


Fall 2010

A Review of Psychosocial Support and the Challenges Faced in Disclosing HIV Positive Status to Children in Kibera

Katherine Lesyna

SIT Study Abroad, ktlesyna22@yahoo.com

Follow this and additional works at: http://digitalcollections.sit.edu/isp_collection


 Part of the [Civic and Community Engagement Commons](#), [Immune System Diseases Commons](#), [Inequality and Stratification Commons](#), [Medicine and Health Commons](#), [Social Psychology Commons](#), and the [Social Welfare Commons](#)

Recommended Citation

Lesyna, Katherine, "A Review of Psychosocial Support and the Challenges Faced in Disclosing HIV Positive Status to Children in Kibera" (2010). *Independent Study Project (ISP) Collection*. Paper 965.

http://digitalcollections.sit.edu/isp_collection/965

This Unpublished Paper is brought to you for free and open access by the SIT Study Abroad at SIT Digital Collections. It has been accepted for inclusion in Independent Study Project (ISP) Collection by an authorized administrator of SIT Digital Collections. For more information, please contact digitalcollections@sit.edu.



A Review of Psychosocial Support and the Challenges Faced in Disclosing HIV Positive Status to Children in Kibera

Katherine Lesyna

SIT Kenya: Health and Community Development
Fall 2010
Academic Directors: Odoch Pido and Jamal Omar
Academic Advisor: Donna Pido

Table of Contents

Abbreviation	3
Acknowledgements	4
Abstract	5
Introduction	6
Overview of HIV/AIDS Epidemic.....	6
Children and HIV/AIDS.....	7
Psychosocial Support: Counseling and Disclosing.....	9
Setting	12
Methodology	14
Discussion and Analysis	15
Support in Kibera.....	15
Disclosing to Children.....	17
Challenges Faced by Caregivers.....	22
KIPOTEC Psychosocial Support Day.....	25
Conclusion	27
Recommendations	29
Appendices	30
Works Cited	32

Table of Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ARV	Anti-Retroviral Drugs
CDC	Center of Disease Control
HIV	Human Immunodeficiency Virus
KIPOTEC	Kibera Post Test Club Network
Ksh	Kenyan shilling
MSF	Medicins San Frontieres
NASCOP	National AIDS and STI Control Programme
NGO	Non-governmental Organization
OVCs	Orphans and Vulnerable Children
PLWHA	People Living with HIV/AIDS
PMTCT	Post Test Club
PTC	Prevention of Mother to Child Transmission
WHO	World Health Organization

Acknowledgements

KIPOTEC, thank you for welcoming me into your organization. Special thanks go to Caroline Makaya. Carol, you taught me a lot over the course of the past month from your experiences and the experiences of others. You were a pleasure to work with and I couldn't ask for a better research partner.

I would also like to thank the wonderful academic advisors Odoch Pido and Jamal Omar for a great semester. I would also like to thank Donna Pido for giving me advice on this research project.

To my fellow SIT students, thank you for the continuous support.

Abstract

The AIDS pandemic has become an increasingly global problem as well as an everyday reality for most people living in sub-Saharan Africa. In 2009, an estimation of the number of adults and children living with HIV/AIDS in sub-Saharan Africa totaled around 22.4 million.¹ The people that have been affected most by the pandemic are women and children.

In Kenya, about 1.5 million people are infected with HIV, about 180,000 of them being children.² While a lot has been done to reduce HIV infections and treat those who are infected, children have been left behind until recently. There is still much more to be done with pediatric HIV, especially for guidance of caregivers in disclosing children's HIV status. Disclosure is a difficult process and lack of trainings and resources, as well as psychosocial support makes the process even more challenging.

This project will examine pediatric care of children in Kibera, Kenya living with HIV, specifically the counseling services available to them. The aim of this project is to assess the psychosocial support programs that are in place in Kibera to help HIV children cope with their status. However its main focus is to examine the disclosure process and training available to caregivers and health care workers as well as the challenges facing HIV positive children and their caregivers.

¹ UNAIDS and World Health Organization. AIDS Epidemic Update. December 2009.
<http://data.unaids.org/pub/Report/2009/JC1700_Epi_Update_2009_en.pdf>.

² UNAIDS Global Report on the Global AIDS Epidemic 2010.
<http://www.unaids.org/globalreport/Global_report.htm>.

Introduction

Overview of the HIV/AIDS Epidemic in Kenya

Kenya has been greatly impacted by the HIV/AIDS epidemic over the past couple decades. While there has been an increase in education and health services, more and more people are becoming infected with HIV every year.³ HIV, Human Immunodeficiency Virus, is a virus that spreads rapidly via three different modes of transmission: sex, blood to blood, and mother to child. In Kenya, approximately 1.5 million people live with HIV, a 6.3% prevalence rate.⁴ About three fifths of Kenyans infected with HIV are female, while about four fifths of all HIV infected people do not know their status.⁵

While the majority of HIV cases occur in the youth ages 15-24, the impact that the pandemic has had on children is significant and many times overlooked. There are about 160,000 new HIV infections each year, about 33,000 of them are infections in children due to mother to child transmission.⁶ The total number of HIV positive children in Kenya is about 180,000.⁷ Treatment and care for HIV positive children have been overlooked in the past, however organizations and campaigns, both national and international are starting to focus more on the effects of HIV on children.

Many times mothers do not know their HIV status when they are pregnant or are in denial and do not take precautions to protect their child. Mother to child transmission can occur during pregnancy, at birth, or during breastfeeding. Throughout Kenya, an increase in Prevention of Mother to Child Transmission (PMTCT) Counseling and availability of resources has occurred. Mothers are now required to get tested if they are pregnant and recommended to attend counseling during pregnancy. Medicins San Frontieres (MSF) clinics provide free baby formula to HIV positive mothers to help reduce the risk of transmitting HIV to their child through breastfeeding. Also, because ARVs are provided by the government free of charge if the patient's CD4 count is below 350, mothers are either already taking medication or are given them for pregnancy. Taking medication helps reduce the viral

³ National AIDS Control Council. Kenya National AIDS Strategic Plan: Delivering on Universal Access to Services 2009/10-2012/13. November 2009.

⁴ UNAIDS Global Report on the Global AIDS Epidemic 2010.

⁵ Women Fighting AIDS in Kenya (WOFAK). <<http://www.wofak.or.ke/>>.

⁶ National AIDS Control Council. Kenya National AIDS Strategic Plan.

⁷ "Kenya: Support Disclosure of HIV Status to Children." Human Rights Watch. Dec. 1, 2010. <<http://www.hrw.org/en/news/2010/12/01/kenya-support-disclosure-hiv-status-children>>.

load in the body, therefore reducing the risk of transmitting HIV to the child during pregnancy or at birth.⁸ There are precautions that can be taken to avoid mother to child transmission, however children are still becoming infected and require adequate care and treatment.

Children and HIV/AIDS

It is necessary to review care for HIV positive children due to difficulties in diagnosing HIV in children, the faster progression of HIV in children than adults, and their high risk and exposure of other opportunistic infections.⁹ The difficulty in diagnosing HIV in children persists to be a problem in treatment of infants with HIV. Testing to diagnosis a child provides a significant challenge. It is necessary to wait for the child to be 18 months old before an accurate test can be given due to a lack of antibodies in the infants when they are born. There are tests that can directly test for the virus rather than the antibodies so there isn't an issue of distinguishing between maternal and infant antibodies. This can be done on children younger than 18 months but it requires more laboratory infrastructure which is very limited in Kenya currently.¹⁰ It is difficult to diagnose them with HIV/AIDS because the symptoms shown are usually common infections in any child. A WHO pediatric clinical staging (Appendix A) has been established to help determine whether a child is HIV positive or not at the stage at which the disease is at in the child. There are three clinical stages that have various symptoms that enable the caregiver to place them in a certain stage and help initiate ARV therapy.¹¹

Some key elements of caring for HIV-infected children include providing growth monitoring, nutritional care, immunizations, quick medical treatment of other infections and prophylaxis to prevent any further infection, access to Anti-Retroviral treatment, and counseling services. Problems with adherence to ARVs and access to treatment present difficulties in treating children living with HIV. Children in general have trouble swallowing medications and so they need to take the drug in syrup or powder form. This leads caregivers

⁸ Support for International Change. HIV Education and Teaching Curriculum. Version 3. December 1, 2008.

⁹ AIDS in Kenya: Trends, Interventions, and Impact..Ministry of Health. Seventh Edition, 2005.

¹⁰ Ministry of Health, *AIDS in Kenya*

¹¹ Ministry of Health, *AIDS in Kenya*

to breaking up tablets into manageable doses, which leads to the problem of possibly giving the child the wrong amount of the medication.¹² Access to treatment is also a major struggle in the fight against pediatric AIDS. While there are drugs and medical services for children living with HIV available, the question is whether the children that actually need the treatment and medical services have access to them, which is more commonly the case.¹³

While many children have become infected with HIV by mother to child transmission and have struggled to gain access to treatment, there are significantly more children that are affected by the AIDS pandemic other than the ones that have become infected. An increasing number of children have been orphaned due to death of their parents from HIV/AIDS. In Kenya, it is estimated that about 1.5 million people have died of AIDS and have left about 1.6 million orphans.¹⁴ Orphaned children face the challenge of having to become the head of the household, somehow searching for a way to continue their education and still find a way to provide shelter and food for themselves and their siblings. Not only has the AIDS pandemic orphaned these children, but many of these orphans have also contracted the virus themselves, either from mother to child transmission or from being taken advantage of by men that can provide money to the desperate children looking for food.¹⁵ Once again, these children struggle to find access to treatment and basic human necessities to keep themselves healthy or follow through with their treatment if they do acquire the proper drugs.

However, one of the most important elements of providing care is making sure that the child and their caregiver have emotional support. Especially as the child grows, it is suggested to provide them with support to “empower them to deal with their sexuality, adherence to medication, and peer pressure”.¹⁶ Psychosocial support and counseling services are also critical in revealing their status to the child, making sure that their perception of HIV/AIDS and their level of understanding are sufficient enough that the child will be able to cope with their status, and be able to react towards their parents, particularly their mother in a healthy way.

¹² “HIV, AIDS, and Children.” AVERT. <<http://www.avert.org/children.htm>>.

¹³ UNICEF. “Children and AIDS: Fourth Stocktaking Report.” 2009. <http://www.unicef.org/publications/files/Children_and_AIDS_Fourth_Stocktaking_Report_EN_120209.pdf>

¹⁴ Ministry of Health, *AIDS in Kenya*

¹⁵ Nicholas Anyuor, “Virulent AIDS Virus Wreaks Havoc in Africa”

¹⁶ Ministry of Health, *AIDS in Kenya*

Psychosocial Support: Counseling and Disclosing

Psychosocial Support defined by the World Health Organization is support based on the psychological and social problems of people living with HIV, their caregivers, and families.¹⁷ The *psycho* encompasses belonging and faith for the future, the *social* encompasses belonging and participation, as well as a development of life skills, and the *support* focuses on self-worth (Appendix A). The aim of psychosocial support is to enhance children's, families', and communities' ability to cope, and to achieve personal and social well-being.¹⁸

Being infected by HIV affects many aspects of people's lives and the goal of psychosocial support is to focus on the physical, psychological, social, and spiritual well-being. Psychosocial support is meant to enable both those infected and their caregivers to be able to cope with their status, aiming at helping people make informed decisions, cope better with illness and deal more with stigma and discrimination.¹⁹ It also contributes to better adherence of drugs as treatment literacy and importance of adherence is included.

As a critical aspect in coping with HIV/AIDS infection, psychosocial support is lacking in Kenya's national guidelines of management of HIV/AIDS, especially for children. It is necessary that counseling trainings for psychosocial support are included in health care education for both health care providers and community health workers.

Psychosocial support also needs to be structured and changed based on different groups infected by HIV and their specific needs, as well as location and access to resources. The 2008 Kenya country progress report presented to the UN Special Session on HIV/AIDS outlined the lack of pediatric psychosocial support and awareness on the part of caregivers.²⁰

The most difficult challenge involved in psychosocial support is the disclosure of the child's status. On December 1, 2010, World AIDS Day, the Human Rights Watch called on the Kenyan government to train health workers and caregivers on how to disclose their

¹⁷ World Health Organization. Psychosocial Support. <<http://www.who.int/hiv/topics/psychosocial/support/en/>>

¹⁸ Huni, Noreen M. "Enhancing psychosocial support of children affected by HIV/AIDS: A Special Focus on Memory Work." Conference of aidsfocus.ch, Swiss Platform of HIV/AIDS and International Cooperation. Berne, 2005. 11. <www.aidsfocus.ch>

¹⁹ World Health Organization, Psychosocial Support

²⁰ "Kenya: No guidance on caring for HIV-positive children" Plus News. 23 June 2009. <<http://www.plusnews.org/Report.aspx?ReportId=84956>>

child's HIV status.²¹ Kenya's National Guidelines for HIV Testing and Counseling require the caregiver to disclose the child's status, leaving health workers with the inability to do so unless the caregiver has given permission. The only time a healthcare worker can disclose their status is if the child pregnant, married or sexually active, leaving health care workers in a tough situation.²²

According to the Convention on the Rights of Child, children under the age of 18 have the right to knowledge of their own health.²³ However, due to Kenya's National Guideline, stated above, this right is violated if the status of the child is not disclosed to them as they get older, denying them information and participation in their own health.²⁴ The challenges of not telling children their status as they get older only become more prevalent. Not knowing their status effects adherence of medication, internalization of stigma and discrimination, anxiety, and anger towards the caregiver.²⁵ As the child gets older, they start getting tired of taking medication, otherwise known as treatment fatigue, and if they don't know why they need to take medication, they are less likely to feel the need to take it consistently. Disclosure also becomes an issue once the child becomes sexually active and does not know their status, putting others at risk of getting infected without knowing. One difficult issue of disclosure is that the caregivers are worried to tell their children because they could feel guilty for infecting them at birth, as well as it requiring them to come to terms with their own status. They also do not want to expose their children to the same stigma and discrimination that they experience.²⁶ Parents also struggle with the issue of secrecy and are concerned that if they disclose their status to their child, the child will tell the wrong people unknowingly and put the parent at risk for stigma and discrimination.

Even if the caregiver is prepared to disclose the status to their child, the materials and trainings on how to do so are lacking. The Kenya National Guidelines for Voluntary Testing and Counseling only provides two short paragraphs for both parents and counselors on how

²¹ Human Rights Watch, "Kenya: Support Disclosure of HIV Status to Children"

²² National AIDS and STI Control Programme, Ministry of Public Health and Sanitation, Kenya. *Guidelines for HIV Testing and Counseling in Kenya*. Nairobi: NASCOP; 2008.

²³ UN General Assembly, *Convention on the Rights of the Child*, 20 November 1989, United Nations, Treaty Series.. <<http://www.unhcr.org/refworld/docid/3ae6b38f0.html>>.

²⁴ Human Rights Watch, "Kenya: Support Disclosure of HIV Status to Children"

²⁵ Human Rights Watch, "Kenya: Support Disclosure of HIV Status to Children"

²⁶ Human Rights Watch, "Kenya: Support Disclosure of HIV Status to Children"

to disclose to children, basically stating that children should be told their status in an “appropriate and supportive environment” and that caregivers must “use their own judgment when the child can safely receive knowledge of their HIV status” making sure to be “sensitive to the needs and emotional capacity of the child.” Caregivers should also introduce age-appropriate knowledge regarding HIV as soon as possible, while social workers should help caregivers in case “difficult questions arise”.²⁷ This vague and brief description on how to disclose to children does not provide caregivers with much guidance. However, there have been movements towards the formation of a committee by the National AIDS and STI Control Programme (NASCOP) to deal with child testing issues and better guidance for caregivers and health care workers in psychosocial support and disclosure.²⁸ While this is a good step forward, it has yet to make a huge impact on the life of individuals in Kenya and there is still much more to be done.

The lack of attention of psychosocial support in treating for pediatric HIV is affecting both caregivers and the children that are living with HIV. This research aims at looking into psychosocial support, how caregivers disclose to their child and the challenges that the caregivers and their HIV positive children face in Kibera.

²⁷ NASCOP, “National Guidelines for Voluntary Counseling and Testing”

²⁸ Human Rights Watch, “Kenya: Support Disclosure of HIV Status to Children”

Setting

Kibera, one of the largest slums in Africa, is located in Nairobi, Kenya's capital city. The slum, or informal settlement, is located approximately five kilometers from the city center. Kibera is broken into villages, some of which are: Kianda, Soweto, Gatwekera, Kisumu Ndogo, Lindi, Laini Saba, Siranga, Makina, Mashimoni and Raila.²⁹ The population of Kibera slum has been widely debated with widely known figures believed to be between half a million to two million people. However, the 2009 Kenya Population and Housing Census results the population of Kibera is a mere 170,070 people.³⁰

As one walks through the informal settlement of Kibera, along the uneven, rocky dirt pathways, stores, saloons, pubs, school, multiple non-government organizations (NGOs) line the road. Scattered along the pathways are piles of trash, mainly torn plastic bags. The drenches collect water, human waste, and trash. The Ugandan Railway runs through the slum, and people throw their garbage into the railroad tracks, letting it pile up into massive heaps, requiring the railroad workers to clean the tracks at least once a month. Following the narrow paths diverging from the main road will lead to the homes of the residents of Kibera. The houses are made of wood and mud walls with corrugated iron roofs, approximately 12ft x 12ft.³¹ The majority of the houses are one room for a variety of different sizes of families, sometimes for a family of six or more. The sleeping area is usually separated from the main sitting room by a curtain to provide some privacy.

Within Kibera, there are many different post test clubs (PTC) created to support people living with HIV. A PTC is a support group of HIV positive women, men, and children from around Kibera that meet about once a week to support each other in daily life. PTCs provide psychosocial support to peers, share HIV-related information and health education to people living with HIV/AIDS (PLWHA), and engage in different advocacy projects to promote good health.³² However the primary role of a PTC is to provide psychosocial support to its members.

²⁹ Community Support Group Kibera, www.csgkibera.org

³⁰ Karanja, Muchiri. "Myth shattered: Kibera numbers fail to add up." *Daily Nation* 3 September 2010.

³¹ Kibera UK, "Facts and Information about Kibera," www.kibera.org.uk

³² Kongs, Eva. "Post Test Clubs in Nairobi towards a model for PLHIV grassroots support." *Medicins San Frontieres* (Belgium). Nairobi. April 2008.

Kibera Post Test Club Network (KIPOTEC) is an umbrella that connects and monitors many of the PTCs in Kibera. KIPOTEC has 42 PTCs registered under the network, encompassing approximately 800 people, around 300 of them being OVCs and 100 of those being HIV positive. In order for a PTC to register under KIPOTEC, the PTC, as a whole, must pay a 1000 Ksh initial registration fee and then a yearly fee of 200 Ksh. These fees are used for small events and maintenance of the office. Funded by outside donors, KIPOTEC's services provide an array of different activities in the community including basic counseling on HIV/AIDS, psychosocial support for PLWHA, income generating activities (IGA), orphans and vulnerable children (OVC) care and support, networking and communication, training of communication, and training of community service providers.

KIPOTEC holds many different events throughout the year, open forums about HIV/AIDS and how to live a healthy life, as well as psychosocial support days for children, forums on the prevention with positive campaigns, and other educational seminars and door to door campaigns. The Prevention with Positive campaign is based off the idea that reduction of new HIV infections is led by those who already know their status. PLWHA have a duty to make sure that they don't infect anyone else by accepting their status and sharing their knowledge with others.

The main goal of KIPOTEC is to unite the PTCs that exist in Kibera to provide a stronger support network than having sporadic individual groups that lack basic funding and support.

Methodology

In order to obtain research on the challenges that HIV positive children face and the psychosocial support available to them, I interviewed 40 caregivers of HIV positive children in Kibera, a training officer at Medicins San Frontieres (MSF), and a Lea Toto social worker. MSF clinics provides basic health care to the Kibera slum, while Lea Toto is an outreach program from Nyumbani's Children's Home that focuses on the care of HIV positive children.

The caregivers were chosen at random by the KIPOTEC staff and all interviews were voluntary. Interviews were conducted either at the KIPOTEC office or at the caregiver's home. The majority of interviews were conducted in Kiswahili with a translator, a member of the KIPOTEC staff. The interviews were always conducted with a KIPOTEC staff member present. The caregivers were asked the same questions regarding their children, medications, and disclosure of the child's status (Appendix B). Not all children were present during the interviews due to school but if they were, observations were made about the nature of the child.

The MSF training officer and Lea Toto social worker were voluntary interviews conducted to learn more about the specific organizations and what they are doing in the field of pediatric HIV. Both were conducted in English and the questions asked regarded the trainings that each organization provides and how many children they serve and the manner they do so.

In association with KIPOTEC, a Psychosocial Support Day was held on November 27th for children infected with HIV. For the day, a story and coloring book was created to encourage children to continue to take their medication. For the older children that knew their status, the book was used to start a discussion on HIV/AIDS and the challenges of taking medication. Observations were made regarding the interactions between the children and their perceptions of the HIV/AIDS.

In order to protect the identity of the people I interviewed, the names were changed. Data was compiled based on the interviewee's answers.

Discussion and Analysis

Although there has been a significant movement towards the realization of the need for pediatric care of HIV positive children, there is still much left to be done. While medical research and progress has been made, psychosocial support for children and how to care for them has been left off the agenda.³³

Support in Kibera

In Kibera, there are many different NGOs that exist to provide PLWHA easy access to medication and counseling services. The primary organizations providing medical care and trainings for PLWHA, particularly children are Medicins San Frontiers (MSF) and Lea Toto.

MSF has just started to add pediatric care to its agenda, as before they usually just referred all children to Lea Toto³⁴. Now that the realization that pediatric HIV is an increasing problem and many children still do not have access to medication, they decided to scale up their pediatric care.³⁵ They have less than a thousand children, but provide children empowerment activities such as one-on-one counseling and a one week activity in which they use their Heroes book, a comic book designed to put a face on the epidemic. During this activity, they focus on empowering the children and raising awareness so when the child starts asking questions about why they are taking medication, they understand and do not resist due to fatigue or anger. Some challenges, however, that are involved in the disclosure of a child's status involve the children's caregivers as many are not empowered nor have the training to be able to tell the children their status. Emphasis is put on making sure that the process of disclosing the child's status happens early so after they have gone through training the chance of bitterness with parents and resistance against taking medications lessens.³⁶

³³ Hejoaka, Fabienne. Care and secrecy: Being a mother of children living with HIV in Burkina Faso, *Social Science & Medicine* (2009)

³⁴ David*. MSF Training Officer. Personal Interview. November 15th, 2010

³⁵ "Nine out of ten children are denied life-saving HIV/AIDS treatment: MSF calls for scale-up of pediatric HIV care." Medicins San Frontiers. 28 November 2008. <<http://www.msfaccess.org/media-room/press-releases/msf-welcomes-unitaid-patent-pool-endorsement/nine-out-of-ten-children-are-denied-live-saving-hiv-aids-treatment/>>.

³⁶ David*. MSF Training Officer. Personal Interview. November 15th, 2010

The psychosocial support trainings that they hold are based off the Heroes book that was created after a nine year HIV/AIDS program in Busia, Kenya from 2000-2009 by MSF.³⁷ The focus of this project was to put a face to the HIV/AIDS epidemic, particularly in rural areas and share stories of people that have helped change the perception of the disease in their communities. The book, “The Heroes, Us!,” consists of six stories of HIV patients in Busia, Kenya—four adults and two children. Their stories were illustrated and made into a relatable comic book by four famous Kenyan cartoonists, James Kamawira, Frank Odoi, Paul Kelemba, and Godfrey Mwampekwa. Each of the six stories has different lessons from overcoming stigma and becoming community activists to the importance of anti-retroviral treatment.³⁸ This project was meant to empower people and encourage them to talk about HIV/AIDS by creating a fun, light hearted book.

The other organization that plays a major role in caring for HIV positive children in Kibera is Lea Toto, where over 500 children receive care and support. Lea Toto is an outreach program that started in Kibera in 2003 and was extended from Nyumbani’s Children’s Home, an orphanage for HIV positive children. Lea Toto is an NGO primarily funded by USAID. Lea Toto aims at providing basic medical and nursing care counseling and psychological support, nutritional support, HIV transmission prevention education, and promotion of community empowerment/ownership, among many others.³⁹ They focus on home-based community care and work with both the children and their caregivers, providing support and trainings for both.

Due to the government’s policy of free ARVs (CD4 count below 350) the children receive free medication at Lea Toto. Of the number of caregivers interviewed, approximately 80% are getting their medication at Lea Toto (the next most common place was MSF). Lea Toto provides food every month for the families of the children, enough for each person in the family as well as attempts to support those who cannot afford school fees. Psychosocial support trainings are held every month that consist of life skills education and recreational

³⁷ Medicins San Frontieres (Spain). HIV Stories from Busia, Kenya: “The Heroes, Us!”. 2009. < <http://www.msf.es/kenya-comic/>>.

³⁸ Murekio, Murugi. “Gado, Maddo, Kham, and Fran Illustrate HIV/AIDS book.” Common Lifestyle. Dec. 1, 2009.< <http://www.capitalfm.co.ke/lifestyle/8/HEALTH/4497-Gado-Maddo-Kham-and-Fran-illustrate-HIVAids-Book.html>>.

³⁹ Lea Toto: The Need, www.nyumbani.org

activities. It is recommended by Lea Toto that a child starts those trainings around the age of eight, around the same time that the child's status should be disclosed to them by their caregivers. However, it depends greatly on the character of the child and caretaker circumstances as to when the status should be disclosed.

Disclosing to Children

Disclosing HIV status to children can be daunting and difficult, especially if the caregiver is provided with little advice or training. One of the most important aspects of disclosing to a child is dependent on their age. It is recommended that disclosure is done earlier rather than later though to avoid the risk of resentment and treatment fatigue.⁴⁰ In addition, younger children tend to be more capable of accepting issues because they have had less exposure to peer pressure. According to Human Rights Watch, disclosure can happen as early as age six, while Lea Toto recommends disclosure at age eight and the World Health Organization recommends including children age ten and over in the testing process.⁴¹ However all organizations made it clear that it really depends on the maturity of the child and their ability to understand what being HIV positive means. They must have enough education to understand their status and cope with it in a healthy way.

The Human Rights Watch established important reasons for governments to promote disclosure to children as early as possible. If children know their status, adherence increases because they are actively participating in their medication and know why they need to take it. If they become sexually active, they are able to protect others and prevent the spread of the virus. If children talk about HIV at an early age and make it acceptable to talk about, there is more acceptance of the disease and less chance of denial, at the same time overcoming stigma. If the child is told in a supportive way, they are generally more self- confident and accepting of their status.⁴²

⁴⁰ Karen*. Lea Toto Social Worker. Personal Interview. 16 November 2010.

⁴¹ Human Rights Watch, "Kenya: Support Disclosure of HIV Status to Children"

⁴² "Why Governments should Promote Supportive Disclosure: Five Reasons to Tell Children When they are HIV-positive". Human Rights Watch. Dec. 1, 2010. <<http://www.hrw.org/en/node/94635To>>.

All the caregivers had different stories to tell about the challenges they face and the disclosure process. Out of 40 caregivers interviewed, 42 HIV positive children were examined with an average age of seven years.

Table 1. Data collected from Interviews of Caregivers with HIV positive children.

# of HIV positive children	Average Age of Children (yrs)	% of children that know their status	Average age they were told (yrs)	% of children who ask why they are taking medication but don't know their status	Average age of those who are asking (yrs)	% of children attending trainings	% of caregivers attending trainings
42	7	22	10	33	7.5	55	88

Nine of the children knew their status and the average age they were told was ten years. Using Lea Toto's standard of disclosing at age eight, about seven more of the children ages eight and older should know their status but don't. While it does vary from child to child, it is critical to disclose earlier than later. According to Senior Children's Rights Researcher at Human Rights Watch, Juliane Kippenberg, "Accepting HIV is more painful when children find out late, particularly during adolescence."⁴³ Children need to have a supportive environment and enough education about the disease that they understand how to live with and do not take it as a death sentence, before they are shaped by the perceptions of the outside environment.

Eleven out of the 33 children, who do not know their status, have asked their parents why they are taking medication while other children, like classmates, neighbors, or siblings are not. The other 22 children are either too young to ask or have not asked about why they are taking medication yet. For the children that do ask, the caregivers generally tell their children reasons varying from malaria to a headache to a necessity for life to medication that will help one to grow bigger and stronger. The average age of the children that have asked is seven and a half years which supports Lea Toto's theory that at eight years a child will start asking questions and should know why they are taking medication. A comment from a mother illustrates a common response among caregivers:

⁴³ Human Rights Watch, "Kenya: Support Disclosure of HIV Status to Children"

My son, David, asks me every single day why he is taking medication and the other children are not. I just tell him ‘Remember those days you were in the hospital when you were younger? These are so you don’t need to go back to the hospital’ I’ll tell him his status when he’s big enough to understand, but for now that is what I tell him.⁴⁴

Others however choose to disclose as soon as the child starts asking questions like Mary*, the mother of five year old Stacy who doesn’t want to lie to her child:

My daughter, Stacy, hasn’t started asking me why she is taking medication yet because she is only five years old. I plan to tell her when she is nine or whenever it’s the right time. If she starts asking me why she’s taking medication, I will disclose her status to her. I don’t want to lie to her because she will remember that I did so.⁴⁵

Trainings on how to disclose the status to the child is critical in helping the caregiver do so. However trainings are minimal and advice is many times hard to get. According to NASCOP, pediatric health workers and counselors are very minimal. Only about 1,800 Kenyan health workers are trained in pediatric HIV.⁴⁶ If caregivers do attend trainings, it may provide some good advice but the process of disclosure is still very difficult. Only about five caregivers interviewed were not attending any trainings, meaning that the majority of caregivers have some sort of support or advice to help them disclose. However, attending trainings helped only some of the caregivers while many are still struggling with what they are actually going to say when disclosing their status to their child.

Betty, a mother who has attended trainings on adherence is still thinking about what she is going to tell her five year old daughter:

I don’t know what I’m going to do. My daughter, Madeline, hasn’t started asking me why she’s taking medication because she is still young, but I just

⁴⁴ Jacklyn*. Personal Interview. 17 November 2010

⁴⁵ Mary*. Personal Interview. 17 November 2010

⁴⁶ Plus News, “Kenya: No guidance on Caring for HIV positive Children”

don't know what I am going to tell her or when I'm going to disclose her status. I just don't know what to do.⁴⁷

Betty is struggling to figure out what she is going to tell her daughter Madeline, but luckily she has some time to think about it. However for thirteen year old Julius, time is running out. Julius, who became sick with rashes only two years ago and got tested, still doesn't know his status. He hasn't asked why he is taking medication but his mother, Millicent, tells him that he is taking medication for his headaches. Julius is also not going to any training, probably because of the recent diagnosis. Millicent has four older children and a younger child (HIV negative) but Millicent doesn't know whether or not they know Julius's status:

I haven't disclosed to any of my children but it is possible that they have figured it out but they just don't want to say anything. The problem with telling children is that they go to school and tell their friends that they are sick with HIV and that's when stigma begins.⁴⁸

What Millicent doesn't know is that by not disclosing to Julius early “could do a lot of harm, unwittingly. It can shatter a child's emotional and physical health and carry stigma about HIV to the next generation,” according to Juliane Kippenberg of Human Rights Watch.⁴⁹ By trying to avoid stigma, she is actually on the way to continuing it into the next generation, by setting an example for her children that the disease is still stigmatized. Another issue Millicent arises is the issue of secrecy. Adults generally don't trust children to keep their status a secret. They fear that the children will share it openly, unaware of the stigma associated with the disease. Because of that the child faces the risk of being discriminated against as well as the caregivers, who are also most likely HIV positive.

About 23 children are currently attending psychosocial support trainings at Lea Toto, MSF, or KIPOTEC. The average age of the children was eight years, while those who were not attending were generally too young with an average age of 4.5 years. For those who attend trainings, they meet friends that are experiencing the same things they are going through like taking medication and participate in recreational activities, as well as building

⁴⁷ Betty*. Personal Interview. 17 November 2010.

⁴⁸ Millicent*. Personal Interview. 13 November 2010.

⁴⁹ Human Rights Watch, “Kenya: Support Disclosure of HIV Status to Children”

life skills. For those who already know their status, they are educated about HIV and trainings provide an open forum to discuss their problems, ask questions, and share stories. They are able to talk about why they are taking medication and in general understand the medications and disease. For Ivan, who has attended psychosocial support at Lea Toto and KIPOTEC for about four years and learned his status at the age of nine, taking medication is not a big deal: “I take medication everyday so I can prevent getting opportunistic infections and the HIV does not advance to AIDS. Finding out I was HIV positive was not a big deal, I don’t really care.”⁵⁰

However for others who know their status it isn’t the same way. Flora is thirteen years old and found out her status last year after her father’s death. She has attended Lea Toto trainings for about four years:

Before my daughter, Flora, knew her status, I used to answer her questions about medication with anything that came to mind at the moment. My daughter knows her status now after we talked about her father’s death. We talked about how we’ll die if we don’t take our medication. She knows the medication is helping her, that its ‘goodness’, But she doesn’t like that she’s HIV positive at all. Every time a program about HIV/AIDS comes on the television, Flora will get upset and will just go to sleep without watching it.⁵¹

A loss of hope can be a problem in disclosure. Psychosocial support and proper education and understanding can help in the child’s ability to accept their status. Flora also had to experience with her father’s death at the same time as finding out her status which is emotionally draining on any child. In general, children are able to accept their status but it may take a longer time if the disclosure is associated with a parent’s death. Disclosing to children is a challenging process and many caregivers are still figuring out what to do based on how their child reacts to certain events and information.

⁵⁰ Daniel and Ivan*. Personal Interview. 17 November 2010.

⁵¹ Anna*. Personal Interview. 17 November 2010.

Challenges Faced by Caregivers

As a caregiver of an HIV positive child, there are many different challenges to deal with aside from disclosing. HIV positive children require a lot of care and support in order to stay healthy, like having a well balanced diet for the ARV drugs to be effective, making sure they are staying clean and hygienic, and maintaining the strict schedule that medications require. Many common challenges among caregivers were the inability to provide enough nutritious food to their child because they have a very low income or no job at all. Putting food on the table is hard enough, making it well balanced is an entirely different story. In Kibera, hygiene and sanitation is also harder for children due to a dirty, polluted environment in which they play and walk on a daily basis.

However, one of the biggest challenges is adherence for the children because they depend on someone else to give them their medication. Because ARVs require a rigid schedule and the medications must be taken at the same time every day, caregivers struggle with being busy with other things. Sometimes even the children remind the caregivers to take the medication: “My son, Matthew, doesn’t know his status and when he asks why he is taking medication, I tell him he can stop when he gets better, but he always takes them. When seven pm comes, he knows he has to take them and sometimes even reminds me to give them to him.”⁵² Many times even the older children in the family remind their sibling to take the medication if the caregiver is busy. At times, they make sure that their sibling takes it, playing the role of another caregiver because they know the importance of the medication. Due to the stigma surrounding the disease, the number of people that can support and take care of the child when the caregiver is limited if disclosing is a problem.

While psychosocial support for children is critical in accepting their status, caregivers also need psychosocial support. If they are the mothers then they too are HIV positive and dealing with both statuses at the same time, trying to take care of their child and themselves. If the caregiver is struggling with their status, it can cause a lot of stress and anxiety in both the caregiver’s and child’s life. Samantha, a mother of a one year, eight month old boy, John, is stressed about many different things: “My husband and I separated five years ago when he found out I am HIV positive so now I am struggling to pay school fees and feed my children.

⁵² Nancy*. Personal Interview. 17 November 2010.

My stress affects John. He is very sick, almost bedridden and my CD4 count has been dropping as well.”⁵³ Samantha’s stress is affecting both her son and her own health. Samantha found out her HIV status when she was pregnant with her five and half year old son, who is negative. She was able to take precautions and use formula instead of breastfeed. However, because her husband left her shortly after, when she gave birth to John she believed she had no other options than to breastfeed John. MSF, however, provides free baby formula to HIV positive mothers with babies. In Kibera, many people have the knowledge but at times lack the means to carry out that knowledge.

Since MSF provides free baby formula so mothers don’t have to breastfeed their child there is the means of carrying out that knowledge if taken advantage of. Baby formula reduces the risk of transmission because breast milk contains a high amount of the virus. However, many people deal with cultural barriers in the prevention and treatment of HIV, many times at the judgment of others. For example, breastfeeding is a highly cultural practice and a mother will instantly be asked questions as to why they are not breastfeeding their child if anyone sees them. This poses a dilemma of having to disclose their status to the inquisitor or deciding to breastfeed inconsistently so they don’t have to share their status, which actually puts the baby at higher risk for HIV infection.

Other cultural beliefs and traditions can also inhibit treatment. Many people when they are first tested are in denial of their status and at times leads to drastic measures of treatment. Katherine, a mother of six year old girl Miriam, had to deal with a conflict of cultures:

We found out Miriam was HIV positive when she was two years old. My husband was in denial and couldn’t accept Miriam’s status. He viewed HIV as witchcraft and wanted to treat her with traditional medicine. We would boil traditional herbs and give her to drink, but it didn’t work. Miriam continued to get sick until finally my husband accepted two months ago that she could start medication.⁵⁴

⁵³ Samantha*. Personal Interview. 17 November 2010.

⁵⁴ Katherine*. Personal Interview. 12 November 2010.

Cultural beliefs and denial interfere with treatment and cause a delay in getting medications which could result ultimately in the child's death. Denial in caregivers greatly affects their own health but also the health of the child. Yvonne, mother of four year old Brian is in complete denial of her own status. Brian was found to be HIV positive a year ago when he started to get very sick, but Yvonne has yet to be tested and she refuses to do so. While she is taking care of her son and giving him medication, what she is going to tell him when he gets older is yet to be answered. She won't be able to disclose to her son if she is still in denial which puts both her and her son in a tough situation.

Another fear among caregivers is leaving their child alone to fend for themselves. Kristine, mother of six year old Michael, expressed her biggest fear as leaving behind her son with no one to take care of him: "One of the biggest challenges for me as a HIV positive mother with an HIV positive son is the fear that I live with all the time, the fear that I'm going to leave him alone."⁵⁵

Leaving children behind is a common occurrence as the number of orphans from HIV/AIDS is very high. There are approximately 1.6 million orphans with at least one parent dying of AIDS.⁵⁶ Many time children are left as head of the households, in charge of taking care of their younger siblings, working to earn school fees, and providing for their brothers and sisters. Chances are at least one of those children are infected with HIV as well to make life even harder. Lucas is seventeen years old and his parents both died from AIDS. He takes care of his two younger siblings, while his older brother is finishing secondary school. Lucas is no longer in school because he has to find casual labor to take care of his family. His youngest sister, Lilly, is HIV positive. Lilly lost her hearing and started to lose her sight before she got put on medication. Lucas struggles with making sure he comes home from work on time to give her the medication. Luckily, Lilly is able to remind Lucas about the medication, even though she has never asked what it is for. Orphans, especially those infected with HIV, require caregivers to help them stay healthy and provide them with

⁵⁵ Kristine*. Personal Interview, 12 November 2010.

⁵⁶ Ministry of Health, AIDS in Kenya

emotional support. Even though Lucas and Lilly are alone with their two other siblings, Lilly is lucky to have a brother like Lucas that is willing to take care of her.⁵⁷

From disclosure to the feeling of possibly leaving their child behind, caregivers of HIV positive children face many challenges in caring for their children. Psychosocial support is needed for both caregivers and children to help cope with their status and encourage them to live a long healthy life with HIV.

KIPOTEC Psychosocial Support Day

As a culmination of the research, a psychosocial support day was held on November 27th at MSF Olympic Training Hall 9am-1pm by KIPOTEC. The goal of psychosocial support days are for HIV positive children to make friends with other children that are going through the same experiences such as taking medication. The children that attended are registered in KIPOTEC and mobilized and informed about the psychosocial support day. There were 34 children that attended with an average age of 7.5 years.

Once all the children had arrived, the session started with a prayer by one of the children and led into introductions of each other, which included the name, age, school, and village. Discussions of expectations of the day and child rights were intertwined with songs and stories led by volunteers. The children's expectations were to learn, sing, pray, eat, have fun, and tell stories. Many of the children were full of energy and loved to participate while others were very shy. The children also participated in a child rights discussion in which children volunteered and offered different child rights: to be happy, learn, play, clothing, food, shelter, name and nationality, right to participate, parental care and love, and freedom of speech.

After a break, the day was focused on the coloring book that I created called "The Hero in the Jungle" (Appendix C). After discussion of the story, the children came up with lessons that they learned, the two main ones being that if you are sick, you should go to the hospital. Also, if you are sick, you won't be able to go to school or play. After they established the lessons in the book, some of them shared who their heroes were, a few being Lawrence the lion, a character in the book, God, medicine because it makes you strong and

⁵⁷ Lucas*. Personal Interview, 20 November 2010.

healthy, and their mothers. The children were then split up into two groups. One group was the children that were 8 years older and the other was those younger than 8 years. For the children that were younger than eight years old, they colored the book together.

For those who were older than eight years, they knew their status so there was a discussion about HIV/AIDS, taking medication, challenges that existed, and any questions that were lingering. To start off the discussion, the children went around in a circle and introduced themselves by name and stated that they were taking medication: “Ninameza dawa.” (“I am taking medication”) All the children knew they had HIV/AIDS and were taking medication called ARVs. They also all established that their medication was important to stay strong and healthy so they could continue to go to school and church. Questions were answered about the disease and HIV/AIDS information was reviewed, mainly what it is and how it is transmitted. The perception of HIV/AIDS was that it is just a disease that they have to take medication for to stay healthy. They went through what the abbreviations of HIV and AIDS stand for and were able to name the main ways of transmission: sex, mother to child, and blood transfusion/ sharing of sharp objects. After the discussion was finished, they were able to color in the coloring books and draw their heroes and share with the group.

Overall the children enjoyed the day. For the older children, they were able to share stories and meet friends going through the same thing they are going through, while the younger kids were able to color and enjoy themselves. The day was a success and hopefully the children that attended will continue to attend psychosocial support trainings in the future.

Conclusion

Many children in Kenya have been affected by the AIDS epidemic, either from being orphaned by parents who died of AIDS or by being infected themselves. Pediatric care of HIV positive children has, until recently, not been at the forefront of HIV/AIDS management. PMTCT counseling has made a huge impact on the reduction of children being born with HIV, and the number of children that have access to ARVs are increasing, slowly but there is a movement by MSF and the government to realize these problems.

However, many times the mental and emotional aspects of dealing with HIV infection stands in the shadow of the movement towards an increase in access to prevention and treatment. PLWHA, at any age, need psychosocial support to cope with their status. However, the unique aspect of children is that they always depend on their caregiver and the disclosure of their status and the education they receive about HIV is based on the caregiver's ability to accept their own status.

HIV Positive children and their caregivers in Kibera face many different challenges from lack of basic nutrition and hygiene to lack of mental and emotional support. Caregivers have to deal with making sure they are caring for the child, especially making sure medication is given at the right time. Many caregivers are stressed which affects the emotional state of the child as well. Caregivers stress about making sure they are taking care of their child, how to disclose their child's status, and the possibility that they could leave their child behind.

Disclosing status to children is very difficult and requires support or some sort of guideline for caregivers that they can follow. It is evident from talking to caregivers that there is a severe lack in guidance and support on how to disclose to their child. While the government is slowly starting to implement new policies for psychosocial support in children living with HIV, there is still much more that needs to be done.

The Human Rights Watch called upon the Kenyan government to make changes in support for caregivers and to establish guidelines. Human Rights Watch recommends that the government provides accessible and clear guidelines for the process of disclosure, allow health workers to disclose the HIV status to the child if the child is ready and wants to know, provide counseling for caregivers on how to disclose, train more health care workers on

pediatric HIV and the disclosure process.⁵⁸ However every child is different and part of the main reason why standardizing a process of disclosure is difficult. It is important that the Kenyan government establishes that it depends on the child's character and ability to understand the status rather than a set of guidelines to be followed by every child. Training of health care workers with a basic set of guidelines or advice should be the first step in implementing more psychosocial support for HIV positive children.

⁵⁸ Human Rights Watch, "Kenya: Support Disclosure of HIV Status to Children"

Recommendations

There are many different aspects that could have been taken to research this project further. In order to improve this project, it would be beneficial to talk to NASCOP and the National AIDS Control Council to evaluate the steps that they claim to be taking in improving guidelines and creating some sort of guidance for caregivers. It would also be beneficial to talk to children that have grown up with HIV and discuss their perceptions of the disease, their reactions, and how they have dealt with their status. It would be interesting to look at how their status was disclosed to them and what recommendations they would have for other caregivers.

It would have been helpful to talk to more caregivers and observe more of the children. Talking to trained health workers and evaluate what they learn in their trainings would also be an interesting aspect to look at and could contribute to an analysis of how the government can develop and change guidelines for disclosure by caregivers. It would also be interesting to compare different settings and the access children have to treatment and support in an area that is not scattered with different NGOs, such as Kibera.

Appendix A

A.1 WHO Pediatric HIV Infection Clinical Staging

WHO Pediatric clinical Staging
<p>Clinical Staging I</p> <ul style="list-style-type: none"> • Asymptomatic • Generalized lymphadenopathy <p>Clinical Staging II</p> <ul style="list-style-type: none"> • Unexplained chronic diarrhea • Severe persistent or recurrent candidiasis outside the neonatal period • Weight loss through failure to thrive • Persistent Fever • Recurrent Severe Bacterial infections <p>Clinical Staging III</p> <ul style="list-style-type: none"> • AIDS-defining opportunistic infections • Severe failure to thrive • Progressive encephalopathy • Malignancy • Recurrent septicaemia or meningitis

A.2 REPPSI Definition of Psychosocial Support

Domain	Description	Possible Programmatic Application
<p>Psycho Belonging, faith for the future</p>	<p>When an organization or community group provides/organizes / stimulates, etc, and therefore creates a platform that makes it possible for an individual child to disclose feelings, realities, etc., and provides some form of counseling.</p>	<ul style="list-style-type: none"> • Group processes / group counseling • Debriefing in experiential learning, plays • Home visits with quality time spent with children • Drop in centers
<p>Social Belonging, participate, life skills</p>	<p>When an organization or community group actively influences the social environment in the direction of reintegration of affected children into “normality” and creates comprehensive understanding of the specific situation of children (i.e. create somewhat durable social structures)</p>	<ul style="list-style-type: none"> • Training of caregivers and guardians • Community sensitization • Orphan organizations • Kids clubs • Child participation in community committees
<p>Support Self-worth</p>	<p>When an organization or community group explores and systematically builds up the internal / own resources of children in order to enhance their resilience</p>	<ul style="list-style-type: none"> • Life skills training • Positive feedback to children about their performance • Solution-focused approaches / participatory methods / creative self-expression

Appendix C. See “The Hero in the Jungle” Coloring Book**Appendix D**

World AIDS Day Poem: Written for World AIDS Day Celebration December 1, 2010

What’s in a name?

By Katie Lesyna

Today we stand, united as one
Together against a disease that has had its fun,
Whose name weighs much more than a ton

But, what’s in a name?
It’s a disease that just came
And we have let it have its fame

No border or culture can stand in its way
We must let our differences run astray
Making sure to never use the word ‘they’

For unity across cultures is a global must
And we cannot let our hope rust
Because leaving people behind would be unjust

Now it’s time for a change
Let’s make this disease something strange,
Something that is no longer so easily exchanged

Let’s hold hands with our neighbors, our families and friends
Because they are the people that we should defend
And let’s bring hope to their lives instead of showing them the end

The name of this disease is AIDS
And it has haunted us for decades
But together we can make it fade

Works Cited

Bibliography

- AIDS in Kenya: Trends, Interventions, and Impact. Ministry of Health. Seventh Edition, 2005.
- Anyuor, Nicholas. Virulent AIDS Virus Wreaks Havoc in Africa. Tuesday, August 24, 2010. The Standard.
- Anyuor, Nicholas. Never Too Young to Take Charge of Families. Tuesday, August 24, 2010. The Standard.
- “What is Kibera?: Basic Information.” Community Support Group Kibera. 30 November 2010. <<http://www.csgkibera.org/>>.
- “Children and AIDS: Fourth Stocktaking Report.” UNICEF. 2009. <http://www.unicef.org/publications/files/Children_and_AIDS_Fourth_Stocktaking_Report_EN_120209.pdf>.
- “Facts and Information about Kibera.” Kibera UK—the Gap Year Company. 30 November, 2010. <<http://www.kibera.org.uk/Facts.html>> .
- Hejoaka, Fabienne. Care and secrecy: Being a mother of children living with HIV in Burkina Faso, *Social Science & Medicine* (2009), doi:10.1016/j.socscimed.2009.05.041
- “HIV, AIDS, and Children.” AVERT. October 22, 2010. <<http://www.avert.org/children.htm>>.
- Huni, Noreen M. "Enhancing psychosocial support of children affected by HIV/AIDS: A Special Focus on Memory Work." Conference of aidsfocus.ch, Swiss Platform of HIV/AIDS and International Cooperation. Berne, 2005. 11. <www.aidsfocus.ch>
- Karanja, Muchiri. "Myth shattered: Kibera numbers fail to add up." Daily Nation 3 September 2010. <<http://www.nation.co.ke/News/Kibera%20numbers%20fail%20to%20add%20up>>
- “Kenya: No guidance on caring for HIV-positive children” Plus News. 23 June 2009. <<http://www.plusnews.org/Report.aspx?ReportId=84956>>
- “Kenya: Support Disclosure of HIV Status to Children.” Human Rights Watch. Dec. 1, 2010. <<http://www.hrw.org/en/news/2010/12/01/kenya-support-disclosure-hiv-status-children>>.
- Kongs, Eva. “Post Test Clubs in Nairobi towards a model for PLHIV grassroots support.” *Medicins San Frontieres* (Belgium). Nairobi. April 2008.
- Lea Toto: The Need. Nyumbani: Watoto wa Mungu. November 30, 2010. <http://www.nyumbani.org/lea_need.htm>.

- Medicins San Frontieres (Spain). HIV Stories from Busia, Kenya: “The Heroes, Us!”. 2009. <<http://www.msf.es/kenya-comic/>>.
- Murekio, Murugi. “Gado, Maddo, Kham, and Fran Illustrate HIV/AIDS book.” Common Lifestyle. Dec. 1, 2009. <<http://www.capitalfm.co.ke/lifestyle/8/HEALTH/4497-Gado-Maddo-Kham-and-Fran-illustrate-HIVAids-Book.html>>.
- National AIDS Control Council. Kenya National HIV/AIDS Strategic Plan. 2005/6 -2009/10. June 2005.
- National AIDS and STI Control Programme, Ministry of Public Health and Sanitation, Kenya. *Guidelines for HIV Testing and Counseling in Kenya*. Nairobi: NASCOP; 2008.
- National AIDS Control Council. Kenya National AIDS Strategic Plan: Delivering on Universal Access to Services 2009/10-2012/13. November 2009.
- National Guidelines: Prevention of Mother to Child HIV/AIDS Transmission (PMCT). Ministry of Health, Republic of Kenya. NASCOP. Second Edition, 2002.
- “Nine out of ten children are denied life-saving HIV/AIDS treatment: MSF calls for scale-up of pediatric HIV care.” Medicins San Frontieres. 28 November 2008. <<http://www.msfaccess.org/media-room/press-releases/msf-welcomes-unitaid-patent-pool-endorsement/nine-out-of-ten-children-are-denied-live-saving-hivaids-treatment/>>.
- Support for International Change. HIV Education and Teaching Curriculum. Version 3. December 1, 2008.
- “The Scourge of Pediatric AIDS in Kenya.” MSF/Doctors without Borders. Nov. 1, 2005. <<http://www.doctorswithoutborders.org/news/article.cfm?id=1743>>.
- UN General Assembly, *Convention on the Rights of the Child*, 20 November 1989, United Nations, Treaty Series.. <<http://www.unhcr.org/refworld/docid/3ae6b38f0.html>>.
- UNAIDS Global Report on the Global AIDS Epidemic 2010. <http://www.unaids.org/globalreport/Global_report.htm>.
- UNAIDS and World Health Organization. AIDS Epidemic Update. December 2009. <http://data.unaids.org/pub/Report/2009/JC1700_Epi_Update_2009_en.pdf>.
- “Why Governments should Promote Supportive Disclosure: Five Reasons to Tell Children When they are HIV-positive”. Human Rights Watch. Dec. 1, 2010. <<http://www.hrw.org/en/node/94635To>>.
- Women Fighting AIDS in Kenya (WOFAK). October 22, 2010. <<http://www.wofak.or.ke/>>.
- World Health Organization. Psychosocial Support. 30 November 2010. <<http://www.who.int/hiv/topics/psychosocial/support/en/>>

Interviews

1. David*. MSF Training Officer. Personal Interview. 15 November 2010.
2. Karen*. Lea Toto Social Worker. Personal Interview. 16 November 2010.
3. Beatrice*. Personal Interview. 12 November 2010.
4. Rosemary*. Personal Interview. 12 November 2010.
5. Samantha*. Personal Interview. 12 November 2010.
6. Katherine*. Personal Interview. 12 November 2010.
7. Jane*. Personal Interview. 12 November 2010.
8. Millicent*. Personal Interview. 13 November 2010.
9. Kristine*. Personal Interview. 13 November 2010.
10. Irene*. Personal Interview. 15 November 2010.
11. Jennifer*. Personal Interview. 15 November 2010.
12. Carolina*. Personal Interview. 15 November 2010.
13. Lillian*. Personal Interview. 15 November 2010.
14. Monica*. Personal Interview. 15 November 2010.
15. Elizabeth*. Personal Interview. 15 November 2010.
16. Margaret*. Personal Interview. 16 November 2010.
17. Yvonne*. Personal Interview. 16 November 2010.
18. Marcy*. Personal Interview. 16 November 2010.
19. Daniel*. Personal Interview. 16 November 2010.
20. Jacklyn*. Personal Interview. 17 November 2010.
21. Nancy*. Personal Interview. 17 November 2010.
22. Anna*. Personal Interview. 17 November 2010.
23. Mary*. Personal Interview. 17 November 2010.
24. Angeline*. Personal Interview. 17 November 2010.
25. Betty*. Personal Interview. 17 November 2010.
26. Rosa*. Personal Interview. 19 November 2010.
27. Laura*. Personal Interview. 19 November 2010.
28. Diana*. Personal Interview. 19 November 2010.
29. Susannah*. Personal Interview. 19 November 2010.
30. Pamela*. Personal Interview. 19 November 2010.
31. Edith*. Personal Interview. 19 November 2010.
32. Lucas*. Personal Interview. 20 November 2010.
33. Florence*. Personal Interview. 20 November 2010.
34. Alice*. Personal Interview. 20 November 2010.
35. Julia*. Personal Interview. 20 November 2010.
36. Lauren*. Personal Interview. 20 November 2010.
37. Michelle*. Personal Interview. 20 November 2010.
38. Sarah*. Personal Interview. 20 November 2010.
39. Grace*. Personal Interview. 24 November 2010.
40. Irene*. Personal Interview. 24 November 2010.
41. Eunice*. Personal Interview. 24 November 2010.
42. Lillian*. Personal Interview. 24 November 2010.

*All names have been changed to protect the confidentiality of the people interviewed.