniform and continued ill health was also cited recording a total 38% and 31% respectively.

#### 4.3.4 Disclosure of Status, Stigma and Discrimination Issues In Schools

**Table 11: Designation of Persons’ Disclosed To About Child Status by Number of Children Currently Enrolled in School.**

<b>Designation of person</b>	<b>Primary</b>	<b>Secondary</b>	<b>Total</b>
Teacher	11	5	16
School Head	2	0	2
Friend	0	1	1
None Response	2	8	10
<b>Total</b>	<b>15</b>	<b>14</b>	<b>29</b>

Table 11 above shows the person’s child respondents had disclosed their HIV status to at school by their job position and relationship to the child. Sixty six percent of the twenty nine children currently enrolled in school acknowledged disclosing their status to someone at the school. The designation of persons to whom the children had disclosed their status included the class teacher, the school head and a friend. The

number of child respondents who disclosed their status to teachers were 16 (55%) while, 2 (7%) reported disclosing to the school head. Only 1 (4%), child reported having disclosed status to a friend. Reasons for non-disclosure of status to other persons especially friends were given as fear of stigmatization. It can therefore be deduced that fear of stigmatization remains one problem faced by children infected with HIV. These findings confirm Garanganga's (2009) findings in a focus group discussion with children infected with HIV in which the researcher reported fear of stigmatization as one reason cited by children for non disclosure of HIV status to friends. The findings are also similar to Reece et al (2007) and India HIV/AIDS Alliance (2009) who noted that social stigma prevented people living with HIV from revealing their status. The social labelling theory states that the labelled will always find some coping strategy in this case the child respondents represent labeled society whose coping strategy has been to remain silent about their status so as to avoid negative effects of stigma.

Analysis of figures in table 11 shows a decrease in the number of children disclosing their status in secondary school. Child respondents reasons change in school environment set up as they moved into secondary school as contributory factor for reluctance in disclosing status to teachers. The HIV infected child respondents noted that as they moved into secondary school, the number of teachers in contact with the child increased, as each subject has an individual teacher hence limiting attachment of child to teacher. In the given circumstances the respondents opted to keep silent about their status so as to safeguard against breach of confidentiality about their status. The ecological systems theory states that interactions between the person and the environment can influence the person's behaviour (Berk, 2000). In this case limited interaction between teachers and the children in secondary school can be the reason

for lack of trust among students to confide their issues of concern to teachers when they start secondary school.

#### 4.3.5 .Access To Psychosocial Support Services in Schools.

**Figure 10: Percentage Distribution of the Number of Children Acknowledging Presence of HIV Programs in Schools**

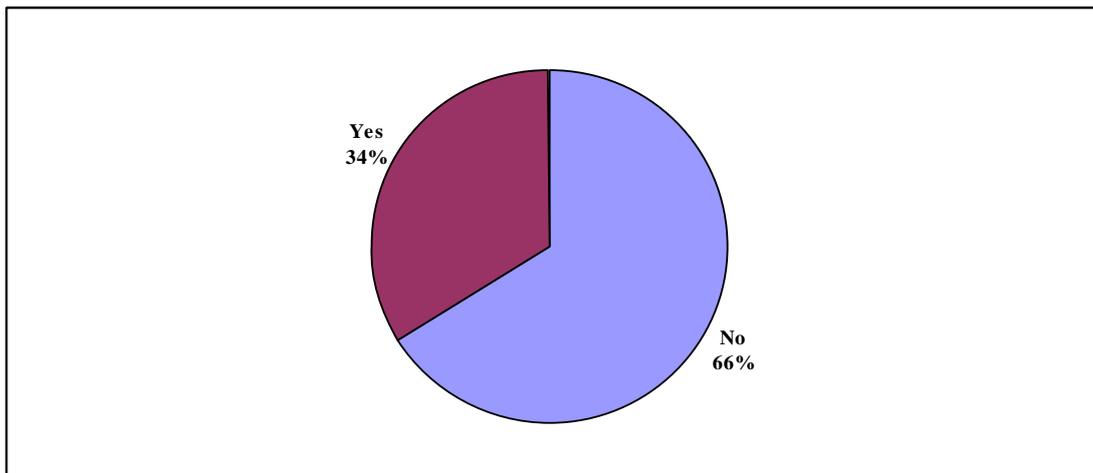


Figure 10 above, indicates the number of children who acknowledged presence of HIV/AIDS related programs in their respective schools. Only 34% (10) of the children acknowledged the presence of HIV/AIDS related programs in their schools.

**Table 12: Percentage Distribution of the Number of Child Respondents Reporting Various Types of HIV/AIDS Related Programs in Schools**

Type of service	Frequency	%
Lessons on HIV	7	24%
Drama Clubs	5	17%
Counseling	3	10%

Table 12 above shows the percentage distribution of the number of child respondents reporting various types of HIV/AIDS related programs offered in their respective schools. CHLWHA mentioned three types of HIV/AIDS services or programs in schools. The type of services reported included lessons on HIV/AIDS, HIV/AIDS drama clubs and counseling services. Lessons on HIV/AIDS were the most commonly reported with a total of 24 percent of the children. Drama Clubs were reported to be 17 percent while counseling services recorded a total 10 percent. Closer analysis of the figures in table two reflect a small number of children acknowledging presence of HIV/AIDS related programs in the school. During interviews the children noted that they attributed limited psychosocial support services in school to increased concentration on academic services by the school while ignoring other child welfare issues. One child had this to say and I quote:

*“At my school the teachers are concerned about teaching and having us write tests. I have never heard of any programs on HIV/AIDS”*

One key informant pointed out that schools were now mandated by the Ministry of Education to provide at least one lesson per week in each class on HIV/AIDS. However, due to staff shortages and pressure of work most teachers would forego this pre-requisite. The key informant also noted that in every school there is at least guidance and counseling teacher but that due to pressure of work this teachers' scope of work is limited to a few students. The findings reflect that HIV/AIDS support services in schools remain limited. The same observations were made by Garanganga (2009) who reported limited access to psychosocial support services as one challenge faced by HIV infected children.

#### **4.3.6 Children's Recommendations on Type of HIV/AIDS Programs To Be Offered In Schools**

The children recommended the following HIV/AIDS programs to be included in the school curriculum:

- Lessons on HIV/AIDS
- Counseling Services
- Support Group Services
- HIV/AIDS Drama Clubs

The child respondents recommended that lessons on HIV/AIDS issues include topics on adherence, herbal therapy, and other new emerging findings on HIV/AIDS. In terms of counseling services the child respondents noted the need to have more than one teacher that they could entrust their concerns in school in addition to the usual guidance and counseling teacher. Major concerns for counseling included dating and relationship information. Regarding the issue of support groups' child respondents recommended that the groups have a mixture of both HIV positive and HIV negative children so they can exchange information and learn more about HIV. This could help in educating other children about the disease and also help them accept children infected with HIV.

#### **4.4 SECTION C: PSYCHOSOCIAL NEEDS AND PROBLEMS OF CHILDREN INFECTED WITH HIV.**

This section discusses the psychosocial issues of HIV infected children which included needs and problems in the psychosocial area.

##### **4.4.1 Membership of Child Respondents to Social Groupings**

Only 11(32%) of the children acknowledged membership to various social groupings in the community. The most commonly mentioned types of social group were HIV/AIDS support groups and church based youth groups. Children in support groups comprised mainly those attending research health centers such as the UZ-UCSF Arrow Pediatric HIV/AIDS Research project. Support groups are part of the widely recommended psychosocial support services for persons infected with HIV. These usually comprise people of homogeneous background so they can share on experiences and learn from one another on how to cope with the illness. Key informants gave a number of reasons for limited number of children reporting to be members of support groups. One such explanation was that organizations offering psychosocial support services for CHLWHA remain few. Garanganga (2009) in a study entitled “Palliative Care Needs of HIV Infected Children in Zimbabwe” also reports psychosocial support services for children as limited.

#### 4.4.2 Relationship with Other members of the community

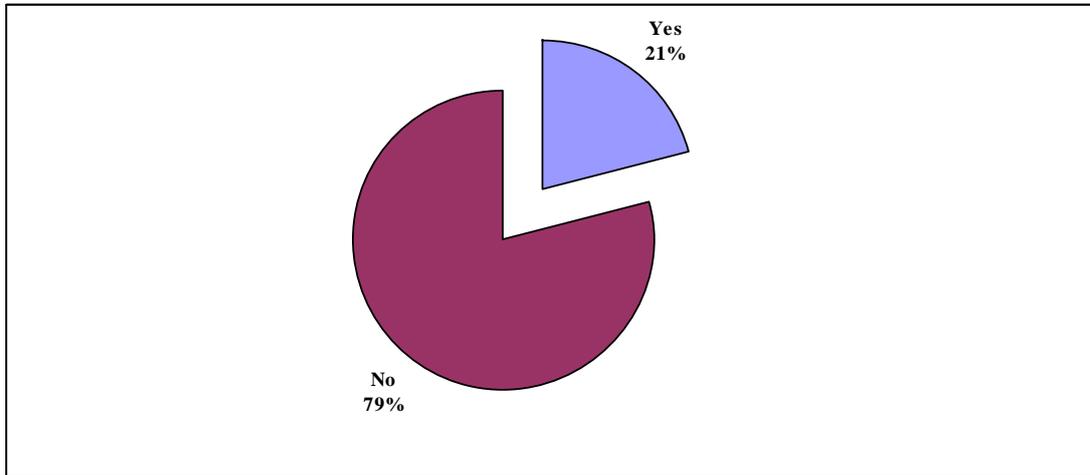
**Table 13: Ratings on Child Respondents Relationship with Other Members of the Society**

Type of relationships	Good	Fair	Poor
Other children at home	91%	9%	0%
Adults at home	77%	14%	0%
Other Children in the community /neighborhood	74%	24%	3%
Adults in the community /neighborhood	77%	21%	3%
Other children at school	65%	15%	3%
Members of staff at school	71%	12%	0%

Table 13 above, provides a summary of child respondent's ratings of their relationships with various members of the society at home, school and in the neighborhood. More than 65 percent of the children rated their relationships with other children and adults at school and home and in the neighborhood as good. Those who rated the relationships as fair ranged between 10% and 20%. Only one child reported having poor relationships with other children at home and school. The child reported that other children at school or in the neighborhood refuse sharing saying he could spread the skin rash to them. These findings are similar to UNICEF (2007) and Plan International (2006) who report that children from HIV affected households are susceptible to unfair treatment in the home and school environment.

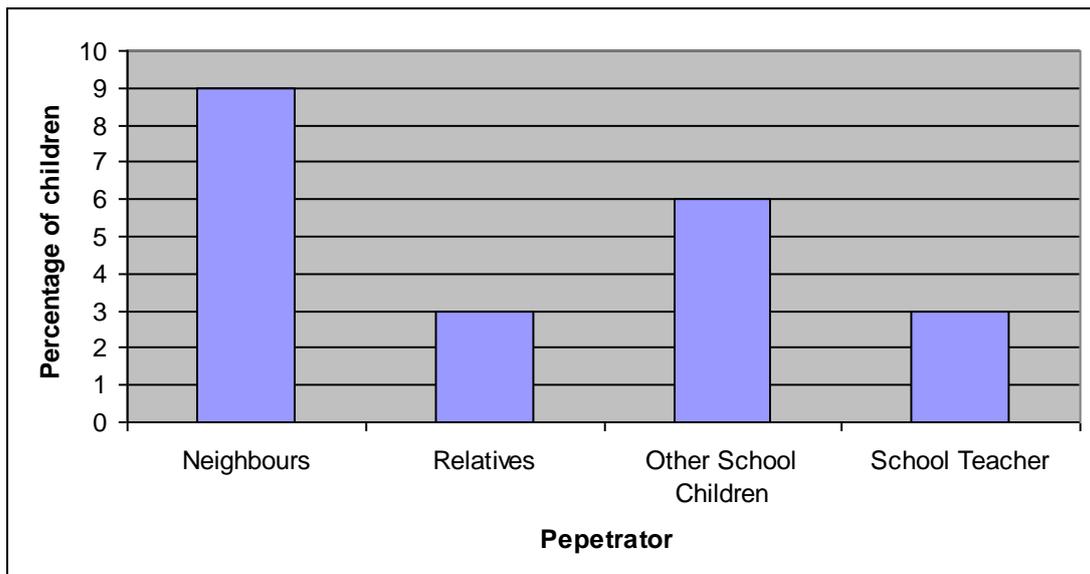
#### 4.4.3 Stigma and Discrimination

**Figure 11: Percentage of Children Who Experienced Stigma**



Twenty one percent of the child respondents reported experiencing stigma in the past three months. Figure 11 above, shows the number of children who reported experiencing stigma. The study shows that some of the HIV infected child respondents had experienced stigma.

**Figure 12: Perpetrators of Stigma**



The child respondents reported a number of perpetrators of stigma. These included neighbours, relatives, other school children and teachers at school as shown in figure 12 above. Nine percent of the children reported neighbors as the most common source of stigma while six percent reported other school children. Relatives and school teachers were reported by one percent of the children each.

The child respondents noted type of stigma as ranging from being isolated by other children, being given nicknames to being denied to participate in sporting activities at school. One child had this to say and I quote:

*“Other children in my community refuse to play with me. They say their mothers do not allow them to play with me as I could spread the skin rash to them.”*

The key informant noted that stigma and discrimination in communities was still prevalent despite the massive campaigns. The key informant went on to say that adolescents reported incidence of stigma more often than younger children. The key informant noted age as key a factor in comprehending whether an act will be discriminatory or not. These research findings confirm the observations by Moyo et al (2002) and Cloete et al (2010) that HIV/AIDS related stigma was still prevalent in the communities despite massive campaigns against stigma. These findings also concur with those by UNAIDS (2010) who reported that results from 10 countries (Bangladesh, Paraguay, China, Dominican Republic, Fiji, Myanmar, Rwanda, and United Kingdom) countries provided rich evidence of the multi layered ways in which stigma and discrimination manifested itself in the lives of HIV infected people. Zimbabwe’s National Policy on HIV/AIDS (2000) guiding principle number 2 and 16 speak of the protection of HIV infected persons including children from stigma and discrimination and protection of their human rights.

#### 4.4.4 Other Psychosocial Problems Faced by Child Participants

The child participants reported a number of other psychosocial problems that they faced. They also reported they had difficulties in sharing these problems with others. The other psychosocial problems apart from stigma and discrimination included issues on positive living, reproductive health issues, dating and relationships, and concern about what will happen to them in future. Within the positive living issues category child respondents reported that they needed a platform for sharing information on issues such as side effects of the HIV medication, drug adherence, stigma and discrimination, what will happen to them in future and how to manage some pain and other opportunistic infections. Reproductive health issues; dating and relationship issues were raised by older child participants particularly those in late adolescent stage aged between 16 years and 18 years. One child confirmed having to end the relationship with her boyfriend as she did not know how to handle disclosure issues. She said and I quote:

*“I had to end the relation with my boyfriend after he had insisted wanting to know if the allegations that he had learnt were true. He said other boys in the neighborhood were saying I was HIV Positive. I did not know how to react and respond. I had no one to talk to about this. I opted out of the relationship as the best solution”*

The findings confirm Ferrand et al (2009) findings that the main psychosocial stressors for adolescents were anxiety about sexual relationships, future planning, feelings of hopelessness and difficulties in identifying with HIV negative peers.

#### 4.4.5 Emotional Issues

**Figure 13: Age at Which Child's HIV Status Was Disclosed**

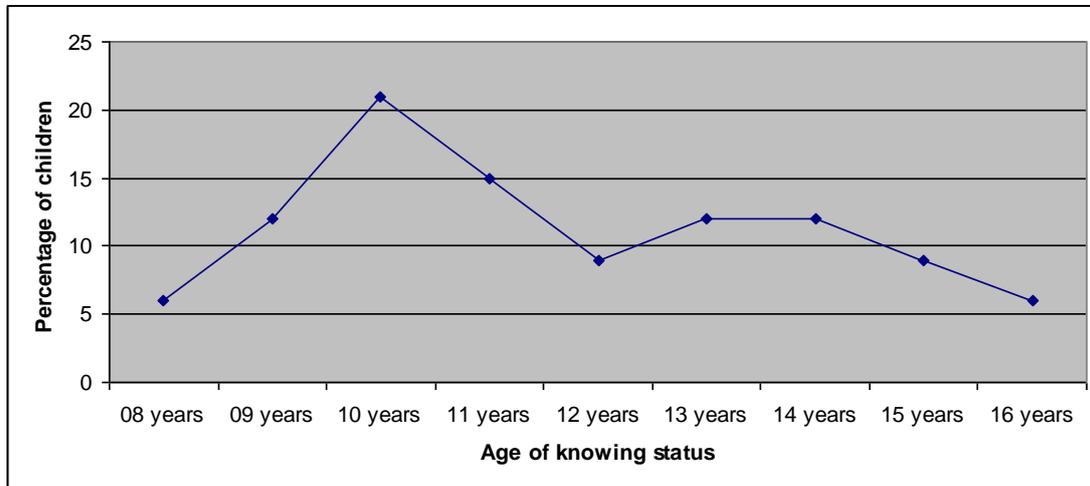
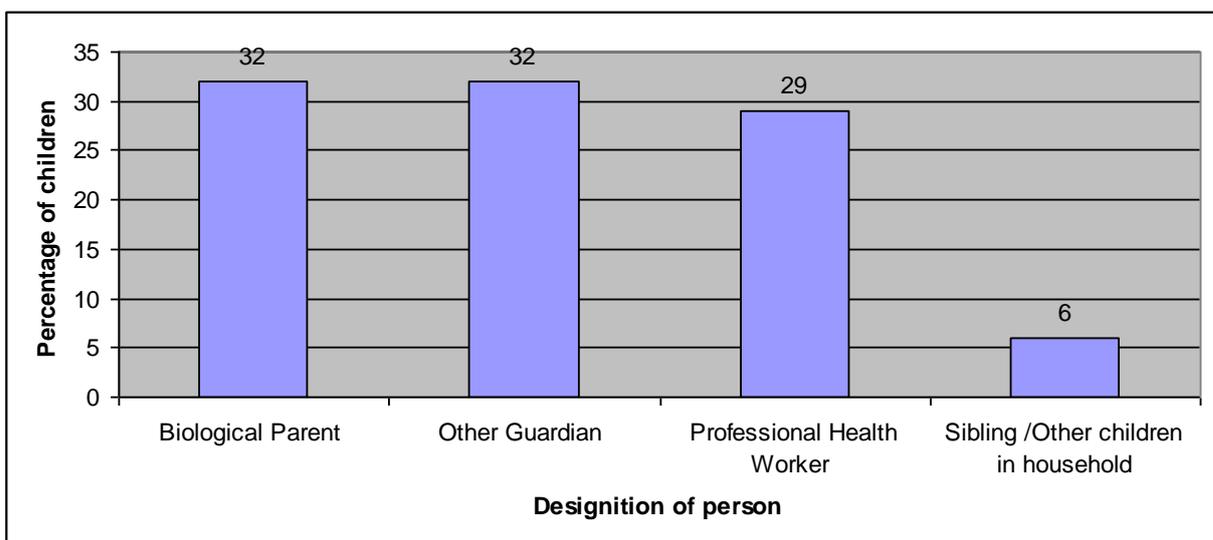


Figure 13 above, shows the various ages at which the child participants had their HIV status disclosed to them. The age of disclosures ranged from 8 years to 16 years. The modal age was reported as 10 years.

**Figure 14: Designation of Person Who Disclosed Status to Child**



The above figure provides a summary of the categories of persons who disclosed to the children about their status. Thirty two percent of the children reported being informed about their HIV status by their biological parent; the other thirty two percent

reported guardians such as grandparents and aunts while twenty nine percent reported professional health workers such as counselors. These findings concur to Maruva et al (2006) findings that children often learnt about their status after counseling and testing by health workers through biological parents, siblings, guardians and professional health workers. Analysis of findings depicts a gradual increased role of biological parents and other guardians in disclosing to children about their status. In the current research the two groups scored a total 64% (32% each) showing an increase in participation of guardians in their children’s health activities.

These findings also have some elements that match Maruva et al (2006) findings which reported that a small proportion of children learned about their status through conversations with other children. Six percent of the child respondents reported learning about their status through conversations with other children in the household.

**Table 14: Percentage Distribution of Child Respondents by Type of Emotional Reaction on First Learning about their HIV Status**

<b>Type of Emotional Reaction</b>	<b>Frequency</b>	<b>Percentage</b>
Shock	9	26%
Anger	5	15%
Denial	3	9%
Blame	2	6%
Acceptance	15	44%

The child participants noted a number of emotional reactions on first learning about their condition. The above table shows a number of reported emotional reactions by the child respondents on first learning about their HIV condition. The most commonly cited first reaction was acceptance recording a total 44 percent. The other 27 percent reported getting into shock on first learning about their condition .A number of explanations can be put forward for increased reports of children quickly accepting their condition. Discussions with the child respondents revealed that those who were quick to accept their condition were children who had gone through professional counseling and those whose guardians had taken time to explain to them about their condition. Also the group comprises those who learnt about their condition at early developmental stages of ages 8 years, 9 years, and 10 years. These child participants expressed that they did not fully understand the implications of the condition at that time .One child participant related her experiences as follows:

*“My mother had spent the previous year explaining to me about HIV/AIDS, methods of transmission and would encourage me to watch HIV/AIDS programs on television such that when she later disclosed to me about my status I was quick to understand and accepted my condition.”*

Children who learnt through inquiring why they were taking medication and by way of conversation with other children reported being shocked, angry and blamed either the guardians for not letting them know about their status or their parents for passing the infection to them.

Child participants were also asked to explain their current emotional status regarding their HIV condition 94% (32) reported to be at acceptance stage .Only 6% (2) reported to be at denial stage.

During interviews with the child participants reported a number of strategies that helped them cope with their condition which included counseling from guardians and professional health workers; and reading more on HIV/AIDS issues. When individuals are confronted with life threatening events they get into a crisis. Roberts (2006) notes that in such situations continued counseling and information sharing forms part of the intervention strategies that help affected persons cope as recommended in the crisis intervention theory.

## 4.5 SECTION E: COMMUNITY SUPPORT SERVICES FOR CHILDREN

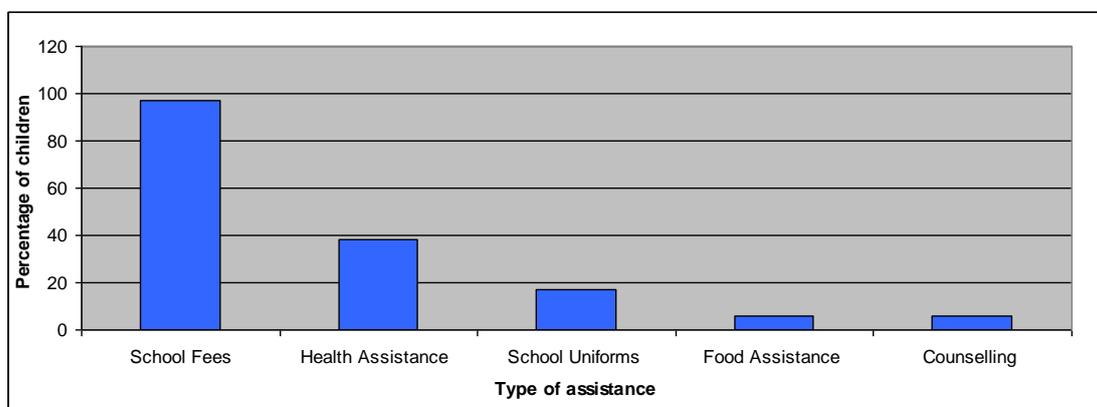
### LIVING WITH HIV

This section discusses the assistance that Children get from SOS Children’s Villages, the type of challenges faced by SOS Children’s Villages in providing that support and the support that children are receiving from other community stakeholders.

#### 4.5.1 SOS Children’s Villages Support Services

All children interviewed are current beneficiaries on the SOS community outreach program. One key informant reflected a number of support services offered to children infected with HIV/AIDS. SOS Children’s Village target population include orphans and other vulnerable children who include HIV infected children. These included education assistance in the form of school fees and school uniforms, food pack assistance (20kg mealie meal , 1 kg beans , 1kg dried kapenta fish and 1.5 litres peanut butter), medical assistance by way of payment of hospital prescribed drugs , psychosocial support services in the form of counseling, recreational therapy, and life skills training to children.

**Figure 15: Type of Assistance provided by SOS Children’s Villages**



Child participants were also asked to outline the type of assistance they had received

from SOS in the past three months. The child participants acknowledged having received educational support in the form of school fees and uniforms, health assistance, food assistance and counseling services. The most commonly reported type of support received from SOS was school fees recording a total 100% of the child participants while 18% reported receiving school uniforms assistance as shown in figure 15 above. Thirty two percent of the child participants reported having received health assistance in the form of payment of prescribed medication.

Food assistance and psychosocial support services in the form of counseling and life skills training remained low, with each recording 6 percent of the children reporting having received such services.

#### **4.5.2 Challenges Faced by SOS in Providing Services to Children Infected and Living With HIV/AIDS**

Interviews with one of the key informants reflected a number of challenges faced by the organization in providing services to HIV infected children. One of the greatest challenges was outlined as mobilizing children for psychosocial support services (life skills training, recreational therapy) during school days. The most flexible time was said to be during the weekends and holidays .However, the option was still not able to offer the best results as some children would have been sent away on holiday to other relatives while others will be attending extra lessons. Some parents and guardians were reported to have also raised concerns over their children attending program sessions during holidays as this was the time they expected them to help them with other household chores such as planting and harvesting of maize. The key informant noted that some guardians did not value non economic activities hence they were reluctant to encourage children to attend psychosocial support services.

Another problem mentioned by the key informant included the structure and composition of benefiting households. The key informant noted the difficulties experienced in conducting home visits and keeping track of benefiting children as most of the children were in the custody of guardians who were lodgers. These guardians were said to be highly mobile and the SOS Children’s Village outreach team had to depend on the guardian’s ability to come forth and update their household data. Thus cases in which households relocated would end up missing on some interventions such as psychosocial support services.

Another challenge reported was that of limited availability of donor funds within SOS Children’s Village to cover the scope of the problems. Hence, some interventions like food assistance and provision of school uniforms were limited to the very needy leaving out some deserving others.

**Table 15: Comparison Analysis of Type of Assistance by Organization**

<b>Name of organization</b>	<b>Health Assistance</b>	<b>Food Assistance</b>	<b>School Fees</b>	<b>School Uniforms</b>	<b>PSS Support</b>
SOS	38%	6%	97%	17%	6%
Mashambanzou	18%	30%	N/A	N/A	0
Research Institute	15%	N/A	N/A	N/A	15%
Other	N/A	9%	0	6%	12%

In an effort to understand other type of community support service currently available to CHLWHA the child respondents were asked to outline other organization that had offered them any form of support during the past three months and type of support

services provided .The child respondents revealed three other community organizations that had offered them support. These organisations were named as Mashambazou, Research Institutions (UZ-UCSF, Coughnaught Clinic) and other local religious organizations. The child respondents also reported receiving food aid, school fees and health assistance from these organizations. Assistance in the form of psychosocial support services remained little or absent. Apart from SOS Children's Villages, research and religious institutes where mentioned as centers where children would receive psychosocial support services in the form of counseling and other support group services. Hence , comparison analysis of type of assistance from other organizations show that few children benefited from psychosocial support services reflecting some limitations in service provision in this area. These findings confirm Garanganga (2009) and Mhaka-Mutepfa (2010) findings which reflected limited availability of organizations offering psychosocial support services for children affected by HIV in Zimbabwe.

The findings of this study also observed a duplication of health delivery activities within the same target population. Children on the SOS Children's Villages outreach program are entitled to provision of medication, a facility offered to the same target beneficiaries by Mashambazou. Hence in a way double dipping may be a common occurrence among aid recipients.

### 4.5.3 Needs of HIV infected children

**Figure 16: Percentage Distribution of Child Respondents by Various Types of Needs.**

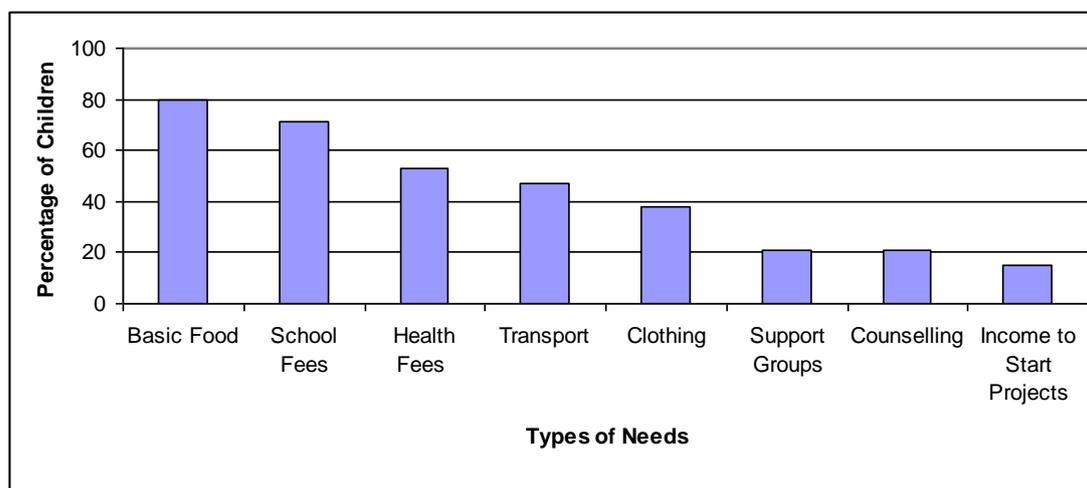


Figure 16, above shows the various types of needs reported by the child respondents.

The child respondents cited a number of needs and these included access to basic food, access to education assistance, and provision of psychosocial support services such as counseling, clothing, health assistance in the form of provision of payment of consultation and medication fees, and access to income to start projects. The most commonly reported need was access to basic food recording a total eighty percent. Seventy percent of the child respondents reported education assistance, while fifty three percent reported health assistance. In terms of health assistance children acknowledged the need for assistance to payment of other medical tests apart from the usual HIV screening tests. School fees assistance included provision of vocational training fees, school uniforms, and stationery and extra lesson fees. Clothing assistance was reported by thirty eight percent of the children. Psychosocial support services in the form of counseling services were cited as a need by a total twenty one percent of the child respondents. A total of twenty one percent of the child

respondents mentioned the need for support groups. The child respondents noted that counseling services and support group services would help them share experiences on positive living and also provide them with an opportunity to have questions on dating and relationships answered. The other fifteen percent of the child respondents noted the need for capital to start projects. These respondents included children out of school youths who are post “O” Levels.

The findings concur with those by Garanganga (2009), who reported priority needs of HIV infected children as food, education assistance and health assistance. Vambe (1997) also reports that caregivers of CHLWHA require assistance in provision of basic food. The child respondent’s needs may be analyzed using Maslow’s Hierarchy of Needs. According to Maslow’s Hierarchy of basic needs physiological needs (food, water) form the first level of human needs (Simmons et al: 1987). The theory states that failure to provide such elementary basic needs will result in a crisis that inhibits progression into other stages which include need for safety, love and belonging and self actualization. HIV infected person require food to help them remain in good health. ARV drugs also require that one takes adequate food for them to function effectively. Inability to secure basic food may defeat governments efforts of providing free ARV drugs as recipients may opt selling the drugs to access their perceived priority need which will be food.

The findings also match Maruva et al (2006) who also reported some of the needs of HIV infected children as being education and clothing assistance. Social Workers employ various social work methods (group work, casework, community work) to facilitate in helping children infected with HIV meet their needs. Social Worker can take up advocacy, direct change agent and executive role in helping children meet their need. According to Beckett (2006), direct change agent roles include provision

of therapy and counseling services, while executive roles include administrative duties such as design and management of legislation, policies and program. In this scenario this would mean design of food relief programs for HIV affected households, sourcing funding for school fees assistance programs and other sustainable projects such as income generating projects.

## **CHAPTER 5**

### **SUMMARY, CONCLUSION AND RECOMMENDATIONS**

#### **5.0 INTRODUCTION**

This chapter gives the summary, conclusion and recommendations in view of the findings.

#### **5.1 SUMMARY**

The aim of the study was to establish the challenges faced by HIV infected children. The objectives of the study were to ascertain health, education and psychosocial needs of children infected with HIV, to establish challenges faced by HIV infected children in the quest to manage their sickness and to establish how children infected with HIV are benefiting and being helped to cope through the SOS outreach community program. The study was carried out in three high density suburbs in Harare. A total of thirty four children infected with HIV participated in the study. Additional information was obtained from seven key informants.

The study established a number of psychosocial, educational and health problems faced by HIV infected children. Health related challenges were outlined as follows: lack of adequate basic food, inadequate supplementary diet, drug shortages, inability to obtain bus fare to travel to the health institutions, inability to obtain consultation fees for treatment of opportunistic infections, delayed service delivery during consultation visits, delayed processing of ART screening tests and continued ill health. Variations in intensity of some of the above mentioned problems were noticed depending on type of treatment service sought and or centre where one accessed such services.

On the other hand psychosocial challenges were outlined as stigma and discrimination, lack of access to adequate information about HIV/AIDS issues and

anxiety about what will happen to the children in future. Older children had other specific problems such as being worried about how to handle sexual relationships. Irregular school attendance was cited as one of the school related problems. Reasons for missing school included collection of ART medication and or ill health. Inability to obtain school stationery and lack of proper school uniforms were also noted as one of the challenges that children faced.

A number of needs of HIV infected children were established. The health needs included access to basic food, access to consultation fees, access to drugs, and access to transportation fees. Psychosocial needs established included the need for increased access to counselling services and support group services, increased access to information on positive living, access to clothing and the need to increase type of HIV/AIDS services offered in school. The educational needs were outlined as the need for assistance in payment of school fees, purchase of uniforms and school stationery .Adolescents also noted the need for vocational training educational fees and income to start projects.

SOS Children's Villages is offering a number of support services to children infected with HIV. The services include education assistance in the form of school fees, school uniform; health assistance by way of providing out of stock prescribed non ART medication from health centres and provision of food packs; psychosocial support services in the form of counselling. School fees were the most commonly reported type of assistance received from SOS Children's Villages by the child respondents. Other community service providers to children infected with HIV were noted as research institutes, religious organisations and other non governmental organisations

such as Mashambazou. Type of assistance offered by these other institutions replicated that offered by SOS Children's Villages.

Key informants noted lack of adequate financial resources as one of the institutional problems faced by SOS Children's Villages in providing assistance to HIV infected children. The key informant also noted other barriers to service provision such as result of the high levels of mobility of urban households.

## 5.2 CONCLUSION

Drawing from the findings the children infected with HIV are faced by a number of health, psychosocial and education related problems. The major causes of these problems are rooted in lack of adequate financial resources at national and household levels. Inadequate financial resources at household level limit the ability of guardians to adequately provide for the needs of HIV infected children. The result being inability to raise clinic consultation fees, inability to raise bus fare to collect medication, inability to provide basic food and pay for the educational needs of HIV infected children. At national level the finding reflect that limited financial resources results in drug shortages, inadequate health equipment and staff shortages. The situation perpetuates a number of problems to children infected with HIV which include delayed clinic service delivery, delayed processing of ART screening test and erratic drug supplies. Other psychosocial challenges such as stigma and discrimination are rooted in the attitude of the society at national, community and household level. Although national policies speak about just and fair treatment of all HIV infected person it appears most psychosocial support services and interventions have been biased towards adults. Children continue to suffer in terms of access to psychosocial support services such as counselling and support groups. The needs of HIV infected adolescents have also been overlooked. The needs include professional advice on dating and relationships and anxiety over what will happen in future. Welfare organisations like SOS Children's villages have come up with a number of assistance programs to try and help children access their needs such as payment of school fees, provision of non ART drugs and purchasing of school uniforms. The assistance has its own shortfalls in terms of effectively and efficiently providing for the needs of HIV infected children. One weakness has been greater emphasis on

provision of material support and placing little emphasis emotional and other psychological needs of HIV infected children. Hence, Zimbabwe like any other developing country need to continue to make consented efforts with various stakeholders for ensured maximum support to meet HIV infected children's needs and alleviate their problems. Food assistance and lack of psychosocial support services remains one of the other greatest needs and challenges faced by HIV infected children.

### 5.3 RECOMMENDATIONS

Based on the study findings, the following recommendations are made:

- There is need for strengthened collaborative efforts between government and other non governmental organisations to ensure increased food availability to the children diagnosed with HIV in order to ensure normal growth and development and strengthen the immune system.
- The health sector needs to draw mechanisms to ensure that children do not miss school while attending to non emergency medical issues such as collection of monthly allocation of ARV drugs. Introduction of flexi timings in ART centres will help children infected with HIV avoid frequent absence from school i.e. weekend clinics for medical reviews and medication collection.
- Behaviour change and peer education training materials should be tailor maid to incorporate emerging needs of HIV infected children such as dating, relationships, disclosure of HIV status to partners just to mention but a few.
- Active involvement of children in production of age appropriate HIV/AIDS Information Education Content (IEC) materials.
- Clothes and blankets should be provided or sourced by both the public sector and NGOs as a basic need to keep the children warm.

- Develop comprehensive monitoring systems in schools to ensure maximum HIV/AIDS support services to all children i.e. counselling, lessons on HIV/AIDS.
- The relevant government ministries, boards and departments and i.e. Ministry of Health and Child Welfare, and Department of Social Welfare and National AIDS council should hold awareness campaigns to conscientise stakeholders, well-wishers and the general public to be involved in the provision of services to meet needs of children infected with HIV and mitigate on challenges faced by such children.
- The relevant government ministries, boards and departments should continue to draw various fundraising and financing mechanism so as to ensure adequate supply of drugs, staff retention and purchase of health machinery and equipment so as to facilitate provision of adequate and timeous delivery of ART and other related health services.
- Promote greater child participation and develop child focused HIV/AIDS program services, including support and advocacy to protect and promote rights and needs of children.
- Improve and strengthen psychosocial support services to children infected with HIV in the bid to increase number of children accessing and benefiting from psychosocial support services i.e. counselling, support groups, peer education.

- The study findings have confirmed the prevalence of stigma and discrimination among local communities despite massive campaigns. There is need for continued multi-pronged strategies to decrease prevalence of stigma and provision of relevant support services to affected communities.
- Strengthen linkages between relevant stakeholders by improving communication channels and strengthening referral and networking systems for complimentary service provision by NGOs and the government to children infected with HIV. This helps eliminate duplication of services within the same target population.
- There is need by SOS Children's Villages to create a platform for information sharing on beneficiary registers and project activities in areas of implementation (Glen View, Glen Nora and Budiriro) so as to safeguard against duplication of activities and foster the spirit of complimentary service provision.
- Findings reflect relief services as the most common type of support offered to household of CHLWHA. There is need for collaborative efforts between SOS Children's Villages and other stakeholders to provide relevant sustainable support services such as income generating activities, nutrition and herbal gardening, agricultural production activities. This will help households become self reliant at the same time strengthening income and food source to better respond to the needs of HIV infected children.

- There is need for SOS Children's Villages, other NGOs and relevant government ministries to look into issues of financing other educational opportunities such as tertiary and vocational education for industrial skills development for children infected with HIV who would have completed Ordinary and Advanced Level Education.
- Social Workers need to take an active position in advocacy, networking linking and provision of therapeutic services to children infected with HIV as they are the legal custodian of children's rights.
- This study was carried out in three selected high density suburbs in Harare. Further studies are recommended in other parts of the country in order to strengthen the research findings of this study and to develop strategies to alleviate problems faced by children infected with HIV and AIDS.

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## APPENDIX 1: QUESTIONNAIRE FOR CHILDREN INFECTED WITH HIV

### A STUDY ON THE CHALLENGES FACED BY CHILDREN INFECTED WITH HIV: THE CASE OF CHILDREN ON THE SOS CHILDREN'S VILLAGES COMMUNITY OUTREACH PROGRAM (GLEN VIEW, GLEN NORA AND BUDIRO)

Respondent code [            ]

#### SECTION A: DEMOGRAPHIC DATA

1. Age [            ]
2. Sex                      Male [   ]                      Female [   ]
3. Mobility Status  
Homebound [   ]                      Bedridden [   ]                      Well and About [   ]
4. Household Size  
Adults [   ]                      Children [   ]                      Total [   ]
5. Relationship of guardian to child  
Biological parent [   ]                      Relative (*aunt, niece*) [   ]  
Sibling (*Sister /Brother*) [   ]                      Grandparent [   ]  
Other (*specify*) [   ]
6. Orphan Status                      Single [   ]                      Double [   ]                      N/A [   ]
7. Age of caregiver [            ]
8. Household's major sources of income (*circle all that apply*)  
Casual Labour [   ]                      Formal Employment [   ]

Self Employment [ ] Pension [ ]  
Remittances [ ] Petty trade [ ]  
Other (specify) [ ]

9. Households average monthly income [US\$ ]

## SECTION B: HEALTH CONDITION

10. Diagnosis of illness (*Circle all that apply*)

HIV [ ] TB [ ] Other (*Specify*) [ ]

11. Are you currently taking any HIV treatment medication Yes [ ] No [ ]

12. Do you know the type of medication prescribed to you

Yes [ ] No (*Skip to 17*) [ ]

13. If yes please specify type of medication (*Tick all that apply*)

ARVs [ ] Cotrimoxazole [ ] Herbal Treatment [ ]

Other (specify) [ ]

14. Centre where one is accessing medication

Local Clinic [ ] Central hospital [ ] Mission hospital [ ]

Research Institute Other (Specify) [ ]

15. Are you experiencing any challenges in accessing (ART) medication

Yes [ ] No [ ]

16. If yes please specify

Delayed processing of ART screening services [ ]

Drug shortages (Name of drugs) [ ]

Inability to obtain clinic consultation fees [ ]

Inability to obtain fees for special medical exams [ ]

Inability to obtain transportation fees [ ]

Long queues before service delivery at health centres

Other please specify [ ]

17. Are you experiencing any challenges in managing your the HIV Status?

Yes [ ] No (*Skip to 22*) [ ]

18. If yes (*please specify*)

Inability to obtain basic food [ ] Delayed Service Delivery [ ]

Inability to obtain fees for prescribed drugs [ ] Drug Shortages [ ]

Inability to raise transportation fees [ ]      Delayed ART screening test [ ]

Inability to secure good supplementary dietary requirements for HIV infected persons [ ]

Inability to obtain hospital consultation fees [ ]    Other (*Please specify*) [ ]

19. In the past three months did you fall sick?    Yes [ ]      No (*skip to 24*) [ ]

20. Please specify type of ailment

Persistent headaches [ ]      Cough [ ]      Skin Rashes [ ]

Persistent diarrhoea [ ]      Eye Infections [ ]      Ear Infection [ ]

General body pains [ ]      Other (*specify*) [ ]

21. How did you manage the sickness?

Visited the a local clinic [ ]      Visited private doctor [ ]

Sought herbal treatment [ ]      Visited traditional healer/faith healer [ ]

Did not seek any medical health services [ ]      Other (*Specify*) [ ]

22. Did you experience any challenges in seeking medical attention or managing sickness?    Yes [ ]      No(*Skip to 24*) [ ]

23. If yes please explain

Could not afford consultation fees [ ]

Could not afford cost of prescribed drugs [ ]

Could not afford prescribed medical tests [ ]

Shortage of drugs at the local health centres [ ]

Other *specify* [ ]

24. How many meals do you consume in a day [ ]

### **SECTION C: EDUCATION**

25. Are you currently enrolled in school

Yes [ ]      No (*Skip to 35*) [ ]

26. If yes please specify level of educational Grade/Form \_\_\_\_\_

27. Did you attend school regularly last term?

Yes [ ] (*Skip to 30*)      No [ ]

28. If you missed school what was the reason
- |                                    |                                 |
|------------------------------------|---------------------------------|
| Continued ill health [ ]           | Non payment of School Fees [ ]  |
| Lack of teacher incentive fees [ ] | Collect of ART medication [ ]   |
| Lack of birth certificate [ ]      | Other Please <i>specify</i> [ ] |
29. What has been the effect of missing school on academic performance
- |  |                              |
|--|------------------------------|
| Missed an exam [ ]                                     | None [ ]                     |
| Inability to catch up with syllabus taught lessons [ ] | Other ( <i>Specify</i> ) [ ] |
30. Is there anyone in the school who knows about your HIV status?
- Yes [ ]                      No (*Skip to 32*) [ ]
31. Specify designation of person
- |             |          |            |                   |
|-------------|----------|------------|-------------------|
| Teacher [ ] | Head [ ] | Friend [ ] | Other specify [ ] |
|-------------|----------|------------|-------------------|
32. Does your school have any HIV/AIDS related programs?
- Yes [ ]                      No [ ] (*Skip to 34*)
33. If yes can you kindly state these?
- |                           |                        |
|---------------------------|------------------------|
| Counselling [ ]           | Support Groups [ ]     |
| Supplementary feeding [ ] | Lesson on HIV/AIDS [ ] |
| Drama Clubs [ ]           | Other specify [ ]      |
34. Could you state any HIV/AIDS programs that you would recommend which are currently not offered at your school
- |                           |                        |
|---------------------------|------------------------|
| Counselling [ ]           | Support Groups [ ]     |
| Supplementary feeding [ ] | Lesson on HIV/AIDS [ ] |
| Drama Clubs [ ]           | Other specify [ ]      |
35. What are the reasons for not being currently enrolled in school?
- |                                |                                    |
|--------------------------------|------------------------------------|
| Non payment of school fees [ ] | Continued ill health [ ]           |
| Lack of birth certificate [ ]  | Lack of teacher incentive fees [ ] |
| Other (specify) [ ]            |                                    |

#### **SECTION D: SOCIAL RELATIONSHIPS**

36. Are you a member of any social grouping on HIV/AIDS?
- Yes [ ]                      No [ ] (*Skip to 38*)
37. Specify Name and Type of Group [ ]

38. Comment on your relationships with other members of the society and give explanations for your answer

Category	Good	Fair	Poor
Other children at home			
Adults at home			
Other children in the neighbourhood			
Adults in the neighbourhood			
Other children at school			
Teachers at school			

39. In the past three months did you ever feel someone stigmatised or discriminated you Yes  No  (skip to 41)

40. If yes specify type of relationship with stigmatiser (tick all that apply)

- Biological parent  Relative (aunt, niece)  Friend   
 Sibling (Sister /Brother)  Teacher  Neighbour   
 Other children at school  Other specify [ ]

41. Can you explain type of stigmatised .....

42. Are there other psychosocial problems that you face? (Excluding stigma and discrimination) Yes  No  (Skip to 43)

43. Specify type of problems faced

- Positive living  Dating and relationship problems   
 Reproductive Health  Anxiety about what will happen in the future   
 Other (please specify) [ ]

44. At what age did you know of your HIV status [ ]

45. Kindly specify relationship of person who disclosed your status to you?

- Biological parent  Professional Health Worker   
 Relative (aunt, niece)  Sibling (Sister /Brother)  Other specify

46. Can you briefly describe the incidence that led to knowing about your status?  
.....

47. How did you feel when you learnt about your status (*Tick all that apply* )

Denial [ ] Shock [ ] Anger [ ] Blame [ ] Acceptance [ ] Other (*specify*)

48. Could you kindly specify how you managed these feelings?.....

49. How do you feel about your status at the present time

Denial [ ] Shock [ ] Anger [ ] Blame [ ] Acceptance [ ] Other (*specify*) [ ]

**SECTION E: SUPPORT SERVICES FROM SOS CHILDREN'S VILLAGES  
AND OTHER COMMUNITY STAKEHOLDER**

50. Type of support received (*Tick all that applies*)

Counselling [ ]

Support Group Services [ ]

Payment of health fees [ ]

Payment of school fees [ ]

Provision of school fees [ ]

Food Assistance [ ]

Recreational Therapy [ ]

other (please specify) [ ]

51. Rating of support received

52. Good [ ]

Fair [ ]

Poor [ ]

53. Please explain for your answer  
.....

54. Are there any other organisations providing you with support services in the  
community? Yes [ ] No (*Skip to 55*) [ ]

55. If yes *please specify name of organisation and type of services received*  
.....

56. Can you kindly list your most important needs?

Food Assistance [ ]

School fees [ ]

Counselling [ ]

Health fees [ ]

Support Groups Services [ ]

School uniforms [ ]

Clothing and blankets [ ]

Clinic Transport fees [ ]

Income to start projects [ ]

Information on HIV/AIDS [ ]

Increased access to Medication [ ]

other (*specify*) [ ]

57. Any other comment

.....

**THANK YOU FOR PARTICIPATING IN THIS STUDY**

**APPENDIX 11: QUESTIONNAIRE FOR KEY INFORMANTS**

**A STUDY ON THE CHALLENGES FACED BY CHILDREN INFECTED WITH HIV: THE CASE OF CHILDREN ON THE SOS CHILDREN'S VILLAGES COMMUNITY OUTREACH PROGRAM (GLEN VIEW, GLEN NORA AND BUDIRIRO)**

**Respondent code [ ]**

**SECTION A: DEMOGRAPHIC DATA**

1. Sex    Male [ ]                      Female [ ]
2. Position \_\_\_\_\_
3. How many children are currently enrolled on your program
4. Can you briefly outline eligibility criterion for enrolment into your program
5. How many of the children enrolled on the program are HIV positive
6. Of the HIV infected children enrolled can you specify their numbers or give proportions by age group, sex, and orphan status

<b>Age Category</b>	0 years to 5 years	5 years to 10 years	11 years to 18 years
---------------------	--------------------	---------------------	----------------------

Number of Children			
--------------------	--	--	--

Age Category	Males	Female
0 years to 5 years		
5 years to 10 years		
11 years to 18 years		

Age Category/Orphans Status	Single	Double
0 years to 5 years		
5 years to 10 years		
11 years to 18 years		

#### 7. Guardians Source of Income

### **SECTION B: HEALTH CONDITION**

8. What are the needs of children infected with HIV?
9. What are the problems faced by HIV/Infected children in accessing health delivery services?
10. What type of services does the organisation provide in trying to meet the educational needs and problems of HIV infected children?

### **SECTION C: EDUCATION ISSUES**

11. What are the school related needs of HIV infected children?
12. What challenges to HIV infected children face in trying to access?

13. What type of services does the organisation provide in trying to meet the educational needs and problems of HIV infected children?

**SECTION D: PSYCHOSOCIAL ISSUES**

14. What are the psychosocial needs of HIV infected children

15. What are the psychosocial problems faced by HIV infected children

16. What type of services does the organisation provide in trying to meet the educational needs and problems of HIV infected children?

**SECTION C: ORGANISATIONAL CAPACITY**

17. What type of challenges do you face as an organisation in trying to meet the need and or mitigate against the challenges faced by children infected with HIV?

18. What measures and efforts has the organisation put in place to deal with challenges faced?

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19. Any other comments

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**Thank you for taking part in this study.**

