

Evaluation of The Effectiveness of Support Groups for Children Living with HIV And  
Aids: A Case Study of Two Hospitals In Nairobi

by

Stella Kemuma Nyagwencha

In accordance with Daystar University policies, this thesis is accepted in partial fulfilment  
of requirements for the Master of Arts degree.

Date:

---

Josephine Omondi,  
MBCHB, MMED, Cert-child psych., Supervisor

---

Kimani Chege, DMin,  
Reader

---

Kimani Chege, DMin,  
H.O.D, Psychology, Counselling & Child Development

---

Alice Munene, PsyD,  
Dean, School of Human & Social Sciences

EVALUATION OF THE EFFECTIVENESS OF SUPPORT GROUPS FOR CHILDREN  
LIVING WITH HIV AND AIDS: A CASE STUDY OF TWO HOSPITALS IN NAIROBI

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

Signed: \_\_\_\_\_  
Stella Kemuma Nyagwencha

Date: \_\_\_\_\_

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## DEDICATION

I dedicate this work to my lovely sons Omondi and Ochieng, my husband William Chienjo and my father Davison Nyagwencha. Your encouragement, patience and sacrifice motivated me to work long hours.

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## ABSTRACT

The effect of HIV and AIDS on children is devastating. Since AIDS currently has no cure, the survival of HIV positive children relies on management of the disease through early identification, diagnosis and comprehensive care and support. These are followed by clear standard systems of psychosocial support through support groups. Very little is documented concerning the efficiency of these support groups for Children Living with HIV and AIDS (CLWHA). The purpose of this study was to evaluate the effectiveness of support groups for CLWHA at Kenyatta National Hospital (KNH) and Mbagathi District Hospital (MDH).

The researcher used descriptive research design and data was collected using in-depth interviews, questionnaires and participant observation. The research findings of this study showed that MDH and KNH support groups had ad hoc policies, goals and objectives. Strategies had been put in place in both hospitals to achieve the goals and objectives of the support groups. The SGMs were facilitated by trained facilitators and co-facilitators (100%) and children attending support group meetings (SGMs) better adhered to medication (90%) at MDH and (94.4%) at KNH. Both support groups had scheduled meetings while (100%) of the children reported that they were happy with the SGMs. The children had improved academically (55%) at MDH and (100%) at KNH, socially (60%) at MDH and (83.4%) at KNH while emotionally (100%) of the children at MDH and (94.4%) at KNH had improved since they joined the support groups. The CLWHA attending SGMs and facilitators (100%) reported that SGMs were effective in providing support to HIV positive children. The above mentioned indicators led the researcher to conclude that support groups were effective in providing support to CLWHA.

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## LIST OF ABBREVIATIONS

ACTS:	Aids Care and Treatments
AIDS:	Acquired Immune Deficiency Syndrome
ART:	Antiretroviral treatment
CLWHA:	Children Living With HIV and AIDS
HIV:	Human Immunodeficiency Virus
KNH:	Kenyatta National Hospital
MDH:	Mbagathi District Hospital
NACC:	National Aids Control Council
NASCOP:	National AIDS and STDS Control Programme
PLWHA:	People Living with HIV and AIDS
SGM:	Support Group Meeting
SGMs:	Support Group Meetings
SPSS:	Statistical Package for Social Sciences
UNAIDS:	United Nations Programme on HIV and AIDS
UNICEF:	United Nations Children's Fund
USAID:	United States Agency for International Development
WHO:	World Health Organization

## CHAPTER ONE

### BACKGROUND OF THE STUDY

#### Introduction

Dyk (2005) argues that, HIV and AIDS are destroying many lives especially in Sub-Saharan Africa and the epidemic continues to get worse instead of better. According to UNAIDS (2008), at the end of 2007, there were 2.1 million children below 15 years living with HIV and AIDS around the world. Among those infected, 71% lived in Sub-Saharan Africa, the continent hardest hit by the epidemic. An estimated 370,000 children became newly infected with HIV in 2007. Research shows that 9 out of 10 CLWHA live in Sub-Saharan Africa. Other than Sub-Saharan Africa, large numbers of children with HIV also live in the Caribbean, Latin America and South/South East Asia (UNAIDS & WHO, 2006).

Without treatment, hundreds of thousands of these children across the world who become infected with HIV every year will die as a result of AIDS. In Africa, research shows that one in three newborns infected with HIV die before the age of one, over half die before age two while most die before age five (WHO progress report, 2009 September).

According to a report by USAID in (2005, January), in Africa, even with the scale up of prevention of mother to child transmission programs, the number of HIV infected babies continued to increase significantly. Rates of early virological testing of HIV-

exposed infants remained low. In 41 reporting countries, only 15% of children born to HIV-positive mothers received a HIV test within the first two months of life.

Early identification and diagnosis is important for the survival of children infected with HIV and AIDS. Identification and diagnosis is supposed to be followed by clear standard systems of follow-up of children identified as HIV positive nationwide. Lack of necessary investment and resources like adequate testing, prevention programs as well as stigma and discrimination are some of the reasons that make it difficult to prevent children from getting infected. Therefore, children continue to suffer the consequences of the epidemic. Increased efforts are needed to expand access to HIV care and treatment services for children.

The CLWHA experience many conflicting emotions, especially when such children face rejection from their friends. They become frightened, isolated and unsure of the future which then looks hopeless. Such children may face stigma and rejection in their educational institutions and home environments which eventually affect their self esteem and growth. Psychosocial care is meant to complement clinical and spiritual care by enhancing antiretroviral (ART) treatment and going beyond management of accompanying symptoms, it is required to help its members deal with stigma associated with HIV and AIDS.

Adler (2001) recognizes that stigma and discrimination are key barriers to combating the HIV and AIDS epidemic. The central guideline and principal in all strategies needs to be to reduce stigma and discrimination and support groups is one way of doing so. Whereas there are many support groups for adults living with HIV and

AIDS, very few support groups have been set up to provide psychosocial support to CLWHA. HIV support groups often become a major source of love and acceptance from people with similar experiences.

According to Wangusi (2003), Kenya was among the world's worst for AIDS patients to live, a new United Nation's Report said. Its AIDS control and care system was among the poorest and lacked respect for the rights of patients. According to Nyaga, Nikimari, Mwabu, and Kimenyu (2004), the Government of Kenya recognizing the seriousness of AIDS, had come up with various policy initiatives to stem the scourge. The Kenyan government had done its best to support adults living with HIV and AIDS in terms of provision of free or cheap ARV's, economic and social support to those infected and development of the Voluntary Counselling and Testing Centres (VCT). However, CLWHA had not received equal attention. The care that was provided to children had centered on provision of basic needs like food, clothing and shelter, and provision of antiretroviral drugs while ignoring the power of support groups in providing psychosocial support. The aim of care, for CLWHA, needed to be comprehensive enough to improve their quality of life per se.

In support groups, children learn that they are not alone and that they can build a new life. It also helps them develop coping skills to deal with the challenges they face. Therefore, the care of a HIV infected child requires a broad multidisciplinary child faceted approach to include growth, immunity, nutritional care and immunization, prompt treatment of opportunistic infections, antiretroviral, psychological support and palliative care.

The first paediatric AIDS clinic in Kenya was established at Coast General Hospital in September, 2001. At the moment, every government Provincial and District hospital in Kenya had a support group for CLWHA. However, although more Comprehensive Care Centres had been established throughout the country, the needs of HIV-positive children while recognized were not given the same priority as those of HIV positive adults.

### Statement of the Problem

According to Wangusi (2003), over the years, children in Kenya had undergone suffering and humiliation as a result of the HIV and AIDS pandemic. This was because thousands of these children had been abandoned by their mothers, either in hospitals or dumped in pit latrines or rubbish pits upon discovery that they had the dreaded AIDS causing virus.

It appeared that children who survived to school going age did not get an opportunity to attend school and those who did the course content does not address their condition. As much as content on HIV and AIDS was integrated in the Kenyan educational curriculum, it did not address the special needs these children had. Due to lack of knowledge, CLWHA struggled to cope with their condition.

In an attempt to address the gap, the government of Kenya in conjunction with the Ministry of Health established support groups in all Provincial and District hospitals to offer psychosocial support to CLWHA. This was seen as a positive development because according to Reilly and Woo (2004), people living with HIV and AIDS required a complex array of support services including psychosocial support.

However, the effectiveness of these support groups was not known because little or no research had been done on the same. Therefore, it was important to understand how these support groups' functioned, their challenges and effectiveness. A clear understanding of the situation would inform policy makers and stakeholders to put in place the necessary mechanisms to ensure that the support groups achieved their objectives.

#### Purpose of the Study

The purpose of this study was to evaluate whether the KNH and MDH support groups were effective in providing psychosocial support to CLWHA who attended SGMs.

#### Objectives of the Study

The objectives of the study were as follows:

1. To outline the structural organization of support groups for CLWHA at KNH and MDH.
2. To determine the policies, goals and objectives of support groups for CLWHA at KNH and MDH.
3. To determine the strategies put in place to achieve the set goals and objectives.
4. To evaluate the effectiveness of KNH and MDH support groups using the following as indicators: presence of policies, goals and objectives; organizational structure of the support groups; presence of trained facilitators; scheduled meetings and adherence to treatment.



5. To make recommendations to the administrators of KNH and MDH, if any, in regard to their support groups for CLWHA.

### Research Questions

In relation to the objectives, the research questions were as follows:

1. What was the structural organization of KNH and MDH children's support group?
2. What were the policies, goals and objectives of support groups for CLWHA at KNH and MDH?
3. What strategies had been put in place to achieve the set goals and objectives?
4. Were KNH and MDH support groups for CLWHA effective?
5. What recommendations could be made to KNH and MDH support groups' administrators?

### Scope of the Study

This study was conducted in two government hospitals in Nairobi Province i.e. KNH and MDH. KNH represented provincial government hospitals while MDH represented district government hospitals with support groups for CLWHA. This study did not cover all the 8 provincial and 210 district government hospitals in Kenya. The sample for the study was selected from only Nairobi Province hence the findings wouldn't be generalized to all the support groups for CLWHA in the country.

### Justification of the study

According to Dyk (2005), peer group played a very important role in children's social development because it gave them experiences of comradeship (friendship) and relationships, opportunities with experimenting with new forms of behaviour and opportunities to exercise limited forms of independence. The benefits of support groups of peers were even more important to CLWHA because AIDS had no cure but depended on good management of the disease. If these children were to live normal lives like other children, they required plenty of psychosocial support from their peers facing the same challenges. Unfortunately, peer support through support groups had been widely ignored.

In educational institutions, where these children spent most of their time, no special programs or support groups had been started to help them meet their special needs or cope with the challenges they faced. Religious organizations also appeared not to have done any better in establishing support groups for CLWHA. The researcher therefore chose to do research in this area so that research findings could, help bridge the gap in disseminating information concerning support groups and how they were run. This research hoped to fill this gap.

The researcher chose to do research in Nairobi which was an urban centre due to the high prevalence of the disease in Nairobi. According to the Republic of Kenya (2009, September), HIV prevalence was higher in urban centres than in rural areas seen in the fact that in 2007, 6.7% of rural residents were infected with HIV compared to 8.4% of urban residents aged 15-49 years.

The researcher chose to evaluate KNH support group for the following reasons: it was a Provincial hospital and the biggest government referral hospital in East and Central Africa. It had also been at the forefront in the development of paediatric HIV training curriculum and lastly because of its proximity to the researcher. Further, the researcher chose MDH support group to represent government District hospitals with support groups for CLWHA and also due to its proximity to the researcher.

### Assumptions

In relation to the purpose of this study, the research findings proved the following assumptions:

1. All the children who attended the support groups at KNH and MDH were HIV positive although at KNH support group 5.6% of the children thought they were HIV negative and 16.6% reported they did not know their HIV status.
2. The children who attended the support groups fell within similar age group of 10 to 15 years although a few children of 16 and 17 years were still found in both support groups.
3. The information the researcher was given by the sample group was accurate and without any bias.
4. The guidelines and procedures that existed in both KNH and MDH support groups were not the same due to lack of national policies, goals and objectives for support groups.

### Limitations and Delimitations of the Study

1. Observation of children during SGMs could have interfered with their behaviour. The researcher therefore used participant observation to be able to observe unnoticed while group proceedings took place as usual.
2. There seemed to be a lack of clear national government policies, other literature and guidelines for support groups for CLWHA. Therefore, the researcher relied on primary data from interview with administrators and facilitators.
3. Access to children who were considered to be minors was a challenge. The researcher worked with those children whose parents gave consent. None of the respondents was forced to participate in the study.
4. There was a challenge on schedule of meetings as both support groups were held on Saturday in the afternoon. The researcher used research assistants to collect data. Further, schedule of meetings was not strictly adhered to. The researcher therefore waited patiently for the SGMs to be organised.
5. Access to consent from the KNH Ethics Board. The researcher complied with all the requirement of the Ethics Board and waited for approval before collecting data.

### Significance of the Study

It was hoped that the findings of this study would be used in the following ways:

1. The findings of this study would provide information to the government and organizations such as National Aids Control Council (NACC), NASCOP, ACTS

and other NGO's in their policy initiatives towards providing adequate care and support to CLWHA.

2. The findings of this study would be used by the administrators of support groups to design policies and guidelines for effective running of the groups.
3. The findings of the study would benefit the children attending SGMs in that it would reveal the gaps and challenges of the SGMs which would hopefully be addressed by the stakeholders. In effect the psychosocial needs of the children would be effectively addressed.

### Methodology

The researcher used case study approach which was descriptive research design in nature. Data was collected using qualitative and quantitative research tools. Data for answering the research questions was collected through Interviews, questionnaires and participant observation. Participant observation of SGMs was used to clarify and confirm the information collected through interviews and questionnaires. The population consisted of 217 support groups for CLWHA in government provincial and district hospitals in Kenya. The target population was 9 support groups for CLWHA in government district and provincial hospitals in Nairobi Province in Kenya. The sample size was 49 respondents from KNH and MDH support groups made up of 4 administrators, 7 facilitators and 38 CLWHA attending KNH and MDH SGMs. Data was analyzed using SPSS version 17 software. These will be discussed in greater detail in chapter three.

## Definition of terms

### *AIDS*

According to Wilkinson (1987), AIDS is an acronym for *Acquired Immune Deficiency Syndrome*. It is called acquired because it has to be transmitted and immune deficiency syndrome because it is the body's immune system that it attacks. The researcher adopted this definition of AIDS for the study.

### *Child*

According to UNAIDS (2009), a child was a human being below 14 years although there were times they had defined a child to be a person of below 18 years. In this study, a child referred to a person of below 18 years. This age was consistent with the definition of a child by the support groups.

### *HIV*

HIV according to Kaplan and Brandeau (1994) stands for Human Immunodeficiency Virus. Human because it occurred in humans and attacked the immune system. It had the same meaning in this study.

### *Psychosocial Support*

According to Regional psychosocial Support Initiative (REPSSI, 2004) psychosocial support were interventions and methods that enhanced one's ability to cope, in their own

context and enabled them to achieve personal and social well being; enabling children to experience love, protection and support that allowed them to have a sense of self worth and belonging. The researcher adopted this definition in this study.

### *Support Group*

According to Gerald (2005), a group was a collection of three or more individuals who interacted about some common problem or interdependent goal and could exert mutual influence over one another. The term support group shall have the same meaning in this study.

### Summary of Chapter

The need for support groups for CLWHA in every community was significant. This was especially so because there was no one way of managing HIV and AIDS patients. Most patients living with HIV and AIDS were dealing with physical, financial, emotional, spiritual, and social issues. If they were to receive holistic support, then all these areas had to be adequately addressed in the comprehensive care and support programs. Support group services, which formed part of comprehensive care and support programs, for children could be designed to address physical, academic, emotional, spiritual and social concerns of the children. The purpose of this study was to evaluate KNH and MDH support groups to establish their effectiveness in providing psychosocial support to CLWHA.

## CHAPTER TWO

### LITERATURE REVIEW

#### Introduction

In this chapter, the researcher will look into the theoretical framework and discuss background information on HIV and AIDS, support groups and the dynamics of support groups. The various literatures support the objectives of the study.

The HIV and AIDS pandemic is causing untold suffering especially for children who are still considered ‘the missing face of AIDS’ (UNAIDS, 2008). This is so because children are not yet included in global or national advocacy, prevention, treatment or support strategies. According to UNAIDS (2002), an estimated 2.5 million children worldwide under age 15 were living with HIV and AIDS at the end of that year making it a global problem. It is estimated that 42 million people are now living with HIV and AIDS. About one-third is aged 15-24. According to UNAIDS (2008) an estimated 370,000 children in Sub-Sahara Africa contracted HIV in 2007 only.

When HIV and AIDS occur in children, it presents itself differently than in adults. Many children will fail to grow and develop normally. In 2005, the United Nations Children’s Fund (UNICEF) addressed a call to action to all those working to protect children from the consequences of the epidemic. It urged the international community to unite for children living with AIDS to ensure that the next generation of children is AIDS free (UNAIDS, 2008).



## Theoretical framework

Maslow believed that human beings were interested in growing rather than simply restoring balance or avoiding frustration. Maslow described the human being as always desiring something and as one desire is satisfied, another rises to take its place. In the desire to self-actualize, the individual moves forward toward growth, happiness and satisfaction Engler (1995).

Maslow's hierarchy of needs according to Engler (1995) include: physiological needs, safety needs, belonging and love needs, self-esteem needs and finally self-actualization. Physical needs are the strongest as they pertain to the physical survival and biological maintenance of the organism. They include provision of basic needs like food, clothing, and shelter, water, to avoid pain and to enjoy. According to Bormann and Bormann (1992), the basic principle is that unsatisfied needs are motivators of behaviour. Motivation needs arise from deficiency needs which arise out of the organism's requirement for physiological survival. Organisms then engage in activities to reduce these drives. Children therefore seek to meet the lower needs e.g. physiological, before the higher needs e.g. need to self actualize. The needs of the next rung begin to dominate the individual's attention and actions immediately after the basic physiological needs are met.

Safety needs refer to an organism's requirements for an orderly, stable and predictable world. Bormann and Bormann (1992) argue that we usually want to look into the future and feel we know pretty well what will happen. Children through support groups need to feel secure about the future and what will happen. Further, children need

law and order to be able to establish patterns which govern their life. Patterns bring about predictability and in turn stability in the lives of children. Children need to feel safe physically, socially, emotionally and mentally.

According to Engler (1995), belonging and love needs can only be met once the physiological and safety needs are met. The individual seeks affectionate and intimate relationships with other people, needing to feel part of various reference groups such as the family or support groups. Children of school going age need to feel love and belonging in their educational institutions for effective learning and growth to take place.

According to Bormann and Bormann (1992), social needs are important in developing cohesive workgroup because they are the needs the group is uniquely equipped to gratify. They include the need to belong to a group and to give and receive acceptance.

Self-esteem needs include need for respect from others and need for self-respect. Self-esteem entails competence, confidence, mastery, achievement, independence and freedom. Respect for others entails recognition, acceptance, status and appreciation. This is necessary both in the children's homes and educational institutions. Bormann and Bormann (1992) argue that this stage is where groups can provide the most powerful rewards to its members. This is so when members feel recognized, respected and appreciated.

Self-actualization refers to the desire to fulfil one's highest potential. This is possible only if the lower needs have been sufficiently met. Characteristics of self-

actualizers include awareness of inner rightness of themselves, of nature and of the peak experiences in life. Honesty permits them to know their feelings and to trust them, freedom which allows them to withdraw from the chaos around them, and finally trust themselves, their mission in life, others and nature.

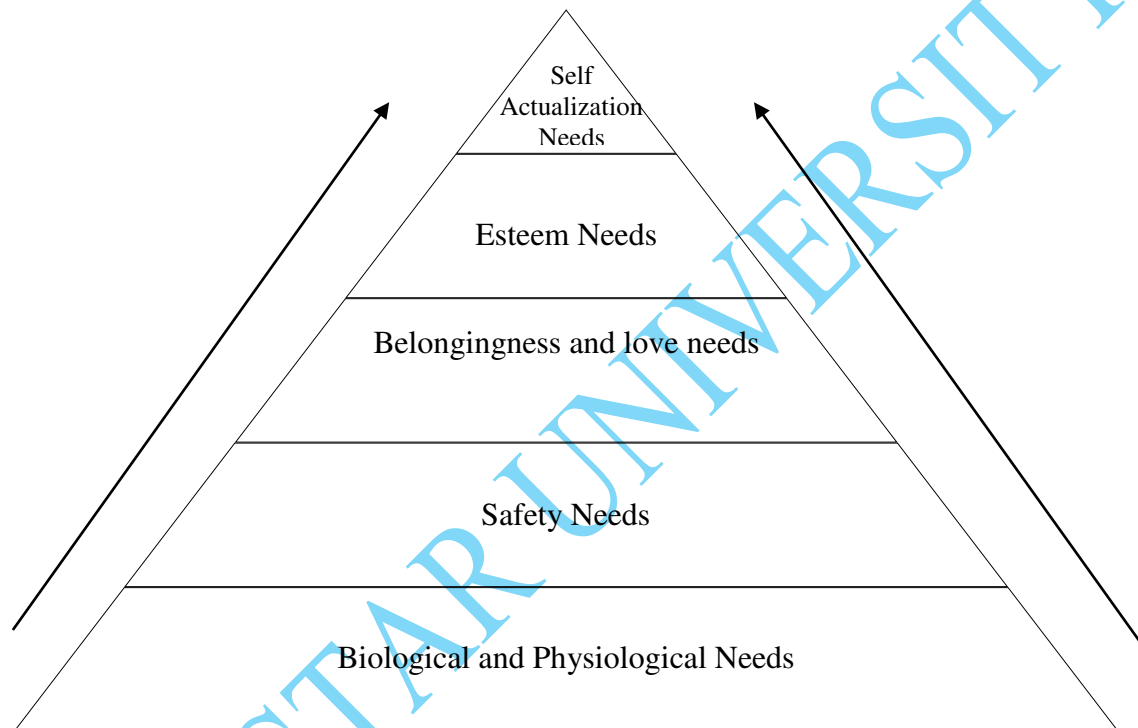


Figure 2.1: Abraham Maslow's Hierarchy of Needs (adopted from Engler, 1995)

Maslow's theory of hierarchy of needs adequately applies to children and the manner in which they seek to have their needs met. These needs could be met in their families or support groups. A child suffering from HIV and AIDS requires proper food and nutrition to be able to boost his or her immunity to fight opportunistic infections. Most homes established for HIV and AIDS children adequately cater for these needs just

as families strive to ensure their children get food for survival. Support groups also provide incentives like food to the children who attend the support groups therefore meeting to a certain extent the physiological needs of the children.

Safety needs refer to an organism's requirements for an orderly, stable and predictable world. This can be seen in HIV and AIDS orphans who when adopted into stable families or taken into caring children's homes grow well just as other children. Children require to be protected from dangers without and within the family. Children thrive best under predictable programs. Support groups also have predictable programs with scheduled meetings and programs. In the first meeting in the support group, rules and regulations should be established by the members, boundaries set and routines established and communicated to members.

According to UNAIDS (2009, August), children infected with HIV and AIDS face stigmatization from their peers, in their homes, neighbourhood or even in school. Support groups then offer a safe environment where they can find unconditional acceptance from people facing the same challenges.

In support groups, as the need for belonging and love is fulfilled, these children develop self-esteem. This is so because through psycho-education they are taught life skills which make them more self-dependent, confident, independent and competent. Training programs also include 'hero book' and treatment literacy which enables them to adhere to treatment rules. They also go for outings and fun trips where they feel accepted and that boost their self-esteem. A healthy self-esteem is a realistic appraisal of one's capacities and has its roots in deserved respect from others. Engler (1995) on self-esteem

concludes that when these needs are not met, an individual feels discouraged, weak and inferior.

Is it possible for CLWHA to be self actualized? Engler (1995) argues that individuals can be self-actualized. In that respect, CLWHA can be self-actualized through the support groups where children share their experiences in a safe environment. In support groups they receive information, education on topical life issues, receive a forum for behaviour change and promote adherence to treatment. These children are then able to exploit their talents and capacities.

Maslow's Hierarchy of needs has been utilized in Support groups like: singles club although they assume that those joining the support group have already met the first two levels of needs; people with chronic vestibular dysfunction who are unable to meet even the basic physiological needs and a support group for individuals with personal problems like alcoholism. These are just a few examples of instances where Maslow's hierarchy of needs model has been used to provide a basis for running support groups.

#### Transmission of HIV and AIDS

HIV is transmitted through three major routes: sexual contact by exchange of body fluids like semen and vaginal fluid, blood exchange through transfusion or injecting needles in drug use and lastly perinatally from mother to child during pregnancy and childbirth. According to the Republic of Kenya (2002), approximately 30-40% of babies born to HIV positive mothers will be positive. When a baby is born, the HIV and AIDS test does not work correctly because the test used is for checking for antibodies which are

the body's reaction to HIV. It is important to note that new born babies carry antibodies from their mothers so that all babies of an infected mother will test positive for HIV, whether or not they are actually infected themselves. According to Adler (2001), one has to wait for at least 18 months for the mother's antibodies to be used up and become undetectable (seroreversion) and for the baby to have time to make its own. Around a year after birth the baby can be tested again. In 90% of cases the baby is not infected before labour begins.

According to UNAIDS (2002), most infections from mother to child occur during birth itself. The sicker the mother during pregnancy, the higher the viral load and the more likely her baby will get infected. Without treatment, around one in four babies will be infected after birth, but this can be as low as 8 in 100 when drugs like AZT (Zidovudine) or HIV protease inhibitors are given to the mother from around 14 weeks of pregnancy until birth and to the infant for 6 weeks afterwards. When drugs are used and the baby is delivered by caesarean section, the infection rates can be as low as one baby in 50. HIV can infect a baby because their lining of the mouth and stomach are so thin that the virus is able to cross during breastfeeding. A HIV positive mother with child maybe advised that it is safest not to breastfeed her child. If she has to, then she should breastfeed strictly for at least a period of 6 months and not mix breastfeeding and formulae feeding (Kaplan & Brandeau, 1994).

## Stigmatization

Dixon (2004) will never forget the first person he met with AIDS, “a young student desperately ill in a hospital side room. He was totally alone in that awful room and about to die. He was amazed that anyone in a London teaching hospital should be abandoned in such a state. However, he understood because that is how things were in 1987, a time when no hospice in Britain would accept someone with AIDS. Nurses refused to visit people with AIDS at home and even some doctors refused to prescribe appropriate medicines.”

Wilkinson (1987) says it was not only the care workers who were rejecting people with AIDS but the church was also caught up with finger pointing and moral debates while taking very little practical action. It is the fear of death, the fear of the unknown that is the main reason why AIDS is so scary. Even with increased knowledge and awareness on HIV and AIDS in the twenty first century, we still see denial, prejudice and fear by individuals and governments.

According to Nyblade, L. et al (2003), the late Jonathan Mann, the former head of WHO's Global Program Fund on AIDS, identified stigma as a 'third epidemic' early in the history of HIV, the first two being the hidden but accelerating spread of HIV and the visible rise of AIDS cases. Mann recognized that stigma, discrimination, blame and collective denial were potentially the most difficult aspects of the HIV and AIDS epidemic to address, but also that overcoming them was key to overcoming the AIDS epidemic.

According to UNAIDS (2002), PLWHA suffer stigmatization, denial of opportunity and support as a result of sero-status. They define it as a behavior or policy/law that unfairly and negatively impact upon the rights, life and opportunities of a person living with HIV.

Sudha, Carla, Srikrishnan, Carl and Go et al (2009, June), support that stigma against persons living with HIV and AIDS is a barrier to seeking prevention education, HIV testing and care. There are several sources and forms of stigma: Fear of transmission by a PLWHA is a primary source of stigma. Forms of stigma include enacted stigma, community stigma, and internalized stigma. Enacted stigma is one that measures how respondents would act toward PLWHA. Community stigma refers to perceived community norms about and behaviours toward PLWHA. Internalized stigma occurs when an uninfected individual either believes in stigmatizing PLWHA, or when a PLWHA believes that he deserves to be stigmatized. Barriers to seeking HIV counselling-and-testing services include: those not infected fearing infection from people already infected, those infected fear disclosure to family or community members, and of a sexual partner's reaction (which includes physical and sexual violence) upon disclosing HIV-positive status. Other barriers include unsupportive community norms and fear of stigma and discrimination by health providers.

According to Ichikawa and Natpratah (2004), the vigorous public health efforts stigmatized the disease especially in the early years of the epidemic. This led to discrimination against people living with HIV and AIDS despite their increasing need for care for their physical impairment and psychological distress. Most children infected with



HIV and AIDS present with a variety of psychological issues, including depression, anxiety and learning disabilities. As they grow and reach adolescence, their problems become more pronounced and difficult to manage. Some of the questions such children ask include; how did I get infected? When am I going to die? How was my mother infected? Are my parents dying? If my parents die, what will happen to me? Can I infect someone else? Can I have children? Who do I tell that I am HIV positive? What am I going to do when I grow up? Who am I and where do I belong? Such questions can be answered at the support group.

Nyblade, L. et al. (2003) observes that to be able to tackle stigma, programs need to consider the following: create greater recognition of stigma and discrimination, foster in-depth, applied knowledge about all aspects of HIV and AIDS through participatory and interactive process, provide safe spaces to discuss the values and beliefs about sex, morality and death that underlie stigma, find common language to talk about stigma and ensure a central, contextually-appropriate and ethically-responsive role for people with HIV and AIDS.

While all individuals and groups have a role in reducing stigma and discrimination against people living with HIV and AIDS, policy makers and programmers have a greater role to look for ways to reduce stigma. This should begin with key groups like families caring for people living with HIV and AIDS, NGO's and other community based organizations, religious and faith organizations, health care institutions and media. Support groups are also key in fighting stigma and discrimination against PLWHA. The effectiveness of a support group can be measured by looking at the

ability of the group to help its members adequately cope with enacted stigma, community stigma, internalized stigma or any other kind of stigma.

#### Comprehensive care and support

While many organizations, globally and locally, are working to make resources available and to provide services and support to children affected by HIV and AIDS, they have to date had little large-scale impact (Richter & Desmond, 2008). One reason for this, they believe, may be the tendency to target specifically orphans and child headed households in impoverished circumstances. This is because much larger numbers of children are hungry, grow poorly, have few opportunities to develop their potential and have little protection from abuse and exploitation.

Since 2001, HIV-related health services have expanded dramatically in Kenya. They include the widespread availability of testing and counselling, and treatment with antiretroviral drugs both to prevent mother to child transmission and to improve health and prolong life for people with advanced HIV infection. Kenya has now entered an area in which there is new hope in preventing, treating and caring for people with AIDS (Nyaga, et al. 2004).

According to the Republic of Kenya, policy on HIV and AIDS in Kenya, the role of HIV Care and Treatment program is to provide continuum of holistic care which is physical, social, psychological, spiritual and emotional support. They should take into account nutritional needs of those with HIV, protection, and improvement in management of opportunistic diseases, sexual transmitted infections, malaria and

Tuberculosis (TB). In the health sector, major challenges which remain is to provide more intensive services required in HIV care and treatment, to integrate these services into existing programs and to attain high levels of quality care, accountability and reporting. In the education sector, all infected and affected learners, educators and other personnel in the education sector have the right to access holistic care, treatment and support in line with available resources. However, there seems to be a limitation in the work force of health workers, knowledge and skills in laboratory services (Kenya's health policy framework, 1994).

Among those living with HIV and AIDS, depressive symptoms as well as low levels of social support have been found to interfere with HIV treatment adherence and contribute to worse HIV health outcomes. According to Carrieri, et al., (2003) social support, often defined as perceived emotional support, is one of the few factors consistently associated with lower levels of depressive symptoms as well as better HIV medical adherence and treatment outcomes. According to Dyk (2005), among the strategies put in place to improve adherence to antiretroviral treatment is enlisting a support system which includes enlisting the help of family members, friends, peers and support groups in the community.

According to Reilly and Woo (2004), PLWHA require a complex array of social support services. It is therefore critical for those working with this population to know the kinds of support that are most effective in helping PLWHA to be able to sustain their health, safety and well being. According to Substance abuse treatment for persons with HIV and AIDS, optimally, primary care should be multidisciplinary with social workers,

physicians, physicians-in-training and nurses and counsellors. The staff must have proper training to screen, assess and counsel clients.

Rabkin, Johnson, Lipsitz, Remien, Williams, et al. (1997) in their research indicate that among chronically ill and disadvantaged individuals, support received, compared with support perceived as available, has greater effect on depressive symptoms. Research indicates that receiving social support contributes to an individual's psychological well-being when it is offered within relationships characterized by reciprocal support exchange. Reciprocity, or provision and receipt of support within interpersonal relationships is associated with elderly, chronically ill individuals' positive appraisals of support and lower levels of depressive symptoms.

According to King and Martodipoero (1978), the objectives of caring, for institutions that care for sick children, is to make the care they give as good as possible referring to quality while ensuring they cover all the children in need in a community. Care refers to how a child is examined, diagnosed, managed and treated. Coverage on the other hand refers to knowing all the children in the community who need caring. The challenge for every community becomes how to identify all the children infected with HIV and AIDS and offering all of them comprehensive care and support. In a health care unit, treatment and support should be designed to respond to the needs and demands of PLWHA their families. This often requires considering issues of stigma, fear, neglect and impoverishment that complicates clinical practice.

According to Dixon (2004), Christians from every tradition can also unite easily with the aim of providing unconditional, compassionate care for all affected by HIV and

AIDS. In their response, they should remember that many people are infected through the actions of others rather than their own behavior, just like some children are infected during delivery. Christians are called to express unconditional love of God to all in need regardless of how they come to be HIV positive. People with AIDS can be very sensitive to reactions. They wonder if the person they have met will accept or reject them. As with cancer or other terminal illnesses, a person can swing rapidly from anger, to denial, sadness, despair, hope, optimism, questioning, resignation, fighting, giving up, wanting active treatment, or even wanting to die.

Peer pressure is very effective in developing individual thinking and social understanding among children. Peers can help deal with stigma and discrimination issues which occur within family, community and school systems. The role of the peer group is to reinforce and sustain positive and healthy behavior. Organizers of care for people living with AIDS should therefore consult with, listen and act on needs of PLWHA. It is they who are most in need and who can give critical insights into the programs work. They need to be fully integrated into the program development.

According to Regional Psychosocial Support Initiative (REPSSI), (2004), lack of psychosocial support for children affected by AIDS can lead to secondary social problems such as: Crime, violence, reduced literacy, segregation, discrimination, stigmatization, substance abuse, child sexual abuse, teenage pregnancy, mental illness, increased HIV infection and child labour. This in turn can lead to family disintegration, lack of parenting skills and mentor, chronically traumatized adults, destroyed social networks, splintered communities and lack of mentoring and transfer of life skills among

others. All of the above finally lead to a dysfunctional society, breakdown of civil society, jeopardizing years of investment in national development, loss of security and stability at national level and economic, political and societal instability.

### Support Groups

According to Corey (2008), groups can be used for therapeutic or educational purposes or for a combination of both. Some groups focus primarily on helping people make fundamental changes in their ways of thinking, feeling and behaving. Groups with an educational focus help members learn specific coping skills. Counselling groups for adolescents is especially suited because it gives them a place to express conflicting feelings, to explore self doubts and to come to the realization that they share these concerns with their peers.

Support groups are especially important to persons who are HIV positive. This is because so many emotions confront people after they have been diagnosed to be HIV positive. As they face changing social supports and financial situations, they can become frightened, bewildered, and worried. When others reject them and treat them inappropriately, they can become depressed, angry, and isolated. Support groups in general should be designed to provide people with HIV a relaxed and informal place to share their experiences and build new friendships and peers to discuss their experience of HIV in their lives.

In support groups, People living with AIDS meet others who have had similar experiences. They learn they are not alone and that they can build a new life. A

participant in a support group wrote on the CAM electronic bulletin board about a group he had belonged to:

I could share with these people my deepest secrets and still be loved. I would give up an arm or leg to have a new support group. I have tried to start one but it never panned out.... When I first became sick it was the group that gave me the strength to keep going. In the group we talked about life and we also got a guest to come in and teach us nutrition, legal aspects, alternative medicine and many other programs.... It saved my life so I know how important it can be for others.

In general, people usually gain acceptance, support, nurture, and intimacy from their birth families, close friendship groups, and/or religious groups, such as churches and synagogues. However, too often, these groups reject individuals when their HIV positive status becomes known, especially, if the person contracted AIDS from injecting drug or same gender sex. HIV support groups often become a major source of love and acceptance.

Kimberly and Serovich (1996) state that, therapists who work with HIV clients and their families should be aware that the need for social support may fluctuate and vary greatly depending on the client throughout the disease process. Need may be higher at times of acute illness or at times of disclosures while to others at initial diagnosis. Group attendance can therefore fluctuate per meeting. Members take breaks from the group, as well as vacations. They come whenever they need to since regular attendance is not required (Anderson & Shaw, 1994).

In the researcher's opinion, regular attendance is important to ensure adherence to treatment unless a member is taken ill and cannot attend meetings. A support group for

HIV positive persons probably should be ongoing, rather than time-limited. New group members will come although a clear process for new group members entering should be established. Support group members who have been in the group for long may leave as a result of increased illness or death. Although HIV support groups must experience a lot of mourning, celebrations should also be a part of group life. They should plan special events and get-togethers particularly during the holidays. When a member returns after an illness, they should have a special meal to welcome him back.

For a support group to be effective, it requires to have policies, goals and objectives which provide guidance in the running of the support group. National policies are meant to provide guidelines on how an issue is going to be handled and determine the distribution of resources. At the initial stages of the diagnosis of the first case of HIV and AIDS in Kenya in 1984, the focus was on how to deal with the scourge in terms of blood safety. The evolution of Kenya's policy on HIV and AIDS may be summarized as follows:

1. After 1984, the Kenyan government centralized the National AIDS response within the Ministry of Health. The response was to be in three phases: 1984-1987, 1988-1991 and 1992-1995.
2. First phase (1984-1987), the National AIDS council was created. Media sensationalized and stigmatized any discussion of HIV and AIDS.
3. 1987-1991, the first five year medium term plan (MTPI) was launched. National AIDS Committee with the help of WHO established an AIDS program Secretariat (APS) to control the spread of HIV and AIDS.



4. At the end of 1987, National AIDS Committee changed to National AIDS Control Program.
5. Second Phase 1988-1991, the government appraised the HIV situation and acknowledged it as a public health problem.
6. 1997 the National HIV and AIDS surveillance system was put in place. Government response driven by Ministry of Health
7. Third Phase 1992-1995, the second medium term plan spanning five years, 1992-1996, was launched.
8. Activities now focus on strengthening the District level coordination of activities.
9. A five year strategic plan (1999-2004) of Ministry of Health was developed through NASCOP.
10. On November 25<sup>th</sup> 1999, HIV was declared a national disaster and National AIDS Control Council (NACC) was created.
11. In 2000-2005 the Government of Kenya developed the first Kenya National HIV and AIDS Strategic Plan (KNASP).
12. The second KNASP for 2005/6-2009 is the one providing the framework to Kenya's current response to HIV and AIDS.

In the policies formulated between 1984 and 2004 very little or nothing has been mentioned on how to deal with children infected with HIV and AIDS. There seems to be lack of clear national policies and guidelines on follow-up of children diagnosed to be HIV positive. Further, if there, the few policies and guidelines are not widely disseminated to ensure stakeholders in paediatrics comprehensive care and supports are

aware of them. The presence or absence of policies determine how effective a support group will be in providing psychosocial support to children infected with HIV and AIDS.

### Goals of support groups

One of the most important aspects of group effectiveness is the group's ability to define its goals and achieve them sufficiently (Johnson, 1975). Johnson defines group goals as the future state of affairs desired by enough members of a group to get the group working towards its achievement. Goals and objectives of support groups are derived from the policies and act as road maps to achieve the policies. Clear policies are required to be able to have clear goals. All HIV and AIDS support groups are required to have goals to be achieved for them to be more effective. Goals of support groups can be just like goals of groups which according to Corey (2008) should include:

1. Teaching a child to learn to trust oneself and others.
2. To Increase awareness and self-knowledge of an individual for them to be able to develop a sense of unique identity.
3. To recognize commonality of members needs and problems and to develop a sense of connectedness among members.
4. To assist members to learn how to establish meaningful and intimate relationships.
5. To increase self-acceptance, self-confidence, self-respect of members.

6. To help members to achieve a new view of oneself and others among others.

Three aspects are therefore important in achieving goals: the group goal itself, the tasks the group must perform in order to accomplish the goals and the process of interaction among the members necessary to accomplish the goals (Johnson & Johnson, 1975).

### Group Rewards

According to Bormann and Bormann (1992), groups can give members rewards at each hierarchy of needs. A group becomes more attractive to its members if it provides more rewards than any other group could, making one work for it leading to improving the group's cohesiveness. The rewards could be material rewards. Money can be given to members to fulfil the basic physiological needs like food, drink, shelter and health care. However, when basic physiological needs are met in the group, people no longer work for them.

Secondly, security rewards. The group can provide its members with security. It provides members with a secure social environment when the group establishes ways of meeting and working. A person finds security rewarding when he knows what to expect when working with other members of the group. Thirdly, social rewards. This occurs when a group makes members feel that they belong. When an individual feels that the group is treating them as people of little worth, he never knows what to expect and feels rejected, when this happens, the individual may leave the group.

Fourth, prestige rewards. This occurs when a group develops a good reputation and in turn sheds its prestige on all its members. Members may wear some public sign of membership like pins, a ring or a special piece of clothing. Fifth, esteem rewards. The group provides self esteem rewards when one is made to feel important within the group, is well received, well liked and looked up to. Sixth, work rewards. The group may provide the members with an opportunity to do the kind of work they like to do. Some groups provide members with an opportunity to do exciting and significant things.

Lastly, they enable one to lose self in a cause. Some special groups generate cohesiveness by working for a special cause. A group should therefore clearly state their goals/basic beliefs and reiterate them for all new members. HIV and AIDS support groups can provide the rewards stated above to its members if well organized and coordinated. All support groups should strive to provide as many of these rewards to their members (Bormann & Bormann, 1992).

#### General types of support groups

Support groups can be grouped as follows:

1. Those that follow a suggested, often ritualistic, format. Such support groups may have established written guidelines but use rotating facilitators, for example, the 12-step groups, including HIV Positive 12- step groups, some types of church groups meeting for prayer, action, and/or study.
2. Those that use rotating facilitators or no designated facilitators. They follow either a loose regular format or are free form. Such support groups may include some types of

church groups meeting for prayer, action, and/or study, such as covenant groups or social groups.

3. Those that are facilitated by trained volunteers. These support groups usually have some kind of verbal or written agreement about the format of the meetings and the ground rules for the group. They include a variety of HIV-related support groups sponsored by AIDS support and other organizations, bereavement groups, church small groups, parents' groups and social action groups.
4. Those that are facilitated by trained professionals. The format and guidelines of these groups vary with the professional's style of leadership and the purpose of the group. They include HIV and AIDS support groups run by therapists, social workers, clergy, group psychotherapy, general groups and groups focusing on a certain issue, such as physical abuse or recovery from addiction and support groups for trained volunteers.

Administrators of support groups have the freedom to choose the kind of support group that they feel would best meet the needs of the children and enable the group to meet its goals and objectives. When established with the appropriate guidelines, whatever type of support group will provide a nonjudgmental environment where people with similar experiences vent their feelings. According to Corey (2008), practical concerns in the formation of a group include:

1. Open versus Closed groups. In closed groups, no new members are added for the predetermined duration of its life. This offers stability of membership making continuity possible and fosters cohesion. In open groups, new members replace those who are leaving which can provide new stimulation. A disadvantage of

open groups is that new members can have difficulty fitting in the group because they are not aware what had been discussed previously. Open groups can also have adverse effects on the cohesion of the group. The leader needs to devote time to preparing new members and helping them become integrated.

2. Voluntary versus involuntary membership. This can be formed from members who are there on their own choice or even be formed from involuntary members who include referral cases. Members who join a group voluntarily benefit the most from the group because they are willing to invest themselves in the group process. Someone who is not motivated to join a group but is sent there involuntarily has fewer chances of succeeding in the group although they can succeed if adequately prepared.
3. Homogenous versus heterogeneous groups. The group leader has the responsibility of deciding the homogeneity of the group. It can be composed of people of similar age and common interest or problem. A group containing homogenous members may be more effective than one that is heterogeneous. However, a heterogeneous group represents a true picture of the social structure that exists in the everyday world.
4. Meeting place. This needs to be agreed upon before meetings begin. A good setting should offer privacy to the members, be spacious, attractive and should allow face to face interaction between members.

5. Group size. The organizers of the group need to choose the desirable size for the group. This will be determined by the age of the clients, the experience of the group counsellors and the type of problems explored.
6. Frequency and length of meetings. The type of group and experience of the counsellor also determine how often and for how long the group should meet. For children, it is better to meet more frequently for shorter periods of time than fewer times for a longer period.
7. Short term versus long term groups. It is advisable to set a termination date at the outset of a closed group so that members have a clear idea of their commitment. The duration varies depending on the type of group, the population and the requirements of the group.

Some of these issues should be included in the policy of the organization, e.g. whether to have open or closed support groups, homogenous versus heterogeneous groups and this information communicated to members of the support group in the initial meeting. Meeting places and time can be decided by the group or still be an administrative issue. What is important is that there should be proper communication to ensure that there is consistency in the running of the support group. A HIV and AIDS support group needs to be formed keeping in mind the best kind of group that would meet the needs of CLWHA.

## Facilitation of Support Group Meetings

For a support group to be effective, it needs to be facilitated by professionally trained personnel. Anderson and Shaw (1994) hold that the role of the facilitator of a support group is to ensure the group starts punctually. The facilitator should have a quick check-in with each person to be able to establish priority of needs of members: For example, a member may expect to visit a sick family member, a group member may have received frightening news, or a grieving member may be feeling overwhelmed. After that, the facilitator's role becomes more secondary as he listens and reinforces and ensures that people share feelings and not intellectualizes or lecture. The facilitator also encourages members to share cross-generational perspectives and ideas as quoted by LaQueur (1972) in the same book. In meetings, People should actively comfort one another; much hugging should take place spontaneously. At the end of the session there is a fifteen-minute opportunity for announcements, socializing, community news, and closure.

A support group, whether formed from a spiritual, pastoral or psychosocial perspective, must be facilitated by experienced, compassionate and competent persons. Good facilitators help the group achieve an emotional climate and a level of communication which will facilitate the growth of all group members. Facilitators model an attitude of support, caring, concern, and respect for all. Each facilitator brings his unique training, experience, and personal style to the group.

The role of facilitators according to Kimberly and Serovich (1996) is to set basic boundaries for the support group. They should make it clear that the group norm is



tolerance of each individual's uniqueness. They should demonstrate respectful and caring behavior by listening carefully to what each group member says and addressing each one with respect and dignity. They model asking questions and expressing disagreements in a supportive and non-threatening way.

Gerald (2005) identifies seven general characteristics of a leader, who in a support group is the facilitator, as being well informed and able to provide direction and structure for the meeting. Effective leaders are skilful communicators who can adapt their leadership style to meet the needs of the group. Further, effective leaders provide consideration in addition to structure which refers to consideration of members. Effective leaders adapt a democratic style and manage complexity of group process and decision making process.

Co-facilitators can be a better leadership model than a single facilitator. For example, where the group is a mixed-sex group, a male and female team of facilitators can be very effective. If at least one of the facilitators is HIV positive, the group may experience this as especially affirming and encouraging. However, it is important that the co-facilitators and facilitators get along and work well together.

### Stages of Group Development

Though each group is unique, support groups tend to move through certain stages. The facilitator should know these stages and phases and be ready to guide the group. Gerald (2005) defines the group as a system that moves in levels of differentiation, from undifferentiated to differentiated. Initially, the group begins with no interrelationships

between members as it is then an aggregate of people, a roomful of strangers. As the group matures, relationships deepen and individuals become interdependent. Everything each member does affects the other members. Gartner describes four key stages in this differentiation process as safety, dependency, counter dependency, and independence stage. These stages are not linear; the group moves back and forth between them. For closed support groups, although each group has its own process, closed support groups generally go through the phases as follows:

In the safety stage of closed support groups, members are often reluctant to attend the group for various reasons. First, teens tend to be suspicious of anything highly recommended by their parents. Secondly, they can also have a tremendous fear that entering a therapy group means they are crazy and that the group leaders will interrogate them or try to tell them what to do. Thirdly, many members are frightened that they will encounter someone they know in the group and thus inadvertently disclose their parents' status to others. Members in the safety stage are encouraged to recognize similarities and differences in each other and seek the commonality between them. Members are encouraged to choose their own topics and begin group discussions. This gives the members a sense of control and empowerment. Due to the stigmatization associated with HIV and AIDS, members tend to continually revisit the safety stage and initially want to deny the reason they joined the group.

In the dependency stage, members take a dependent position, believing the group leaders will cure them Gerald (2005). The overall atmosphere is one of passivity. The group is continuing to work out aspects of safety and trust. Members are frightened of

taking the initiative to start a group discussion and tend to sit back and wait for the leaders to intervene.

In counterdependency stage of closed support group development, group members are still dependent on the leaders but are fighting their dependency needs. Substantial conflict of members with those in authority characterizes this stage. The counterdependency stage can be extremely challenging for the leaders as it makes them feel intimidated and inadequate. If the group leader keeps in mind, however, that the anger and rebelliousness characteristic of this stage is not a personal attack, he will be in a better position to endure this phase.

In the independent stage, members have achieved autonomy (Gerald, 2005). They now have a sense of who they are and how they can continue in their lives. At this stage, the group's work is completed because there have been sessions in which the group has clearly made strides toward autonomy and individuation. In this session the members are able to talk about their powerful feelings openly with one another. As members are feeling very close to each other, the group has difficulty ending the session but agree that the discussions would continue the following week. As members begin to differentiate from each other and assert their autonomy, they can reveal their feelings of sadness, anger, and despair.

## History of KNH Support Group

KNH is the oldest hospital in Kenya and is located in Nairobi city off Ngong Road. It was started in 1901 and it was then called Native Civil Hospital. In 1952, the name was changed to King George VI. After independence, it was renamed after Jomo Kenyatta, the first president of Kenya and called Kenyatta National Hospital. Kenyatta is the largest national referral & teaching hospital in East and Central Africa. All services are provided by doctors who are specialists in their areas. In 2003, a support group for CLWHA was started although it was not well structured. It was meant to take care of children as they waited for their HIV infected parents to get treatment. The children would be given snacks to eat since they would get hungry and also be given paper to draw. Children of all ages would attend. In 2005, the support group program became structured with the children being divided into different ages: play group (1-6 years), second group (7-9 years) who meet from Monday to Friday every week just as the play group. The third group is aged 10-15 years and they meet monthly.

KNH and other institutions under National AIDS and STDS Control Program (NAS COP's) leadership developed a paediatric HIV training curriculum in 2004 to try and address paediatric HIV care.

## History of MDH Support Group

MDH is located in Nairobi district off Mbagathi Road. It was built in the early 1950's but was opened on 17th May 1956 by the then Deputy Governor of Kenya, Sir Fredrick Crawford. It was then called South Hill Hospital for Infectious Diseases. It was

then run as a component of the main hospital, Kenyatta National Hospital, which was then called King George VI. On 1st July 1995 it was taken over by the Ministry of Health (MOH) as a district hospital in Kenya and was then renamed Mbagathi District Hospital. In 2003 a HIV and AIDS clinic was established for adults living with HIV and AIDS. Mbagathi District Hospital Center for paediatrics care began in 2005 as a program for children and teenagers activities.

They currently have two support groups for CLWHA: preteens (10-13 years) and teens (14-18 years). These are facilitated by counsellors, peer counsellors and nurse counsellors. Currently approximately 34 children attend preteens SGMs and they meet monthly. Approximately 20 teens attend the SGMs fortnightly too. Two counsellors are always in attendance to facilitate the meetings.

#### Summary

There are many misconceptions amongst people in the world about how HIV and AIDS is transmitted. Because of that, people with HIV and AIDS are victimized through avoidance, detachment and so on. Prejudice (or negative attitudes towards other people) usually develops during the preschool years and continues to middle childhood years due to the influence of reinforcement, modelling and imitation. To avoid such, there is need for psycho education not only for the people infected with HIV and AIDS but the affected as well.

Support groups play a vital role in providing psychosocial support to those infected with HIV and AIDS especially children through peer support. Support groups

provide a forum where those infected get unconditional love from those whom they share similar experiences. There is no known cure for HIV and AIDS, therefore a holistic approach needs to be used to meet the emotional, physical, psychological and spiritual needs of those infected. There is no one single way of management of HIV and AIDS, management therefore, should focus on the specific needs of the patient.

Management of the HIV infection can therefore be by use of antiretroviral drugs, eating proper diet, social support groups and counselling and motivation. Good care includes catering for the physical, emotional, social and spiritual needs of CLWHA. These could be given in hospitals, nursing homes or the patient's own home.

DAYSTAR UNIVERSITY

## CHAPTER THREE

### RESEARCH METHODOLOGY

#### Introduction

The study used the case study approach which according to Kothari (2004) involved a careful and complete observation of a social unity which could be a person, a family, an institution, a cultural group or even the entire community. In this study, the focus was on two support groups dealing with CLWHA. Case studies deal with the processes that take place and their interrelationships, the researcher adopted a methodology that addressed the purpose of the study. This section outlines the methodological issues including the design for the study, the population which the researcher sampled from, the sampling procedure and issues concerning data collection and analysis.

#### Research Design

Research design has been defined by Kothari (2004) as “The blueprint for the collection, measurement, and analysis of data” (p. 31). Kothari explains that the design a researcher adopts in a particular enquiry, sets out conditions for collecting and analyzing data in a manner that aims to combine relevance to the research purpose with economy in procedure. This shows that the researcher must be guided by his/her research objectives in selecting a particular design. In this case, the researcher adopted the descriptive design which basically describes certain variables in the study. This design used qualitative and quantitative research tools to test hypotheses or to answer questions concerning the

current status of the subjects in the study (Mugenda & Mugenda, 1999). It focused on primarily describing such things such as possible behaviour, attitudes, values and characteristics. The purpose of the study was to evaluate the effectiveness of the support groups hence this design provided the researcher a set of tools to adequately achieve the objectives of the study.

### Population

The researcher established that there were support groups in all government provincial and district hospitals. Therefore, the researcher inferred that there were 217 support groups in government provincial and district hospitals in Kenya. The population of this study was all (217) support groups established for CLWHA in Kenya. The support groups are made of three categories of subjects namely administrators, facilitators and CLWHA between the ages of 10 and 15 years of age. The researcher therefore sampled and used the input from all the three categories of subjects to facilitate the study.

### Target population

The target population was support groups for CLWHA in government hospitals in Nairobi Province in Kenya. Nairobi province had 9 districts with one being a game park. Therefore there were 10 support groups for CLWHA. However, the researcher sampled from the support groups for CLWHA from Kenyatta National Hospital and Mbagathi District Hospital for data collection. These two centres were selected because they had established support groups and were also perceived to be on the forefront in implementing policies formulated in Kenya for support groups of CLWHA. KNH was



selected purposively to represent the provincial hospitals that had support groups whereas MDH represented the district hospitals in Nairobi that had the facility.

### Sampling Process

The sample size for the study was 49, with the breakdown as follows: the CLWHA who attend the support groups were conveniently sampled based on their availability at the meetings. For KNH support group, a total of 18 children participated in the study by wilfully responding to the questionnaires administered whereas 20 children participated in the study from MDH. The disparity in the number was explained by the fact that the population of children in Mbagathi was higher than Kenyatta. The children were drawn from the ages of 10 and 15 years because they were believed to be mature in expressing their opinions about the support groups.

In addition to the children who attended the support groups, facilitators of SGMs from both KNH and MDH totalling 7 were purposively interviewed using semi structured questionnaires. Three (3) facilitators were interviewed from MDH because that was the total number of facilitators of SGMs while at KNH 4 facilitators were interviewed. At KNH 1 facilitator was chosen from each of the categories of nurse counselor, psychologist, counselor and social worker who were authorized to attend and facilitate the SGMs. The views of the facilitators concerning the effectiveness of the support groups were crucial because they interacted with the children directly on meeting days. By virtue of their frequent interaction with the children, it was believed that they had clear understanding of the challenges facing the children as well as the support groups.

Finally, the administrators of the support groups were also purposively interviewed using semi-structured interview. The administrators more or less served as the link between the support groups and the government on policy and administrative issues. The total number of the administrators was 4 with 2 administrators from KNH and 2 from MDH support groups.

#### Methods of Data Collection

Descriptive designs as already explained uses quantitative and qualitative data to describe the characteristics of the subjects in an enquiry. Therefore, the researcher used three tools mainly survey questionnaires, semi-structured interviews and participant observation to collect data from the subjects of the study. The survey questionnaires were administered to the children. The researcher presented the questions in both English and Kiswahili to enable those who were not fluent in one language to adopt the other.

In addition, semi-structured interview questionnaires were administered to the administrators while semi-structured questionnaires to facilitators for their opinions on issues related to operational, administrative, policy and other relevant issues addressing the research questions. To minimize bias, the researcher also carried out participant observation by attending a couple of SGMs to observe how the sessions were organized. The findings of the qualitative and the quantitative data have been analyzed and discussed in chapter four.

## Data Analysis and Reporting

The quantitative data obtained from the use of survey questionnaires were analyzed using the SPSS (Version 17) and summarized with percentage charts and tables for better presentation in chapter four. The data was classified into usable categories like demographic information, opinions, goals and objectives. The qualitative data were also presented in tables and charts because they were designed and administered as open-ended questionnaires.

## Ethical Considerations

The purpose of ethical consideration for the research was to ensure that the research process would not cause any physical, emotional, mental and psychological or any other harm to the subjects. Further, the researcher wanted to comply with the standards of research set by the psychological associations and KNH Ethical Committee.

## Approvals

*Institutional approval:* The researcher received permission from Daystar University to conduct this research. Further, the researcher received approval from the ethics board at KNH and the hospital administration in MDH to carry out the research in their respective institutions. In view of this, the researcher did abide by the rules and regulations from the two hospitals.

*Informed Consent:* the researcher received informed consent from the respondents who were administrators and facilitators (See Appendix C and D) and the

parents/guardians of the children who attended SGMs (See Appendix A). This was necessary because the children were below 18 years and were legally incompetent therefore parental consent was mandatory and statutory. Research assistants were trained to take informed consent. The children were also asked to give their assent to participate in the study (See Appendix B).

*Confidentiality:* to ensure confidentiality, the questionnaires and interviews did not have slots for personal names; rather, they were coded with numbers to maintain anonymity. In instances where the respondents provided personal information, they were not used in the report of the findings. The researcher again ensured that the research assistants conformed to the code of confidentiality by signing personal agreement forms (See Appendix E).

#### Risks of Research

This being a social study, there was no possibility of respondents getting physical harm. However, there was a likelihood of psychological harm. Psychological harm was avoided by not asking embarrassing questions or expressing shock and disgust while collecting data. Questions that could bruise a respondent's self esteem, self worth or questions that could force the respondent to recall unpleasant occurrences against their will were avoided as these might have created psychological harm, discomfort or resentment (Mugenda & Mugenda, 2003). The researcher in cases of psychological harm to respondents would have referred them to a trained counsellor for counselling or done it herself because she was qualified to counsel.

## Summary

The researcher used descriptive research design which was qualitative and quantitative using survey method. The researcher further combined questionnaire, interview and observation as methods of data collection. The researcher chose the sample using purposive sampling. Data was then coded, tabulated and analysed using the SPSS version 17 software package for social sciences. The findings of the study are presented in chapter four.

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## CHAPTER FOUR

## ANALYSIS AND PRESENTATION OF FINDINGS

## Introduction

The purpose of the study was to evaluate the effectiveness of support groups for CLWHA. The researcher selected two government hospitals, namely, Kenyatta National Hospital and Mbagathi District Hospital that had support group centres as case study. Three data collection tools were used. They were participant observation, in-depth interviews and survey questionnaires. The findings of this study have been presented in this chapter. The researcher discussed the findings of both support group centres concurrently because they answered the same questions in the data collection tools.

## Socio-demographic Data

Table 4.1: Age and gender of children in the SGMs.

Gender		Male			Female			
		10-13yrs	14-17yrs	10-13yrs	14-17yrs	N/R	Total	
Name of hospital	MDH	Number	6	5	4	5	0	20
		%	30.0	25.0	20.0	25.0	0.0	100.0
hospital	KNH	Number	4	2	9	2	1	18
		%	22.2	11.1	50.0	11.1	5.6	100.0

The data collected indicated that 38 children participated in the study, 20 from MDH and 18 from KNH. Table 4.1 shows the gender and age distribution of the children in both support groups. Out of the 38 respondents, 10 children were males aged between 10 and 13 years while females of the same age group were 13. The study incorporated the

responses of 7 male and 7 female children aged between 14 and 17 years who were still in the support group for preteens. One of the reasons that could have led to the children aged 14 to 17 years still being in the preteens support group was that some of these children were not willing to graduate to the teens support group due to emotional attachment. Notwithstanding their age range, their responses provided useful insight for the study. The data shows that the KNH and MDH support groups were attended by children of mixed gender and of similar age range. However, one child did not indicate his/her gender.

Table 4.2. Age and gender of facilitators

<i>Gender</i>		Male		Female		Total
		25-35 yrs	36-45 yrs	25-35 yrs	36-45 yrs	
MDH	Number	1	0	0	2	3
	%	33.3	0.0	0.0	66.7	100.0
KNH	Number	0	0	1	3	4
	%	0.0	0.0	25.0	75.0	100.0

In addition to the questionnaires administered to the children who attended the SGMs at KNH and MDH, the researcher again administered questionnaires to the facilitators of the support groups. A total of 7 facilitators participated in the study, 3 from MDH and 4 from KNH. Table 4.2 shows that 1 male and 1 female facilitator are aged between 25 and 35 years and 5 female facilitators are aged between 36 and 45 years. Since the children who attended SGMs were of mixed-gender as seen in table 4.1, having mixed-gender facilitators offered better leadership style (Gerald, 2005).

## The HIV and AIDS Status of the Children

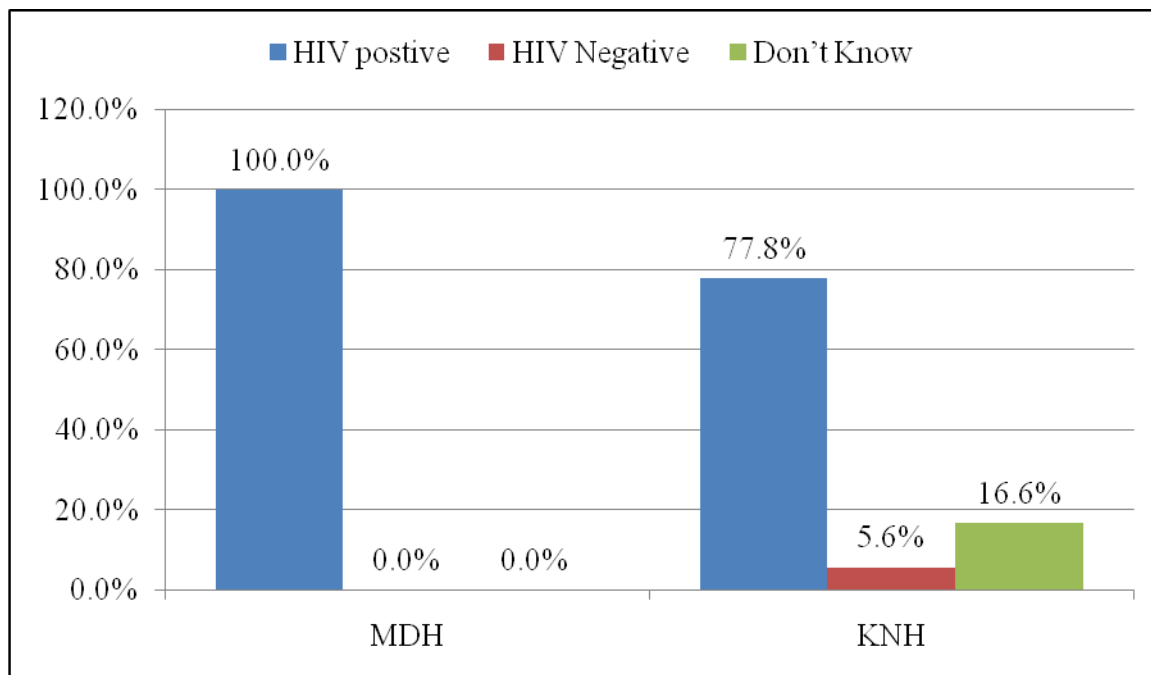


Figure 4.2: HIV and AIDS status of children respondents

The nature of the study necessitated that the HIV and AIDS status of the children be ascertained. The children were therefore asked to indicate their HIV status. The response is summarised in figure 4.2. At MDH, 100% of children who attended SGMs indicated they were HIV positive and that they knew their status after going through the recruitment phase. At KNH, 77.8% of the children who attended the SGMs indicated that they were HIV positive. However, 5.6% said they were HIV negative while another 16.7% of the children stated that they did not know their HIV status.

During the interview with administrators and facilitators, they reported that all the children who attended SGMs were HIV positive. The researcher therefore included in the study the children who reported their HIV and AIDS status as negative and neutral. The



researcher inferred that the people (doctors and parents) who referred the children to attend the SGMs knew that the children were HIV positive but the children were not aware of their status or were aware but were still in denial. According to Johnson (1975), group goals are the future state of affairs desired by enough members of the group to get the group working towards its achievement. Children who were HIV negative in a support group for children who were HIV positive would not benefit from the SGMs since they wouldn't desire the same outcome from SGMs since they would perceive that they did not share a common problem with the others. It is therefore important for children attending SGMs for HIV positive children to be aware of their HIV status.

Table 4.3: Whether the children have ever told their friends their HIV status

Name of hospital	Response		Total (%)
	Yes (%)	No (%)	
MDH	30.0	70.0	100.0
KNH	11.0	89.0	100.0

According to table 4.3, more children had not disclosed their HIV status to their friends, MDH (70%) and KNH (89%) as compared to those who had told their friends their HIV status, MDH (30%) and KNH (11%). One facilitator at MDH reported that they discouraged the children from indiscriminate disclosure to protect them from stigmatization. Fear of stigmatisation may explain why majority of the children had not disclosed their HIV status to their friends.

Table 4.4: The reaction of friends after disclosure by the CLWHA

<i>Name of hospital</i>	Response	Frequency	Percent
MDH	They supported me	6	30.0
	Not applicable	14	70.0
	Total	20	100.0
KNH	They made fun of me	1	5.5
	No comment	1	5.5
	Not applicable	16	89.0
	Total	18	100.0

In response to how their friends reacted when they told them their HIV status, according to table 4.4, at MDH, 30% of the children reported that they received support from them. At KNH, 5.5% said their friends made fun of them while another 5.5% did not give their comment. The researcher agrees with Sudha, Carla, Srikrishnan, Carl and Go et. al (2009) that stigma against PLWHA was a barrier to seeking prevention education, HIV testing and care. The remaining 70% and 89% at MDH and KNH respectively reported that the question was not applicable since they had not told their friends their HIV status. According to Nyblade, L. et. al (2003), for the community to be able to tackle stigma, programs need to create greater recognition of stigma and discrimination and foster in-depth applied knowledge about all aspects of HIV and AIDS. That could have contributed to the support received by 30% of the children at MDH who reported that they received support from their friends. Unfortunately the CLWHA who attend KNH SGMs did not receive the support they needed.

### Structural Organization of the KNH and MDH support groups

During the in-depth interview, the administrators gave brief accounts of how the support groups were started both at KNH and MDH. At KNH, one administrator said the support group was started more than 5 years ago whereas the second recounted that when she took up the position somewhere between 2005 and 2006, the group was already established. At MDH, the support group in the administrators' opinion began approximately five years ago. Unfortunately there was no documented evidence to support the establishment of both support groups. However, the researcher infers that the unstructured manner in which the support groups were started may explain why it was not very clear exactly when the support groups were started. However, one can conclude that both support groups were started approximately five years ago.

In the quest to find out whether there was an organizational structure at KNH and MDH support groups, one administrator at KNH reported that there was no clear cut structure of leadership in regard to the support group while another administrator indicated that the Head of Department of Patient Support Centre was the leader followed by Deputy Head, Psychologist in charge, then finally the team of facilitators. At MDH, the administrators reported that the doctor was in charge of the support group, followed by the matron and then the counsellors/facilitators. However, there was no written down organogram to confirm the same.

The in-depth interview with administrators at both hospitals also revealed that the support groups were open in that members could join and leave the groups at their own volition (Corey, 2008). However, at MDH, all children were taken through a recruitment

phase before they were allowed to join the SGMs. The recruitment phase entailed that the child must be aged between 10-15 years (ability to comprehend), the child must know their HIV status and if they were not aware, then disclosure was done, willingness of the child to join the support group, they must be trained on Hero Book and treatment literacy.

### Policies, Goals and Objectives of Support Groups

According to Johnson (1975), a group's ability to define its goals and achieve them sufficiently was one of the most important aspects of the group's effectiveness. Administrators were asked to list the goals and objectives of the support groups in order to establish whether there were national policies, goals and objectives of the support groups. Administrators at KNH and MDH reported that there were no national policies, goals and objectives guiding the organization of support groups. However, one administrator at KNH said that the government had developed a public sector HIV and AIDS work plan policy but it was not specific to the health sector or support groups. To facilitate the running of the support groups, the children and facilitators designed short terms goals and objectives to guide the meetings, which they called their constitution. The administrators at MDH reported that they had developed policies guiding the support which they called protocol, guidelines and quality manual. However, when the researcher requested for a copy of the constitution/protocol/guidelines or quality manual but they were not available. One facilitator reported that these were developed by individual facilitators and therefore not representative of the institutional administration of support groups.

According to the administrators at MDH, the initial goal for the support group,

when it was started, was for it to take care of the children as their parents were being treated. Other goals included: to educate the children on HIV and AIDS, to help them cope with their situation, to act as a forum for them to express themselves and to help them adhere to medication. All the administrators at MDH reported that the goals of the support group hadn't changed.

The administrators at KNH mentioned the following as some of the current goals of their support group: (1) to empower patients to deal with issues as they learn from other members, (2) to teach them life skills, (3) to promote HIV awareness, (4) to provide psychological acceptance, (5) to encourage positive living, and (6) to prepare children for disclosure of HIV status and to ensure adherence. The administrators at KNH gave conflicting information when asked whether the goals and objectives of the support group had changed or not. One said the goals had changed since the support group began while another reported that the goals had not changed. Therefore, the researcher inferred that the policies, goals and objectives of the support groups at KNH and MDH for CLWHA were ad hoc and varied depending on the administrators and facilitators.

Table 4.5. Whether the children respondents knew the goals of the support group and participated in the formulation of them

		<i>If yes, did you participate in formulating them?</i>				Total
		Yes	No	N/R		
<i>Do you know the goals of the support group?</i>	MDH	Number	15	4	1	20
		%	75.0	20.0	5.0	100.0
	KNH	Number	14	3	1	18
		%	77.8	16.7	5.5	100.0

To support the opinions of the administrators, the children were asked whether they knew the goals of their support group and whether they participated in their

formulation. Table 4.5 shows that majority of the children, 77.8% at KNH and 75% at MDH said they knew the goals of their support group and actually participated in the formulation of the same. The children clarified that they suggested the goals after each SGM in readiness for the next meeting. The researcher inferred that the goals were short term and not long term goals. Another 20% of the children at MDH and 16.7% at KNH said they did not know the goals hence did not participate in their formulation. At MDH, 5% of the children and 5.5% at KNH did not respond to the question.

It was also important to establish whether the facilitators were aware of the goals and objectives of the support groups. All the facilitators at KNH and MDH (100%) said they were aware of the goals and objectives of their respective support group. Their responses were summarised in table 4.6.

Table 4.6. Goals of the support group as stated by the facilitators

	MDH		KNH	
	Frequency	Percent	Frequency	Percent
Psycho-education	1	16.6	3	37.5
Social support	2	33.4	5	62.5
Adherence to medication	2	33.4	0	0.0
To provide a forum where children can express themselves	1	16.6	0	0.0
Total	6	100.0	8	100.0

The respondents were asked to state two goals of the support group. Table 4.6 lists the goals as stated by the facilitators. They mentioned social support (62.5%) at KNH and at MDH (33.4%), psycho education (37.5%) at KNH and (16.6%) at MDH. The facilitators at MDH also mentioned that the children better adhered to medication (33.4%) and the SGMs provided a forum for children to express themselves (16.6%).

Clear policies are required to have clear goals (Corey, 2008). Therefore lack of national and institutional policies, goals and objective at KNH and MDH could have led to facilitators not being very conversant with the goals of the support group seen in table 4.6 where they mentioned different goals.

### Strategies to Achieve the SGM Goals and Objectives

The administrators at KNH and MDH support groups reported that there were strategies put in place to achieve the goals and objectives of the support groups. The following were listed as some of the strategies put in place at KNH to ensure that the goals and objectives were achieved: (1) training of staff (2) creating awareness to other staff to enable referral (3) sourcing for donor funding (4) providing toys for children (5) looking for volunteers (6) working with partners. However, one administrator at KNH reported that no strategies had been put in place to achieve the goals and objectives of the support group since there were no national goals and objectives in the first place.

The facilitators at MDH listed the following strategies as having been put in place to achieve the goals and objectives of the support group: (1) scheduled monthly meetings (2) sharing of experiences during SGMs (3) discussions on various topics (4) peer education (5) organizing trainings and field trips for the children during the school holidays (6) approaching donors for funding.

MDH administrators on the other hand listed the following strategies as having been put in place to ensure the support group was effective: (1) calling the children to remind them to attend the SGMs (2) constantly updating partners to make them aware of

what was going on and inviting them to attend SGMs (3) availability or reimbursement of transport(4) proper preparation for meetings(5) use of trained counsellors(6) availability of a venue for meeting (7) provision of security during meetings. The children were not usually accompanied by their parents or guardians during SGMs unless they lived very far (outskirts of Nairobi). Parents were then also reimbursed transport whenever they accompanied their children for SGMs.

The researcher inferred that whereas strategies had been put in place at KNH and MDH support groups to achieve the ad hoc policies, goals and objective, the strategies were not the same because of lack of clear national policies, goals and objectives but varied depending on the administrators and facilitators.

#### Funding

The research findings showed that the KNH and MDH support groups did not receive funding from the same sources. The following were some of the sources of funding for the support group at KNH as identified by the administrators: (1) Presidential Emergency Program Aids Relief (PEPFAR) which provides medication(2) Aids Care and Treatment (ACTS) who pay for investigating opportunistic infections, medications, stationery, pay for personnel to facilitate SGMs, provision of snacks for children (3) Pathfinder International Program. However, it was noted that SGMs at KNH were sometimes not regular due to lack of funds or the funds were not being released on time. The administrators at MDH on the other hand reported that their support group received funding from United States International Aids for Development (Aphia ii) in partnership with the Ministry of Health.



Table 4.7. Number of children attending SGMs

		Response		Total
		11 to 20	21 to 30	
MDH	Number	2	1	3
	%	66.7	33.3	100.0
KNH	Number	2	2	4
	%	50.0	50.0	100.0

According to table 4.7, the facilitators at KNH and MDH gauged the number of children attending SGMs to range from 11 to 30 at both support groups. This showed that an average of 20 children attended SGMs. Attendance in open support groups was expected to vary depending on the needs of the individual children throughout the disease progression (Kimberly and Serovich, 1996).

Attendance to SGMs

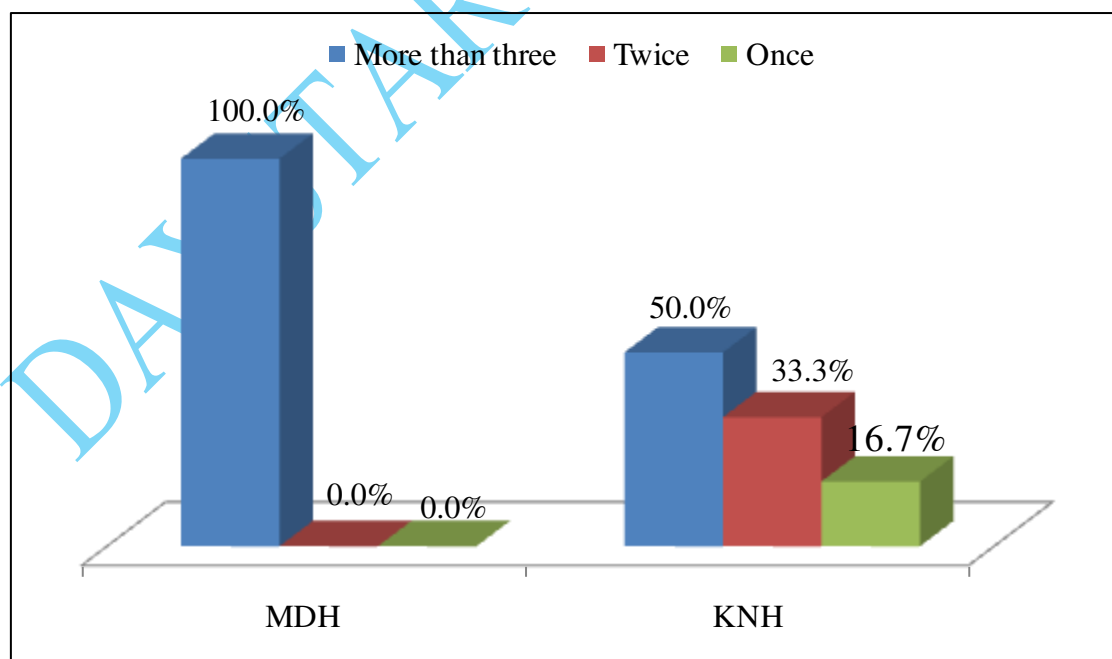


Figure 4.3. The number of times the children had attended the SGMs

It was important for the researcher to establish how many times the respondents had attended SGMs as it would determine the kind of information they had on how SGMs were run. Figure 4.3 shows that 50% and 100% of the children respondents at KNH and MDH respectively had attended the SGMs more than three times. However, 33.3 % at KNH had attended the SGMs twice and 16.7% had attended once. The variance in attendance of CLWHA to SGMs at KNH and MDH further indicated that these support groups were open and not closed support groups. According to Corey (2008), in open support groups new members replace those who are leaving.

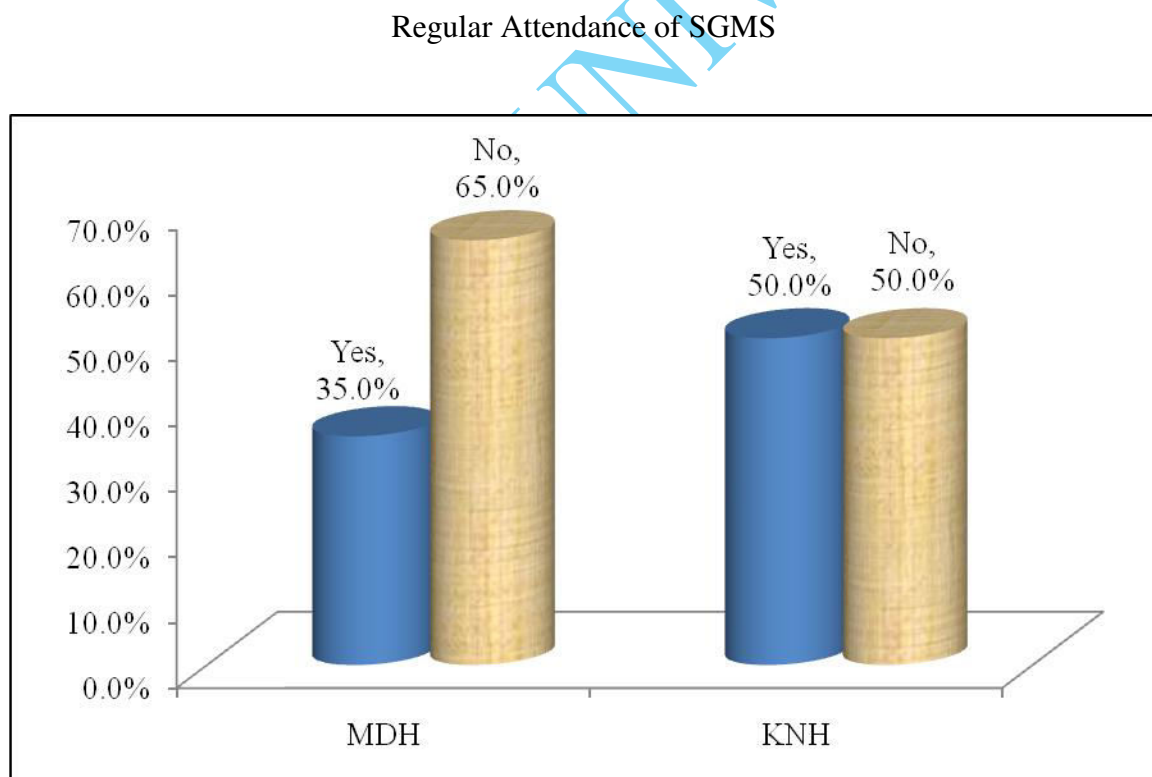


Figure 4.4: Whether the respondents regularly miss the SGMs

When the children were asked whether they regularly missed to attend SGMs,

35% at MDH and 50% at KNH said they sometimes missed to attend SGMs. However, 65% at MDH and 50% at KNH said they never missed to attend SGMs. Those who said they missed the meetings were asked to state some of the inhibiting factors that contributed to their inability to attend the meetings. Their responses have been summarised in table 4.8

Table 4.8: Reason(s) given by children who miss SGMs

	MDH		KNH	
	Number	Percent	Number	Percent
Because of school attendance	5	25.0	4	22.0
Because of poor communication	1	5.0	0	0.0
Because of church attendance	1	5.0	0	0.0
Because I had no time	0	0.0	1	5.6
Because I sometimes feel lonely	0	0.0	1	5.6
When we sometimes travel	0	0.0	1	5.6
No comment	0	0.0	2	11.2
Total	7	35.5	9	50.0

The reason given by the children who frequently missed attending SGMs were due to school attendance (25%) at MDH and (22%) at KNH. At MDH, the children reported they missed due to church attendance (5%) and poor communication of the meetings days to the children (5%). Some children at KNH missed to attend SGMs due to lack of time (5.6%), due to travelling (5.6%) and due to loneliness (5.6%). However, (11.2%) of the children at KNH did not give a comment. It would be important for the administrators of the support groups to look into ways of working with the CLWHA to minimise their absenteeism to SGMs to ensure that the children receive the much needed

psychosocial support.

Table 4.9. Frequency of SGMs: facilitators' responses

Name of hospital	Frequency of SGMs	Number	Percent
MDH	Monthly	3	100.0
	Total	3	100.0
KNH	Weekly or monthly	1	25.0
	Quarterly or when funds are available	1	25.0
	Twice a month	1	25.0
	Twice during the school holiday (post disclosure) and weekly during clinic day	1	25.0
	Total	4	100.0

Facilitators were asked to state the frequency of SGMs. Table 4.9 shows that all the facilitators (100%) at MDH agreed that their SGMs were held once a month.

However, facilitators at KNH gave differing responses to the schedule of SGMs which were as follows: once a week, once a month, quarterly, when funds are available, twice a month, twice during school holidays. The same contradiction on frequency of SGMs was seen when administrators at KNH reported that the SGMs were held twice a month, once a week, once in three months and once a month. Another administrator admitted that information on support groups was not well circulated and hence lack of proper information. According to Corey (2008), the schedule of SGMs is one of the practical concerns that should be addressed in the policies of support groups. Lack of known scheduled meetings reduces the efficiency of support groups especially since the CLWHA at KNH and MDH join SGMs by referral.

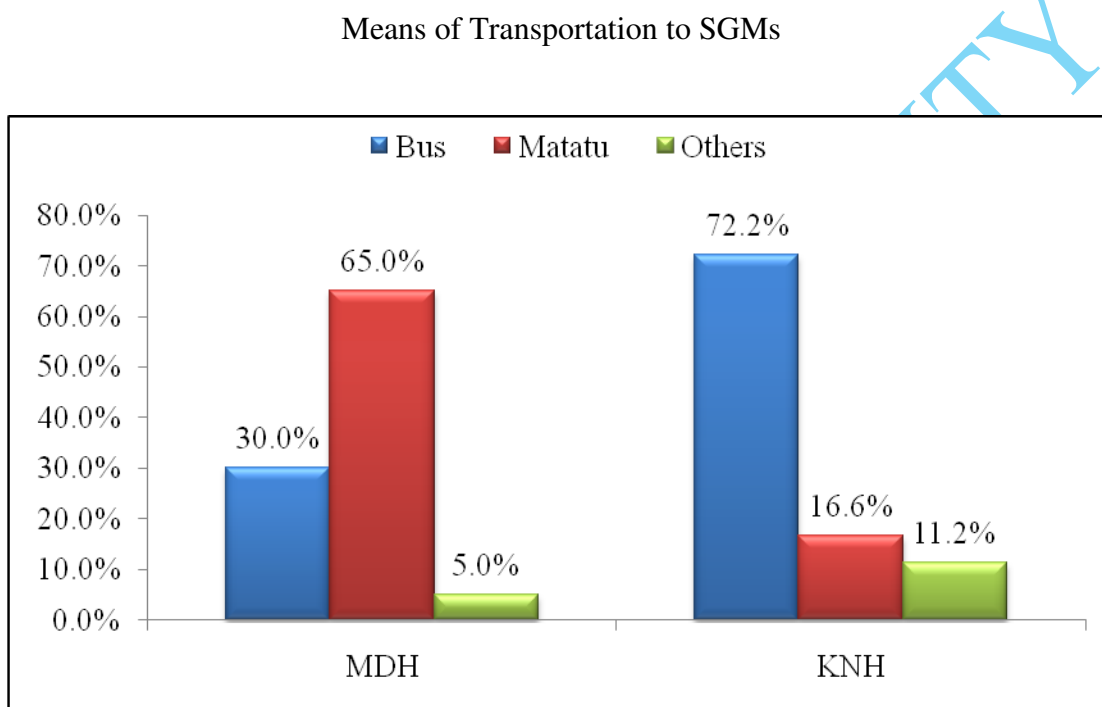


Figure 4.5. Means of transportation to SGMs

The children who attend SGMs at KNH and MDH commute from different parts of Nairobi and its environs. The researcher therefore wanted to understand the different means of transportation they used to explore whether it affected their attendance and whether there was need for them to be given incentives in the form of reimbursement of transport.

According to figure 4.5, 30% of the children at MDH and 72.2% at KNH used buses to travel to SGMs. At MDH, the most commonly used means of transport was

matatus (65%) while at KNH only 16.6% used matatus to travel to SGMs. Other means of transport used by 5% of the children at MDH and 11.2% at KNH included railway transport, taxi and going on foot. The reimbursement of transport used by the children attending SGMs is therefore necessary since it could be seen that indeed the children used means of transport that require payment of fare to attend SGMs.

#### Knowledge about the Support Groups

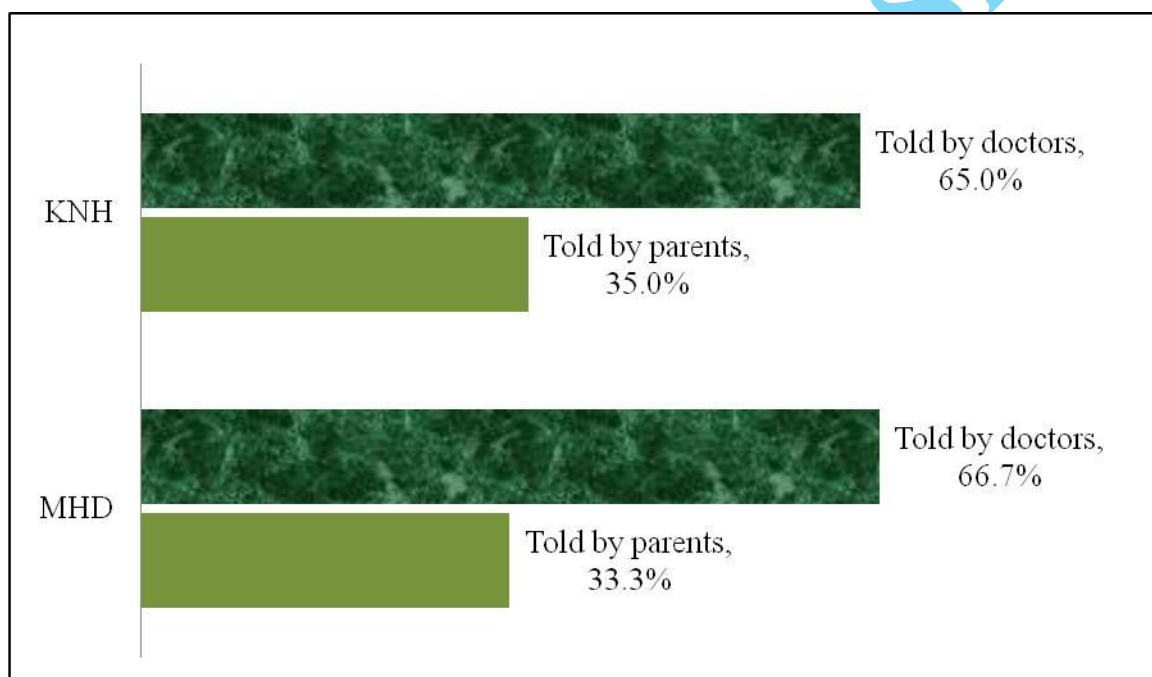


Figure 4.6: Those who introduced the children to the support groups

According to figure 4.6, a bigger percentage of the children (66.7%) at MDH and (65%) at KNH, reported they were advised to attend the SGMs by their doctor. The other (33.3%) at MDH and (35%) at KNH were told by their parents. According to Corey (2008) membership to groups can be voluntary or involuntary by referral. One can therefore infer that membership to KNH and MDH SGMs is involuntary as it is by

referral. It is important to note that at MDH the children after referral had to go through a recruitment phase as previously reported by the administrators and facilitators.

### The Effectiveness of the SGMs

#### *Facilitators*

On the effectiveness of the SGMs, 100% of the facilitators at MDH and KNH felt that the respective support groups were effective in providing support to CLWHA. Being the facilitators of the SGMs, their opinion carried a lot of weight on the effectiveness of the support groups. The reasons given are presented in table 4.10.

Table 4.10. Reasons for responses by facilitators on the effectiveness of the support groups

	KNH		MDH	
	Frequency	Percent	Frequency	Percent
Adherence to treatment	4	33.3	1	20.0
Empowered	4	33.3	3	60.0
Coping	4	33.3	1	20.0
Total	12	99.9	5	100.0

Table 4.10 shows the reasons given by facilitators as to why they reported their support groups were effective. They reported that children better adhered to treatment (33.3%) at KNH and (20%) at MDH. Further, the children were more empowered (33.3%) at KNH and (60%) at MDH and were better able to cope with challenges faced (33.3%) at KNH and (20%) at MDH. The reasons given by facilitators of SGMs on the effectiveness of support groups are in line with the goals and objectives of the support groups. Therefore the researcher inferred that the reasons given are good indicators of the

effectiveness of the support groups.

*Opinions of Administrators on the effectiveness of the SGMs*

The same question was posed to the administrators at KNH and MDH. One administrator at KNH said that they felt that the SGMs were not effective in providing support to CLWHA but the rest agreed with the facilitators. Below are some of the reasons the KNH administrator who felt the SGMs were not effective gave:

There are no standard operating procedures and if they are there they are not known therefore they cannot trickle down to the juniors. Meetings are not regular and children are not divided according to their age or when they were infected (Mode of infection) and whether the children were attending school regularly.

In the opinion of the administrators at MDH the support group was effective in providing support to CLWHA. Some of the reasons they gave for the positive answer included the children's CD4 count had improved and they adhered more to medication. The children who attended the support group took more responsibility over their health and were more open and empowered. Further, the children had accepted their situation and they gave feedback that they were happy with the SGMs. Lastly the children continued attending SGMs even if they had to walk. The children attending SGMs, facilitators and administrators of support groups all mentioned adherence to medication as one of the indicators of effectiveness of the KNH and MDH support groups. This confirms that the support groups were effective in providing support to children living with HIV and AIDS since it was one of the indicators of the effectiveness of support groups in this study.



### Presence of Trained Facilitators

In regard to who conducts the SGMs, all administrators (100%) at KNH and MDH agreed that only trained facilitators conduct the SGMs. Use of trained professional facilitators was another indicator of the effectiveness of the SGMs (Anderson & Shaw, 1994).

Table 4.11: The qualification of the facilitators of the support groups from the children's perspective

		Response		Total
		Yes	No	
MDH	Number	19	1	20
	%	95.0	5.0	100.0
KNH	Number	16	2	18
	%	88.9	11.1	100.0

According to table 4.11, 95.0% of the children at MDH and 88.9% at KNH responded that the facilitators were qualified to conduct SGMs. However, 5.0% of the children at MDH and 11.1% at KNH felt that the facilitators were not qualified. Though the number of children who felt that the facilitators were not qualified is small but their opinion cannot be overlooked.

Personnel conducting SGMs

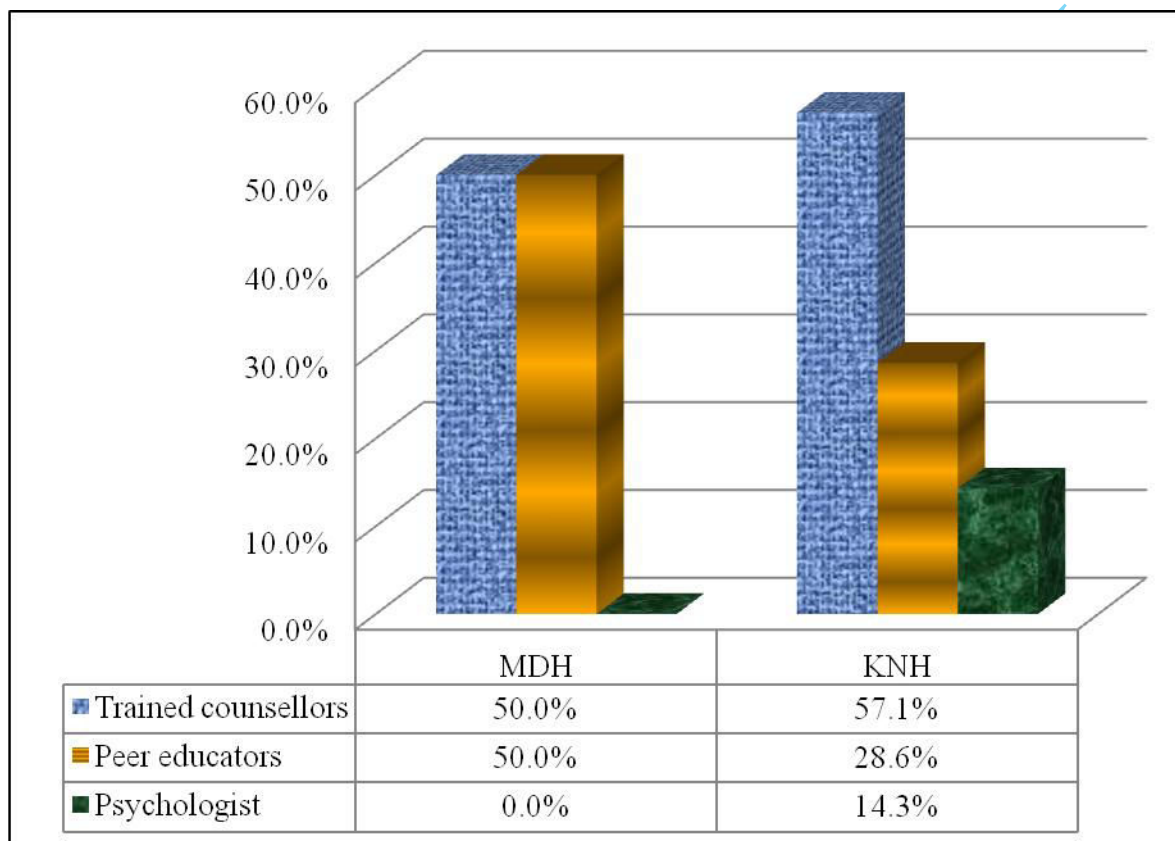


Figure 4.7: The personnel who conduct the SGMs

According to figure 4.7, at MDH, the SGMs were facilitated by two categories of personnel; these were trained counsellors 3 (50.0%), and peer educators 3 (50.0%). At KNH, according to the facilitators, the SGMs were conducted by trained counsellors 4 (57.1%), peer educators 2 (28.6%) and psychologists 1 (14.3%). The peer educators and psychologists assisted as co-facilitators which offered a better leadership model (Gerald, 2005).

Table 4.12. Are you trained to counsel children infected with HIV and AIDS?

		Response		Total
		Yes	No	
MDH	Number	3	0	3
	%	100.0	.0	100.0
KNH	Number	4	0	4
	%	100.0	.0	100.0

According to table 4.12, all the facilitators (100%) at MDH and KNH indicated that they were trained to counsel children infected with HIV and AIDS. According to this study, this was one of the key indicators of the effectiveness of SGMs. According to Anderson and Shaw (1994), a support group must be facilitated by professionally trained personnel for it to be considered effective. KNH and MDH support groups used trained facilitators.

Table 4.13. The number of trained counselors present in SGM meetings

Number of counsellors		Responses		Total
		Two	Three	
MDH	Number	3	0	3
	%	100.0	0	100.0
KNH	Number	2	2	4
	%	50.0	50.0	100.0

According to table 4.13, the facilitators at KNH reported that at any SGM, two (50%) or three (50%) trained counsellors were present. The facilitators at MDH, 100% reported that two trained counsellors were present in any SGM. This further confirmed

the use of co-facilitators in SGMs at KNH and MDH which offered a better leadership model (Gerald, 2005).

#### Adherence to Medication

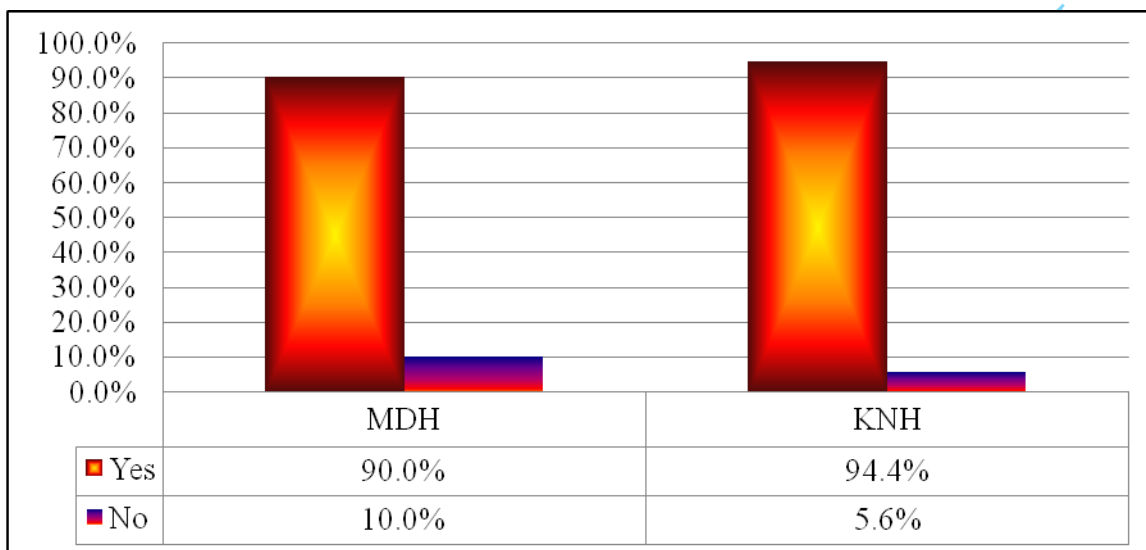


Figure 4.8: Whether the respondents practice what they are taught at the SGMs

Although the facilitators did not directly administer the ARVs, they guided the children as to how to effectively take them to prolong their lives. In this regard, the children were asked to ascertain whether they practiced the lessons they received from their facilitators.

According to figure 4.8, an impressive 94.4% of children at KNH and 90% at MDH said they did practice what they were taught at SGMs. However, 5.6 % at KNH and 10% at MDH said they did not practice what they were taught at SGMs. Going by this response, the researcher can infer that the effectiveness of the facilitators and the commitment of the children to the SGMs were not in doubt. However, the facilitators and

administrators at both SGMs need to find out the reasons why some children did not practice what they were taught at SGMs.

### The Strengths of the SGMs

Both support groups were found to have strengths although they differed. Following are some of the strengths of the support group according to the opinion of the administrators at MDH: (1) children actively participated in SGMs (2) good turn up during meetings (3) children demonstrated initiative during meetings (4) oneness between group members (5) acceptance of all group members (6) the support they gave each other.

Administrators at KNH listed the following as some of the strengths of their support group: (1) availability of good facilitators (2) children participated actively (3) support groups were run professionally by well trained facilitators (4) good rooms/child friendly services/staff (5) children were empowered to know they were not alone (6) children given hope (7) a sense of sharing/belonging among members (8) and it encouraged openness and disclosure. The differences in the strengths of the KNH and MDH support groups only showed that the format and guidelines of these support groups varied with the professional's style of leadership.

## Children Satisfaction with the Support Group

Table 4.14: Whether the respondents were happy with the SGMs and would advice friends living with HIV and AIDS to attend

		<i>Will you advise a friend infected with HIV to attend the SGMs</i>				<i>Total</i>		
		Yes		No		Number	%	
		Number	%	Number	%			
<i>Are you happy with the SGMs?</i>	MDH	Yes	19	95.0	1	5.0	20	100.0
		No	0	.0	0	.0	0	0.0
	KNH	Yes	18	100.0	0	.0	18	100.0
		No	0	.0	0	.0	0	0.0

The researcher cross tabulated two questions to understand the happiness of the children with the SGMs and how that happiness or otherwise would translate to positive or negative testimony to other CLWHA to attend the SGM. Table 4.14 shows that 100% of the children at KNH and 95% at MDH felt that they were happy with the SGMs and would at the same time, advice friends infected with HIV and AIDS to attend the SGMs.

However, 5.0% of the children at MDH felt that they were happy with the SGMs but would not advice a friend to attend. Although the majority of the children indicated they were happy with the SGMs, the small percentage that was unhappy cannot be overlooked.

Table 4.15: What children respondents like about the SGMs

<i>Things liked about the SGMs</i>	Name of Hospital			
	MDH		KNH	
	Number	%	Number	%
Learning	4	19.0	6	26.1
Encouragement	2	9.5	6	26.1
Adherence to medication	2	9.5	0	0.0
Entertainment	1	4.8	2	8.7
Socializing	3	15.0	4	17.4
Self awareness	3	15.0	4	17.4
Coping	5	25.0	1	4.3
Total	20	100.0	23	100.0

The researcher asked the children at MDH and KNH what they liked about their SGMs. According to table 4.15, (19%) of the children at MDH and (26.1%) at KNH felt that they liked the learning they received at SGMs and the encouragement received (26.1%) and (9.5%) at KNH and MDH respectively. The children liked socializing (15%) at MDH and (17.4%) at KNH and self awareness created by psycho education (15%) at MDH and (17.4%) at KNH. The children also enjoyed the entertainment given during SGMs (4.8%) at MDH and (8.7%) at KNH) and fact that they now coped better with the challenges they faced (25%) at MDH and (4.3%) at KNH. Lastly, 9.5% of the children at MDH liked the fact that they now adhered to medication. According to Bormann and Bormann (1992) groups can give members rewards at each hierarchy of needs as seen in the varied reasons given by the children as to why they liked attending SGMs.

### The Impact of the Support Group on the Children

In response to whether the support group had helped them in any way, all the children (100%) at KNH and MDH responded that the support group had helped them greatly. The reasons given were tabulated in table 4.16.

Table 4.16. Reasons given by the yes respondents

	KNH		MDH	
	Number	Percent	Number	Percent
Psycho education	7	19.4	3	7.5
Adherence to medication	4	11.1	11	27.5
Encouragement	3	8.3	0	0.0
Enhanced personal growth	0	0.0	12	30.0
Knowing my status	0	0.0	9	22.5
No response	22	61.1	5	12.5
Total	36	100.0	40	100.0

The respondents were asked to give two reasons how the support group had helped them. The major reason given according to table 4.16 were due to the children better adhering to medication (11.1%) at KNH and (27.5%) at MDH. The children felt that they had been helped by the psycho education (19.4%) at KNH and (7.5%) at MDH which led to their enhanced personal growth (30%) at MDH. The children had been helped by knowing their HIV status (22.5%) at MDH and (61.1%) at KNH. However, (12.5%) of children at MDH did not give a response as it was an open ended question. These reasons contributed to the rewards the children perceived to receive from the SGMs.



Table 4.17. What respondents do differently now - socially

Name of hospital	Responses	Number	%
MDH	I have been able to have a lot of friends and I trust them	7	35.0
	I get along better with family	3	15.0
	I teach people how to make their choice and be more courageous	1	5.0
	I am polite and happy	1	5.0
	No response	8	40.0
	Total	20	100.0
	KNH	I get along well with friends	12
I get along with my family		3	16.7
I teach others how they can get HIV		2	11.1
No response		1	5.5
Total		18	100.0

The children at KNH and MDH were then asked to list what they felt they did differently since they joined the support groups. The responses were summarised in table 4.17 . The children attending SGMs reported that they got along well with friends since they joined SGMs (66.7%) at KNH and (35%) at MDH. They also got along well with family members (16.7%) at KNH and (15%) at MDH. They felt they were now able to teach others how they could get HIV (11.1%) at KNH and (5%) at MDH while (5%) of the children at MDH said they were now happy. However, 40% of the children at MDH and 5.5% at KNH did not respond to the question. These reasons show how the children had improved socially since they joined the SGMs.

Table 4.18: What respondents did differently now – academically

Name of hospital	Response	Number	%
MDH	Improved academic performance	7	35.0
	Do not disclose my status to my colleagues	3	15.0
	I am happy therefore concentrate on my studies	1	5.0
	I gained more knowledge than before	1	5.0
	I have confidence which helps me pass my exams	1	5.0
	I work hard to achieve my goals	1	5.0
	No response	6	30.0
	Total	20	100.0
KNH	I perform better	18	100.0
	Total	18	100.0

According to table 4.18, the children reported that they performed better academically after joining SGMs (100%) at KNH and (35%) at MDH. Other reasons why they felt they had improved academically at MDH included being able to concentrate on their studies (5%), gaining more knowledge (5%), having more confidence (5%) and they worked hard to achieve their goals (5%). At MDH, (30%) of the children did not respond to the question. Academic performance of a CLWHA can be affected by constant absenteeism due to opportunistic infections. It is important to note that the children who attended KNH and MDH SGMs had improved in academic performance due to the psychosocial support received from attending SGMs.

Table 4.19. What respondents did differently now – emotionally

Name of hospital	Response	Number	%
MDH	I don't cry anymore	10	71.5
	I am happy	2	14.3
	I used to look sad but no longer do that	1	7.1
	I have learnt how to live positively	1	7.1
	Total	14	100.0
KNH	I don't cry often	13	72.2
	I am happy	2	11.1
	Sometimes I cry	2	11.1
	No comment	1	5.6
	Total	18	100.0

In response to emotional changes since they joined SGMs, the children reported that they did not cry often (72.2%) at KNH and (71.5%) at MDH, they were happy (14.3%) at MDH and (11.1%) at KNH and they had learnt how to live positively (7.1) at MDH. The children also reported that they were no longer sad (7.1%) at MDH. However, 5.6% of the children attending SGMs at KNH did not give their comment. These emotional benefits of SGMs further contribute to the psychological rewards the children received from attending SGMs.

#### Incentives and Rewards to CLWHA

All the administrators at KNH and MDH agreed unanimously (100%) that material incentives were given to the children who attended SGMs and their facilitators. The children were reimbursed the transport they used and given snacks during the SGMs. Facilitators on the other hand were provided with a small fee or allowance. A group becomes more attractive to its members if it provides more rewards than any other group can (Bormann & Bormann, 1992) .

Table 4.20: The relationship between the rewards received and SGM attendance

				<i>Would you still attend the meeting even without being given the reward?</i>		
				Yes	No	Total
<i>Are you given any reward when you attend the SGMs?</i>	MDH	Yes	Number	15	3	18
			%	75.0	15.0	90.0
		No	Number	2	0	2
			%	10.0	.0	10.0
	KNH	Yes	Number	16	1	17
			%	88.9	5.6	90.
	No	Number	0	1	1	
		%	.0	5.6	5.6	

The children were asked whether they received material rewards during SGMs. According to table 4.20, 75% of the children at MDH and 88.9% at KNH reported that they received rewards when they attended the SGMs but would still attend if the rewards were withdrawn. However, 15% at MDH and 5.6% at KNH reported that they received rewards when they attended SGMs but would not continue attending SGMs if the rewards were withdrawn. However, 10% of the children attending SGMs reported that they did not receive rewards when they attended SGMs but they would still attend the SGMs without the rewards. This contradicts the information provided by administrators at KNH and MDH who reported that all the children attending SGMs received rewards. The administrators therefore needed to ensure that all the children attending SGMs received material rewards and not be discriminatory in reward giving.

Table 4.21. What the children do not like about the support group

	MDH		KNH	
	Number	%	Number	%
Nothing	14	70.0	10	55.5
Lack of frequent meetings	3	15.0	4	22.2
Improper organization of SGMs	3	15.0	1	5.6
HIV status	0	0.0	1	5.6
Rewards given	0	0.0	2	11.1
Total	20	100.0	18	100.0

The researcher asked the children to report what they did not like about the SGMs so that it would form the basis for recommendations. Table 4.21 shows that (55.5%) of the children at KNH and (70%) at MDH liked everything about the SGMs; (22.2%) at KNH and (15%) at MDH said they did not like the fact that meetings were not frequent; (15%) at MDH and (5.6%) at KNH did not like the improper organisation of the SGMs; (11.1%) at KNH said they did not like the rewards (money and food) provided during SGMs; while (5.6%) at KNH said they did not like the fact that they were HIV positive. The administrators of the support groups could improve on the areas the children had identified as what they did not like.

#### Challenges of the Support Groups

According to the administrators at KNH, some of the challenges in the support group were as follows: (1) Some clients did not come back (2) some needs of the children were more than they could offer (poverty) (3) some children didn't respond to treatment due to lack of psychosocial support and family factors (4) no follow up of the children especially if they stopped attending SGMs (5) insufficient finances (6) lack of space leading to congestion in rooms (7) lack of sufficient human resource and (8) inability to

follow up in case of default.

According to the administrators at MDH, some of the challenges of their support group were as follows: (1) Low funding which sometimes made it impossible to meet and fare reimbursed was too little (2) lack of policies to guide the support group (3) lack of proper training of facilitators on child therapy (4) burnout of facilitators (5) some children who went to schools were stigmatized by friends or teachers (6) adherence was a problem especially in boarding schools and (7) some guardians mistreated the children yet the support group couldn't provide alternative shelter due to lack of funds.

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## Recommendations

### *Kenyatta National Hospital (KNH)*

The recommendations of the two hospitals were presented separately to enable the administrators at both hospitals to isolate the issues that pertained to them. The following are the recommendations from administrators at KNH. On policy issues, they felt that it was important for the government to work in conjunction with the Ministry of Health to come up with policies relevant to issues regarding CLWHA. Further, they felt there was need to develop policies for psychosocial care plan, being an important component of psychosocial support.

On administration, they recommended that protocols needed to be developed at the national level with clear outline of services expected and staff be trained and in serviced according to needs assessment.

On matters of funding, the administrators recommended that the government needed to draw a budget line for HIV and psychosocial support for CLWHA and to develop accountability and transparency in funding. Enthusiastic drivers needed to work with private sectors to support and fund support groups. Other key areas of the recommendations were that, all government facilities should have psychosocial support systems. Further, there is need to improve the facilities used during SGMs like playing ground and meeting room. There is need for information dissemination to the public to increase access and care of CLWHA and to ensure follow up visits for the children and their guardians.

The facilitators on the other hand gave recommendations that there was need to improve on communication of policies pertaining to support groups for CLWHA to all stakeholders and that meetings needed to be more regular i.e. weekly rather than monthly basis. They thought there was need to employ more facilitators to reduce the current high ratio of children to facilitators (10:1).

On funding, they recommended that funds be released on time and be availed consistently. Further, the process to be made faster and funds be increased due to continuous recruitment of children. Child friendly clinics needed to be built with materials like books and video rooms and more counsellors to be available to conduct one on one counselling in case of emergencies.

At KNH, 35% of children respondents said they had no recommendations for the support group as they were happy with SGMs as they were. However, 5.5% of the children did not respond to the question and the other 38.5% gave the recommendations that they needed to act and encourage others more, playing more, the support group should pay for their fees, they should be taught more about HIV and AIDS, they should be taken to many places and that support groups to meet more frequently.

#### *Mbagathi District Hospital (MDH)*

Administrators at MDH recommended that policies should be formulated, there was need for improvement on the organisation of the SGMs and that there was need to change the name of the support group to post-test clubs to avoid members getting disappointed when no financial support was given to them. Patients who joined the SGMs



thought they would receive financial assistance (monetary) therefore it was difficult to sustain the program with the name as it was.

Whereas the support group was being funded by NGO's, there was need for the government to fund the support group. The government needed to take ownership, put focus on children because once treatment was started, there was no follow up done due to lack of funds. Since these children attended schools, the administrators recommended that schools incorporate teachers in the care of CLWHA in order to avoid stigma and discrimination in schools. Children infected with HIV and AIDS refused to take medication for fear of being stigmatised in school. Teachers should therefore be taught how their pupils who are living with HIV and AIDS should adhere to medication and learn methods of managing the disease.

To increase the effectiveness of the support groups, there was need to train more people in child therapy, ensure sustainability of support groups in case the donors were not there or if they withdrew, increase incentives given e.g. fare to children and improve the quality of snacks given and lastly increase meetings to fortnightly instead of monthly. Since the groups were growing, there was need to separate the groups into smaller manageable groups, to begin a kids club, introduce support groups in schools which would sensitize other children and finally have more outside activities for the children attending SGMs; e.g. football team needed uniforms, balls and a playing field.

The following were the recommendations given by the facilitators at MDH; policies laid down should have both short term and long term goals with standard protocols to guide in facilitation, administrators of support groups should take

responsibility over support groups to ensure sustainability of the programs. Further, they should adopt new approved approaches on funding and bring in more partners.

At MDH, the children on the other hand recommended that the frequency of meetings be increased to weekly and the meetings be consistent, they be given more rewards when they attended SGMs and that they needed a field to carry out different co-curricular activities. However, 30% of the children liked the support group as it was and had no recommendations. Another 20% recommended that the support group should help their friends who abuse drugs, not chasing away people and adding them money.

#### KNH Observation Report

The researcher wanted to clarify the information received through questionnaires and interviews by participant observation of a support group in session. The following is an account of how the SGM at KNH was conducted. The following people were present: the group facilitator, co-facilitator, nutritionist, a doctor/clinical officer, 19 male and female children and the participant observer.

The SGM did not start at the scheduled time which was 9am but started at 1pm with the following activities taking place. The group began by 'breaking the ice' when the facilitator introduced herself and the co-facilitator and welcomed everyone. The children looked nervous but as the group progressed many could be seen to relax. They played a game which helped in introductions where one would mention their name, where they go to school, what one did, their hobbies and talents. Another member would pick another person and introduce them to the rest of the group and the person who had

been introduced would introduce the person who had introduced them. The latter would then throw a ball to someone else until everyone had introduced each other. By the end of the game everyone had mastered the other members' name. This game created a good rapport among the members and it broke the ice. The members were now free to talk to each other and the goal of breaking the ice was accomplished.

The facilitator and the co-facilitator were directing the support group and the doctor gave a talk about hygiene, opportunistic infections like TB, cholera and others and how to avoid contracting them. The nutritionist taught about the need for the children to be seeing her every time they came for their scheduled clinics. The participant observer who was the research assistant was asked to take minutes and record the members who were present.

As the meeting progressed, it became clear that most children were referred by the doctor because she seemed to know most of them. There was a lot of interactive discussion on every topic that was raised e.g. hygiene, opportunistic infections, facing challenges, adherence to medication, having knowledge of the medicine and consistent attendance of clinics. The children asked a lot of questions which were answered by the facilitators and other children present. Except for a few children, the rest seemed to be at ease as they were contributing to the discussions freely. There was order in the group and respect among the children.

There seemed to be open and mutual communication as children expressed their feelings openly. There was good understanding among the members. Children would question whatever they did not understand and clarifications were done. Individuals sat

close together giving an impression of giving of support. The children showed a lot of interest in whatever was taking place. Very few children occasionally showed lack of interest or sadness.

There seemed to be order due to the manner in which the activities took place. The norm that was observed was that there was no disturbance during the group process leading to no break during the activities. All the children behaved well. It is important to note that the group was an open group because new children joined the group that day.

#### MDH Observation Report

The following people were present during the SGM at MDH: there was a facilitator who was a female and male co-facilitator, two visiting facilitators together with the research assistant which made five grownups. Twenty one male and female CLWHA were present in the SGM.

The group session began at exactly 2:30pm though the children began to trickle in as early as 1:00pm. As the children trickled in, they socialized while others played games like football while they took soft drinks and snacks. These provide a great link for the children before the official session began. The children seemed happy and in a cheerful mood. There was a great degree of bonding among the children as it was evident that they were well acquainted with each other and the facilitators.

During the session, the children were taken through lectures on topics the children chose. There was active contribution by all. Once in a while the facilitator reminded the children who seemed disruptive the ground rules. The interaction was free as the children gave their opinion without prejudice.

The SGM seemed to be very organized. The activities seemed to flow smoothly as one activity led to the next. A report of how the children had gone on since the last meeting was given by all the children who were willing to share. They also shared their experiences, adherence to medication and CD4 count. Those experiencing complications or other psychological problems were given individual attention or group therapy depending on the gravity of the matter. The co-facilitator assisted the facilitator all through.

After the re-cup session, they entered into a discussion on selected topics affecting the children and participation of all children was encouraged. During the SGM, it was evident that the group norms were observed e.g. respect for others' views, participation by all and beginning and ending with prayer among others. The SGM ended at approximately 4:30pm.

#### Summary of Chapter

This chapter has looked at the research findings of this study. In summary the findings were as follows; The KNH and MDH support groups were open types of support groups, both had scheduled meetings although KNH did not always adhere to the schedule due to financial constraints, the SGMs were facilitated by trained counselors with co-facilitators, the organizational structure of both SGMs were there although not very clear or written down, there were no national policies, there were ad hoc goals and objectives in both support groups. Children were given rewards and incentives when they attended SGMs. Various strategies were put in place by KNH and MDH support groups to achieve the set objectives of the SGMs. The children who attended SGMs, facilitators

and administrators agreed that the SGMs were effective in providing support to CLWHA with the exception of one administrator at KNH who did not agree that their support group was effective.

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## CHAPTER FIVE

### DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS

#### Introduction

This chapter discusses the findings of this research, conclusions are made on the basis of the findings and then the researcher makes recommendations. The researcher also provides suggestions for further research in the areas that were not covered in this study.

#### Discussion of the Main findings

Data was collected from two support groups for CLWHA in Nairobi province i.e. KNH and MDH. The research findings from KNH and MDH SGMs showed that both support groups were homogenous because they were made up of children of the same ages and with a similar problem concerning how to manage HIV and AIDS. The researcher agrees with Corey's (2008) assertion that homogenous groups are more effective than heterogeneous groups because of the shared interest and problems. The underlying principle is that the shared interest or problems become the basis of forming goals and objectives which the group members work to achieve.

Out of the 38 children who participated in the study, 23 were aged between 10 and 13 years while 14 children were aged between 14 and 17 years. One of the reasons that could have led to children of over 15 years still being in the support group for the preteens was that some of these children were not willing to graduate to the teens support

group. The researcher can infer that because of the friendship and bond that were formed when they became members of the preteens support group accounted their unwillingness or delay to join the teens support group. Notwithstanding their age range, their responses provided useful insight for the study.

The general assumption was that the memberships of SGMS were supposed to include only CLWHA, who were also fully aware of their HIV status. However, the study found that not all the children of KNH support group had knowledge of their HIV status. This is because 5.6% of the children reported that they were HIV negative while another 16.7% reported that they did not know their HIV status. These could be the children who indicated that they had attended SGMS once or twice. The researcher confirmed the HIV status of the children from the administrators at both hospitals and it was reported that all the children who attended the SGMS were HIV positive.

The researcher can infer that either the HIV status of these children had not been disclosed to them or that they were still in denial after disclosure. In either way, the situation presents grave challenges to the group because children who do not know their HIV status but attend SGMS face a dilemma of practising or taking seriously what they were taught hence endangering their lives.

When the children were asked whether they had told their friends their HIV status, majority (70%) at MDH and (88.9%) at KNH had never told their friends their HIV status. The researcher agrees with White and Carr (2005) when they state that stigma, denial and silence regarding HIV are the norm. Stigma and denial act as barriers to seeking prevention education, HIV testing and care (Sudha, Carla, Srikrishna, Carl &



Go et al, 2009). However, it is important to mention that the facilitators at MDH reported that they discouraged the children from indiscriminate disclosure to people to avoid stigmatisation. That could also have contributed to the children not disclosing their status. The researcher agrees with Nyblade et. al (2003) that the community needed to come up with programs to create greater recognition of stigma and discrimination and foster in-depth knowledge about HIV and AIDS to be able to adequately tackle stigma.

#### Structural organization of KNH and MDH support group

The study found that there were no written leadership structure of organisation although the structure was known verbally to the facilitators and administrators. The KNH and MDH support groups were open as opposed to closed. In open support groups, members can join and leave as they wished. This researcher made this observation because there was variance in the number of times the children had attended SGMs where some children had attended SGMs three times, others two times while some once. The researcher agrees with Anderson and Shaw (1994) that group attendance can fluctuate per meeting as members were allowed to take breaks as well as vacations from the group. School and church attendance listed in table 4.8 were some of the reasons given by the children as to why they missed to attend SGMs.

Open support groups require expertise to bring all the members both new and continuing to benefit from each meeting. The study found that the facilitators at KNH and MDH were trained and equipped to handle the support groups.

The study found that the membership to MDH and KNH support group was by

two main agents. Twenty five out of the 38 children reported that they were introduced to the group by their doctors while 13 of the CLWHA said it was their parents. However, the CLWHA at MDH support group were taken through a recruitment phase to adequately prepare them because one of the conditions was that one must be willing to join the group. Children not willing to join were not forced to for the same reason that psychosocial support cannot be forced upon an individual unless one was willing to receive it. KNH support group lacked a recruitment procedure which led to children joining the SGMs without knowing their HIV status or thinking they were negative.

MDH support group had a schedule for SGMs and it was adhered to. At KNH it was not clear the schedule for SGMs. According to Corey (2008), in order for children support groups to be efficient, they should meet more frequently but for shorter periods of time than fewer times for longer periods of time. The researcher supports Corey because when the meetings are far spaced, in between meetings the children encounter a lot of challenges and they do not receive the support needed at the right time. The KNH and MDH support groups can therefore be made more effective by increasing the frequency of meetings. Further, information on schedules for SGMs should be included in the policies of the support groups and communicated to all stakeholders.

#### Policies, Goals and Objectives of Support Groups

Policies are necessary for the support group to be considered effective as they address practical concerns in the formation of the support groups (Corey 2008; Johnson & Johnson, 1975). However, the administrators and the facilitators at KNH and MDH reported that although there were no national policies guiding support groups, the groups

themselves formulated their own goals in consultation with the children. In spite of the existence of ad hoc goals and objectives, the researcher observed that the absence of broad national policies and guidelines somehow compromised the effectiveness of the support groups.

#### Strategies to Achieve Goals and Objectives of Support Group

With the absence of national policies, goals and objectives of support groups at KNH and MDH, one can infer that it was very difficult for the administrators to come up with strategies to increase the effectiveness of the support groups. The researcher therefore inferred from the findings that since the support groups were operating on ad hoc goals, and then the strategies set must have been ad hoc and varied depending on the administrators in power, facilitators and children attending SGMs.

#### Effectiveness of KNH and MDH Support Group

According to Anderson and Shaw (1994), facilitators have to be trained in order for the group to be considered effective. All the administrators and facilitators reported that the support groups were facilitated by trained professionals. However, the children (92%) reported that their facilitators were trained to facilitate SGMs. The manner in which the support groups were organised and run in an ad hoc manner probably influenced the children's opinion on the effectiveness of the facilitators. This in turn influenced their attitude as to whether they could receive the support they needed.

The support groups at KNH and MDH used both male and female co-facilitators. Corey (2008) states that co-facilitators offered a better leadership model than single

facilitators. Therefore, the researcher can infer that the combination of main and co-facilitators offered the support groups the richness of depth in terms of leadership necessary to meet the needs of the children as well as the goals and objectives of the support group. Further, the use of male and female facilitators and co-facilitators offered an even better leadership style because these support groups were for mixed gender and the different genders may have different needs at different times in the stages of their disease progression.

Inconsistency in following the schedule of SGMs at KNH was one of the findings of this research. However, the MDH support group had consistent SGMs. The inconsistency was brought about mainly by lack of funds since the support groups received all their funding from NGO's and not the government. There was need for more reliable sources of funding which would ensure that meetings were consistently held. The procedure of getting the funds within the system was sometimes noted to delay SGMs.

Three out of the 4 administrators reported that the support groups were effective because in their opinion, the group provided the psychosocial needs of the children. The administrators who reported that the support group was ineffective cited lack of clear policies as the major reason. The facilitators on the other hand reported that the support groups were generally effective in spite of the daunting challenges.

The children reported that they were happy with the SGMs and disclosed how the SGMs had addressed their educational, health, social and emotional issues. According to Corey (2005), groups can be used for therapeutic or educational purposes. Academically, 83.3% of the children reported that they performed better because of their encounter in

the support group. In most cases, CLWHA had problems coping with academic work because of the crisis they suffer. Sometimes because of prolonged illnesses/opportunistic infections, children miss classes and this unquestionably affects their academic performance. This just emphasises the need for schools to work hand in hand with the support groups that offer psychosocial support to children attending their institutions.

The children also reported that they practised what they were taught by adhering to medication. This was an important indicator to the effectiveness of the support group because if the children didn't practise what they were taught, the quality of their life would be poor since HIV and AIDS had no cure but depended on good management. Unfortunately, 10% at MDH and 5.6% at KNH said they did not practise what they were taught in SGMs. It was not possible to establish whether these were the children who did not know their HIV status or whether they just chose not to practise what they were taught. Such children, when identified require individual counselling to be able to address the issues they had that made them not practise what they were taught in regard to improving their quality of life.

The study found that 50% of the children at KNH and 65% at MDH never missed to attend SGMs. The researcher agrees with Kimberly and Serovich (1996) that CLWHA require varying levels of support at varying stages in the progression of their disease, hence the fluctuation in attendance. Fun activities and celebrations should be part of the group life to welcome back members who had been absent due to illness.

According to Bormann and Bormann (1992), groups can give members rewards at each hierarchy of needs. Support groups have the potential to meet the biological and

physiological needs, safety needs, belongingness and love needs, esteem needs and self actualization for the children attending them. The effectiveness of the support groups is what will determine to what level/extent the support group will meet these needs. The administrators and the facilitators reported that the children were given rewards including snacks and transport reimbursement. The children confirmed this finding and noted that although they appreciated the gesture, that was not their motivation for attending the support groups as 88.9% of children at KNH and 75% at MDH reported they would still attend the SGMs in the absence of rewards and incentives. This shows that the children value the psychosocial rewards they receive from SGMs more than the monetary rewards. This is not to discount the importance of the incentives or rewards provided by the support group.

#### Conclusion

HIV and AIDS are destroying many lives especially in Sub-Sahara Africa. There being no cure for HIV and AIDS, early identification and diagnosis is important for the survival of children infected with HIV and AIDS. These should be followed by clear standard systems of follow up. The aim of care for CLWHA should be comprehensive enough to improve their quality of life. Support groups for CLWHA provide psychological support needed for the well being of these children.

From the findings of the study of KNH and MDH support groups for CLWHA, the researcher concludes that indeed support groups are effective in providing support to CLWHA. Some of the indicators that led to the conclusion that support groups are effective in providing support are: It was seen that the children who attend SGMs

improved in adherence to medication, they had better coping strategies, they were more empowered to meet the challenges they faced on a daily basis, they had shown improved academic performance, they socialized more and were able to cope with friends and family members. The use of trained facilitators and co-facilitators had also contributed to the effectiveness of the support groups and presence of policies, goals and objectives though ad hoc.

However, the absence or presence of the following aspects were seen to reduce the effectiveness of the support groups: Lack of national policies, goals and objectives of support groups, lack of clear structural organisational framework, poor communication among the stakeholders leading to communication breakdown, lack of funds and lack of consistent meetings.

#### Study Recommendations

From the research findings, the researcher would like to make the following recommendations. Some may have been part of the recommendations given by the administrators, facilitators or children attending SGMs.

1. There being no national policies, goals and objectives at KNH and MDH support groups, the government and other NGO's involved in policy development of support groups for CLWHA need to develop a national policy framework for support groups. Further, the administrators of support groups need to derive their goals and objectives from the national policies of the support groups to ensure effectiveness and consistency in the running of support groups.

2. The administrators need to develop clearly written down strategies from the goals and objectives of the support groups and communicate them to all stakeholders of support groups. The researcher also recommends shorter meetings (not longer than two hours) that are held more frequently (fortnightly). Further, the administrators of support groups could develop a program that brings the support groups together e.g. the KNH support group could organize to have a joint session with MDH support group for the members to share ideas and even socialize more.
3. The administrators need to broaden the psycho education offered in SGMs to include life skills and technical skills that could be used for income generating purposes.
4. The government and other NGO's need to also fund SGMs to ensure sustainability of the support groups and for accountability purposes. Further, the government needs to identify an organisation that will coordinate the activities of support groups for CLWHA at the national level to be able to bring about consistency and effectiveness in how the support groups are run.
5. The government needs to train more people on child therapy to reduce the huge ratio of counselor/facilitators to children.
6. The administration needs to look into developing and adapting clear system of disclosure to children who have tested HIV positive and need to join SGMs. This could be done by introducing a recruitment phase before the children can join the support groups.



### Areas of Further Research

This study looked at the effectiveness of support groups for CLWHA. It focused on two government hospitals, KNH and MDH. For further research, there is room to evaluate the effectiveness of the support groups for CLWHA in private hospitals.

Further research could be done to establish whether there is a correlation between the lifespan of the CLWHA who attend SGMs as opposed to those who do not attend SGMs. Further research can also be done on the attitude of the children infected with HIV and AIDS from birth(Prenatal) as opposed to those who acquire it after birth e.g. from rape.

Finally, research can also be done to establish the correlation between adherence to medication, support groups attendance and CD4 counts of the children attending SGMs.

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## APPENDICES

## APPENDIX A: Informed Consent Form for parents/guardians

Stella Kemuma Nyagwencha

Daystar University

Topic: An evaluation of the effectiveness of support groups for CLWHA: A case study of Kenyatta National Hospital and Mbagathi District Hospital.

I am Stella Kemuma, a masters student in counseling psychology at Daystar University is undertaking a research to find out more about support groups for CLWHA at Kenyatta National Hospital and Mbagathi District Hospital. The research findings may be used to help improve the management and organization of support groups for CLWHA. Any improvements in support group organization and management will enable the children who attend such support groups to benefit more from the group meetings.

In this research I will interview many children attending support group meetings at the two medical institutions. They will be asked a number of questions concerning the support group meetings. It is standard practice in research studies involving children to seek the consent of parents/guardians. The selected children will also be asked for their consent; both the guardian and child may consent independently. This proposal has been reviewed and approved by Kenyatta National Hospital Ethics Board which is a committee whose task it is to make sure that research participants are protected from harm. If you wish to find about more from the KNH ethics Board, contact Prof. K.M. Bhatt (Chairperson, KNH/UON-ERC) on tel. No. 725272, P.O. Box 20723. If you have questions later, you can call me on 0722373032 or my supervisor Dr. Josephine Omondi (Child Psychiatrist KNH) on 0720474609

The researcher intends to administer questionnaires to the children who attend the support groups at Kenyatta National Hospital and Mbagathi District Hospital between the

months of May and August 2010. The questionnaires will take approximately 15 minutes to fill.

This letter is an invitation that your child participate in this research. The researcher assures you that your child's identity will be protected through coding of questionnaires. If your daughter/son does not wish to answer some of the questions included in the questionnaire, she/he may skip them and move on to the next question. The information received and generated from the research will be used purely for academic purposes and will also be submitted to the management of KNH and MDH as recommendations to help improve the management of support groups in the respective institutions. Your child's contribution will therefore enhance or improve on the support group strategies and policies.

The researcher therefore seeks your permission to administer this questionnaire to your child. If you are willing for your child to participate in this research, please sign in the space provided below and return the form to the researcher.

I parent/guardian, agree for my child to participate in this research. The purpose of the study has been explained to me and I look forward to contributing to the welfare and psychosocial care given to the children who are HIV positive.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## APPENDIX B: Assent form for children attending support group meetings

Stella Kemuma Nyagwencha

Daystar University

Topic: An evaluation of the effectiveness of support groups for CLWHA: A case study of Kenyatta National Hospital and Mbagathi District Hospital.

I am Stella Kemuma, a student doing masters in counseling psychology at Daystar University. I am doing a research study to find out how well the support groups for CLWHA work. The purpose of this research is to learn more about the support groups, how they are ran and then suggest to the management of KNH and MDH how they can be improved to serve you better. Any improvements in support group organization and management will help you meet your goals of attending support group meetings.

The researcher intends to give written questions to the children who attend the support group meetings at Kenyatta National Hospital and Mbagathi District Hospital between the months of May and August 2010. If you decide that you want to be part of this study, you will be asked to answer some written questions, which will take you about 15 minutes to answer.

I am going to give you information and invite you to be part of this research study. You can choose whether or not you want to participate. We have discussed this research with your parents/guardian and they know that we are also asking you for your agreement. If you are going to participate in the research, your parent/guardian also has to agree. But if you do not wish to take part in the research, you do not have to, even if your parents have agreed. There may be some words you don't understand or things that you want me to explain more about because you are interested or concerned. Please ask me to stop at anytime and I will take time to explain.

The researcher assures you that your identity will be protected through numbering of questionnaires. Your name will not appear anywhere on the question paper therefore



no one will know these answers came from you personally. If you do not wish to answer some of the questions included in the questionnaire, you may skip them and move on to the next question. The information received from the research will be used only for academic purposes and will also be given to the management of KNH and MDH as suggestions to help improve the management of support groups in the two institutions. Your contribution will therefore enhance or improve on the support group strategies and policies.

This proposal has been reviewed and approved by Kenyatta National Hospital Ethics Board which is a committee whose work is to make sure that people who take part in research are protected from harm. If you wish to find out more from the KNH ethics Board, contact Prof. K.M. Bhatt (Chairperson, KNH/UON-ERC) on tel. No. 725272, P.O Box 20723. If you have questions later, you can call me on 0722373032 or my supervisor Dr. Josephine Omondi (Child Psychiatrist KNH) on 0720474609

The researcher therefore seeks your permission to administer this questionnaire to you. If you are willing to participate in this research, please sign in the space provided below and return the form to the researcher. If you decide not to be in the research, it's okay and nothing changes. This is still your clinic and everything stays the same as before.

Do you understand? Is this OK? If it is, kindly fill in the following section.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## APPENDIX C: Informed Consent Form for administrators

Stella Kemuma Nyagwencha

Daystar University

Topic: An evaluation of the effectiveness of support groups for CLWHA: A case study of Kenyatta National Hospital and Mbagathi District Hospital.

I am Stella Kemuma, a student doing masters in counseling psychology at Daystar University. I am doing a research study to evaluate the effectiveness of the support groups for CLWHA. The purpose of this research is to learn more about the support groups, how they are ran and then give recommendations to the management of KNH and MDH. Any improvements in support group organization and management will help the children who attend them meet the goals of attending support group meetings.

The researcher intends to interview you because you are an administrator in charge of support groups for CLWHA. If you decide that you want to be part of this study, you will be asked to answer some questions, which will take you about 20 minutes to answer. I will also interview other administrators in charge of support groups for CLWHA at KNH and MDH. I am going to give you more information and invite you to be part of this research study which will take place between the months of May and August 2010.

The researcher assures you that your identity will be protected through coding of interviews. Your name will not be written anywhere on the question paper therefore no one will know these answers came from you personally. If you do not wish to answer some of the questions included in the questionnaire, you may skip them and move on to the next question. The information received from the research will be used only for academic purposes and will also be recommended to the management of KNH and MDH as suggestions to help improve the management of support groups in the two institutions. Your contribution will therefore enhance or improve on the support group strategies and policies.

This proposal has been reviewed and approved by Kenyatta National Hospital Ethics Board which is a committee whose work is to make sure that people who take part

in research are protected from harm. If you wish to find out more from the KNH ethics Board, contact Prof. K.M. Bhatt (Chairperson, KNH/UON-ERC) on tel. No. 725272, P.O Box 20723. If you have questions later, you can call me on 0722373032 or my supervisor Dr. Josephine Omondi (Child Psychiatrist KNH) on 0720474609

The researcher therefore seeks your permission to administer this questionnaire to you. If you are willing to participate in this research, please sign in the space provided below and return the form to the researcher.

I agree to participate in this research. The purpose of the study has been explained to me and I look forward to contributing to the welfare and psychosocial care given to the children who are HIV positive.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

DAYSTAR UNIVERSITY

## APPENDIX D: Informed Consent Form for facilitators

Stella Kemuma Nyagwencha

Daystar University

Topic: An evaluation of the effectiveness of support groups for CLWHA: A case study of Kenyatta National Hospital and Mbagathi District Hospital.

I am Stella Kemuma, a student doing masters in counseling psychology at Daystar University. I am doing a research study to evaluate the effectiveness of support groups for CLWHA. The purpose of this research is to learn more about the support groups, how they are ran and then give recommendations to the management of KNH and MDH. Any improvements in support group organization and management will help the children who attend them meet the goals of attending support group meetings.

The researcher intends to administer a questionnaire to you because you are one of the facilitators of support group meetings for CLWHA. If you decide that you want to be part of this study, you will be asked to answer some questions, which will take you about 15 minutes to answer. I will also interview other facilitators in charge of support groups for CLWHA at KNH and MDH. I am going to give you more information and invite you to be part of this research study which will take place between the months of May and August 2010.

The researcher assures you that your identity will be protected through coding of interviews. Your name will not be written anywhere on the question paper therefore no one will know these answers came from you personally. If you do not wish to answer some of the questions included in the questionnaire, you may skip them and move on to the next question. The information received from the research will be used only for academic purposes and will also be recommended to the management of KNH and MDH as suggestions to help improve the management of support groups in the two institutions. Your contribution will therefore enhance or improve on the support group strategies and policies.

This proposal has been reviewed and approved by Kenyatta National Hospital Ethics Board which is a committee whose work is to make sure that people who take part in research are protected from harm. If you wish to find out more from the KNH ethics Board, contact Prof. K.M. Bhatt (Chairperson, KNH/UON-ERC) on tel. No. 725272, P.O Box 20723. If you have questions later, you can call me on 0722373032 or my supervisor Dr. Josephine Omondi (Child Psychiatrist KNH) on 0720474609

The researcher therefore seeks your permission to administer this questionnaire to you. If you are willing to participate in this research, please sign in the space provided below and return the form to the researcher.

I agree to participate in this research. The purpose of the study has been explained to me and I look forward to contributing to the welfare and care given to the HIV positive.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

DAYSTAR UNIVERSITY

## APPENDIX E: Research Assistants

## Personal agreement for maintaining confidentiality

I \_\_\_\_\_ of \_\_\_\_\_

P.O. Box \_\_\_\_\_

Affirm that I will not disclose any information obtained from the respondents in the process of data collection as I help the researcher collect the data. I will only discuss the respondents with the supervisor of the research.

Research Assistant: \_\_\_\_\_ Date \_\_\_\_\_  
Signature

Researcher: \_\_\_\_\_ Date \_\_\_\_\_  
Signature

## APPENDIX F: Interview for Administrators

Interview No: \_\_\_\_\_

I am Stella Kemuma, a student at Daystar University pursuing Masters of Arts in Counselling Psychology. I will administer the interview myself. This interview seeks to evaluate the effectiveness of support groups for children living with HIV/AIDS. You are requested to respond to the following questions. The findings of this research are intended to help improve support groups for children living with HIV/AIDS in Kenya.

The information received will be used for the purpose of this study only and will remain confidential. Kindly answer the questions appropriately.

1. Sex:                      male ( )                      female ( )
2. How old are you? -----
3. How long have you served in this institution as an administrator of the support groups for CLWHA
4. When was this support group started? -----
5. What were the initial goals and objectives of starting this support group?-----  
-----
6. What are the current major goals and objectives of the support group?
  - i.) -----
  - ii.) -----
  - iii.) -----
  - iv.) -----
  - v.) -----
7. What are the strategies put in place to achieve the goals and objectives of the support group?
  - i.) -----
  - ii.) -----
  - iii.) -----
  - iv.) -----
  - v.) -----
8. Where do you receive funding for the support system? -----  
-----
9. How often do the support groups meet?-----
10. Who conducts the support group meetings?
  - i.) Trained counselor ( )
  - ii.) Untrained counselor ( )

- iii.) The children themselves ( )
- iv.) any other-----

11. How many children attend your support groups meetings?

- i.) Between 1-10 ( )
- ii.) Between 11-20 ( )
- iii.) Between 21-30 ( )
- iv.) any other -----

12. What is the structural organization of the support group? -----

-----  
-----  
-----

13. In your opinion, is the support group effective in providing social support to children living with HIV/AIDS?

- Yes ( )
- No ( )
- I don't know ( )

ii) Kindly list the indicators that show that it is effective in providing psychosocial support to children living with HIV/AIDS?-----

-----  
-----  
-----  
-----

14. Are there any policies guiding the support group? Yes ( ) No ( )

ii) If there are, who develops them? -----

iii) What are the major policy guidelines on the following?

finances-----

-----

organization-----

-----

15. What type of support group do you have? Open ( ) Closed ( )

Explain more about them -----

-----  
-----



16. Do you give incentives to the facilitators and children who attend support group meetings?      Yes ( )      No ( )

If you explain more -----  
-----  
-----

17. What are some of the challenges this support group faces?  
-----  
-----  
-----

18. In your opinion what are the strengths of your support group?

19. List some of the measures which have been put in place to ensure the success of the support group? \_\_\_\_\_  
\_\_\_\_\_

20. Are the children accompanied by their parents?    Yes ( )    No ( )

21. What would you recommend to the ministry of health or academic institutions concerning support groups for children living with HIV/AIDS with regard to:

i) Policies \_\_\_\_\_

ii) Administration \_\_\_\_\_

iii) Funding \_\_\_\_\_

iv) Any other area \_\_\_\_\_

## APPENDIX G: Questionnaire for Facilitators/Counsellors

Questionnaire No: \_\_\_\_\_

## 1. Questionnaire for facilitators/ counselors

I am Stella Kemuma a student at Daystar University pursuing masters in arts in counseling psychology. I will administer the interview myself. This interview seeks to evaluate the effectiveness of support groups for children living with HIV/AIDS. You are requested to respond to the following questions. The findings of this research are intended to help improve support groups for children living with HIV/AIDS in Kenya. The information received will be used for the purpose of this study only and will remain confidential. Kindly fill in appropriately.

1. Sex:                      male ( )                      female ( )

2. Age:                      Below 25 ( )                      36-40 ( )

25-30 ( )                      41-45 ( )

31-35 ( )                      46-50 ( )

51 and above ( )

3. How often does your support group meet?

i.) Once a week ( )

ii.) Once in two weeks ( )

iii.) Once in a month ( )

iv.) Specify any other \_\_\_\_\_

4. Who conducts the support group meetings?

i.) Trained counselor ( )

ii.) Untrained counselor ( )

iii.) The children themselves ( )

iv.) Specify any other \_\_\_\_\_

5. How many children attend your support groups meetings?

iii.) Between 1-10

iii.) Between 21-30

iv.) Between 11-20

iv.) Specify any other \_\_\_\_\_

6. How many trained counselors are present in any support group meeting at any one time? One ( ) two ( ) three ( ) more than four ( )

7. Are you trained to counsel children infected with HIV/AIDS?

Yes ( )

No ( )

8. Are you aware of the goals and objectives of the support group?

Yes ( )

No ( )

ii) If yes, Name two of them \_\_\_\_\_

9. In your opinion, is the support group effective for children living with HIV/AIDS? Yes ( ) No ( )

i.) Kindly list the indicators that led you to give the answer above.

-----  
-----  
-----

10.) What are your recommendations to the head of this institution concerning the support group?

- i) Policies -----  
-----
- ii) Administration-----  
-----
- iii) Funding-----  
-----
- iv) Any other area-----  
-----  
-----

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## APPENDIX H: Questionnaire for children

Questionnaire No: \_\_\_\_\_

## 2. Questionnaire for children attending support groups.

I am Stella Kemuma, a student at Daystar University pursuing Masters in arts in Counseling Psychology. This interview seeks to evaluate the effectiveness of support systems for children living with HIV/AIDS. You are requested to respond to the following questions. The findings of this research are intended to help improve support systems for children living with HIV/AIDS in Kenya. The information received will be used for the purpose of this study only and will remain confidential. Kindly fill in appropriately

1. Sex:                      male ( )                      female ( )

2. Age: \_\_\_\_\_ years

3. What is your HIV status?

HIV positive ( )                      HIV negative ( )                      I don't know ( )

4. How many times have you attended support group meetings?

None at all ( )                      Once ( )                      Twice ( )                      More than three times ( )

5. Are you happy with the support group meeting? Yes ( )                      No ( )

6. Can you advice a friend infected with HIV and AIDS to attend your support group program? Yes ( ) No ( )

7. What do you like about the support group?-----  
-----

What don't you like about the support group? -----  
-----

8. What means of transport do you use to travel to attend the support group meeting e.g. walking, bicycle, car, bus or matatu? -----

9. Do you ever miss support group meetings? Yes ( ) No( )

9.ii) If yes what makes you miss the meetings-----  
-----

10. Do you practice what you are taught at the support group meeting? Yes ( ) No ( )

11. In your opinion has the support group helped you in anyway? Yes ( ) No ( )

11.ii) If yes write two ways it has helped you-----  
-----

12. What do you do differently now compared to before you joined the support group?

i) Socially ( friends or family)-----  
-----

ii) Academically( at school)-----  
-----

iii) Emotionally ( e.g. do you cry more, )-----  
-----

13. Are you given any rewards when you attend the support group (e.g. money, food, gifts)? Yes ( ) No ( )

i) Would you still attend the meeting even without being given the rewards?

Yes ( ) No ( )

14. Do you know the goals of the support group? Yes ( ) No ( )

ii) If yes, did you participate in formulating them Yes ( ) No ( )

15. In your opinion are the people who lead the support group meeting well trained to lead? Yes ( ) No ( )

16. Who told you to start attending the support group meetings?

Told by my parents ( )

Told by the doctor ( )

Told by my friend ( )

I decided to go on my own ( )

Any other -----

17. Have you ever told your friends your HIV status? Yes ( ) No ( )

ii) If yes, how did they react?

Avoided me ( )

They didn't show any emotion ( )

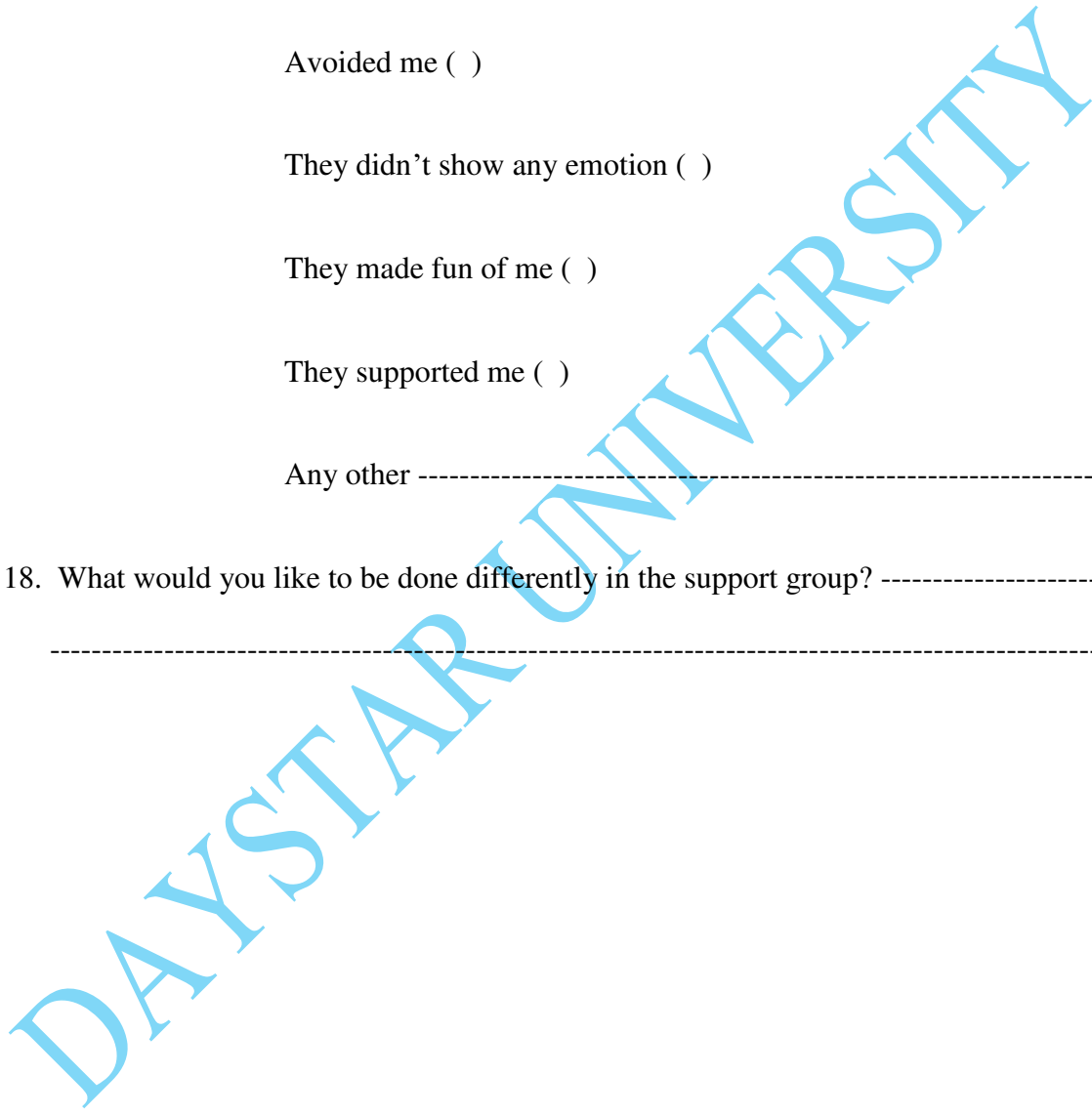
They made fun of me ( )

They supported me ( )

Any other -----

18. What would you like to be done differently in the support group? -----

-----





## APPENDIX G (iii): Fomu ya maswali ya watoto

Fomu ya maswali nambari \_\_\_\_\_

Fomu ya maswali kwa watoto wanaohudhuria vikundi vya msaada.

Mimi, Stella Kemuma, ni mwanafunzi katika chuo kikuu cha Daystar ambapo ninafanya digrii ya Uzamili katika Saikolojia. Haya mahojiano yanalengakutaahmini ufanisi wa njia za msaada kwa watoto wanaoishi na virusi vya ukimwi. Unaulizwa uyajibu maswali yafuatayo. Matokeo ya utafiti huu yanalenga kusaidia kuimarisha njia za msaada kwa watoto wanaoishi na virusi vya ukimwi nchini Kenya. Ujumbe uliopokelewa utatumika kwa minajili ya somo hili pekee na utadumu siri. Jaza fomu hii kwa weledi au kujaza pengo.

1. Jinsia: Mvulana ( ) Msichana ( )
2. Umri: Miaka \_\_\_\_\_
3. Hali yako ya virusi ikoje ? nina virusi ( ) sina virusi ( ) sijui ( )
4. Umehudhuria mikutano ya vikundi vya msaada mara ngapi?  
Sijawahi ( ) mara moja ( ) marambili ( ) zaidi ya mara tatu ( )
5. Unapendezwa na mkutano wa kikundi cha msaada? Ndio ( ) la ( )
6. Unaweza kumshauri rafikiyo aliyekumbukizwa virusi vya ukimwi kuhudhuria mpangilio wa kikundi chako cha msaada? Ndio ( ) la ( )

7. Ni kipi kinachokupendeza kuhusu kikundi cha msaada?

---

---

8. Ni kipi hukipendi kuhusu kikundi cha msaada?

---

---

9. Ni njia gani za usafiri unazotumia kuhudhuria mkutano wa kikundi cha msaada mfano kutembea, kuendesha baisikeli, kupanda gari, basi au matatu?

---

10. Umewahi kukosa kuhudhuria mikutano ya kikundi cha msaada? Ndio ( ) la ( )

ii) Ikiwa ndio, ni sababu gani hukufanya ukose kuhudhuria mkutano?

---

---

11. Unafanya mazoezi ya yale unayofunzwa katika mkutano wa kikundi cha msaada?

Ndio ( ) la ( )

12. Kwa mawazo yako kikundi cha msaada kimewahi kukusaidia kwa njia yoyote?

Ndio ( ) la ( )

ii) Ikiwa ndio andika njia mbili ambazo kimekusaidia

---

---

13. Ni lipi sasa unalofanya tofauti ukilinganisha na kabla hujajiunga na kikundi cha msaada? i) Kijamii( marafiki au familia)

\_\_\_\_\_

ii) kielimu ( shuleni)\_\_\_\_\_

iii) Kihisia ( mfano wewe hulia zaidi au...)\_\_\_\_\_

14. Unapewa zawadi zozote unapohudhuria kikundi cha msaada(mfano, pesa, chakula, tuzo) ? ndio ( ) la ( )

ii) Unaweza kuendelea kuhudhuria mkutano hata kama hutapata zawadi?

Ndio ( ) la ( )

15. Unajua malengo ya kikundi cha msaada? Ndio ( ) la ( )

ii) Ikiwa ndio ulihusishwa katika kuunda malengo haya? Ndio ( ) la ( )

16. Kwa mawazo yako, watu wanaongoza kikundi cha msaada wamefundishwa na kufuzu vyema ili kuongoza? Ndio ( ) la ( )

17. Ni nani aliyekuambia uanze kuhudhuria mikutano ya kikundi cha msaada?

Niliambiwa na wazazi wangu ( ) niliambiwa na daktari ( )

niliambiwa na rafiki yangu ( ) niliamua kwenda kivyangu ( )

niliamua jingine lolote ( )

18. Umewahi kuwaambia marafiki zako kuhusu hali yako ya virusi? Ndio ( ) la ( )

ikiwa ndio walifanyaje?

Walinitenga ( )

hawakuonyesha hisia zozote ( )

walinichekelea (walinichezea share) ( )

walinisaidia ( )

na jingine lote \_\_\_\_\_

19. Ni nini ambalo ungelipenda lifanye tofauti katika kikundi cha msaada?

\_\_\_\_\_

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## APPENDIX I: Direct Observation Schedule

The observation focused on the following areas

- Who is present in the meeting?
- How can you describe them?
- What roles are they playing?
- How did they become part of the group?
- Who directs the group?
- What is happening?
- What are people doing and saying?
- How are they behaving?
- How and what are they communicating?
- What body language are they using?
- When does this activity occur?
- How is it related to other activities or events?
- How long does it last?
- What makes it the right or wrong time for this to happen?

- How is this activity organized?
- How are the elements of what is happening related?
- What rules or norms are evident?
- How does this activity relate to other aspects of the setting?

The researcher will make notes of all of these aspects after time spent in the setting and then develop the notes into a coherent written record of her experiences in the context under study. The notes will then be used to develop and refine other data collection method. They will also be used to elaborate on findings from other data collection methods.

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APPENDIX J: KNH Ethics Board Approval

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APPENDIX K: KNH Hospital Approval

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APPENDIX L: National Council for science and Technology Approval

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