Care, support and treatment of HIV-positive orphans in selected residential institutions for HIV-positive children in Nairobi, Kenia

by

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DECLARATION

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ABSTRACT

As the AIDS epidemic has continued to spread among the world population it has had a double effect on children through infection and/or being rendered orphans through the death of their parents. With the growing developments in the area of pediatric HIV that have led to establishment of standards in the care of HIV positive children, the study sought to determine the standard of care, treatment and support that residential institutions provide to HIV positive children under their care and how they meet the requirements needed in caring for them. This study used an exploratory design to gain insight on the subject area. A qualitative method with semi-structured interview guide was used targeting the administrators in two residential institutions that care for HIV positive children.

The study established that high standards are applied in the care of HIV positive children in the two residential institutions in line with recommended standards. Unfortunately even with the advent of pediatric antiretroviral therapy (ART) treatment and Prevention of Mother to Child Transmission (PMTCT) programmes there has not been a significant decline in the intake and referral of HIV positive children into the residential homes. The HIV positive children are not exempt from stigma and discrimination and need a great deal of support to cope with this and other psychosocial issues in all areas of their lives. Recommendations are proposed for policy makers, Government, children's department and donors to improve in the holistic care of HIV positive children.

OPSOMMING

Hierdie studie het ten doel gehad om die standaarde van sorg aan MIV-weeskinders in ‘n aantal versorgingsinstellings in Nairobi, Kenia te ondersoek.
‘n Kwalitatiewe metode ,met semi-gestruktureerde vraelyste , is gebruik om inligting in te samel. Die studie het vasgestel dat relatiewe hoë standaarde van sorg vir hierdie kinders, in die twee instellings wat ondersoek is, bestaan. Dit blyk egter dat daar ‘n beduidende agteruitgang is in die gebruik van antiretrovirale middels deur die hierdie MIV-positiewe kinders en dat die administrasie van die medikasie aan die kinders nie op ‘n voldoende standaard is nie. Daar word verder gevind dat selfs die kinders nog steeds blootgestel is aan ‘n redelike hoë mate van stigma en diskriminasie en dat hulle deurlopende sielkundige ondersteuning nodig het.
Wydlopende voorstelle ter verbetering van die beter versorging van MIV-positiewe weeskinders word in die studie gemaak.

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CHAPTER 1. INTRODUCTION

AIDS was first recognized in children in 1983 by Rubenstein in New York, two years after the virus was isolated in France and subsequently it has gone on to infect up to the present 2.5 million children infected globally with 2.3 million or (90%) of the world's children living with HIV currently living in sub-Saharan Africa (UNAIDS, 2010). The first cases in the East African region were also reported in the early to mid-1980s (ANECCA, 2003).

Children get HIV through three main modes of transmission namely vertical transmission where the mother with HIV passes the virus to her baby during pregnancy, labour or delivery and breastfeeding. This is the commonest way that children get HIV; through sex (child sexual abuse/rape); and through blood to blood contact such as through unsafe blood transfusion or sharing dirty needles. In Africa, high rates of maternal HIV infection, high birth rates, lack of access to currently available and feasible interventions, and the widespread practice of prolonged breastfeeding translate into a high burden of pediatric HIV disease. The transmission risk for a child born to an HIV-infected mother in an African setting without interventions for prevention of mother to child is about 30-40% (ANECCA, 2003). In 2009, an estimated 15.7 million women above the age of 15 were living with HIV globally, and 1.4 million of them became pregnant. Nearly 90% of these expectant mothers were living in 22 countries in sub-Saharan Africa and India (UNAIDS, 2011). An estimated 370,000 children contracted HIV during the perinatal and breastfeeding period in 2009, despite an acceleration of the Prevention of Mother to Child Transmission (PMTCT) approximately 1000 children continue to get infected with the virus every day (UNAIDS, 2010). An estimated 370,000 children contracted HIV during the perinatal and breastfeeding period in 2009, despite an acceleration of the Prevention of Mother to Child Transmission (PMTCT) approximately 1000 children continue to get infected with the virus every day (UNAIDS, 2010). Even though the coverage of programmes to stop HIV infections among children has more than doubled in the last few years, progress is insufficient and does not meet the prevention and treatment needs of women and children (UNAIDS, 2011).

The number of children younger than 15 years receiving ART increased by 80,000 (or 29%) in 2009 to 354,000 (UNAIDS, 2010). Antiretroviral coverage for children is lower than that for

adults 28% for children compared to 37% coverage for adults. A number of countries report sharply lower antiretroviral therapy coverage for children than for adults. In six of the high burden countries, antiretroviral therapy coverage for children is less than half that of adults with large differences in countries such as Cameroun (30% adults versus 11% children), Mozambique (32% versus 12%), Uganda (43% versus 18%) and Kenya (50% versus 30%). Only two countries South Africa and Bostwana reported greater antiretroviral therapy coverage for children than for adults. (UNAIDS, 2010). In 2006 The Population Council pointed out that while efforts to get more children on treatment are increasing, important information is lacking to guide program and policy implementation. For example, there has been little documentation of experiences in the identification, treatment, and management of young children who are HIV-positive, scarce information about how communities, caregivers, and health providers can work together to improve access to treatment for these children (Population Council, 2006).

Even though the HIV adult prevalence worldwide has decreased and access to treatment has also increased resulting in lowered mortality rate, the number of children 0 – 17 years who have lost their parents due to HIV has increased instead of decreased from 14.6 million in 2005 to 16.6 million in 2009 an increase of two (2) million (UNAIDS, 2010) of whom the majority of these orphans almost 90% are in sub-Saharan Africa which is the worst affected region globally. The growing number of children who have lost parents to AIDS or whose lives will never be the same because of it is one of the most difficult challenges of the HIV/AIDS epidemic (UNAIDS et al, 2004).

An orphan is defined as a child under the age of 18 years who has lost one parent and is classified as paternal or maternal depending on which parent has died or as single or double orphans if one or both parents have died. (UNAIDS et al 2004). A larger proportion of orphans have lost their parents to AIDS than to any other cause of death – meaning that were it not for the AIDS epidemic, these children would not have been orphaned (UNICEF 2006). Kenya's current population is estimated at 38.6 million of which 18 million are children; 46% live below the poverty line and this includes about 8.06 million children. The impact of HIV/AIDS accounts for about 48% of the Orphan and Vulnerable Children (OVC) out of the estimated number of 2.5 million children (KNBS and ICF, 2009). The HIV/AIDS orphans can be grouped into two broad

categories: those orphaned by HIV/AIDS and are HIV negative and those orphaned and are HIV positive.

Traditionally orphans should be taken in by the extended family but due to various reasons such as poverty, unwillingness and fear of added responsibility, the children especially the ones who are HIV positive end up in institutional care often referred to as children's homes. Families of HIV-positive children as likely to be adversely affected by HIV and AIDS themselves and so will be unable to offer support for the development of their children. AIDS has put a tremendous strain on single parents, extended families and traditional community safety nets. Government social safety nets are often absent (UNESCO, 2008). Supporting parents and communities should also be a core component of any rehabilitation programme for children. This study found a big gap in programmes that consistently support parents and communities care for children, especially where the households is poor and vulnerable (Ken, 2007).

Since the advent of HIV/AIDS there has been a significant increase in the number of residential care facilities for children in Kenya and sub-Sahara Africa as a whole which have been opened by Children's department, NGOs, faith and community based organizations, and compassionate individuals. Currently there are over 300,000 children in residential institutions in Kenya (Little Angels Network, 2012). Some of the homes take in all orphans while others take in specifically HIV positive orphans only. In sub-Sahara Africa in particular, HIV is in part responsible for a changing care landscape, as growing number of children orphaned by parents dying from HIV related illness is being used as a rationale for the unchecked expansion of many different forms of residential care (EveryChild, 2001). According to records from the Children's department, there are a total of 590 registered homes in Kenya of which 89 are in Nairobi. There is however no classification of homes for HIV-positive children specifically from other homes. The first children's home for HIV positive children in Kenya was opened in 1992 by the late Reverend Angelo D'Agostino. Children of God Relief Institute "Nyumbani" which means home in Swahili was established in response to the rising number of children abandoned because of being infected with HIV. Other homes specializing on HIV positive children were later opened in Kenya. There is much that remains unknown about the number of children in residential care in sub-Saharan Africa because estimates are available only for a limited number of countries.

Although few countries maintain data on private institutions, reports indicated that the number of privately funded residential facilities has grown rapidly in recent years. A study in Zimbabwe found that between 1994 and 2004, 24 new institutions were built and the number of children in residential care doubled. Another study across six countries found that 35 per cent of the residential care facilities it identified had been established since 1999 (Hennessey 2001 cited in Ken, P.L.A, 2007).

Residential institutions for children in Kenya are established in accordance with The Children (Charitable Children's institutions) Regulations, 2005. The regulations stipulate that institutions shall be run in a way consistent with the guiding and overriding rights contained in the Convention on the Rights of the Child, 1989, and the African Charter for the Rights and Welfare of the Child, to ensure maximum survival and development of children, non-discrimination of children, respecting of children's right to air opinions and securing of the best interests of children (Ministry of Home Affairs & National Council for Children's Services, 2005).

Orphans have special needs due to the unnatural environment they grow up in with the absence of their parents or caretakers. HIV positive orphans have even greater needs due to their condition. HIV infection progresses more aggressively in infants than in adults due to their underdeveloped immune system hence the infected children are also more susceptible to falling sick with the normal child illnesses especially if the child is malnourished or gets opportunistic infections or other ill health conditions such as diarrhoea or malaria which should be avoided. It is important to provide comprehensive care for HIV-exposed or those infected with HIV in the broader context of other child health strategies (ANECCA, 2006).

HIV-positive children need special and additional care to ensure they live. It is therefore important to understand the nature of the care required for HIV-positive children/orphans. The following important components of care of HIV-infected children provide a baseline for the analysis of the care required to adequately take care of HIV positive children which is important to be able to carry out the study to analyze the care given to HIV-infected children in residential institutions.

All children need continuous growth and development monitoring especially for the first five years. Growth failure rate is greater in HIV-infected children than in uninfected children. Assessment of growth and development is particularly important because some infected infants deviate from their previous growth pattern, and their growth velocity slows significantly. The introduction of combination antiretroviral therapy has decreased the prevalence of failure-to-thrive among HIV infected children (Zeicher & Read, 2006).

All children need adequate and appropriate food to maintain normal immune and other body functions. HIV-infected children, like other children need energy, protein, vitamins and minerals to grow, play and develop normally. Lack of a balanced diet results in malnutrition and ill health. Poor nutrition weakens the immune system and predisposes children to common infections and for those who are HIV-infected to Opportunistic infections (OIs) (ANECCA, 2006). HIV infection can impair the nutritional status of infected children from early in life. HIV-infected children are additionally at risk from: decreased intake because of oral disease (thrush); anorexia associated with illness; increased loss of nutrients because of diarrhoea and malabsorption; increased metabolism because of HIV-infections or other infections; inadequate childcare if the mother is sick or deceased (ANECCA, 2006).

HIV infected children should receive routine peadiatric immunizations according to country regulations. In Africa these include BCG for TB which is endemic in Africa, influenza, measles, yellow fever, chicken-pox.

HIV disease progression monitoring: This includes the evaluation of the immune function in HIV-infected children through the determination of the absolute number of CD4+, CD8+; and the viral load. Routine monitoring should be performed every 3 months in a stable child and more frequently if there are any contra-indications (Zeicher and Read, 2006). Staging is a standardized method for assessing disease stage/progression and for making treatment decisions. It is important to stage children with HIV because staging clarifies the prognosis of individual patients; may strengthen the clinical diagnosis of HIV infection when laboratory infection is unavailable; and it affects the type of treatment interventions including indications for starting and/or changing ART. The recently developed WHO peadiatric staging, which relies more on

readily clinical entities, may be more appropriate for the majority of HIV care settings in sub-Saharan Africa (ANECCA, 2003).

Treatment of HIV infection: Once the HIV status has been established, it is important to put the child on Anti-Retroviral Therapy (ART). The goals of treatment with ARV drugs are to prolong the survival of the HIV-infected child; promote optimal growth and development; preserve, enhance or reconstitute the immune system and therefore reduce opportunistic infections; and suppress HIV replication and therefore prevent disease progression. HIV-infected children should also be monitored for their response to antiretroviral therapy, as well as adherence to drug therapy. Education of, and support for patient [….]: It is important to involve older children in their own medical/psychosocial management which may also increase adherence. Disclosure of infection status is recommended to be done when the child is capable of understanding the information (Zeicher & Read, 2006).

Opportunistic infection prophylaxis: Due to the increased risk of acquiring opportunistic infections, the routine care of HIV-infected children should include prevention of such infections. The risk of infection is co-related with the degree of immunosuppression (Zeicher & Read, 2006).

Mental health evaluation and monitoring: HIV-infected children may have a side variety of mental health needs including emotional, cognitive learning and behavioral problems. They also face loneliness, fear, depression and bereavement. Counseling is also important (Zeicher & Read, 2006).

As a result of these greater needs, children who are born HIV positive are more likely to be abandoned and end up in residential care than children in the general population. HIV may directly lead to entry into residential care due to parental death as a means of accessing health care and nutrition for HIV-positive children or be a contributing factor associated with poverty or abuse that often pushes children to residential care (EveryChild 2001).

1.1 Research objectives

The aim of this study was to establish the kind of care, treatment and support being given to HIV positive orphans in children's home for HIV positive orphans in order to add to the knowledge base on the situation and make recommendations on how this can be improved.

The more spesific objectives of the study were:

- to identify the needs of HIV positive orphans;
- to analyze the existing nature of support given to HIV positive orphans in children's homes;
- to identify the gaps between the needs and the present support in the homes;
- to make recommendations on how different stakeholders can provide better support for the HIV positive orphans in institutional care.

CHAPTER 2. LITERATURE REVIEW

It was not until 2005 (twenty five years into the epidemic) that a serious and concerted effort on the effect of HIV and AIDS in children was lauded. UNICEF and UNAIDS initiated the *Call to Action: Unite for Children. Unite for AIDS Campaign* "with the goal of putting the "missing face" of children at the centre of the HIV/AIDS agenda" (UNICEF, 2005). The report cautioned that the Millennium Development Goal (MDG 6 – Combat HIV/AIDS, Malaria and other diseases) would not be achieved if the impact of AIDS on children continued to be ignored and consequently achievement of the other MDGs would also be impacted. The report noted that while world leaders had stepped up their commitment and political leadership to fight the disease, the children were missing out referring to them as the "missing face" in HIV/AIDS. Subsequent to the this report, there has been a sequential report each year updating on the status of issues surrounding HIV/AIDS and children and by the fifth stocktaking report in 2010 (three decades into the epidemic), "the story of how the AIDS epidemic is affecting children is being rewritten." Children are now central to strategies and actions to avert and address the consequences of the epidemic, however, it is reported that 1000 babies continue to be born with HIV everyday [….], (UNICEF et al, 2010).

2.1 Care of HIV positive children

There is still not adequate attention on HIV positive children who are a special group of the Orphan and Vulnerable Children (OVC). The Moses and Mientjes study argues that a global and local preoccupation with orphans as being the children most severely affected by HIV, and as the primary category of children requiring alternative care as a result of the HIV epidemic may have diverted attention away from the extent to which HIV-positive children populate institutions in South Africa. Responses to the HIV epidemic leading to an increase in the number of residential care facilities for children across sub-Saharan Africa have prompted concerns that large numbers of orphaned children are being placed in institutional care. There is little empirical research into the role that institutions are playing in the provision of care to children affected by HIV in the sub-Saharan Africa region. The analysis identifies important gaps in the HIV prevention, treatment, care and support interventions within these facilities (Moses and Meintjes, 2010).

One of the first global documents produced on the issue of children orphaned by AIDS - A UN Framework for the protection, care and support of orphan and vulnerable children living in a world with HIV/AIDS (UNICEF et al, 2004) - that targeted senior leaders and decision makers around the world who influence policies, programmes and resources directed to orphans and vulnerable children, did not give special mention to the HIV positive child.

The overall aim in the care of all children should be to maintain health and prevent diseases for optimum growth to adulthood. This is achieved through providing a balanced diet, giving recommended immunizations and a comfortable and supportive environment to grow, play and interact in. The high mortality in HIV-infected children in Africa may result from intercurrent infections, malnutrition, lack of access to basic health care, lack of or delayed definitive diagnosis, and lack of access to primary HIV care and ART. Hence "the effective management of pediatric HIV begins with timely and accurate diagnosis. Life threatening immunodeficiency can develop rapidly and unpredictably. Studies have shown that very early treatment can slow down the progression of immunodeficiency" (Zeicher & Read, 2006). In most of sub-Saharan Africa there are limited pediatric HIV diagnostic facilities and therefore most HIV-infected children are diagnosed very late in the course of illness, or not at all. The HIV DNA PCR virologic testing, a test more appropriate for younger infants, is much more expensive and currently available only in research and referral labs (ANECCA, 2006). According to a study carried out by Horizon it was found that cost is a barrier to pediatric treatment, caregivers demonstrated low knowledge of pediatric HIV and treatment options; attitudinal barriers including fear and losing hope deter caregivers from seeking pediatric HIV care and the widespread belief that HIV-positive child is a "lost cause" persists; and HIV-related stigma prevents caregivers from seeking pediatric HIV care. In Thailand, numbers of HIV positive children placed in institutions increased tenfold between 1992 and 1997 (Hennessey 2001 cited in Ken, P.L.A, 2007).

HIV positive children need special care due to the high probability of morbidity and mortality hence persons taking care of them should have some training in caring for them. The Children (Charitable Children's Institutions) Regulations requires that the institutions have a sufficient number of suitably qualified, competent and experienced persons working at an institution with a

special requirement for a person in charge of the health of the children accommodated. In view of the special care needed to take care of HIV-positive children, in a peadiatric study in three Kenya provinces selected because of high HIV prevalence and the availability of pediatric HIV care services, health workers revealed knowledge gaps and low confidence regarding pediatric HIV diagnosis protocols, calculating medication dosages, management of multiple illnesses. A lack of standardized or coordinated training for health care workers on the management of pediatric HIV was identified in South Africa, where most doctors and nurses reported receiving no formal training in ART, instead using self-study from books and online courses (Horizon, 2010). Msosa in a study of the health information needs of caretaker of orphans found that some of the participants were trained while some were not. Where training had been received, it was for one week and was mainly in relation to life skills. The content covered was basically on general child care, developmental changes in children, the need for love and patience towards the orphans and the need for encouraging the children to go to school. The study concluded that there was need for health information among the caretakers of orphans and there is need for more research on the health information needs and mobilize support from the different perspectives to support the caretakers of orphans in order for orphans to benefit from the care being rendered at the centre (Msosa, 2009).

In an exploratory study to gain a deeper understanding of perceptions within the Vryheid Community towards the care of orphans in the midst of HIV/AIDS (Unknown, no date) more than half the sample placed the responsibility of orphan care on the government, welfare departments, churches and non-profit organizations. Respondents were also of the opinion as to how orphaned children should be cared for: foster care with relatives was considered as the placement option of choice by almost half of respondents. Children's homes placements, which would require the removal of children from the local community was considered an option by only a fifth of the respondents. The respondents view that removal from the local community is a secondary option. The study concluded that in the face of HIV/AIDS pandemic, it is largely the extended family that has carried the bulk of responsibility for the safety and protection of its children, the state, welfare organizations, churches, schools community structures and the general public will need to unite in order to ease the burden from the shoulders of the extended families. Mamaila (2005) found community-based care to be a viable option for the care and support of HIV/AIDS orphans, as opposed to institutionalization of these children. Findings

from this study indicated community participation, care and support play a significant role in the placement of HIV/AIDS orphans within the community which is a familiar environment for them. The study concluded that there is lack of policies to guide, support and monitor the establishment of community-based care of children orphaned by HIV/AIDS, community participation is crucial in the placement, support and care of HIV/AIDS orphans within their communities, and partnerships for community-based care should be established amongst community-based organizations, non-governmental organisations, schools, churches and community members.

2.2 Stigma and Discrimination

Stigma and discrimination is one if the negative social effects of HIV infection and disclosure and children and young adults who are infected also experience it. Noting that this study focuses on institutions that house HIV positive children the experience of stigma would be applicable to HIV positive children from a specialized institution of care for HIV positive children and it would be interesting to investigate it. Stigma generally refers to negatively perceived defining characteristic, either tangible or intangible. It is an attribute used to set the affected persons or groups apart from the normalized social order, and this separation implies a devaluation (Gilmore & Somerville 1994). Chirwa (2009) from an exploratory study among ten HIV positive youth aged 19-25 years in Malawi, found that disclosure of HIV positive status among HIV positive youth is difficult and still remains a challenge. The study also established that majority of participants disclose their HIV positive status due to deteriorating health status. Stigma and discrimination was found to be the major barrier to disclosure of HIV positive status while the positive consequences include: psychosocial care, accessing medical services, safer sex practices, and positive living with HIV seemed to be more rewarding because it brought some relief to their life. HIV positive children have been discriminated by being denied enrolment into schools.

A study on supporting the educational needs of HIV-positive learners in Namibia and Tanzania focused more on the education needs of HIV-positive learners in learning institutions and took cognicense of the increased number of children in residential care as a result of HIV/AIDS

noting that the school becomes the adjutant to institutional care. The aim of study was to identify the specific challenges faced by the educational system in responding to the needs of HIV-positive learners and develop a set of recommendations and guidelines about how best to support them. The study highlighted the challenge of stigma and discrimination that every HIV-positive child interviewed experienced as a consequence of disclosure and emphasized greater safety in silence due to intolerant attitudes. The study documented the testimonies of learners due to stigma and discrimination, as a result, the study found that silence is still the preferred option for most HIV-positive learners and their parents or care-givers. The study mentions that HIV-positive learners are subsumed into the wider category of OVC as this reduces HIV-linked stigma. The UNESCO review did not, however, pay adequate attention to the special needs of children/learners in institutions of care.

HIV-positive children have experienced stigma and discrimination the world over. The Population Council undertook a study to explore the special needs of HIV positive young people in primary and secondary schools in Uganda with a view to identifying possible responses by the education sector to these needs. From among 718 young people aged 12 – 19 years this study found that nearly one-in-five of the perinatally infected adolescents currently attending school reported being teased or called nasty names at school because of their HIV status, and one-in-four suspected rumors spreading in school about their sero-status (Obare et al, 2009). Children from institutions that specifically care for HIV-positive children cannot hide their status as it is an open secret since communities around know the function of the homes so how do these homes handle stigma and discrimination directed towards the children? In 2003, Nyumbani the first children's home for HIV-positive children sued the Government of Kenya for prohibiting 91 children from attending government-owned school, where they could access low-cost education, because of their HIV-status. Nyumbani won the case and the children were admitted to the public schools. Do these homes declare the medical information of the children if asked? In the above study in Uganda, it was found that none of the medical forms completed by parents or guardians indicated HIV/AIDS as one of the chronic illnesses. This could be attributed to the fact that parents and guardians sometimes conceal some ailments, perhaps, for fear that their children may not be admitted if their conditions are known or to protect them from discrimination and stigmatization.

2.3 Psychosocial issues

HIV-positive people suffer psychosocial issues and likewise children who are HIV-positive and living in institutions could experience psychosocial problems such as negative attitude, low esteem, worry, sadness/stress, pressure or anger as they try to understand and come to terms with what they are going through and sometimes also face the unfortunate bereavement of other children. In a study by Chirwa (2009) among youth in Malawi, findings revealed that almost all participants expressed a high level of anxiety with HIV positive prognosis. Their anxiety was related to the fear that HIV is a chronic disease that does not have any cure and they are going to die and they also feared stigma from people who would know their HIV positive status. In the Population Council study on young people in Uganda, close to a one-third were worried or sad/stressed to the extent that this affected their concentration on school work. Also more than one-in-three (36%), one third (33%), and an almost similar proportion (30%) of the respondents reporting being worried, feeling sad/stressed or pressure respectively always or most of the time. Ken (2007) in a study of children without parental care in the Caribbean noted since the availability of ARV therapy for children…., the children who now live with a controllable illness face new challenges especially in the psychosocial domain. Revealing their status and debating relationships are all issues they are now experiencing. Most residential care institutions do not have sufficient support for these children and have experienced growing behavioural problems linked to the angst associated with having a HIV status. This study will seek to find out how the institutions handle psychosocial issues in the children they take care of.

The 'changing face of HIV due to ARV therapy has put in question the adequacy of long term residential care programmes for children infected with HIV. […..] there are few programmes that address supporting parents to manage HIV illness at home rather than in a residential facility. The need to address the situation of […..] (these) children is doubly important because of the added stigma and discrimination vetted towards [….] children infected by HIV (Ken, 2007). At the same time the world had made a renewed declaration to work towards elimination of new HIV infections among children (and keep their mothers alive) through a global plan of action. (UNAIDS, 2011).

CHAPTER 3: RESEARCH PROBLEM AND RESEARCH QUESTION

As the AIDS epidemic has continued to spread among the world population children have not been spared through infection and/or being rendered orphans through the death of their parents by the disease, as a result a lot of attention has been paid to the plight of the Orphan and Vulnerable Children (OVC) and the best approach to caring for them with many studies coming up with recommendations on how to look after them.

One of the responses to the issue of orphans has been the formation of residential institutions to care for these children who are either orphaned or abandoned due to their HIV positive status and in some instances both. As the impact of AIDS became manifest through the death of parents and birth of infected children, there was an increasing number of institutions such as both registered and unregistered children's homes and orphanages in response of the epidemic. There is however insufficient research on how HIV positive orphans are looked after in these residential institutions. Moses and Meintjes (2006) noted that with the growth of residential institutions for children in response to the care of children affected by HIV/AIDS, there is limited available research considering residential care for children affected by HIV and AIDS.

The basic effect of HIV in both adults and children is on the immune system through the depletion and dysfunction of the CD4+ cells. There are however, critical differences between the disease progression in children and in adults stemming largely from the lower efficiency of a child's immature (but developing) immune system. These differences result in much more rapid disease progression and a much shorter duration for each stage (ANECCA, 2003). HIV positive children thus need to be given extra care than the uninfected as the virus results in increased morbidity and mortality among children. In addition, pediatric HIV care did not emerge as an area of concern until recently hence it is still an evolving and a complex field especially in Africa which has been hardest hit by the epidemic and has limited resources.

The requirements for the care, treatment and support of HIV-infected children illustrate the complexity of their care. It is against this setting that the research question is based - how do the residential homes that cater for HIV positive children meet these requirements. The focus of this

study is therefore on the management of HIV positive orphans who are in residential institutions of care.

This study seeked to establish the nature of care, treatment and support that these institutions provide to the HIV positive orphans under their care in light of the special requirements in caring for these children. These issues need to be highlighted and brought to the fore to raise awareness on the issue among all stakeholders.

The research methodology decided on in order to shed light on the research question will be discussed in the following Chapter.

CHAPTER 4: RESEARCH METHODOLOGY

The methodology employed for this study was as decribed below.

4.1 Target Group

The target group focused on by the research was administrators of residential institutions that care for HIV positive children. This target group was chosen in view of the ethical considerations.

4.2 Method

This study used an exploratory design to gain insight on the subject area. A qualitative method with semi-structured interview guide (Addendum A) was used targeting the administrators in two residential institutions that care for HIV positive children. The study was based on research questions rather than hypotheses.

A purposeful method was used to identify the children's homes to cover only the institutions taking care of HIV positive orphans.

Data was analyzed based on the responses to the questions and comparing them to the recommended standards of caring for HIV-positive children.

4.3 Ethical considerations

The integrity of the study was ensured firstly by the investigator personally visiting the residential institutions for HIV positive children and getting their approval and willingness to participate in the study. Secondly, the confidentiality and anonymity of the participants will be ensured and will not be disclosed unless necessary and participants were assured of the same. The purpose of the study was communicated to participants and no harm was brought upon them. No permission was required from relevant authorities external of the children's home hence this was not sought. All collected material will be kept securely by the investigator and shredded after completion of the study.

It is recommended that where possible, survey information relating to children should be obtained from an alternative indirect source, such as talking to adults (family, caretaker or community members) close to the child or examining written records (Schenk, 2005) and in line with this ethical recommendation this study obtained information about the care of the children from the indirect sources being the administrators/managers of the homes instead of questioning the children themselves to ensure the best interest of the children is paramount. Written consent was obtained from all participants in the study.

CHAPTER 5: RESULTS

The results of the study are discussed in the following section.

5.1 Interviews

The interviews were conducted with designated officials of the two children's homes. In one Home this was a medical nurse in the other it was the Executive Director of the home. The institutions are henceforth referred to as Homes.

5.2 Background and Care

Both Homes were established by private individuals with a passion for children who are infected or affected by HIV especially those who are HIV positive and abandoned. This at a time when abandonment of HIV positive children was very common due to fear and HIV-related stigma. One Home launched its first home in 1994 to care primarily for abandoned and orphaned babies, particularly those infected and affected by HVI/AIDS, although other vulnerable children are also rescued and cared for. Being non-profit making, the Home depends totally upon the voluntary contributions of local and international well wishers. To date over 1,000 babies have been taken into the Home of whom over 300 were HIV positive upon admission. At the time of the study the main home in Nairobi had the maximum number of children of 52 ranging from 10 days old to two and a half years. After this age the children who are not adopted are moved to another home under the same administration that is located in a different town. The second Home was established in 1992 and since inception has exclusively taken care of HIV positive children hence its oldest child is an adult of almost 30 years and the youngest is less than a year. Currently this Home has 115 children. Both homes confirmed they receive support from the Government in supply of all, in one case, or some drugs for the other and morale support. For both Homes, most of the children are orphans who were abandoned mainly in hospitals and other community places such as streets, shopping centres, churches etc and are brought in by the police or are referred by other homes that do not handle HIV positive children.

It is notable that both homes also reported there had not been a significant decline in the intake or referral of children into both Homes even with the advent of antiretroviral therapy for both adults and children and the Prevention of Mother to Child Transmission (PMTCT) programme. One home stated that in 2012 it had an average enrolment of about 60 HIV positive children each

month and sometimes going as high as 80 with a total enrolment of approximately 3,000 HIV positive children since 2007. Some of those enrolled exit after 12 - 18 months because the child was only exposed to the virus.

5.3 Treatment and disease progression monitoring

The study found that the HIV status of children is established before or as soon as the children are received in the home as part of the routine admission medical review. For one home this must be confirmed with the (Polymerase Chain Reaction) PCR virologic test that is done at a referral laboratory and once the positive status is confirmed the children are immediately placed on pediatric antiretrovial treatment which it gets from a private children's hospital which is supplied with pediatric Antiretroviral Therapy (ART) drugs free of charge by the Government. This is in line with international pediatric HIV treatment guidelines to start children on ARVs as soon as the seropositive status is confirmed. The second Home confirms the HIV status of the children before they are admitted into the Home and about 98% of the children are on pediatric ART, it is interesting to note that a few older children who are slow progressers are not yet on ART and are going on well with regular monitoring. It stated that it gets its drugs under the PEPFAR (President's Emergency Plan for AIDS Relief) programme. Both Homes confirmed that thus far appropriate drug formulations are readily available.

HIV positive children need regular follow-up to monitor disease progression due to the higher occurrence of morbidity caused by the virus. The study found that the children are monitored regularly. One Home reported that it takes the HIV positive children to a private children's hospital for follow-up review every two to three weeks depending on the condition of the child and for other monitoring tests such as CD4+, CD8+ and viral load. It was remarkable to learn that one Home has an in-house state-of-the-art diagnostic laboratory where all HIV testing including CD4+, CD8+, Viral Load, and Resistance testing are carried out for disease progression monitoring hence this done in-house. This laboratory is the only one in the country with the capability to carry out resistance testing and provides these services to external clients.

5.3.1 Training of staff

This study found that in both Homes there are dedicated nurses and available pediatric doctors who take care of HIV positive children and they are continuously trained and kept up-to-date in pediatric HIV areas such as issuing medication, nutrition, testing such as resistance testing and are kept abreast of changes in ARV policies and guidelines and other relevant areas such as Prevention of Mother to Child Transmission (PMCT). This training is mainly offered at a private children's hospital.

5.4 Support of HIV positive children

5.4.1 Disclosure

The study found that the children are informed of their HIV status from the age of eight years. In one Home they are informed of their HIV status between the ages of 8 and 12 years because not all children are HIV positive and this is done through a counseling process with a counselor.

In the other home as all children are HIV positive every child knows that they are HIV positive but there is a nurse counselor who gives individual attention based the needs of each child.

5.4.2 Education of HIV positive children

The education needs of the HIV positive children in the homes are met at the appropriate age according to the national system. One Home meets these needs at several private institutions based on a long standing relationship and fortunately there has not been any challenge in this regard. The condition of the child/children is revealed to the Head teacher only incase of any eventuality and to maintain confidentiality. As a result the children do not experience any stigma and discrimination as there is no open disclosure.

The other Home reported that it has an in-house school for the pre-primary level after which the children attend public schools in the surrounding areas at which free education is offered by the Government and for secondary school they go to boarding schools to help them build independence. The arrangement with the public primary schools has been in place for a long time hence there are no challenges in getting schools for the children despite the knowledge that they Home is for HIV positive children. In new schools the condition of the children is revealed only to the Headmistress and the Matron.

5.4.3 Stigma and discrimination

It was evident from the study that stigma and discrimination do exist and the children do experience being stigmatized and discriminated. One Home however, did not respond to having experienced stigma and discrimination as the children are mainly young and with ART are not different from other children. Children from the Home for HIV positive children were reported to have experienced stigma and discrimination mainly from family members who reject them and sometimes in schools and in society. To address and reduce the negative impact on the children a lot of effort is put in training the children to have high self esteem.

5.4.4 Psychosocial issues

One of the Homes studied handles young children up to about three years after which if they are not adopted they are moved to a new Home in a different town that was not covered in the study hence this did not reveal any psychosocial issues faced by the children as most of them are young. Children from the other Home who are older, do face many psychosocial issues stemming principally from having to deal with being orphans and their seropositive status. Most children suffer from insecurity due to not having any parent(s), which makes some have anger and frustration. Stigma and discrimination is an additional challenge they have to contend with sometimes from their own families and in society. This Home has also had the reality of dealing with the issue of sexuality of the HIV positive children as some are already adults. To address this the home has developed a programme on sexuality for HIV positive teenagers that is taught at the end of primary school. The children are also taught life skills training to equip them with skills to cope with life issues and as noted earlier a lot of effort is put into training them in self esteem to enable them have high self esteem to cope with stigma and discrimination.

5.4.5 Adoption of HIV positive children

The study established that the adoption of HIV positive children is not very common locally in Kenya hence most of the adoptions of HIV positive children in one Home were international adoptions. The same case applied to the other home which noted that the local reluctance to adopt them is based on ignorance of the HIV condition and its transmission. Further, the international adoption requirements are also lengthy and rigorous which discourages this adoption even though the policy preference is for local adoption. It has also been noted that the

older children are easier to adopt as opposed to the younger ones and there is a general preference to foster them as the maximum age of adoption is 18 years. It also emerged that since 2006, this home has placed more emphasis on family re-integration where extended family or relatives can be traced and is now putting more effort to achieve this as opposed to keeping them in the Home. However when this is not possible the children are more vulnerable and are given specialized support to help them integrate in society.

CHAPTER 6. CONCLUSIONS AND RECOMMENDATIONS

High standards of care, that are in line with set local and international guidelines, and are being applied in the care of HIV positive children in the two residential care institutions under the care of trained staff. It would be important to establish that such standards are being applied nationally in all Homes that take care of HIV positive children. Much work remains to be done to standardize the care of HIV positive children in residential care as well as in all levels of society and promote the pediatric antiretroviral therapy and Prevention of Mother to Child Transmission (PMTCT) programmes so as to translate to a significant decline in the abandonment and resultant intake and referral of HIV positive children in the children's residential care institutions.

The possibility and occurrence of stigma and discrimination is still high and children are not exempt from it hence they need of support to deal with the stigma and discrimination and other psychosocial issues that they have to deal with as a result of their condition. As antiretroviral therapy increases the life expectancy of HIV positive children this support needs to be available at all levels of society – in the family, schools, churches and the community at large.

6.1 Recommendations

The following recommendations are made as a result of this study.

6.1.1 Recommendation for policy makers

1. Develop and disseminate policies addressing stigma and discrimination at all levels in schools, work places, churches and in society to stop the rejection of HIV positive children.
2. Develop and institute policies for lifelong free medical care for HIV positive children.

6.1.2 Recommendations for government

1. Establish more referral laboratories with capability to conduct the HIV DNA/RNA PCR virologic test and other HIV progression monitoring tests (CD4+, CD8+, viral load and resistance testing), on a national scale to facilitate the early detection of HIV in children for residential institutions in other parts of the country and the community at large.

2. Ensure that every health facility has a trained pediatric HIV person.
3. Aggressively expand the Prevention of Mother to Children Transmission (PMTCT) programme on a national scale to help reduce the incidence of abandonment of children due to a seropositive status of the mother or the child.
4. Develop and disseminate more information to the public on pediatric HIV illness and management to break the myths and fears that hinder retention of HIV positive orphans in families and their adoption.
5. Improve on its record keeping capacity to assist with relocation of relatives of abandoned children where possible.
6. Facilitate international adoption requirements could be made more flexible to facilitate this adoption when it is preferred.

6.1.3 Recommendations for children's department

1. Separately categorized children's homes that care of HIV positive children and closely monitored them to ensure that the required standards of care for HIV positive children are being met.
2. Where possible, monitor that children are reintegrated with their families and provide the necessary support for a smooth reintegration.

6.1.4 Recommendation for donors

1. Individual and company Corporate Social Responsibility programmes should aim to give special assistance to residential homes that take care of HIV positive children due to their special needs.

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ADDENDUM A

Interview Question Guide for the Research into the Care, Support and Treatment of HIV-positive Orphans in Selected Residential Institutions for HIV-positive children to be undertaken by Ms. Christine M. Weche, Student no. 14708752, Stellenbosch University

Background/Care

1. When was the home established?

2. Is it a private or public home? Is there assistance from the Government?

3. How many children are currently in the home?
    a. What is the age of the youngest and oldest child in the home?

4. How are the children referred or bought to the home?

5. With the advent of ARVs and progammes like PMTCT has the intake or referral of children into the home declined?

Treatment

1. Are all the children confirmed as HIV-infected before or after coming to the home and if not how soon is this done?

2. Are ALL the children on ARVs?

3. When do you start on the ARV for the children?

4. Where does the home get HAART drugs or funds to purchase the drugs?

5. Are appropriate drug formulations readily available?

6. Where are the children taken for follow-up services and proper medical care required HIV-positive children?
    a. Does the home experience any challenges in getting these services.

7. How often are the children taken for follow-up for disease progression monitoring?

8. Where do you get referral services What peadiatric diagnostic facility does the home use to monitor HIV-status – CD4+, CD8+ and viral load? (in view of limited number of such facilities).

9. Are the staff trained in handling HIV positive children?
    a. If yes where? and
    b. What areas are they trained on?

Support

1. Do you disclose to the children that they are HIV-positive?
    a. If yes when is this done?

2. How do you meet the educational needs of the children?
    b. Are there challenges in getting schools for the children?
    c. how are these challenges addressed?

3. Is the condition of the child/children revealed to anyone in the school?
    a. If so to whom?

4. Do the children experience being stigmatized and discriminated?
    a. In which ways?
    b. How are the effects of stigma and discrimination among the children handled?

5. What kind of psychosocial issues do the children face most?
    a. How are these addressed?

6. What is the response towards adoption of HIV positive children?