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Growing up with HIV in Kisumu, Kenya: Participatory Action Research with Young People Living with HIV

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The University of San Francisco

GROWING UP WITH HIV IN KISUMU, KENYA: PARTICIPATORY ACTION RESEARCH WITH YOUNG PEOPLE LIVING WITH HIV

A Dissertation Proposal Presented
to
The Faculty of the School of Education
International and Multicultural Education Department

In Partial Fulfillment
of the Requirements for the Degree
Doctor of Education

By
Zoe Marinkovich
San Francisco, California
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UNIVERSITY OF SAN FRANCSICO
Dissertation Abstract

Growing Up With HIV In Kisumu, Kenya: Participatory Action Research With Young People Living With HIV

Forty-one percent of new HIV infections are in young people between the ages of 15-24 (Masquillier, et al., 2012). In addition to new infections, advances in medications are now making it possible for children born with HIV to survive into adolescence and adulthood (Bland, 2011; Gray, 2010). Due to the growing population of youth living with HIV, there is an increased need for adolescent-appropriate care and intervention. While many studies have examined the role of education in preventing HIV transmission for HIV-negative youth in the Sub-Saharan context, few have focused on the education and experiences of young people living with the virus. Studies that do focus on HIV-positive youth primarily report biomedical information and demographics, leaving out the voices and experiences of these youth. To more effectively meet the needs of adolescents living with HIV in Sub-Saharan Africa, the experiences of these youth must be explored and documented.

The purpose of the study was to use a participatory action research (PAR) approach to answer the question: What is the experience of HIV positive youth living in Kisumu, Kenya? The goal of the study was to engage and empower a small research team of young adults in Kisumu to critically examine the needs and document the voices of HIV-positive adolescents. The research team generated three primary categories of inquiry: (a) stigma and discrimination, (b) school, and (c) substance abuse. Data was collected through individual interviews, focus groups, observation, journals, and meeting notes. A total of 40 adolescents (13-17 years) were recruited from orphanages and youth centers. Preliminary themes were identified through discussion and reflection by the research team and transcripts were later analyzed and coded. From the data emerged six major themes: (a) prevalence of self-stigma; (b) challenges with disclosure; (c) challenges with medical treatment; (d) lack of support in schools; (e) lack of substance use (f) coping strategies and hope. We concluded that although stigma was rampant, adolescents were still able to exert control over their lives and assert their agency through various means. We recommend that additional research be conducted on the experiences of adolescents living with HIV and also offer recommendations for practice.

This dissertation, written under the direction of the candidate's dissertation committee and approved by the members of the committee, has been presented to and accepted by the Faculty of the School of Education in partial fulfillment of the requirement for the degree of Doctor of Education. The content and research methodologies presented in this work represent the work of the candidate alone.

Zoe Marinkovich	May 7, 2014
Author	Date

Dissertation Committee

Shabnam Koirala-Azad, Ph.D.	May 7, 2014
Chairperson	
Emma Fuentes, Ph.D.	May 7, 2014
Lilian Dube, Ph.D.	May 7, 2014

DEDICATION

For my father.

And for children with chronic illness everywhere. May your voices be heard.

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First and foremost, I owe so much to the research team for their enthusiasm and dedication to the adolescents living with HIV in their community. Thank you for your hard work, patience, and expertise. Special thanks to my co-investigator, Lucy, for all of her efforts including presenting this proposal locally, working on numerous drafts of the protocol with me, and her all around awesomeness. Thank you to the clinic staff for your time and guidance as well. Thank you to Geri and Elana for your love and support.

Thank you to all the brave young people who were willing to speak so openly and honestly with us. And thank you to their caregivers who trusted us and who are so dedicated to helping young people living with HIV reach their fullest potential.

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CHAPTER I
INTRODUCTION

Forty-one percent of new HIV infections across the globe are in young people between the ages of 15-24 years. Seventy-nine percent of new infections are in Sub-Saharan Africa (Masquillier, et al., 2012). In addition to these new infections, children born with HIV are now surviving into adolescence due to a doubling of African youth on life-saving antiretroviral (ARV) drugs since 2007 (Bland, 2011; Gray, 2010). Although, as Nglazi et al. (2012) writes, "Sub-Saharan Africa accounts for almost 67% of all people living with HIV/AIDS and yet only a handful of studies in the region have investigated outcomes on ART in the emerging group of HIV-infected adolescents" (p. 2). Due to rising infection rates among young people and advances in medication, there is a growing population of youth living with HIV in Sub-Saharan Africa (SSA) and therefore, an increased need for adolescent-appropriate care and intervention.

While many studies have examined the role of education in preventing HIV transmission for HIV-negative youth in the Sub-Saharan context, fewer have focused on the education and experiences of young people living with the virus (Machlachlan, et al., 1997; Gallant and Maticka-Tyndale, 2004; Dufalo, et al., 2006). The studies that do focus on HIV-positive youth also tend to report biomedical information and demographics, leaving out the voices and experiences of these youth (Steele and Grauer, 2003; Potterton, 2009; Chandwani, et al., 2011).

Grey (2009) writes "few data on the prevalence and disease pattern of perinatally acquired HIV infection in older children and adolescents exist" (p.1). She further writes that for adolescents there is "an urgent need for services that will be able to provide accessible and appropriate . . . interventions” (p.1). Masquillier, et al. (2012) also note that very little research has been done to measure the health-related quality of life or “HRQOL of HIV-positive adolescents in Sub-Saharan Africa” (p. 1). According to Nachega et al. (2009) “Further research on barriers to ART adherence in adolescents is critically needed.” In order to meet the needs of the growing populations of adolescents living with HIV in Sub-Saharan Africa, the experiences and unique issues facing youth living with the virus must be examined.

This study will employed a participatory action research approach to explore the experiences of young people living with HIV in Kisumu, Kenya where HIV prevalence is at an estimated 15% (FACES, 2012). This study sought to answer the question: What is the experience of HIV positive youth living in Kisumu, Kenya?

Statement of the Problem

The challenges all adolescents face as a normal part of development are greatly complicated by an HIV diagnosis. Living in areas of high poverty adds additional stress. Many of these children have been abandoned due to stigma; many more have watched parents die from AIDS-related illness. In Kenya, many households are headed by children who, having lost parents to AIDS, are left to care for their siblings (National AIDS Control Council, 2008). Struggles with medication adherence, nutrition and other health issues are compounded by severe poverty and create additional barriers to education. All of these factors weigh heavily on the psychological state of these youth. Fear of rejection and stigma-related violence, despair and grief affect a young person's ability to cope with this disease. Young people living with such a heavy burden also present a challenge for their communities. Upon reaching adolescence, many of these young people begin to have sexual relationships, potentially transmitting the virus to others (Masquillier, et al., 2012). Also common among adolescents living with HIV is poor medication adherence that can result in drug resistance, illness or death (Masquillier, et al., 2012).

Medication adherence is a major issue with both pediatric patients living with chronic conditions and more specifically for people living with HIV (Shaw & DeLaet, 2010; Steele and Grauer, 2003; Khan et al., 2012; Chandwani et al., 2011). The HIV virus mutates quickly and therefore can easily adapt and become resistant to medications (Pisani, 2009; Timberg and Halperin, 2012). Patients are usually required to take pills daily and are advised not to miss more than one or two pills per month. High adherence is needed to maintain viral suppression. “Poor adherence leads to treatment failure, the development of viral resistance with subsequent reduction in treatment options, increased morbidity and mortality” (Khan, et al., 2012, p. 970). However, facing a lifetime of daily pill intake can be daunting for adults, and even more so for adolescents, especially when some of the HIV medications still have harsh side effects ranging from vivid dreams, to facial lipoatrophy, to nausea (Timberg and Halperin, 2012). According to research in the U.S., antiretroviral adherence among youth is much lower than with adults (Khan, et al., 2012). Additionally, in a study conducted in the U.S. in which emotional and behavioral functioning were assessed, “medication-related stressors” were the most commonly reported by perinatally infected youth (Orban et al., 2010, p. 421). Although there have been fewer studies conducted on HIV medication adherence in Sub-Saharan Africa with adolescents, many that have been done report suboptimal adherence as well (Vreeman et al., 2008, Bland, 2011).

Upon reaching adolescence, youth are able to completely comprehend their HIV status and the full weight of diagnosis sets in, often leading to depression, anger, fear, and their first experiences with stigma (Nglazi et al, 2012; Li et al., 2010). Children and adolescents in the U.S. living with HIV have an “incidence of psychiatric admissions” that is “significantly higher than that reported in the general population” and most commonly for “depression and behavioral disorders” (Gaughan, et al., 2004 as cited in Gray, 2009, p.2). But as Gray (2009) notes, “Few data from southern Africa are available on the psychological manifestations, depressive symptoms, and psychiatric admissions for children and adolescents infected with HIV” (p.2). One of the major causes of mental and emotional stress is the fear associated with disclosure of one's HIV status to a friend, partner, teacher or even a family member because of the deep stigma still prevalent in many communities. Young people have often witnessed discrimination against people living with HIV and are frightened of rejection or even violence. In particular, Orban et al. (2010) found that "youth infected through risk behaviors reported more disclosure-related stressors" (p. 421).

Mental health issues, poverty, stigma and strict medical treatments with side effects make it challenging for youth to remain in care. Many fall out of treatment, stop coming to their clinic appointments and as a consequence build resistance to their drugs, fall ill, or die (FACES, 2012). Further research is needed to address these issues and help keep young people living with HIV healthy and productive.

Background and Need

In Kenya there are 1.5 million people living with HIV (UNAIDS, 2010). In 2008 the UN estimated that over 200,000 of those living with HIV were children (National AIDS Control Council, 2008). Although the government declared "A Total War on AIDS" in 2002, nine years later studies showed that only 48% of young women in Kenya had a comprehensive knowledge of HIV and only 55% of young men had this knowledge (UNICEF, 2012).

Much research has been done on the failure of governments, NGOs and international bodies to curb the spread of AIDS. For example, Gallant and Maticka-Tyndale (2004) reviewed 14 peer-reviewed studies written about 11 HIV-prevention programs designed for youth in Sub-Saharan Africa. The authors found that most programs were successful in changing participant attitudes about others living with HIV, but much less successful in changing "perceptions of personal risk or susceptibility" (Gallant & Maticka-Tyndale, 2004, p.1344). They conclude that these school-based techniques are only somewhat effective and call for further research. Pasani (2008) has examined the failures of abstinence-only sex education in Sub-Saharan Africa as funded by the United States. Oster (2007) and Moyo (2009) have called into question the poor marketing of condoms and the lack of private capital investment in response to the continuing destruction caused by the AIDS virus.

AIDS in Africa continues to be on the global agenda, but as Maathai (2009), Nobel Prize winner, author, activist and Kenyan politician, points out: African voices are silenced as white Western academics and specialists continually explain what the continent needs to lift itself out of poverty and halt the devastation caused by the AIDS virus. She (2009) writes that the result of this foreign-imposed charity model is a false perception that there are no African solutions to the problems facing the continent. Maathai (2009) cites numerous examples from private foundations, to foreign government efforts, to the publications from the UN that continue to present Africa as a problem, its people as nameless victims. She argues that this single story not only influences donors and policy makers abroad, but has real consequences for the psychology of Africans who are also exposed to the same images.

Background of the Researcher

Apple (1997) warned that researchers claiming to "acknowledge the missing voices" often "wind up privileging the white, middle class . . . [researcher's] seemingly infinite need for self-display" and therefore called on researchers to "interrogate our own 'hidden' motives" (p. 127). The following paragraphs both attempt to explain my background and connection to HIV and East Africa, but also to critically examine and acknowledge my privilege and properly position myself within this research.

My first introduction to social justice work and human rights was in high school. A few rogue teachers that were brave enough to speak aloud the racial and economic injustices within our community opened my eyes to new ways of seeing the world, my privilege and my responsibilities.

After four years of undergraduate work and a Master's Degree focused on Equity and Social Justice in Education, I had a deep desire to travel and participate in service work aboard. I was, however, very apprehensive, not wanting to be yet another privileged white American girl off to save the developing world. Was it worse to stand by and do nothing, knowing that I had resources and skills that could possibly be of use? Or would I only make things worse, a neocolonialist in the guise of a do-gooder, another cog in the White-Savior Industrial Complex (Cole, 2012)? The only way to find out, I thought, was to try it and keep my skepticism close. I first traveled to East Africa in 2005 after the completion of my master's degree. With the help of an international community service organization, I was placed at a center for street children in the Kilimanjaro region of Tanzania. Bearing witness to the extreme poverty and many other challenges these children faced had a profound effect on me. I was simultaneously overwhelmed by the sheer number of orphans, discouraged by the complexities created with the involvement of foreign money, and inspired by the creative solutions and local advocacy work I witnessed. Upon my return, I still struggled to find my place in it all, to reconcile my privilege and responsibility, to find a space of true resistance and solidarity.

In 2009, I was hired as the Youth Program Manager for Sunshine Projects (pseudonym), a small nonprofit organization in Northern California. This was my first real introduction to the AIDS Community. A passion I had always had for working with youth living in poverty was narrowed to youth affected by HIV, a deadly virus that now disproportionately affects marginalized communities including youth, women, people of color and those living in poverty (Pisani, 2008). My work with Sunshine Projects inspired my academic curiosity and then the opportunity to expand our work to Kenya in 2010 instigated my desire to conduct research there.

Participatory Action Research presents opportunity to leverage my privilege and skills in order to amplify the voices and value the knowledge of young Kenyans living with HIV. As the primary researcher conducting a participatory action research study, my role requires me to also be an adult ally. “Adult allies must be conscious of the ways that race, class, gender, and culture can shape their relationship with youth" (Nygreen, Kwon, & Sanchez, 2006. p. 115). As a white, well-educated, native English speaking, HIV-negative, American, I come with an incredible amount of privilege, which allows choice and freedom my co-researchers and research participants do not have. In my travels and work it has become apparent that additional value is often placed on the ideas and opinions of Americans in the context of health related issues in East Africa. Additionally, my role in this community has been as a supervisor with connections to funding that make programs and salaries possible, further increasing my status and power. I have, however, developed personal relationships with many of the youth Peer Leaders, visiting their homes, meeting their families and creating a foundation of trust. Careful consideration will be made to address issues of power in our research team meetings.

As a feminist, advocate for youth and budding academic I am searching for a space of resistance, a space where I can leverage my privilege and critique the systems that create and maintain it. As I work towards social change and transformation, however, I remain cautious of Apple's (1997) warning and am willing to unveil and interrogate my "hidden motives" in conducting this research. My work and interest in Sub-Saharan Africa is certainly motivated in part by my white, First World guilt. I am also deeply aware that as I acknowledge this, my whiteness continuously "functions as [I] critique it" (Kidder, 1997). I can retreat to luxury when I am exhausted. I can later choose to return to the work of fighting AIDS and neocolonialism when I am feeling inspired and it is convenient. I accept the level of power and expertise my accent and skin color get me despite my age and gender. In acknowledging this power, there is some choice: to continue to control, shame and make invisible, or to challenge and work to build protective spaces where young people can examine, critique, write, reflect, create knowledge and take action.

Purpose of Study

The goal of the study was to engage and empower a small research team of young adults in Kisumu to critically examine the needs of HIV-positive adolescents and to document their voices with the ultimate aim of increasing the effectiveness of their community's ability to support its adolescent patients. The purpose of this study was two fold. First, this study aimed to explore the experiences of adolescents living with HIV. Second, this study sought to be intentional in methods used so the authentic voices of young Kenyans were captured in order to better identify needs related to growing up with HIV.

Research Question

Using a participatory action research approach, this study aimed to answer the question: What is the experience of HIV-positive youth living in Kisumu, Kenya? The broadness of this research question is necessitated by the Participatory Action Research approach. Creswell (2009) stated that PAR "assumes that the inquirer will proceed collaboratively so as to not further marginalize the participants as a result of the inquiry . . . the participants may help design questions, collect data, [and] analyze information" (p.9). Therefore, I constructed this broad research question with the intention of collaboratively developing specific research questions with the research team, which will ultimately guided our inquiry.

Theoretical Framework: Critical Theory

This research employed a critical theory lens to guide our inquiry and analysis of the problems facing young people living with HIV and ultimately in the development of transformative action. Creswell (2009) states “critical theory perspectives are concerned with empowering human beings to transcend the constraints placed on them” (p. 61). According to Fay (1987), the basic scheme of critical theory involves four elements: "a theory of false consciousness", "a theory of crisis," "a theory of education," and "a theory of transformative action" (pp. 31-32). These first three elements were be useful in guiding our initial sessions as we began to explore how the experience of young people living with HIV are affected by colonialism, gender, poverty and power. Utilizing Participatory Action Research methodology and a critical theory framework enabled the research team to "… simultaneously *explain* the social world, *criticize* it, and *empower* its audience [in this case young people living with HIV] to overthrow it" (Fay. 1987, p. 23). To this end, Freire’s (1970) critical pedagogy and problem-posing technique informed the design of early PAR sessions and ultimately guided us in designing our transformative action.

Critical Theory informed the methodological choice of PAR because it called on us to not only problematize the hegemonic structures within which we currently function and engage in change efforts, but because it also allowed me to approach my work from an asset-based perspective placing value on the community of researchers and their ability to produce new knowledge that is most relevant to their needs. Mathie and Cunningham (2003) write that an asset-based perspective “draws attention to social assets: the particular talents of individuals, as well as the social capital inherent in the relationships that fuel local associations and informal networks” (p. 474). The contextualized expertise as a young person living with HIV gives the co-researchers a valuable insider's perspective to the challenges facing ALWH (Fine, 2007). Lastly, as Creswell (2009) writes, critical theory also provided guidance on how I could situate myself within the research as an adult ally, outsider and person with significant privilege.

Koirala-Azad and Fuentes (2009-2010) write that "beyond being a strategic tool for investigation, PAR provides an epistemological challenge to the social sciences, drawing urgent attention to the topic of where knowledge resides" (p. 2). PAR is a political standpoint as much as it is a methodology. It recognizes the historical legacy of academic research and knowledge production as a tool for legitimizing colonialism, and today: neocolonialism in the name of development and globalization. As Smith (2012) explains:

> Research within late-modern and late-colonial conditions continues relentlessly and brings with it a new wave of exploration, discovery, exploitation and appropriation. Researchers enter communities armed with goodwill in their front pockets and patents in their back pockets, they bring medicine into villages and extract blood for genetic analysis…Research of this nature *on* indigenous peoples is justified by the ends rather than the means, particularly if the indigenous peoples concerned can still be positioned as ignorant and undeveloped (savages) (p. 25-26).

PAR is a reaction to this exploitation and an attempt to reposition indigenous peoples as experts with valid and valuable systems and ways of knowing. Rahman (1991) writes that:

> An immediate objective of PAR is to return to the people the legitimacy of the knowledge they are capable of producing through their own verification systems, as fully scientific, and the right to use this knowledge – including any other knowledge, but not dictated by it- as a guide in their own action (Rahman, 1991, p. 15).

In addition to rejecting the constructions of researcher/subject and pulling indigenous knowledge from the margin to center, PAR demands action. The re-framing of research as tool for empowerment and social change was a key understanding in the intention of this research.

Limitations

The value of this study was in its depth and the contextualized expertise provided by the co-researchers. Its findings are be deeply rooted in the local context, culture, and language and will be loud with the voices of young people living with HIV, experts in the experiences of their own lives.

Due to the small sample size, limited timeframe and lack of resources, the findings of this study cannot be generalized beyond the clinics in Kisumu. However, because our research objective was to amplify the voices and bring to light the complex experiences of ALWH, traditional quantitative methods were not sufficient.

Even though PAR projects are often small in scale, deeply rooted within a particular context and not generalizable in the traditional sense, "across projects we witness stunning, shared lesson about oppression, resistance, youth resilience, collective possibility, disappointment, despair, and desire, that bleed across zip codes" (Ginwright as cited in Fine, 2007, p. 227). Fine (2007) argues that participatory action research challenges traditional definitions of generalizability and presents two alternative forms: theoretical generalizability and provocative generalizability. She defines theoretical generalizability as the extent to which we can "glean lessons about social oppression and forms of resistance" (Fine, 2007, p. 227). This study provides insights not only into the lived experiences of ALWH in Kisumu that heavy in transferability and offer starting points for further research into the experiences of marginalized youth beyond the city limits of Kisumu and beyond an HIV diagnosis. Provocative generalizability is the extent to which the PAR can instill a sense of urgency and a call to action (Fine, 2007). Our hope is that our research challenges others like myself in positions of privilege as US citizens with academic capital to investigate, to care and to take action in our country's role in contributing to the fight against AIDS. Additionally, we hope that in sharing our research others in Kisumu will be moved to address issues raised by adolescents and alongside adolescents.

Delimitations

This research was restricted to the clinic sites in the town of Kisumu due to my previous connections with the clinic sites. While this allowed access to the population and institutions, it also provided challenges regarding researcher bias and sample size. Second, the sample was not be random and depended on participants self-selecting to partake in order to protect their privacy and honor their desire to speak or not to speak about HIV/AIDS. Lastly, because this study was being conducted in order to fulfill the requirements of a dissertation, the time and funding available to support the project was very limited.

Significance of the Study

Although now considered a chronic disease, HIV is still a life-threatening virus without proper care and effective treatment. This study sought to document the voices and experiences of those most affected by HIV through their participation. This study called upon their expertise as young people living with HIV to help in moving towards more appropriate and effective interventions.

Research into the lived experiences of young people living with HIV has implications for education systems as the “role of the education sector and the future of

YPLHIV [young people living with HIV] are intrinsically linked and schools have been identified as one key environment that impacts young people's health and wellbeing" (UNESCO and The Global Network of People Living with HIV, 2012). A deeper understanding of stigma, in-school discrimination, and forced-disclosure can lead to more relevant and effective interventions, producing increased health and education outcomes. High rates of HIV infection in Kenya and other Sub-Saharan countries not only affect the individuals living with the disease, but also their families, their entire communities and the local economies. Curbing the spread of HIV by providing comprehensive and effective education and care to those living with the virus can have tremendous, long-term effects for entire nations. Chandler (2011) argues that "faulty stereotypes of 'youth' – such as the perceptions that young people are necessarily victims or risk-takers – results in many HIV programs based on generalizations about young people, rather than their actual needs and realities. These stereotypes and generalizations dominate million dollar prevention programmes that have little effect on HIV incidence rate among young people." (p. S344). A deep and accurate understanding of youth affected by HIV could lead to more effective prevention and treatment programs.

Definition of Terms

Peer Leader/Co-researcher: The Co-researchers for this study will be recruited from the clinic sites that already have established groups of Peer Leaders. Peer Leaders are 18-24 years olds who have completed secondary school and are providing psychosocial support to youth living with HIV at the clinic sites.

Co-investigators: This term refers to the adult investigators, Lucy and the author.

Young People Living with HIV (YPLWH): Young People Living with HIV, 0-25 years old who are HIV Positive.

Adolescent Living With HIV (ALWH): For the purposes of this study, Adolescent Living With HIV refers to 13-18 year olds who have tested positive for HIV and includes those perinatally infected as well as those who acquired the virus later in life.

Young Adult: For the purposes of this study, the term young adults will be used to describe people between the ages of 18-25 and most often refers to the Peer Leaders/Co-researchers.

Kiswahili: This is a major Bantu language in East Africa and is a national language of Kenya.

Luo: This term refers to an ethnic group of people living around Lake Victoria.

Dholuo: is the mother tongue of the Luo people.

English: This is also a national language of Kenya and the language of the former colonizer.

HIV: Human Immunodeficiency Virus.

AIDS: Acquired Immune Deficiency Syndrome.

ARV or ART: Antiretroviral Drug Treatment for the suppression of HIV.

Medication Adherence: To be fully adherent to ART, the patient must be 95% compliant with the treatment program that usually includes taking daily pills and attending scheduled clinic appointments for lab tests.

Lost to follow up (LTFU): "LTFU is defined as absence from clinic for 6 months if on combination antiretroviral therapy and 12 months if not" or "(1) HIV positive and last known to be receiving ART and absent from the clinic for at least 6 months; (2) HIV-positive child not on ART at last visit and absent from the clinic for at least 12 months; (3) HIV-exposed child absent from the clinic for at least 6 months; (4) HIV status missing for a child was has been absent from the clinic for at least 6 months" (Braitstein et al., 2011).

CD4: CD4 cells are a type of white blood cell or lymphocyte that are most often attacked by HIV. The number of CD4 cells is a measure of immune health and is determined through a CD4 test performed on a small amount of blood that results in a CD4 count. The CD4 count is not an exact number but is used to decide when to start treatment and is then taken every 3-6 month at the start of ART to see if the treatment is working and the immune system is growing stronger. Once the CD4 levels have increased, the tests are usually only recommend every 6-12 months. Healthy levels are between 500-1600. A level of 200 indicates severe immune damage (The Body, 2012).

Viral load: is a measurement of how much virus there is in the blood. There are many ways to measure viral load. The results are reported in virus copies per one milliliter of blood. Virological suppression refers to patients achieving a viral load of < 400 copies/mL (Nglazi, 2012). Virological failure refers to patients who had initially achieved virological suppression (< 400 copies/mL) with two subsequent viral load measurements > 1000 copies/mL (Nglazi, 2012). Achieving an "undetectable" level of virus is the goal, although this only refers to a very low number of virus in the blood, not having zero virus or being cured (The Body, 2013).

CHAPTER II
REVIEW OF LITERATURE

Introduction

On June 5, 1981, the Center for Disease Control first published an article describing what would come to be known as the Acquired Immune Deficiency Syndrome (AIDS). The article reported five cases of a rare pneumonia in gay men living in Los Angeles (Pepin, 2011). Similar cases were soon reported in San Francisco, New York and then in Haitian immigrants in Miami (Timberg and Halperin, 2012). This was the beginning of a global pandemic that would eventually claim the lives of more than 30 million people and leave more than 16 million orphans worldwide (Pepin, 2011).

The purpose of this review of literature is multifold: First to provide historical context for the research problem and examine the necessity for more inclusive research methods. This section will give a description of how colonialism sparked the initial spread of HIV and how neoliberalism and neocolonialism, through academic research and development programs, have not only failed to curb the spread of AIDS, but have helped to create the largest public health disaster in human history. Within this section a comprehensive picture of the HIV epidemic in Sub-Saharan Africa is provided and followed by a background on the response to HIV in Kenya. An examination of studies researching the treatment adherence outcomes and medical related issues for adolescents living with HIV (ALWH) in Sub-Saharan Africa (SSA) will then be provided. The third section will review the current literature on the psychosocial and educational challenges faced by ALWH in SSA. The final section will examine the few studies that have explored youth agency and or included youth perspectives in the discussion of HIV and AIDS.

Historical Background: The Role of the West in the AIDS Pandemic

Soon after the virus that causes AIDS was isolated, scientists formed a hypotheses that the virus had, like many other viruses, jumped from an animal species to humans (Pepin, 2011). The virus was remarkably similar to the Simian Immunodeficiency Virus (SIV) and many scientists believed HIV most likely originated from chimpanzees. In the decades following the emergence of HIV, great advances were made in the field of genetics eventually allowing scientists to begin mapping out the genetic family tree of HIV. Based on two preserved biopsy samples containing HIV from 1959 and 1960 collected near Kinshasa, scientists were able to construct a genetic family tree placing the initial jump from SIV sometime between 1884 and 1924 (Timberg and Halperin, 2012). This genetic timeline was then placed next to the historical record of Kinshasa. This served to significantly narrow the date, now believed to be 1908, and also demonstrated the role of colonialism in the birth of HIV. Worobey (2008) writes:

> This pattern, and the short duration between the first presence of urban agglomerations in this area and the timing of the most recent common ancestor of HIV-1 group M, suggests that the rise of cities may have facilitated the initial establishment and the early spread of HIV-1. Hence, the founding and growth of colonial administration and trading centers such as Kinshasa may have enabled the region to become the epicenter of the HIV/AIDS pandemic (as cited in Timberg and Halperin, 2012, p. 36).

Colonization lead to the creation of mines, rubber and ivory expeditions that required large amount of manual labor and new transportation routes that created fast and effective pathways for HIV to spread.

Timberg and Halperin (2012) describe colonial Leopoldville, today Kinshasa, as a tinderbox, perfectly situated to ignite the AIDS pandemic. Busy transit routes (ships along the river, porters, and later railroads) were built to transport raw materials. These new modes of transportation allowed those infected with the new virus to easily and quickly travel, possibly spreading HIV as they went (Timberg and Halperin, 2012). In order to meet labor needs, men were forcibly taken from communities while others, responding to the changing economy, left the village seeking opportunity in mines and cities. The result was an exponential growth of cities and mining towns with a commercial sex industry growing along side it, further increasing the opportunity for HIV spread (Timberg and Halperin, 2012). Historical records also show Kinshasa and surrounding areas as the site of an explosion of syphilis (brought with the Europeans), one of the sexually transmitted infections that increases the risk of HIV transmission (Timberg and Halperin, 2012). European influence also encouraged the transition of public polygamy to a system marked by multiple “informal wives,” and sexual relationships that were kept secret. This allowed Africans to satisfy the demands of their Euro-Christian colonizers’ notions of morality while also maintaining their cultural traditions, which placed high value on children and fertility. This behavior change also facilitated the spread of HIV by creating hidden and open sexual networks that continue to characterize much of the HIV epidemic pattern in SSA today.

The end of colonialism also brought about two important factors that most likely helped spread HIV (Timberg and Halperin, 2012). One is the mass push for vaccinations and the reuse of needles. The other is the removal of restrictions on Africans’ movement. Under colonial rule, Africans were not allowed to work, live or travel without permission. At the end of colonialism, restrictions were lifted and the modes of transportation were in place to facilitate mass migration and travel from Kinshasa outward to all ends of the continent. Over the next two decades, AIDS was quietly spreading throughout SSA and making its way, through the Carribean to the U.S., Asia and beyond (Timberg and Halperin, 2012).

The post-colonial policies of the West would also contribute to the spread of HIV. Rowen (2009) contends that the failure to meet the needs of those living with HIV and those at risk for HIV infection in Sub-Saharan Africa is primarily because of the neoliberal policies of the International Monetary Fund (IMF). He describes in detail the concerted effort of conservatives to promote neoliberal policy across academic institutions and by investing large sums of money to developing conservative, neoliberal think tanks that would help create an environment where economic policies touting the supremacy of the free market would become accepted as the norm. These neoliberal economic policies would also infiltrate international policy and change international development efforts beginning in the 1980's. The new policies would conform with the ideals of the free market system and all that accompanies it- small government, low inflation, low spending, and as Rowen (2009) demonstrates: the destruction of a fledgling healthcare systems in the face of the worst threats to public health in recent human memory.

The World Bank warned against treating healthcare like any other good to be bought and sold on the free market in 1975. "Healthcare consumers generally have insufficient understanding and information to make sensible choices" and therefore cannot properly perform as rational consumers in a free market (as cited in Rowen, 2009. p. 144). The World Bank further argued that hospitals are more like a natural monopoly and should function more like public utilities because they require such large amounts of capital, which translates into a lack of competition needed to properly function in the market.

In 1978 at the World Health Organization conference in Alma-Ata, Kazakhstan, access to health care was declared a human right (Rowen, 2009). The complex relationship between health, education, the economy and development was recognized and a mandate for world's governments to provide health services for their citizens was declared. The general direction of development during the late 1970s was one toward universal primary health care which was thought to be best achieved through large loans aimed at building up the healthcare systems by mobilizing political support, increasing public expenditures and public sector administrative capacities (Rowen, 2009). This enthusiasm was short lived. Rowen (2009) writes that just a few years after the declaration at Alma Ata, the reality of the lack of funding available to put toward achieving universal primary healthcare helped welcome in a new era.

In 1981 the World Bank published a report known as the 'Berg Report' (or *Accelerated Development in Sub-Saharan Africa*). Rowen (2009) writes "The Berg Report is considered an important turning point in World Bank thinking away from the Keynesian economics, which had dominated from the 1930s-1970s, and towards the market-oriented approaches of neoliberalism" (p.146). The report called for increases in privatization across the industry, for the implementation of user fees, and overall decrease in national budgets including funds allocated for healthcare worker salaries. Arguing for "affordability and effectiveness in healthcare decision-making," the report claimed the only way to achieve primary universal health care was to get the government out and allow the free market to improve the system for the consumer (Rowen, 2009, p. 146). The money to pay for healthcare would have to come from the consumer in the form of user fees, the implementation of which would prove detrimental to the health of the African peoples for the next 30 years. Stein (2008) stated that it was "this kind of flawed reasoning that led to the imposition of user fees in Sexually Transmitted Disease Clinics in places like Kenya in the early 1990s, which discouraged attendance rates at the worst possible time – during the early stages of the HIV/AIDS epidemic in Africa" (as cited in Rowen, 2009, p. 148). The level of poverty in most of Sub-Saharan Africa meant that people were now forced to choose between feeding their family and seeking medical care. Preventative services were no longer an option for the vast majority.

The next 30 years were not only marked by the implementation of user fees, but because healthcare was now privatized, it was an ever shrinking part of the national budgets so there was no mandate to build hospitals or develop any of the other infrastructure (such as roads) needed to deliver healthcare. The International Monetary Fund was overseeing all distribution of funds and developing countries were kept on a tight, neoliberal economic plan of low inflation and low spending to promote macroeconomic stability. In order to maintain macroeconomic stability, the IMF required that countries in Sub-Saharan Africa consolidate their government agencies and reduce their number of employees- including healthcare workers (even though unemployment was and remains staggeringly high) (Rowen, 2009). The increases in public expenditure and public sector administrative capacities called for at Alma Ata conference in 1978 were never given a chance. The result, as we know, is millions dying each year from preventable and treatable diseases like malaria, tuberculosis, and AIDS.

In 2000, after much pressure from activists and the public, these policies began to be questioned and placed under mounting scrutiny. Wealthy governments decided to increase their financial contributions to the developing world's healthcare systems. Billions have been poured into these countries. Unfortunately, the funds have been funneled through the IMF and so little has changed as the IMF still blocks the spending of this new money in an effort to keep inflation and public spending low in order to maintain macroeconomic stability. The situation is now one where there are millions of sick people, many unemployed healthcare workers (except the ones that have left to seek work in other counties), and money to build clinics that can't seem to get built. Rowen (2009) reports that approximately 80% of funding is blocked by the IMF in the name of macroeconomic stability (p.187).

Unfortunately, it is a cycle that seems hard to get out of. Even though most donor countries agree that the neoliberal policies are not working, at least as far as public health is concerned, they still support the IMF and rely on it for recommendations concerning which countries are suitable to receive funding. Being 'blacklisted' by the IMF would mean an end to all donor funding, an even worse situation than being under the IMF's oppressive neoliberal policies (Rowen, 2009).

One of the solutions to this problem has been an increase in the number of NGOs that do the work and provide the services that would otherwise be the government's responsibility. The result has been thousands of tiny projects, some successful, some not. Most of which do not communicate with each other and can only reach small sections of the population. Furthermore there is very little oversight of these NGOs and so quality of care cannot be guaranteed (Rowen, 2009).

Rowen (2009) argues that even though the current health systems are in ruins, there is a movement to return to the principles and strategies laid out at the Alma Ata conference. Unfortunately, as Green (2003) and Pisani (2009) write, the funds that were provided to support the health care system and fund the fight against AIDS were greatly misplaced.

HIV Epidemic Pattern in Sub-Saharan Africa

The epidemic pattern of HIV in Sub-Saharan African countries varies by region (East, Southern, etc.), by country, and even greatly by regions within a country (Green, 2003). However, the countries south of the Sahara share some general characteristics and patterns that separate the African epidemic from the epidemics in Eastern Europe and United States which are largely characterized by high infection rates among marginalized high-risk groups such as men who have sex with men (MSM) and injection drug users (IDU) (Green, 2003; Pasani, 2009). On the other hand, the epidemic pattern in South Asia is marked by high rates of HIV infection among commercial sex workers (CSW) (Green, 2003; Pasani, 2009). This is crucial because HIV is largely considered a global pandemic and solutions that were seen as successful in the U.S. were exported to other parts of the globe and then failed because the epidemic pattern and modes of transmission were different (Green, 2003; Pasani, 2009).

As the next few pages will demonstrate, HIV is complicated. Pisani (2008) writes sarcastically in her book detailing the many failures of international agencies to curb HIV infection: “The World Bank believes poverty and gender inequality spread AIDS. I believe sex and drug injection spread AIDS” (p. 127). The issue of stopping the spread of AIDS is not merely a matter of condom distribution. Neither is it completely tied to the seemingly impossible task of totally eradicating poverty. HIV hits hardest where these issues of power, culture, history, gender inequality, poverty, sex, religion and drug use intersect. Therefore, it is important to understand how each experience, situation, or behavior can create a path for the virus if we are to create the comprehensive and targeted responses these epidemics necessitate.

Heterosexual Transmission

In the United States, AIDS was first known as GRID, or the Gay-Related Immune Deficiency. The disease seemed to be concentrated in specific groups engaged in what became known as “high-risk” behaviors: anal intercourse and injection drug use. Targeted public health responses were designed to minimize exposure to HIV through risk reduction policies that promoted condom and lubricant use to gay men and provided sterilized needles to injection drug users (Green, 2003). They were largely successful and HIV-infection rates in the U.S. and other Western countries began to drop (Green, 2003). These successful responses were then exported to epidemics in other parts of the globe, including SSA. Local solutions in SSA were quickly replaced by risk-reduction programs designed for special populations in the U.S. This effort, backed by Western money and expertise, was successful in undermining local efforts that had achieved lower infection rates such as the “zero grazing” campaign in Uganda (Green, 2003). Not recognizing the SSA epidemic as a generalized epidemic, primarily affecting the heterosexual majority, the programs failed (Green, 2003; Pasani, 2009).

Multiple and Concurrent Heterosexual Partners.

HIV in Sub-Saharan Africa is spread mainly through heterosexual intercourse. The difference in the patterns of heterosexual intercourse in SSA is that “men and women are more likely to have several sex partners on the go at once …" (Pasani, 2008, p. 142). In fact, "women are more likely to report more than one regular sex partner . . . at any given time in the African countries where HIV is higher than anywhere else in the world." (Pasani, 2009. p. 151). While many sexually active heterosexuals all over the world have had multiple partners, cultural norms dictate that the partners are not usually concurrent. This has enormous implications for infection rates because of how the virus multiplies within the body and then spreads. When someone is infected with HIV, there is a brief window during which their viral load is very high, greatly increasing the chances of transmission (Pisani, 2009). If sexual partners are concurrent (as in many relationships in SSA) as opposed to consecutive (as in many relationships in the West), the chances of infection are much greater.

A preference for dry sex in SSA also increases the chances of infection for heterosexual partners. Many women will rub chemicals, clay or leaves on their vagina to de-lubricate before sexual intercourse. This increases the chances of tearing, opening a pathway for the virus.

Condoms are a controversial solution to AIDS in SSA (Green, 2003). The Catholic Church and religious conservatives in the U.S., argue that access to condoms promotes high-risk behavior. Green (2003), while supporting condom promotion as a successful intervention in the U.S. writes that condom promotion has been unsuccessful in SSA. In his research, Green (2003) demonstrates that campaigns aimed at minimizing risk behavior by promoting fidelitiy and fewer sexual partners has been more successful in reducing infection rates. Regardless of the support for condoms from outsiders, condoms are often poor quality, poorly marketed, and not readily available in SSA (Green, 2003; Pisani, 2009; Oster, 2007).

Male circumcision in Sub-Saharan Africa is rare, as is treatment for sexually transmitted infections - both of these make HIV transmission much easier during heterosexual intercourse (Pasani, 2009). Herpes, syphilis, or gonorrhea can greatly increase the likelihood of HIV transmission during heterosexual intercourse because they create open sores and small tears that create an ideal pathway for the virus. Providing treatment for non-HIV sexually transmitted diseases is an important weapon in the fight against AIDS and one of the most cost-effective ways to slow the spread of HIV (Rowen, 2009; Pasani, 2009; Oster, 2004). Foreskin is porous and also an easy pathway for HIV transmission. Studies show that circumcision can lead to a 60% reduction in infection for heterosexually active men (WHO, 2014).

One of the major consequences of an AIDS epidemic pattern characterized by heterosexual intercourse is mother to child transmission. HIV spreads through sex and needles, but also through pregnancy, birthing and breastfeeding (Pisani, 2009). Although advances in medication have reduced the likelihood of mother to child transmission from around 33% to less than 1% in Western contexts (Pisani, 2009), these treatments have yet to reach all of SSA (Pisani, 2009, Timberg and Halperin, 2012).

Intergenerational Sexual Relationships

The World Health Organization (WHO) also points out that young girls are particularly at risk for HIV due to "early marriage, biology, and trafficking" (WHO, 2010. p. 11). A recent WHO report notes that girls who are married young often marry older men who may start the marriage already infected with HIV as they are more likely to have had previous sexual partners. Furthermore, young girls are less likely to be able to negotiate sex and condom use because of power differences relating to gender and age in many communities. Young women across SSA regularly date older, wealthier men before settling down with a husband closer to their age. “The ‘sugar daddy’ phenomenon - understood . . . in light of historical, cultural, and social constructions of masculinity and femininity …intersects with economic decline and HIV/AIDS” (Bajaj, 2009). Bajaj (2009) also notes that intergenerational sex is not limited to young women and older men, but that Sugar Mamas also open intergenerational pathways for the virus to spread to young men.

The biology of young girls is also a factor causing an increase in HIV risk. The cervix is the part of the female anatomy where HIV is most likely to be transmitted during vaginal intercourse. The cervix of young girls is more fragile than in adult women causing a greater chance of injury that would make transmission more likely, but also the tissue itself is more susceptible to infection. Lastly, its been shown that being infected with other sexually transmitted diseases, increases the likelihood of HIV transmission during heterosexual sex. A young female’s anatomy is more likely to be infected with HIV and also more likely to be infected with other STIs, which in turn increases the risk of HIV infection even more (Global Campaign for Microibcides, 2006).

Background of HIV in Kenya

The first cases of HIV in Kenya were reported in 1984 in Nairobi when 26 sex workers tested positive (Kamau, 2012). By 1985, 59% of sex workers were testing positive (Kamau, 2012). In 1989, it became clear that the virus has spread to the general population and in 1991, 13% of pregnant women had HIV (Kamau, 2012). In 2000, the virus reached its peak with HIV prevalence reaching 13% in the general population (Kamau, 2012). According to the United Nations report on AIDS (2008), out of the 37 million people in Kenya, 2 million were living with HIV. In 2007, there was an estimated 150,000 children infected with HIV and over 1 million children orphaned due to AIDS. Across the country, infection rates for young women continue to be much higher, as well as in the Nyanza Province where this study was located.

Kenya's response was slow (Green, 2003), which Kamau (2009) argues may have been due to the government's fear that tourism would have been hurt should the government acknowledge the severity of the epidemic. Finally, a national policy was created in 1990, but it took then President Moi another 9 years to declare it a national emergency (Kamau, 2009).

Kenya declared a "Total War On AIDS" in 2002 (National AIDS Control Council, 2008). Its priorities were and continue to be "preventing new infections, improving the quality of life for infected and affected people (care, treatment and human rights) and mitigating the socio-economic impact of HIV and AIDS with monitoring and evaluation and other support services" (National AIDS Control Council, 2008, p. 15). In 2006 President Kibaki announced universal access to free ART for all, although a year later ART was received by only 35% of the people who required it, and this was due to "poor awareness on the part of parents and caregivers [rather] than non-availability of drugs" (National AIDS Control Council, 2008, p. 26). In 2011, exciting headway was made in meeting universal ART access when a Kenyan pharmaceutical company was approved to manufacture their own ART drugs (PlusNews, 2011). This will hopefully result in significant savings for the government and allow more people to access treatment.

HIV/AIDS Prevention and Control Act

People living with HIV/AIDS in Kenya "are frequently subject to rights abuses such as discrimination and the violation of women's and orphans' inheritance rights. They also encounter difficulties accessing health care, shelter, education and food" (National AIDS Control Council, 2008, p. 28). The HIV and AIDS Prevention and Control Act was meant to act as an anti-discrimination law to help mitigate these rights violations, but has been controversial.

In an attempt to address HIV Stigma and its many manifestations, the ninth Kenyan Parliament passed the HIV and AIDS Prevention and Control Act (HAPCA) in 2006 as an anti-discrimination law. The Act did not enter into enforcement until 2009 and part of the legislation had yet to be fully implemented in 2011.

Section 13 of the HAPCA prohibits compulsory testing, including for the purposes of employment, health insurance, admittance to school, etc. This section of the HAPCA supports the universal human right to privacy and also indirectly undermines discrimination in employment, school, and regarding access to healthcare. This section remains controversial in practice when it comes to pregnant women. In my travels working with HIV clinics and PLWH, it is generally understood that pregnant women in Kenya *must* be tested when they go in to receive prenatal care. The law, however, states that pregnant women have the option to "opt out" of testing should they wish not to be tested and know their status. As Ujiji, et al. (2011) found in their study, women only "opt out" when a testing kit is not available, leading the researchers to conclude that HIV testing of pregnant women is compulsory in practice, if not in written law.

Section 24 of the HAPCA criminalizes HIV infection and is one of the most debated aspects of the law. It came into enforcement on December 1 2010. The AIDS Law Project (2011) writes that the section:

> Provides that a person who is aware of being infected with HIV or is carrying and is aware of carrying the HIV virus shall- (a) take all reasonable measures and precautions to prevent the transmission of HIV to others; and (b) inform, in advance, any sexual contact or person with whom needles are shared of that fact. Further, a person who is and is aware of being infected with HIV or who is carrying and is aware of carrying HIV shall not, knowingly and recklessly, place another person at risk of becoming infected with HIV unless that other person knew that fact and voluntarily accepted the risk of being infected.

Non-disclosure and knowingly infecting someone with HIV carries a prison term of 15 years and can be extended to life in prison. This severe punishment certainly adds to the controversy around this section of the law.

Public health officials are quick to point out that in other countries, specifically with regard to intravenous drug use, that the criminalization of such behaviors are essentially public health issues- not criminal ones. Furthermore, the criminalization of such activity has never deterred people from engaging in risky behavior. In fact, as the case has been with IV drug users in Kenya and elsewhere, once it becomes illegal to even carry a needle and syringe, drug users stopped carrying clean needles or personal needles and instead developed underground systems of secret locations where needles would be stashed in known spots throughout a city and shared among users. Criminalization of HIV, in this case, actually leads to more shared needles and more infection. Critics fear that, likewise, sexually active people that may suspect they have been exposed to HIV will not seek testing and counseling because of fear of punishment (AIDS Law Project, 2011). The AIDS Law Project (2011) states bluntly that "There is no good evidence to show that criminalization of HIV non-disclosure makes HIV positive people more likely to disclose their status, reduces sexual behaviors that place people at risk of HIV, or reduces new HIV infections." Research has shown that one of the best ways to prevent new infections is to treat those living with HIV with antiretroviral therapy, lowering their viral load and therefore the chances of transmission (AIDS Law Project, 2011). The AIDS Law Project also writes that the criminalization of non-disclosure actually works to create a false sense of security for those not living with HIV, creating less need for HIV-negative people to initiate conversations with sexual partners about HIV, possibly leading to more new infections (AIDS Law Project, 2011).

Section 25 of HAPCA calls for the establishment of a Tribunal. "Nearly 83 percent of Kenyans living with HIV face a range of abuses from loss of life and denial of health care to human rights violations and discrimination" (Mwivano, 2010, p. 2). In response to years of suffering the HAPCA has attempted to build in legal recourse for those who have been victims. The Kenyan tribunal is the first of its kind to focus explicitly on HIV/AIDS discrimination (Mwivano, 2010). Plus News (2008) reports that

> One of the main stated goals of the HAPCA is to end discrimination.
> The new tribunal, under the office of the Attorney General, has the status of a subordinate court, with the right to summon witnesses and take evidence. It will handle issues relating to the transmission of HIV, confidentiality, testing, access to healthcare services, discriminatory acts and policies, and HIV-related research. (no page).

The tribunal will hear cases of discrimination and human rights violations from the "'most at risk populations' including gays, lesbians and prostitutes" (Akasa & Aisi, 2011). The law states that any person who has been denied employment, housing or some how suffered at the hands of another, can now formally press charges and have their story heard before a panel of experts. These experts all have professional experience and knowledge of HIV and related issues, and some of the member judges are openly HIV positive as well. The tribunal does not have jurisdiction over criminal charges associated with the HAPCA but does haves the power to determine whether human rights abuses have occurred in violation of the HAPCA (Ogemba, 2011).

Treatment Adherence Issues for Adolescents living with HIV in SSA

Treatment adherence is an issue of great importance for low-income settings because second-line medications are generally not available. If a patient builds resistance to the first line of drugs by missing a pill, alternatives are not available (Campbell, Skovdal, Mupambireyi, Madanhire, Nyamukapa, Gregson, 2011). Adherence is difficult to measure and usually is done so in multiple ways such as MEME (an electronic monitor that records when a pill bottle has been opened), pill counts, viral load, CD4 count, recall and self-reports, and/or prescription refill records.

This section reports the most recent studies that have examined the issue of ART adherence for young people in SSA. Although much more research exists examining this problem in the U.S., the exportation of responses to the epidemic from the U.S. have failed to curb the spread of HIV in SSA (Green, 2003). Therefore, only studies from SSA are included in this review of literature. Furthermore, the issues facing adults and children living with HIV are different from the issues faced by adolescents. Studies on medication adherence issues of those populations have been omitted unless included in the same study as the adolescents.

Bikaako-Kajura, Luyirika, Purcell, Downing, et al. (2006) explored the issue of pediatric adherence through interviews with 42 HIV-positive youth and 42 primary caregivers receiving care at an HIV clinic in Uganda. They found that disclosure and strong relationships with caregivers were most closely related to good adherence. This is inline with the later findings (below) of Campbell et al. (2011) that show when youth have a full understanding of their diagnosis they take an active role in maintaining their health and report better adherence (Bikaako-Kajura, et al., 2006). The researchers noted that barriers to adherence included stigma and poverty but also unwillingness and forgetfulness of caregivers and children when it comes to taking medication.

Nabukeera-Barungi, Kalyesubula, Kekitiinwa, Byakika-Tusiime and Musoke (2007) conducted their study at the Mulago Hospital in Kampala with the goals of determining adherence levels among children and adolescent's as well as being able to identify some factors contributing to non-adherence. They followed 170 children between the ages of 2 and 18 years and determined adherence through pill counts during clinic visits and unannounced home visits as well as a 3-day self-report. Their findings showed variation in each measure with the unannounced pills counts have the greatest disparity from the other methods of measurement. Although they concluded that most of the youth had good adherence, there was an association between good adherence and the youth knowing their HIV status and having been hospitalized more than once. There was no significant correlation between other examined factors such as age, gender, school status, or orphan status. The study excluded youth who forgot to bring their pill box to the clinic since a pill count could not be performed, but this may have positively skewed the results as families more likely to forget the pill boxes may also be more likely to forget to take their pills. This study also fails to account for fatigue with chronic illnesses as youth who had been taking ART for just one month were included.

Vreeman, Wiehe, Ayaya, Musick, and Nyandiko (2008) set out to study the adherence levels of young people living with HIV in resource limited settings, focusing on Western Kenya. Their study included 1516 HIV-positive youth between the ages of 0-14. Data was collected through self-report forms and recorded as either perfect or imperfect adherence. Information on the patients' adherence to their clinic appointments was gathered from their medical records and also categorized as either perfect or imperfect. Additional information about the child's status as orphans was also collected as well as information on households' income, age, gender and whether care was received at an urban clinic or in an outpatient clinic located outside the city center. A multivariable logistic regression was used to assess association between adherence and status as an orphan, then was adjusted for the other demographic information collected. Twenty-nine percent of youth reported imperfect ART adherence, and 57% of children reported imperfect clinic adherence. ART adherence was higher for children with both parents living, although orphan status did not have an association with clinic adherence. The primary means for data collection in this study was self-reporting, therefore this study would have been stronger if the reports had been also compared to lab work and pharmacy records.

Nachega, Hislop, Nguyen, Dowdy, Chaisson, Regensberg, Cotton, and Maartens (2009) compared treatment outcomes and adherence levels of adolescents compared with adults in South Africa through an observational cohort study. One hundred and fifty-four adolescents participated in the study. The findings showed adolescents were significantly less likely to achieve adherence or viralogical suppression as compared to the adults. They also found that adolescents were more likely to experience a rapid viral rebound.

The researchers included in their discussion the limitations of their study, one of which was the small number of adolescents compared with other age groups in the study. They, like the other researchers in the field urge for more research to be done on this problem. Their findings are in contrast to the later findings of Nglazi et al. (2012) described below. This may be due partly to the implementation of more youth centered programing at the Cape Town site since the Nachega et al. (2009) study, but more research is required.

Bakanda, Birungi, Mwesigwa, Nachega, Chan, Palmer, Ford, and Mills (2011) conducted the largest study on adolescents receiving ART in Uganda with over 575 adolescent patients included in their research spanning more than 5 years. Data was collected as part of routine clinical visits that included adherence monitoring. The study included more than 23,000 patients with adolescents making up one of the three sub-groups based on age. Researchers adjusted for “gender, baseline CD4 cell count, and year of therapy initiation” and found that there was no difference between children or adult groups in terms of lost to follow up or mortality. This is in opposition to findings of Nachega et al. (2009). Bakanda et al. (2011) speculate that this may be due to differences in ART program and setting, ranging from level of social support, level of follow up for patients that miss an appointment, or pharmacy refill dates. Bakanda et al (2011) did not explore the context beyond suggesting that further research is needed. Green (2003) writes extensively on the efforts in Uganda to fight HIV, which may also be a significant factor. Uganda was one of the first countries in Sub-Saharan Africa to launch a national campaign and also one of the first to offer ART. A long history of open and public discourse on AIDS in Uganda has led to decreased levels of stigma. The HIV support programs are also more well-established, making it possible that the adolescents receiving care in Uganda have a better chance at receiving optimal care (Green 2003).

Campbell, Skovdal, Mupambireyi, Madanhire, Nyamukapa, Gregson (2011) through interviews and focus groups with 25 nurses and 40 caregivers in rural Zimbabwe, explore and describe what they term as "'adherence-competent community'—defined as those social relations that enable and support the likelihood of optimal adherence despite poverty and social disruption" (p.123). Campbell et al. (2011) argue that unlike in the U.S., treatment in some communities in Africa has been very successful to in part to the African sense of communal responsibility that relieves isolation caused by stigma and provides social support. Focusing on social networks and community context, the researchers sought to examine how social capital can influence adherence.

> We use thematic network analysis to investigate the social landscape of children's adherence in rural Zimbabwe through (i) identifying community-level relationships that assisted children and carers, and (ii) examining the social norms through which social capital impacted on adherence, against the backdrop of the coercion vs. empowerment debate (p. 124).

They found that community support and understanding was one of the primary contributors to adherence. Where stigma had been a barrier, the normalization of AIDS had led to greater support for those living with the virus. In addition to this normalization, the researchers found that the advancement in medications and fewer AIDS related deaths had given people more hope that providing quality care for those living with the virus had a purpose and could be effective. These changes in the perception of HIV also made the job of caring for a child with HIV considered a commendable service to the community rather than something fearful. The second major factor was services provided by NGOs that included community education leading to a decrease in stigma. Additionally, the participants reported that the counseling and youth centered programs helped to facilitate youth adherence. Lastly, programs that provided food delivery to homes with HIV-positive children, especially those being raised by grandparents, reportedly had an impact on adherence as families were able to meet the nutrition requirements of ART. Another successful practice reported involved assigning each child patient a "treatment buddy" that could help the child keep track of their medications and appointments (p. 128). Caregivers also reported that bribing children with treats helped them overcome the well-documented aversion to the taste of ARVs. Lastly, children who were disclosed to were also more likely to stay adherent.

Not surprisingly, functioning health systems were also reported to support optimal adherence. The researchers noted that the regular availability of ART medication and the presence of lab equipment needed to provide proper lab tests created the conditions for ART to be effective but also helped to build trust between the patient and care provider. Having access to the equipment and supplies necessary to deliver effective treatment and this deepening of the relationship with patients, inspired the medical staff interviewed to take more interest in the families they work with, in turn leading to better outcomes. They conclude that

> …in the contexts of reduced stigma and increased treatment availability – the emotional, practical and material support inherent in the actions of the [community, NGOs, service providers, the guardians and children themselves] perpetuated norms of solidarity with affected children, cognition of their social worth, an ethic of care and assistance towards them, and an enhancement of the agency of both children and those concerned with their well-being (P. 129).

These findings demonstrate that high levels of adherence can be achieved even in resource poor settings, by creating a sense of empowerment for the providers, caregivers and children. The primary weakness of this study was that it, like most studies, excluded the voices and opinions of the children themselves.

As mentioned above, Nglazi, Kranzer, Holele, Kaplan, Mark, et al. (2012) compared adherence levels of adults and adolescents in South Africa in order to better gauge the treatment outcomes for adolescents living with HIV in Cape Town. Sixty-five adolescents were compared with more than 800 young adults between 20-28 years of age. Adolescents were more likely to have high viral loads, but also more likely to have stronger immune responses as measured by CD4 counts. Both the adolescents and young adults were found to have similar rate of mortality and loss to follow up.

Although more research is required, emerging literature suggests that adherence issues for youth in SSA are complex and vary by region. Overall, youth living with HIV tend to report suboptimal adherence. Causes for this vary by region but include the presence of functioning healthcare systems, level of stigma in the community, level of support in community and whether or not the youth has been disclosed to. Stigma and lack of resources not only affect the ability of an adolescent to adhere to treatment but also have psychosocial implications.

Psychosocial and Educational Challenges for Adolescents Living with HIV in SSA

Children growing up with HIV face a unique set of challenges such as stigma and discrimination at school, high levels of depression and anxiety, as well as higher rates of poverty. L'Etang (2011) writes "inadequate attention has been given to the provision of long-term psychological intervention to those infected by HIV& AIDS" (p. 222). This section provides a review of current literature examining the psychosocial and educational challenges faced by ALWH.

Remien and Mellins (2007) reflected on a decade of working with ART in their paper on the psychological challenges of living with HIV. They focused primarily on adults in wealthy countries but offered some predictions and recommendations for young people in resource-poor settings as well. They stress that specialized attention is needed to address the wide range of issues that come with living with HIV. They list "mental health, stigma and disclosure, adherence, and sexual behavior" as key areas that need to be addressed as treatment advances and the lifespan of those infected increases (p. S55). They note that the neurocognitive problems which have been observed in children living with HIV "can affect their ability to perform in school, develop friendships, and function independently" (p.S58). They also note that extreme levels of anger directed at parents exists for young people who are perinatally infected, but that these youth are also simultaneously having to deal with the grief that accompanies parental illness or loss (Remien and Mellins, 2007). These experiences can have lasting and serious mental health consequences. The authors call for attention to be paid to children as they mature into adolescence noting that normal developmental stages of drug and sexual experimentation along with strong desires to "belong" can be of extra concern for ALWH because of the issue of transmission and drug resistance. Noting the additional challenges placed on young people in resource poor settings, Remien and Mellins (2007) write that

> Although it may be difficult to justify the provision of mental health or other psychosocial services when individuals do not have food, or shelter, or other basic living needs, to ignore the former may severely limit the ability of individuals and families to sustain the latter, when they are provided (p. S59).

Ultimately, Remian and Mellins (2007) call for mental health services as well as economic initiatives to be integrated into all ART programs.

Ferrand, Lowe, Whande, Munaiwa, et al. (2010) sought to both discover the number of adolescent patients receiving care in Zimbabwe and also conduct an inquiry into the needs of adolescent patients as perceived by the clinic staff. The research was partly in response to the data collection methods used at most clinics that grouped 15-19 years olds in the adult group, meaning there was little data on the treatment outcomes and challenges facing the sub-group of 15-19 years olds. Although not all of the 131 HIV treatment facilities responded, over 24,000 children aged 0-19 were counted in this study. Clinic staff also reported that the primary challenges adolescents faced were psychosocial including lack of support and lack of disclosure. They also reported low adherence. "Respondents described the main psychosocial stressors for adolescents as stigma, difficulty in identifying with HIV-negative peers, anxiety about sexual relationships and future planning, and low self-esteem and feelings of hopelessness" (p. 430). In addition to these challenges many also reported that adolescents had the added responsibility of taking care of a sick family member or living in a child-headed household.

Li, Jaspan, O'Brien, Rabie, Cotton, and Nattrassa (2010) conducted a qualitative study in an urban area in South Africa with the aim of understanding the needs of adolescents on ART. They interviewed a 26 young people between the ages of 10-15 years through small focus groups. They were asked questions about their needs, experiences and plans for the future. HIV was reported as a negative experience but was reported alongside abuse, violence and poverty as negative aspects of life. Youth that reported happiness most often reported it related to strong family relationships. Most youth reported being generally positive about their future although expressed desires to know more about the virus and to have more of their basic needs met (food, shelter, etc). Although this study offered space for young people to express their own needs and feelings, the group was very small and skewed toward younger adolescents. Further research is necessary.

L'Etang (2011) writes that "the need for strategies and interventions aimed at the mental health of young people living with HIV&AIDS is becoming increasingly critical" (p.218). She argues that there is an increasing number of young people living with HIV and suffering from psychological distress. The majority of programs currently offered in South Africa are focused communication interventions or the Voluntary Counseling and Testing model programs (L'Etang, 2011). She argues that neither of these were designed with young people in mind, nor were they designed to provide ongoing and long term mental health support. In her paper, she recounts the development of a cognitive-behavioral intervention program (L'Etang and Theron, 2011) discussed below.

Disclosure

Disclosure is a board term that encompasses the various ways persons living with HIV inform another person about their status. Disclosure for perinatally infected youth, also includes when the child first learned of their own HIV status, usually many years after the parents or caregivers become aware. Haberer, Cook, Walker Ngambi, et al. (2011) found that children in Zambia who were informed of their HIV status early often were more adherent and had better health outcomes. Caregivers, however, often delay disclosure. Two studies conducted in South Africa help to shed light on why caregivers often delay disclosure. Mahloko and Madiba (2012) as well as Madiba and Mokwena (2012) write that disclosure was delayed because caregivers had to first deal with personal fears, which influenced their readiness to disclose. Additionally, they lacked disclosure skills because they had not been trained on how to tell their children about their diagnosis, on how to talk to their children about HIV. Caregivers were scared to deal with a child who reacts negatively to the disclosure, fearing that children would live in fear of dying. Some caregivers thought that their child was too young to understand. And finally, caregivers feared that the child might tell others about the diagnosis and would be discriminated and socially rejected. Turissini, Nyandiko, Ayaya, Marete, et al. (2013) who conducted their research in Kenya, actually administered surveys to 270 youth living with HIV. They found that none of the children reported depression or experiences with stigma post-disclosure.

Vaz, Corneli, Dulyx, Rennie, Omba, et al. (2008) interviewed families about the process of disclosure in Kinshasa. Interviews were conducted with 19 youth and 21 caregivers who had been through the process of disclosing HIV-positive status to the child. The most commonly reported motivation for disclosure was to help the adolescents understand and adhere to their medications. Additionally, caregivers reported that their child would be better able to care for themselves and stay healthy if they knew their status. Some also responded that their reason for disclosure included wanting the child to know why they were ill and suffering, or because they had become of age to understand. Caregivers reported that in preparation for disclosing many prayed, consulted with a nurse or doctor, and others practiced the answers they would give to questions they thought the youth would ask. Most caregivers disclosed after a year from the diagnosis with most youth being 15 years old.

Almost all of the youth reported being surprised when they were told their status and half didn’t understand how they had gotten the virus. Many reported feeling sick or dizzy upon hearing the information and some said that they felt that they would die soon. Most of them also agreed that it was important for them to know their status. Vaz et al (2008) recommended that greater attention be paid to creating programs that help with the disclosure process and can provide ongoing psychosocial support. Part of their recommendation was based on the difficulty they had finding families that had disclosed. Hundreds of families are served at the three clinics included in this study and yet only 22 YPLWH were aware of their status.

One study that sought to explore the connections between disclosure and adherence was conducted in Western Kenyan, the province neighboring Nyanza where this study was conducted. Vreeman, Nyandiko, Ayaya, Walumbe, et al. (2010), similar to Vaz et al (2008), found that only 2 out of 120 children included in the study had been made aware of their HIV status.

Brown, Oladokuna, Osinusia, Ochigboc, Adewoleb and Kanki (2011) also sought to explore the motivations and experiences of caregivers in disclosing to HIV-positive children and adolescents between 6 and 14 years. The study was conducted at a hospital in Nigeria with 96 caregivers participating through questionnaires and interviews. Only 13% of children had been disclosed to. The reasons caregivers gave for not disclosing included: “inability of the children to understand . . . , fear of disclosure to other children… or to family/friends, fear of psychological disturbance of the children… or … fear of blaming the parents” (p.1053). Brown et al. (2011) also noted that of within the small group of youth who had been disclosed to, caregivers reported that almost 2/3 had improved adherence since disclosure. The researchers call for the development of guidelines to assist healthcare workers in counseling parents in the disclosure process. While this study adds to small and growing body of literature concerning ALWH in SSA, this study would have been strengthen by including the voices of the youth themselves.

Schooling

Kamau (2012) conducted an ethnographic case study for her dissertation focused on understanding the stigma children living with HIV face in schools. Her study was conducted at a home for orphans living with HIV in Nairobi, Kenya. She spent 2.5 months collecting data from the youth, as well as the teachers and administrators at the neighborhood schools where the youth attended. Part of her motivation for the study was to counter the current body of knowledge with regard to understanding the experiences of children living with HIV that was based “primarily on observations and perceptions relating to adults” (p.11). From her qualitative study emerged five themes. The first two were negative themes related to stigma and discrimination and included how students and teachers reacted to the stigma and discrimination. Each child in her study had had negative experiences and had been discriminated against or stigmatized. Every student had at least one story to share of being either mistreated directly by teachers, peers, their peers’ parents or being present when negative comments about YPLWH were made. The other themes described supportive and empowering experiences, including teachers providing extra food or academic support or students making friends at school and the group home. Her recommendations include designing curriculum for schools that is inclusive of PLWH, not solely focusing on prevention. Kamau (2012) also urges schools to take an active role in ending stigma and discrimination by bringing HIV-positive speakers into the classrooms who are willing to speak openly about the realities of living with HIV.

Birungi, Obare, Katahoire, and Kibenge (2011) conducted their study in response to the "insufficient attention [that] has been paid to ways of supporting in-school HIV-positive young people" (p. 73). The study examines the experiences of HIV-positive youth in Uganda through a survey directed at adolescents and through interviews with school officials as well as data collected from the student body in the form of essays. Adolescents living with HIV were all perinatally infected, had knowledge of their status, and were recruited through HIV clinic programs throughout Uganda. Seven hundred and eighteen completed surveys. Many adolescents living with HIV reported having to repeat a class; frequent absenteeism due to illness, lack of school fees, or for treatment. Students reported facing stigma, name-calling, discrimination, and experiencing fear that rumors may be spread about their status. Only 16% of HIV-positive students reported that they had formal support through school sponsored clubs or groups (Birungi, et al. 2011).

More than eight schools participated in the study. The adults within in the schools reported that children who showed visible signs of opportunistic infections faced more discrimination than children who were asymptomatic (Birungi, et al. 2011).

Over a thousand essays were collected and student writing confirmed that many students faced stigma, although only 2% of students reported that they themselves would discriminate or mistreat someone based on their HIV status. The authors noted that "those who are in boarding institutions face additional challenges including poor diet, cold showers, and adherence to treatment for fear of being stigmatized" (Birungi, et al. 2011, p.84).

This study was designed to include multiple perspectives but due to the controversial nature of mistreating students based on their HIV status, classroom and school observations would have been a useful addition. Like Kamau (2012), these authors also recommend that focused attention be directed to designing ways for schools to formally address stigma, but also the challenges YPLWH face in getting to and staying in school.

Youth living with HIV are not only confronted by biomedical challenges. The challenges of living with HIV also include neurological and psychosocial issues that affect a young person's emotional development, ability to succeed in school and relate to their communities. Research suggests that further investigation is required and that more attention should be focused on meeting the emotional needs of ALWH.

Youth Agency in HIV Research

While some of the studies mentioned previously took a youth-centered approach to research or at least provided some space for the perspectives of youth (Kamau, 2012; Li et al., 2010; Birungi, et al. 2011), the purpose of the following section is to highlight the few studies that draw on the lived expertise of youth. These studies explore the experiences and opinions of youth with regard to HIV/AIDS and have contributed significantly to our understanding of the complex experiences of young people and HIV.

Bajaj (2008), for example, sought to understand how youth in Zambia encounter HIV in their communities and schools. "Young people's experiences, [she] argues, are central to understanding the disease and its implications for youth and the institutions, primarily schools, in which they participate" (Bajaj, 2008, p. 308). Though interviews, observation, and students diaries, Bajaj (2008) uncovered how the youth establish and exhibit “their agency in creating new languages, identities, and self-conception in response” to HIV/AIDS. She describes how the young people in her study use new, alternative names for HIV and AIDS that both describe the local experience and serve as a coping mechanism. Young people use a local word for HIV that translates: “ ‘Go and say bye to your mother’” (Bajaj, 2008, p. 319). This term reflects a local economic reality that describes how the migrant labor patterns overlap with HIV infection rates. It also hints at the high levels of stigma that often lead to forced isolation or abandonment within families. Finally, this terms also incorporates the medical reality of HIV in this community – although ART is increasingly available, HIV has not yet become the chronic, manageable disease it as in the U.S. Bajaj (2008) also describes how HIV has redefined typical roles for youth, transforming friends into HIV counselors and advisors. Furthermore, she reports that youth, reacting to HIV in their communities, have built their hopes for the future based on their experiences living in a community ravaged by AIDS. The youth in her study wrote in their diaries about their dreams to become doctors, in order to find a cure for AIDS or to one day open orphanages to care for the children left behind by the epidemic. Through Bajaj’s (2008) descriptions, it becomes evident that youth are not passive consumers of HIV prevention education messages, nor are they merely victims. Young people actively recreate roles for their present and future selves, and create meanings, separate from what is presented to them by institutions and the media. Bajaj (2008) makes recommendations for teachers, policy makers, and scholars based on her findings, including that “more inclusion of [youth] voices, experiences, and cultural forms could have a greater impact on promoting safer behaviors” among youth (p.324).

L'Etang and Theron (2011) discuss the use of a PAR approach in developing a Cognitive-behavioral-based Counseling Intervention Program for YPLWH between 18-24 years in rural South Africa (as mentioned above in L’Etang, 2011). Responding to a gap in psychosocial services and indigenous interventions, the researchers sought to include youth and service provider knowledge and expertise in the development of a new intervention. Youth living with HIV and service providers were involved in focus groups, brainstorming sessions and evaluations of the new intervention. Although it is not clear from the article how much of the process of designing these data collection methods the youth had decision-making power in, the youth and service providers did have a lot of input in making alterations to the intervention. L'Etang and Theron (2011) discuss some of the challenges of using a PAR approach which included language issues and youth feeling less empowered when in groups with the service providers. They also provide one example where the program moved forward without youth input and had to be re-written later after being tested on youth. Although it was exciting to read that PAR had been used to develop an intervention for youth living with HIV, the description by L'Etang and Theron (2011) does not read as a PAR project. It does not provide any description of how the youth and service providers decided on the problem, questions, or methods. Rather the article describes how their opinions were included in the evaluation of the intervention, which was developed by an outsider.

Youth Agency in Research for HIV Prevention.

In 2001, UNICEF launched the Right to Know program aimed at increasing youth involvement in initiatives to fight HIV. Based on fundamentals laid out in the Convention on the Rights of the Child stating that young people have right to vital information concerning their health, UNICEF partnered with local organizations, governments and others to teach young people about participatory action research and enlist them in designing prevention programs. The programs in Bosnia-Herzegovina and the Caribbean are described here as well as another similar UNICEF funded program in Tanzania.

Maglajlic´ et al. (2004) describe a PAR project conducted as part of the UNICEF Right to Know program in Bosnia and Herzegovina in 2003. This project was carried out with the help of three local youth organizations at different sites, each with a research team of five youth who were trained in PAR in two workshops before recruiting 15-20 additional co-research participants at each site. They met nine times over the course of six months and were supervised by an adult Head Researcher. Each of the three sites chose a primary research topic from the list of 10 themes supplied by UNICEF. Two groups chose to focus on sexually transmitted infections, with one group specifically focusing on HIV/AIDS. The group that focused on HIV/AIDS designed and conducted a survey to measure HIV/AIDS knowledge among youth in their community. The survey was administered at schools and they were able to gather data from 1,611 participants. Their findings demonstrated a lack of knowledge, especially with the younger participants as well as tendencies to have negative feelings towards people with HIV/AIDS. The researchers then identified two prevention actions: peer education and a media campaign. The published article ends with the groups proposals for action but does not provide follow up information as to whether they were actually able to implement their plans.

Goto et al. (2008) preformed an assessment of the implementation of the UNICEF

Right to Know program in the Caribbean, similar to the one described above by Maglajlic´ et al. (2004). The study used Q method to examine the perspectives and opinions of the adults and young people previously involved with the PAR project to address HIV/AIDS. The researchers sought to learn more about how PAR was utilized and how the process impacted those involved. All participants strongly agreed that involving youth in action against HIV/AIDS was important. They also agreed that the peer to peer interaction played an important role in HIV education. Finally, the participants all agreed that the PAR process was key in developing critical thinking skills in the participants and provided a good way to solve problems besides HIV. Within the group, three clusters emerged that had slightly different takes on the PAR process. Some emphasized the process as being about youth empowerment and ownership, others viewed PAR more an as educational tool. The final cluster was more skeptical and expressed concerns about the power of PAR to actually affect behavior change in youth. This study offers interesting insight to process of PAR by examination the opinions of youth who have participated, and ultimately provides support for PAR to be used addressing health concerns with youth.

Mabala (2002) discusses a PAR projected initiated by UNICEF in collaboration with the Bagamoyo College of Arts in Tanzania. The purpose of this PAR project was to use popular theater as method to break the silence around HIV in the local communities. Young artists from the community were recruited and trained by the popular theater specialists to conduct research and then preform in their communities with the ultimate goal of reducing HIV infection rates among young people, especially those out of school. Two youth artists were chosen from each of the participating districts and provided with a

2-week training that included information about HIV, research methods, as well as workshops on popular theater. The artists returned to their communities and collected data, mainly through observations. Data was analyzed within two categories: problems related to sexuality and HIV and other social problems. Findings differed by district but some reoccurring findings included concern with initiation practices for young girls that encouraged multiple sexual partners, sex in exchange for goods and school supplies, and circumcision performed with unsterilized instruments. Another district's findings focused on practices that encouraged women to have sex to avoid certain cleansing rituals, as abstinence is associated with uncleanliness. Other districts reported on popular songs and social traditions that encouraged early sexual initiation and/or extramarital sexual relationships. Concerns about stigma and associating AIDS with witchcraft were also included along with myths about anal sex or withdrawal before ejaculation during vaginal sex as being effective HIV prevention measure. Additionally, their analysis included unemployment, poverty and other health issues as contributing to the spread of AIDS.

Their job was then to transform their findings into performances that were interactive and included discussion and debate with audience members. This process allowed the young artists to refine their performances before taking them to the large community festivals where they would be seen by hundreds of people. As a result of this project, Mabala (2002) reports that community practices around girls initiations were altered in some areas, that UNICEF supported the creation of more than 100 youth centers where peer education programs were provided, and that the young artist/researchers were asked by the government to continue their work by researching other community problems such low clinic attendance. While Mabala (2002) does not provide extensive details about the successes of this project in changing the behavior of young people in the community, it seems to achieve its goals of empowering the young artists and reaching out of school youth with information about HIV.

Carlson, Brennan and Earls (2012) conducted a study in Tanzania that sought to examine the capacity of youth as actors in their health. The researchers evaluated the Young Citizens Program (YCP) through a cluster randomized-controlled trial. The YCP is similar to the program using popular theatre described above where young people are recruited and then given tools to investigate their community’s HIV knowledge, provide education through public performance, and then evaluate. Carlson et al. (2012) evaluated this program through surveys of both the youth participants and the community members. They found that the youth “displayed enhanced deliberative and communicative self-efficacy” and that when asked, 75% of the community member who sought HIV testing said they were motivated by the youth performances to get tested (Carlson, et al., 2012, p. 7). While this study was not able to provide longitudinal data on the effects of this program on the youth or the community in terms of lowered HIV infection rates, the findings are promising and have helped define a possible role for young people in public health work.

Campbell and MacPhail (2002), write about a non-UNICEF project that involves youth agency by calling for a Freireian approach to sex education. They present a longitudinal case study of a school based peer education program in South Africa. After many interviews and focus groups, they argue for critical thinking and empowerment as mandatory precursors to any effective HIV education and prevention program citing that "the empowerment of young women is an important precondition for safer sex amongst young people" (Campbell & MacPhail, 2002, p. 332). Explaining many of the power complications with more traditional forms of education where the teacher is center, the authors argue for Peer Education programs where behavior change is not demanded through force or shame from the teacher, but constructed within a group of peers.

> "Ideally, peer educational settings should provide a context within which a group of young people may come together to construct identities that challenge the ways in which traditional gender relations place their sexual health at risk" (Campbell & MacPhail, 2002, p. 333).

They argue that people who are disempowered with little opportunity or control in their life are less likely to take control of their health and their sexual behavior. While the authors do not explicitly relate this to young people already living with the virus it is a relevant argument for programs that aim to keep people living with HIV adherent to their medication which can both prevent their own death and further transmission. Also along these lines, the authors discuss what they call the difference between more typical "biomedical" approach to HIV education versus a critical social approach. While having adequate scientific knowledge is important in understanding HIV, deconstructing social gender identity and how it affects one's sexual health is more likely to produce an emotional response and motivate actual behavior change (Campbell & MacPhail, 2002, p. 337).

One of the few things explicitly mentioned in this article and not found elsewhere was a discussion on the lack of sexual role models for youth in South Africa (Campbell & MacPhail, 2002, p. 339). Teachers, who are usually regarded as role models, are often perpetrators of sexual abuse and have high HIV infection rates. Additionally, Campbell and MacPhail (2002) report that parents of participants who were reported as being unavailable to discuss issues around sexual health and relationships and also living in abusive and broken relationships themselves. Campbell and MacPhail are also unique in that they point to high levels of poverty and unemployment as being barriers to effective HIV education for youth. Despair and lack of hope for a good and healthy life in general prevent young people from feeling empowered to control their bodies and their relationships. HIV Education can only be one part of a larger, comprehensive and long term strategy in the fight against HIV. And an educated, critically conscious, and hopeful populous is an important weapon in that fight.

Summary

This review of literature provides historical background to the HIV epidemic in Sub-Saharan Africa with additional information on the current political situation in Kenya. Studies that focus on investigating the ART adherence of adolescents living with HIV were then examined and showed that ART adherence remains a crucial issue requiring additional research. Insights into the lived experiences of young people living with HIV were then provided through research studies that sought to understand how youth living with HIV experience school, stigma and other psychosocial issues. Finally, special attention was given to studies that provided space for youth voice, agency and opinions on HIV-prevention and treatment interventions. It remains clear that the voice and experiences of ALWH have been left out of the majority of the research. The intention of this study is to fill that gap in the literature by focusing on the opinions and experiences of ALWH and bringing young people into the research process through participatory action research.

CHAPTER III
METHODOLOGY

In Kenya there are 1.5 million people living with HIV (UNAIDS, 2010). In 2008 the UN estimated that over 200,000 of those living with HIV were children (National AIDS Control Council, 2008). Since 2004, antiretroviral drugs have become increasingly available in many countries in Sub-Saharan Africa (SSA), allowing many children living with HIV to survive into adulthood (Timberg and Halperin, 2012; Gray, 2009). Increases in new infections among young people and rising pediatric survival rates require that additional research be conducted on the experiences and challenges facing adolescents living with HIV (ALWH).

Using a Participatory Action Research approach, this study explored the question: What is the experience of HIV-positive adolescents living in Kisumu, Kenya? The goal of the study was to engage and empower a small research team of young adults in Kisumu to critically examine the needs and document the voices of HIV-positive adolescents.

Research Design: Participatory Action Research

This research study employed a Participatory Action Research (PAR) approach. PAR is a methodology with roots in feminist and post-colonialist traditions (Apple, 1994, p.ix). PAR is unique in that it challenges traditional dichotomies of researcher-subject by putting the power of knowledge generation in the hands of those traditionally the subject of research. By encouraging “oppressed and marginalized groups to collectively study the issues and conditions that affect their health and well-being,” PAR places value on the expertise of those who have lived the research issue (Powers and Tiffany, 2006. p. S79).

Additionally, PAR advocates for the researchers to take direct action to improve their conditions, guided by the results of their research. Park (1993) describes PAR as “a self-conscious way of empowering people to take effective action toward improving the conditions of their lives” (p. 1).

PAR is conducted in three spiraling stages that encompass education, research and sociopolitical action (Fals-Borda & Rahman, 1991). The first stage involves the research team collectively identifying the research problem and developing research questions. Drawing from this collective understanding of the problem, stage two is defined by a collaborative process of inquiry with methods, data collection and analysis decided upon and conducted by the participant/researchers. In the final stage, researchers plan and take action to affect change based on the findings of their research. These stages are experienced through processes of dialogue and reflection that allow the team to spiral back, repeat, and move forward as the group deems necessary.

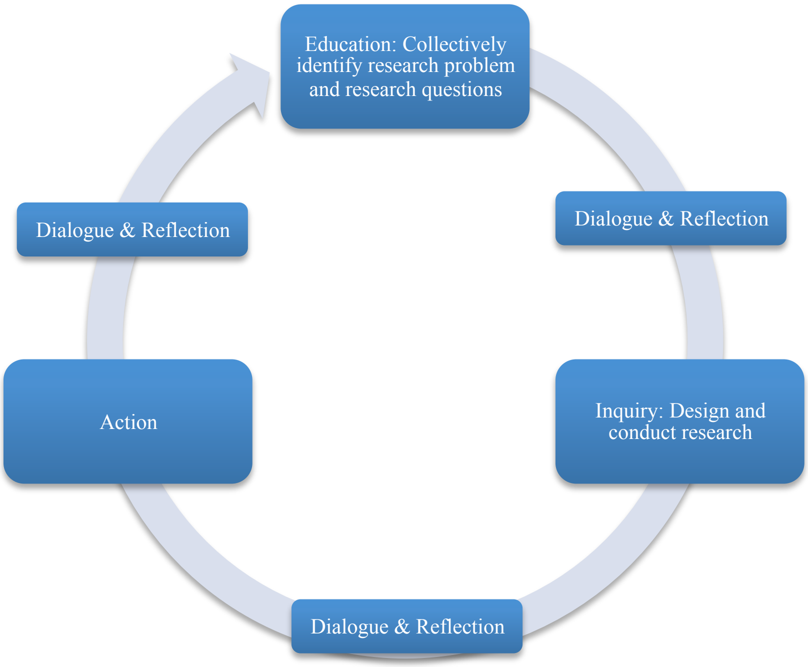

Figure 1. Stages of Participatory Action Research

PAR is held as a methodological approach that allows for the "acquisition of serious and reliable knowledge upon which to construct power, or countervailing power, for the poor, the oppressed and exploited groups" (Fals-Borda, 1988, p. 3). However, the approach is not without its challenges. Nygreen (2009/2010) and Koirala-Azad (2009/2010) question whether PAR is able to achieve its goal of transforming the production of knowledge into an empowering and democratic activity, providing equal benefits for the entire research team.

Nygreen (2009/2010) discusses "tensions between the *values* of PAR and the *practices* of PAR" (p. 14). PAR aims to break out of structures of power that keep knowledge production in the hands of the elite by deconstructing the roles of researcher/subject. Yet, Nygreen writes that PAR cannot neutralize the inherent privilege that university researchers bring to the research. For example, she explains that her co-researchers continually reminded her that it was *her* research for *her* dissertation and the process was never fully owned by all. At the end of their PAR project, she had a completed dissertation and was awarded a doctoral degree, but for her co-researchers, not much had changed. Although PAR aims to disrupt structures of privilege and oppression, it often fails and ends up reproducing that which it sought to transform. Regardless of how egalitarian university-based researchers attempt to be, regardless of the amount of decision-making power they yield to their co-researchers, they are ultimately still occupying positions of power and must still answer to the review boards and dissertation committees.

In addition to the challenges with PAR's philosophical standpoint, conducting PAR presents challenges as well. Nygreen (2009/2010) argues that PAR is not just an approach, but a practice that requires facilitation skills and a knowledge of how to translate abstract theories of democratization and critical theory, that young academics may not yet posses. Nygreen recounts her experience conducting PAR at a high school and reports that although all the stages listed above were completed, the end result felt forced and far from transformative. Koirala-Azad (2009/2010) reports having felt a sense of failure after conducting her first dialogue session in which she and her co-researchers were met with silence on the part of participants. PAR assumes 'the oppressed' will be enthusiastic and committed researchers, ready to engage in critical dialogue. While in opposition to the positioning of the oppressed as the 'passive research subject,' this assumption is also restrictive and therefore problematic, and furthermore reveals privilege, and perhaps naiveté, on the part on the part of the researcher.

Yet, neither Nygreen (2009/2010) or Koirala-Azad (2009/2010) advocate for the abandonment of PAR. While warning that PAR has the potential to be co-opted (as it has been) and to reproduce the very inequalities it seeks to destroy (as it has done), "PAR also offers one potential counter-hegemonic solution" (Koirala-Azad, 2009/2010). Although it may require a less zealous approach, "by reconceptualizing PAR as a tactic within a politics and ethics of critical research for social change . . . we can continue to forge new approaches and collaborations that more effectively uphold the values of PAR" (Nygreen, 2009/2010, p. 30).

Rationale

In order to conduct research that is meaningful and meets the goal of improving the quality of holistic HIV pediatric care in Kisumu, local and lived expertise is necessary. After decades of outsider imposed HIV policy, infection rates remain unacceptably high because for too long the experiences and knowledge of those most affected have been ignored (Pisani, 2008; Green, 2003). As Powers and Tiffany (2006) argue, the "participation of youth in the research process can improve the quality of the research by generating more reliable data and improving data interpretation because it involves those closest to the issues" (p. 80). Powers and Tiffany (2006) further argue that the success of any subsequent program implementation is more successful when youth are involved in the design and production. This has important implications for HIV programs and can mean life or death for youth living in areas with high infections rates.

Lastly, there are many considerations when conducting research across cultural, linguistic and geographic boundaries. Cultural differences can be difficult for an outsider to navigate and due to the researcher's cultural and national identity, interview questions can be offensive, inappropriate, or misleading. Working alongside local researchers is an effective way to mitigate this.

Research Setting

This research project was conducted in the town of Kisumu, Kenya. Kisumu, on the shores of Lake Victoria, is a medium-sized city and the third largest in Kenya. It boasts a vibrant fishing economy and remains an important stop in the trade route from the Indian Ocean to neighboring Uganda. Kisumu is located in the Nyanza Province which has the highest rates of HIV infection in the country, hovering at around 15% and even higher for specific subpopulations (FACES, 2012).

As Maguire (1987) writes, "participatory action research takes an organizational base of some kind to implement and sustain change" (p. 168). This research was partially based at an existing organization with the resources and structure to facilitate access to hidden populations. This organization also extended support to the co-researchers in their development as professionals as well as supported the actions later taken by the research team. The co-researchers were staff recruited from a program of Sunshine Projects (the author's employer), which provides psychosocial support to youth at HIV clinics. A partnership between the HIV clinics and Sunshine Projects was formed in 2011 with the purpose of supplementing the medical treatment at the clinics with therapeutic and psychosocial youth programing. This was accomplished through the recruitment, hiring and training of young adults living with HIV to become Peer Leaders. The Peer Leaders run support groups, summer camps, adolescent clinic days, and social events for adolescents living with HIV. In addition they provide community education programs at schools, orphanages and churches on topics such as HIV, Stigma, and Sexual Health. The two programs in Kisumu are hoping to serve all 1400 youth receiving care at the two clinics in the coming years.

Research Participants

Co-Researchers

Lucy was the Peer Leader Program Coordinator and oversaw the implementation of the above-mentioned partnership. She had a background in nursing and clinical research and had been involved in youth development projects and community based HIV-prevention projects for many years. She played an integral role in the coordination of this research project. Her position as project coordinator meant she was able to help the research team effectively navigate complicated bureaucracies. She had been working with researchers from the U.S. for many years and also helped to facilitate some of the logistical and cultural challenges our team faced. For example, she was instrumental organizing our research meetings and helping us come to a common understanding of time, reaching a compromise between American expectations to be punctual and Kenyan tendencies to start meetings at a more leisurely pace. She was also very helpful in the discussion about researcher bias because she was able to give localized examples to help illustrate how bias operates.

In addition to Lucy, four Peer Leaders were recruited as co-researchers. All the Peer Leaders were from the Luo tribe, which dominates the Kisumu area. They spoke Dhluo as their mother tongue and had learned Kiswahili and English in school. All four co-researchers identified as Christian and all had completed secondary school. Mary was 23 years old and the mother of one child. Unlike the other co-researchers, Mary is HIV-negative and became involved with the clinic because her younger brother is HIV-positive. She was one of the first class of Peer Leaders and had been working with adolescents living with HIV since August 2011. Slichester was the youngest researcher at

19 years old and is living with HIV. She is the newest member of the team and had been working with adolescents at the clinic for 8 months at the time of the research project. Thomas was 23 years old and also living with the virus. Like Mary, he had been working at the clinic for more than 2 years and was also a volunteer at another youth clinic where he received his treatment. Jacob was the eldest researcher at 27 years. He was married with two young daughters. He is HIV–positive and had been working in the HIV community for more than 5 years. The table below shows information about each team member.

Researcher	**Nationality**	**HIV status**	**Education level – completed**	**Age**	**Gender**	**Role in HIV Community**
Zoe	USA	Negative	Graduate	31	F	Program Manager for 5+ years, researcher
Lucy	Kenya	Negative	College	32	F	Program Manager, Nurse, Trainer
Thomas	Kenya	Positive	Secondary	23	M	Peer Leader at 2 organizations for 2+ years
Slichester	Kenya	Positive	Secondary	19	F	Peer Leader for 9 months
Jacob	Kenya	Positive	Some college	27	M	Staff for over 5 years, Peer Leader for 2
Mary	Kenya	Negative	Secondary	23	F	Peer Leader for 2 years, Brother is HIV Positive.

Table 1. The Research Team

Participants

Participants in this study were adolescents living with HIV (ALWH) who were between the ages of 13-17 years old. The team conducted Internet searches and interviewed key community stakeholders to identify organizations serving HIV-positive adolescents in Kisumu. Eleven organizations were contacted; five had HIV-positive youth enrolled in their programs who were willing to participate. Leaders in the organizations were asked to identify adolescents living with HIV and who were aware of their status. Leaders then invited these youth to participate. Forty adolescents were recruited from three orphanages and two youth centers. Adolescents were given a choice between participating in individual interviews or focus groups, depending on their personal comfort with discussing their HIV-status. This option was discussed with caregivers before consent was obtained from both adolescent participants and caregivers. Participants were provided with transportation stipends if travel was required, and all participants were given light refreshments after the interview or focus group. Participants were 40% female; 60% male. The average age was 14.8 years and 33 (82.5%) of the participants were currently enrolled in school.

Protection of Human Subjects

Prior to conducting this research, approval was obtained from the University of San Francisco's Institutional Review Board for the Protection of Human Subjects. Informed consent was obtained from all co-researchers, participants, and participant guardians. Lastly, permission was obtained from all community-based organizations included in this study.

The participants’ right to privacy and confidentiality is an important aspect of the ethical implementation and reporting of this study. Participants' actual names have been changed and any details that might disclose their identity has been modified in a similar manner or omitted so as to protect the participant without jeopardizing the results of the study. Co-researchers’ names have also been changed.

When working with vulnerable populations who have experienced trauma, from HIV-related stigma or the loss of a parent, it is important to be considerate of the psychological effects of questioning about the trauma. Engaging co-researchers who have developed personal relationships with the participants and who have also received training in psychosocial support minimized chance of re-traumatization. Additionally each member of the research team completed the National Institute of Health web-based training course “Protecting Human Research Participants,” as suggested by the researchers at the HIV Clinics.

Project Timeline

The project was completed in three phases: (I) Preparation & Education, (II) Data Collection & Analysis, and (III) Action. The first two phases are presented in this chapter and the final phase is presented in Chapter 4 along with our findings. Phase I and II were conducted over nine weeks in September-November of 2013. The chart below shows the timeline of the phases.

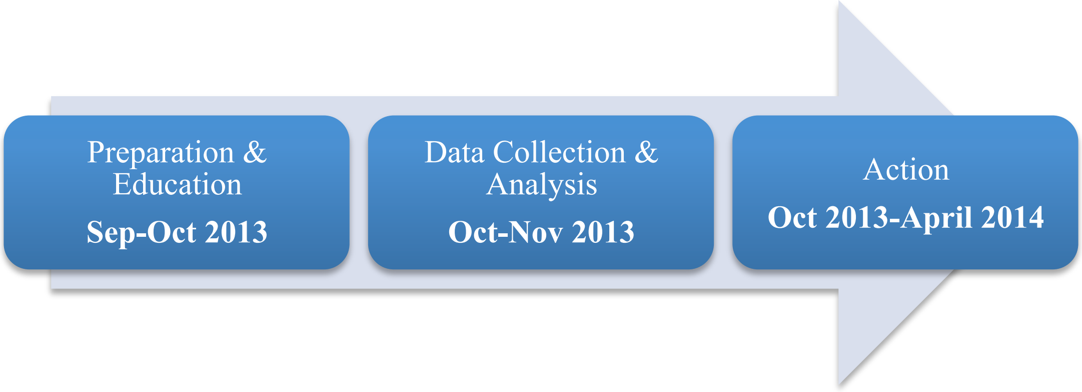

Figure 2. Phases of project.

During these nine weeks, the research team had eight official research meetings that were usually held in the conference room at the HIV clinic. The first meeting and the final two meetings were, however, held at a hotel across the street from the clinic because the clinic space was not available. The table below provides an overview of the research meetings.

Session	Description of activities and topics covered	Length
Meeting #1 Introduction	What is Research? What is PAR? Describe project aim and scope. Discuss roles & responsibilities, confidentiality, and consent	2 hours
Meeting #2 Narrowing our scope	Choosing categories of inquiry, developing interview questions. Develop recruitment plan and timeline. Discuss consent, stipends, and online Protection of Human Subjects Training.	2 hours
Meeting #3 Research Methods	Introduction to research methods, qualitative v. quantitative, PAR, data collection, theory, positioning oneself in research.	2 hours
Meeting #4 Data Collection	Continue review of literature. Lecture on data collection methods. Finalize focus group/interview questions.	2 hours
Meeting #5 Data Collection Skills Practice	Reflect on process. Role play focus groups, practice recording.	2 hours
Meeting #6 Data Analysis and Reflection	Reflect on first round of focus groups and adjust questions, continue recruitment. Begin lecture on data analysis and coding.	2 hours
Meeting #7 Transcription	Translate and transcribe. Researchers divided up the work and each transcribed different sessions.	All Day
Meeting #8 Analysis & Action Planning	Reflect and discuss process, findings. Develop list of 7 major finding. Develop Action Plan.	All Day

Table 2. Research Team Meetings

Phase I: Preparation & Education

Phase I began in Kisumu in September 2013. During this initial phase, co-researchers were recruited from the Peer Leader Program. Our first meeting was at a hotel across the street from the main clinic where the Peer Leaders worked. During our first session I provided background information on the project and explained how it was part of my dissertation. I spent a few minutes reviewing what their duties would likely be as well as providing information about stipends and time commitment. I provided a brief introduction to PAR and the value of contextualized expertise. I then asked the Peer Leaders write down some of the challenges they already knew adolescents were facing, based on their personal experience and/or experience working at the clinics. Writing the challenges on sticky notes generated a large list of potential topics shown below with the tick marks indicating the number of times a specific topic was repeated.

- Stigma & discrimination (llll)
- Poverty
- Political influence
- Education/Skills – drop outs (ll)
- Death
- Media
- School Fees (ll)
- Disclosure (llll)
- Money & Economics – e.g. transportation to clinic (lll)
- Adherence & Side effects (lll)
- Peer pressure (ll)
- Drug Abuse
- Fear of death
- Frequency of clinic visits
- Family Problems, lack of parental love (ll)

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- Frequency of clinic visits
- Family Problems, lack of parental love (ll)

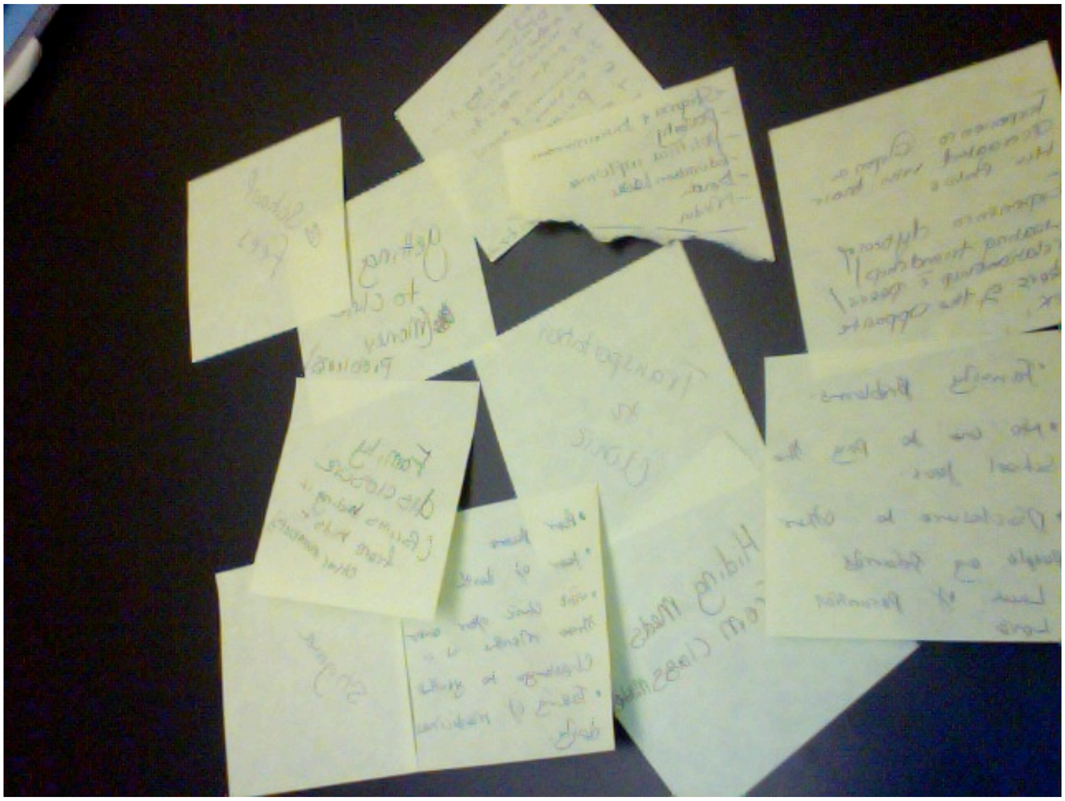


Figure 3. Picture of sticky notes used to generate categories of inquiry.

After generating this list I had planned to conduct a personal narrative activity, but the team had many questions about the project and, for example, wanted further explanation as to why their stipends were so small (the amount was based on their current salary which they also felt was too small). I cancelled the writing activity and instead they guided a discussion on their expectations of being involved with the project. After their questions were answered, I passed out consent forms, articles about PAR and qualitative research. I let them know that if they were still interested in participating that our next meeting would be in two weeks. In the mean time, I encouraged them to start the online Protection of Human Subjects Training and to contact me if they had any other concerns. Over the next 2 weeks I saw the Peer Leaders at the clinic and each one let me know that they were interested in participating in the project as co-researchers.

Our next meeting was held in the clinic conference room. During this meeting we reviewed the concept of consent and I collected their consent forms. Next we discussed stipends for participants. Additionally, the co-researchers were informed that they would received stipends for mobile phone air time used during the project as well as transportation stipends for meetings, outreach trips, and data collection trips. This significantly added to their original stipend and seemed to improve morale. The research team continued the discussion on responsibilities including reimbursements in the case of missed meetings. They decided that if someone was ill or had an emergency that they must notify the team with more than 24 hours when possible. The team also decided to work together as a group to ensure that the schedule was accommodating.

During this meeting we also narrowed our research question. We reviewed the issues generated from the last meeting. The co-researchers decided to added "early marriage" and "opportunistic infections" to the original list. Looking at the list posted on the wall, the team now had to choose the issues they felt were most important and that they wanted to investigate. Each person wrote the two most important issues to them on a small paper and put it in a hat. Even though I planned to facilitate a discussion and reach consensus about the topics, I built in some anonymity so as to avoid the ideas from Lucy or myself influencing the co-researchers. From the issues in the hat, we generated a list of five issues to explore through our research. The team noted at this time that no one had mentioned sex as an issue and paused to reflect on that. We noted that sexual activity of people living with HIV is a popular research topic, but that it did not seem like the central issue to the co-researchers partly because of the age of the participants. The five issues that surfaced as the most important were:

1.) Stigma and discrimination
2.) Education/schooling
3.) Drug and alcohol abuse
4.) Family problems and early marriage
5.) Poverty

For each of the above mentioned categories, the team generated a list of questions to ask adolescents. We then discussed the pros and cons of individual interviews versus focus groups. Finally, we discussed the issue of interview setting and how we would be able to assure privacy during the interview and focus group sessions.

Our third research meeting was focused on learning research methods. I developed a slide show based on Creswell (2009) that provided co-researchers with a basic overview of quantitative and qualitative methods and included an introduction to key terms such as validity, generalizability, and coding. I provided an opportunity for the co-researchers to share what they knew about education based on Tuck's (2008) interactive approach to teaching research methods in a PAR setting, but was met with silence and as a result ended up lecturing.

We then shifted focus to positioning ourselves in the research and I asked them to reflect on what brought them to this work. Although I was hoping they would write in their journals, instead they wanted to discuss their reflections. For Jacob this research project was an opportunity to continue working towards a meaningful career in HIV services. He also had a passion for learning and improving his skills in coordinating community activities, facilitating youth groups and conducting research. Mary shared that it was seeing her brother struggle with his health and with stigma that motivated her to do this research and work with young people living with HIV.

I attempted to engage the co-researchers in what I considered to be an important part of rigorous academic research. I explained what a Review of Literature was and its purpose. I gave an example of how another researcher's work could help inform and guide our research. I shared with them a summary of Kamau's (2012) work, which had been conducted in Nairobi on the same topic. They were interested in hearing about Kamau's findings that validated their own work, but when it came time for them to read articles I selected for them, they seemed to lose interest. In the next meeting when they were scheduled to share about the article that they read, only one co-researcher had actually read the article.

We closed our third meeting by strategizing our recruitment plan and deciding how to conduct outreach at orphanages. This continued in our fourth meeting. The co-researchers were very thoughtful in assigning themselves to specific agencies based on previous experience and connections there. For example, Jacob lived very close to one of the organizations that had agreed to participate. He was well known in the neighborhood and had already facilitated some sexual health workshops for the youth there. He spearheaded our involvement with this organization, which required him stopping by multiple times to meet with new staff and get connected to the supervisor overseeing the case management department.

It was in our fourth meeting that we discussed details of qualitative research methods and data collection. I had planned to share with them some YouTube videos that some professors had created for students in the U.S., but the internet was not working properly and I was only able to show one about the qualities of good qualitative researcher (King-Spezzo, 2011) so instead I gave a short lecture on the topic and provided some handouts from Creswell (2009). We then reviewed the interview questions we had generated and made some adjustments. We decided not to discuss poverty and family issues as separate categories and instead opted to include a few demographic questions in the beginning of the interview session to help us better understand what the family situation and poverty levels of the participants were. One of the co-researchers at this point also brought up the idea of having ground rules for the focus groups sessions. As a team we generated and agreed on a set of basic rules and added them to our instrument.

Finally, it was time to begin practicing. The co-researchers got into small groups and practiced interviewing each other. It was in these mock interview sessions that the concept of knowledge creation surfaced. In pretending to be an adolescent participant, one of the co-researchers began questioning the process, asking questions like "How did you know my status? What are you going to do with this information? Are you just here to do your research and then leave?" The other co-researcher was then put on the spot to answer these difficult questions. Although the co-researchers were not willing to engage in the structured reading and writing activities I had prepared for them on these topics, the information came out organically through the mock-interview process. At the end of the mock interview we paused and shared our concerns about research in general and fears about how the participants might react to our project. I took this opportunity to remind the co-researchers that these important issues regarding the ethics of research was what PAR was designed to address. We would take action in the community based on what the adolescents shared with us and I urged the co-researchers to consider what that action might look like as we continued with our project and began interacting with participants.

Figure 4. Photo of mock interviews.

In our final meeting before we began data collection we took a few moments to reflect on the collaborative process. The co-researchers were very uncritical of the project and shared only praise. My concerns that they were not critical enough was somewhat allayed when they offered each other insightful and constructive feedback during additional mock interview sessions. They offered advice on even the smallest details saying things like: “Don’t say the numbers [of the questions], just say ‘Thank you, let’s move onto the next question.’” For example, Mary suggested that we start with a short game or icebreaker to help the participants relax and feel more comfortable in the group setting.

Our last step was to conduct a final review our interview questions. Most edits focused on the questions we wanted to ask about drug and alcohol use which lead to a conversation that had the entire team laughing, as this quote from my research journal describes:

> I wanted to take a minute to reflect on how hilarious our conversation in last research meeting was when it came to drugs. I asked the team what kind of drugs kids use in Kisumu and they all just started naming all these things that I have never heard of and were cracking themselves up as they teased each other about having tried all the drugs. The drugs were mainly Kiswahili-slang terms' for drugs common in the U.S. but also included Miraa or Khat, which is a legal substance in Kenya. It's a flowering plant that grows in around the Horn of Africa and also on the Arabian Peninsula. Its a stimulant and considered less addictive than cigarettes or alcohol. And they listed all the different kinds of moonshines or bush alcohols. Then my intern and I started sharing all the slang terms we knew for marijuana and other drugs in the US. Everyone was laughing! And we also took a moment to realize that this was a learning moment for all of us and how difficult it would have been for me, alone as an American, to conduct that part of the interviews!

By the end of our 5th meeting we had narrowed down our topic and selected three primary categories of inquiry. We had also written interview and focus group questions, learned about qualitative research methods, and designed a participant recruitment plan. Finally, we had learned how to operate recording equipment, and had all passed the Protection of Human Subjects online training.

Phase II: Data Collection & Analysis

In order to best answer the question "What is the experience of HIV positive youth living in Kisumu, Kenya?" the research team collected data in numerous ways.

Researcher-generated data was collected in the form of a journal, field notes, meeting notes, and email correspondence. Participant-generated data was collected in the form of interviews and focus groups. Interviews and focus groups were voice-recorded, transcribed and when necessary, translated. The research team interviewed 40 participants through three individual interviews and seven focus groups. Most sessions had a primary interviewer and an observer, with the exception of one individual interview for which the researchers decided that the participant was so shy that she would be more comfortable speaking with only one person in the room. Co-researchers conducted all interviews. I observed four of the first sessions until in a reflection session the co-researchers decided that having a white American in the room made the participants feel obligated to speak in English and therefore affected their ability to respond to questions fully, perhaps compromising the data.

Another topic that surfaced during our first research meetings after we began data collection were concerns about the participants' safety and health that need to be addressed immediately. Participants from the very first focus group had little to no understanding of the virus or their medications and at the end of the focus group asked us to return to help them learn more about their drugs. The team agreed that it was important for the participants to understand how their ARVs worked so that they would be more adherent and scheduled a time to return and speak with the participants again. This was the first action we would take a research team.

The co-researchers also decided to add some introductory questions at the start of each interview or focus group after seeing how difficult the participants found starting the session by discussing their families and orphan status. For example, we added a question about their favorite activity or hobby and this did seem effective.

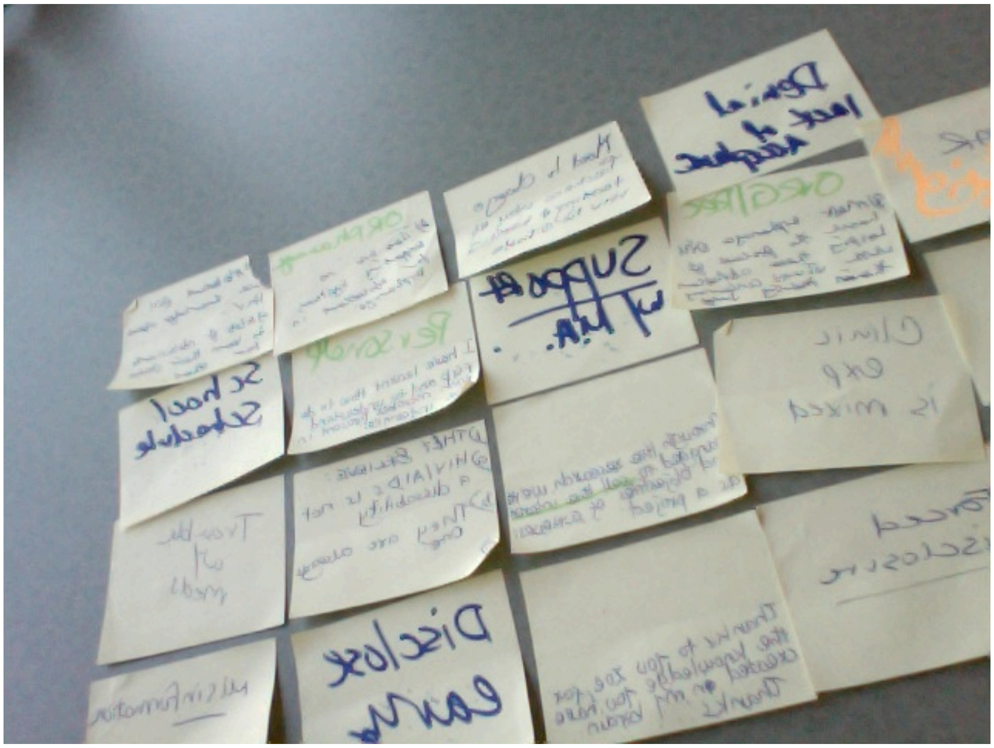
The end of our sixth research meeting focused on Data Analysis, again based on Creswell (2009) and covering the subjects of organizing raw data, transcribing, reading and reflecting, and finally, coding. Although the co-researchers spend much of their working hours near researchers and research studies, data analysis was very new to them. Jacob's comment explains the overall reaction. "Okay, but how to you actually DO that!?" he had exclaimed at the end of the meeting.

When it came time to transcribe we rented out a small room in a hotel for the day and ordered food. We borrowed earphones and laptops and sat around a big table, each one of us plugged in and transcribing. Having had more experience transcribing and being faster at typing, I transcribed all the English parts and they translated and transcribed the Dhluo and Kiswhaili parts that were fewer.

Data Analysis

The transcripts along with the texts of the journal, field notes, meeting notes, email correspondence, were analyzed for emergent themes through a group process and then I coded and analyzed them again.

For our final research meeting, we again rented a nearby hotel room and spent half the morning transcribing the final sections of the recordings. After lunch I revisited how to analyze data and reviewed the coding process. It was clear, however, that the co-researchers were not interested in reading thought the huge stack of transcripts in front of them. Additionally, we were short on time as I had less than one week left in Kenya before needing to return to the U.S. I decided to facilitate analysis through discussion since that seemed to work in our previous meetings. Going around the circle, each researcher shared their biggest learning moment, what they were most surprised to hear from the youth, what they thought they heard most often, and what was most important for others working in the community to know. We generated a list with sticky notes and shown in Figure 5 and then went back through and negotiated the list down, separating actions from findings and personal growth statements.



Picture 5. Photo of the finding

It was a lively discussion and we finally agreed on seven major findings as shown in Figure 6. What emerged were:

1. Linkages. Working together as organizations strengthens our ability to serve adolescents.
2. Self Stigma. Adolescents feel fear, feel alone, and some are in denial about their status.
3. Disclosure. Adolescents experienced delayed disclosure from caregivers, forced

disclosure from other adults and peers. Furthermore, they are not comfortable disclosing to friends, teachers, or partners.

4. Medication Adherence. Youth do not know when to take their medications, or do not have a space to take them privately. Some do not understand how the medicines work in their bodies, leading to poor adherence. Experiences at the clinics are mixed.
5. Lack of Support in Schools. No accommodations, lots of stigma, and inaccurate information leading to forced absenteeism.
6. Violence. Many participants mentioned violence such as rape and beatings.
7. Hope. All youth expressed hope for their futures.

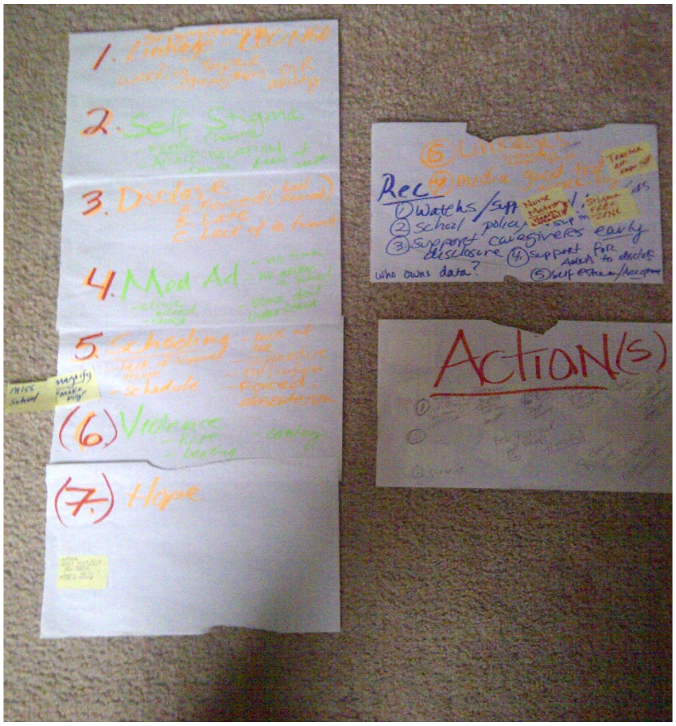


Figure 6 . Photo of seven themes from group discussion as well as actions and recommendations.

The team's recommendations included:

1. Adolescents should be provided with watches
2. School policies should be to provide accommodations for youth with HIV and to provide accurate HIV education.
3. Caregivers need support for early disclosure
4. Adolescents need support for disclosure.
5. Adolescent program should focus on promoting self-esteem and self-acceptance.
6. Organizations working with adolescents living with HIV should collaborate to make sure each child is receiving quality and holistic care.

Finally the team generated an Action Plan, which is detailed in Chapter IV.

After the final meeting I coded and analyzed the transcripts as was originally planned. There was a high degree of inter-rater reliability among the themes that emerged from my individual analysis and the team's findings, although I reorganized slightly based on the frequency with which certain codes appeared in the transcripts. Chapter IV details these themes.

Validity

Participatory Action Research aims to democratize and expand the traditional definition of expert validity. "PAR stands on epistemological grounds that persons who have historically been marginalized or silenced carry substantial knowledge about the architecture of injustice; in their minds, bodies and souls" (Fine, 2007, p. 223). This study employs what Fine describes as contextualized expertise, which is grounded in the daily, lived experiences of those most affected by the research problem. The co-researchers, all personally affected by HIV and deeply entrenched in the HIV community in Kisumu are also trained professionals who have experience working with adolescents. Additionally, many of the co-researchers are themselves, young and HIV positive not far removed from the locations and situations the participants describe. Their contextualized expertise validates this work.

CHAPTER IV
FINDINGS & ACTIONS

There is a growing population of adolescents living with HIV in Sub-Saharan Africa due to increases in new infections and to advances in treatment that allow children born with the virus to survive into adolescence and adulthood. Although there have been numerous studies on adults living with HIV, few researchers have explored the experiences of young people living with HIV and even fewer have sought to include the perspectives of young people in the inquiry process. This study employed a Participatory Action Research approach in order to better understand the experiences of adolescents living with HIV and as an opportunity to engage young people in the research process. Four young adults affected by HIV who work at HIV clinics in Kisumu, Kenya were recruited to form a research team. The team started with the board research question: What is the experience of adolescents living with HIV in Kisumu? From there, the research team generated three primary categories of inquiry: (a) stigma and discrimination, (b) school, and (c) substance abuse. Data was collected through three individual interviews, seven focus groups, observation, journals and meeting notes. Of the total 40 adolescents that participated, 40% were female and 60% male. The average age was 14.8 years and 33 (82.5%) of the participants were enrolled in school at the time of data collection. Focus group and interview sessions were conducted in English, Kiswahili, and/or Dhluo depending on the preferences of the participants and most sessions included all three languages although English was dominant. All sessions were voice recorded, transcribed and, when necessary, translated into English by the co-researchers. Preliminary themes were identified through discussion and reflection by the research team. After the team identified emergent themes, I analyzed and coded the transcripts. My findings confirmed the team's initial findings, although slight adjustments were made based on the frequency of codes appearing in the transcripts.

From the data emerged six major themes: (a) prevalence of self-stigma; (b) challenges with disclosure; (c) challenges with medical treatment; (d) lack of support in schools; (e) lack of substance use (f) coping strategies and hope. This chapter begins by describing the specific sites where data was collected based on observation and meeting notes. Some additional background information is provided about the schools and clinics sites where our interviews took place and which were the topics of much of the discussion. The chapter then explores the six themes by providing direct quotes from the participants as well as data from other sources such as journals and meeting notes. The quotes have been slightly modified to correct for grammar in order to ease reader comprehension. The names of the participants have all been changed to protect their identities. This chapter ends with a description of the actions taken by the research team based on these findings.

Research Sites

Chapter III gave a description of the town of Kisumu and the organizations where the co-researchers work. It is important to also include a description of the sites where participants were recruited from in order to fully understand their words. We had originally reached out to eleven organizations. Of the organizations that responded, only 5 met our criteria of having HIV-positive youth on site who were aware of their HIV-status and willing to participate. Three organizations were housed on large compounds that offered primary and secondary school services as well as full residential services to orphans. One organization was a youth center and health clinic that served a large population of HIV-positive youth and also provided other social and vocational programing. The last organization was a primary and secondary day school that had recently built a health clinic that would soon begin providing all HIV-positive students will their medical treatment within the same compound where they received their education and most meals. Although not a residential program, the organization worked with orphans that had been placed in homes in the community. All but one of the organizations identified as Christian. The research team observed a wide range in terms of funding and quality of care with the organizations that participated as well as the ones we visited that did not participate.

The most well funded organization was a Christian home for street children that had been running in partnership with the local government for twenty years. They had developed a complex four –step rehabilitation program that included academic, religious and psychosocial interventions with the aim of reintegration in three to four months. They had two compounds, one with 96 beds for males and another smaller site with 12 beds for females. Additionally, they had opened a vocation center for youth that were unsuccessful at rejoining school. The administrator reported to the research team that their reintegration success rate was 82%. The compounds were well maintained, clean and youth friendly. There were soccer fields and other games available for the youth. Colorful sculptures of African animals decorated the compound. Most of the children we observed were well dressed, wore shoes, and seemed generally happy. The organization displayed their religious beliefs through colorful flags hanging in the dining hall, each painted with a single word representing a Christian value. Management was a mix of local and foreign, but all had appropriate levels of training and were very dedicated and knowledgeable about each of the children in their care.

One of the participants whom the research team felt was the most well-adjusted was at this facility. This one young man received his medical care at the same clinic where the co-researchers worked and had participated in their week-long psychosocial intervention a month prior to our interview. Although our relationship with him may have influenced our opinion of his health and well-being, the difference in his attitude was fairly extreme especially when we took into consideration his age and orphan status. He reported that in addition to the support he received at the orphanage and clinic, there was a health club at his school. These three points of service provided him with enough support to cope with his diagnosis, the loss of his mother, rejection by his father, and time he had spent living on the street.

In stark contract to this facility was another residential compound across town. The orphanage, recently shut down by the government for not meeting basic standards, had been taken over by a Canadian Christian organization just a few weeks prior to the research team contacting the administration. Within the compound was a full residential orphanage, a primary school and secondary school that served day students and boarding students. The youth we spoke with had all been living on the compound for many years and all attended school on site. Unlike the previously mentioned organization, the staff here had little knowledge about psychosocial therapies or the special needs of children living with HIV. The organization seemed to rely heavily on Canadian volunteers who were very enthusiastic and kind, but had no knowledge of HIV or any of the other issues facing the children living on the compound. The staff was also unaware of the challenges their day students were facing. Christian beliefs at this site were displayed in large murals depicting a white Jesus and dominated our conversations with the administration who spoke often about abstinence only sex education and their own personal spiritual journeys in service to God. The adolescents we interviewed here had the least knowledge about HIV and demonstrated the highest levels of anxiety, anger and fear.

Schools in Kenya

As stated above many of the participating organizations had schools on site. Some of our interviews were conducted after school in classrooms. Regardless of how well funded a program or school seemed, they all severely lacked resources. Most classrooms had chairs and desks that were in ill repair. Paper and writing utensils were scarce, as well as books. The lighting in some classrooms was so bad that on one visit students were moved outside to take their exams in the sunlight. In addition to lack of resources, some sites did not have properly trained teachers and instead used volunteers or community members without teacher training to provide instruction. Education, however, was clearly very important to all of the community members we spoke with. For example, in preparation for the high stakes national exams, students were required to come in on Saturdays to study. One school invited us to their day of prayer prior to the exams for which family members, teachers, church and government officials all attended and offered their prayers and support. Regardless of the quality or lack of resources, school is highly valued, and missing a class for clinic appointments becomes a challenge as further detailed below.

HIV Clinics

The vast majority of HIV Clinics were built with adults in mind. As discussed in Chapters I and II, it was only recently that adolescents in any significant number began coming to the clinics. Many clinics have found themselves ill prepared to accommodate students' schedules or know how to approach sensitive subjects such as sex with adolescents. One of the sites included in this study, however, was constructed in response to this problem. The youth center that housed a health clinic served only children, adolescents, and young adults. The art on the walls, the layout, and location were all designed with the needs of young people in mind and the staff were all trained to serve youth. Participants recruited from this site had higher knowledge of HIV and faced less of the challenges with adherence listed below.

Data collected from the clinics and other sites resulted in the emergence of six major themes presented below.

Prevalence of Self-Stigma

Self-stigma is the internalization of negative ideas or prejudices about HIV held by society. A majority of participants expressed feelings of fear and isolation or self-stigma related to their HIV-status. It is important to note that the shame and fear was not based on experience with rejection post-disclosure but on anticipated discrimination. The majority of participants, when asked about stigma, would say that they had never experienced stigma or discrimination. Later in the session, however, they would share a story that we easily classified as internalized or self-stigma. Additionally, some participants were not familiar with the term stigma and often asked for clarification. This may explain why participants were quick to deny they had experienced stigma but also points to a lack of knowledge about the social implications of living with HIV and a lack of HIV-sensitive psychosocial programs. This first finding was different from the others in that it was common theme that ran throughout all of our sessions and is present in five of the remaining six findings.

Feelings of isolation were common. Desmond, a 15 year old male from the first focus group, when asked about support services at the orphanage, stated: “We came here alone . . . We came here alone. You suffer alone. You live alone.” In every interview or focus group participants discussed being afraid or scared. This fear was most often associated with potential rejection from peers, family, or community members. This notion of being alone illustrated in stories like this one from Brandon (age 14). He described the fear of losing friends due to illness:

> But some people think if they see someone is thin, if someone is coughing a lot, someone is having headache - they say ‘Oh that person might be having HIV-positive.’ So you might lose a lot of friends when you’re coughing or being sick for a long time. But I don’t want to lose my friends.

Similarly, Peter, age 14, discussed living with a constant fear that his HIV status would be discovered and that rejection would follow: “Sometimes you may tell them [your status] and they start looking down on you. . . . [I] am always afraid.” Peter’s thoughts were echoed by others who expressed concern that they would be “laughed at” if classmates were to learn their status.

The fear weighed heavily on participants and our observations noted that many youth appeared to have low-self esteem and feelings of shame and anxiety about keeping their status a secret. Elizabeth (age 16), although living with HIV herself, stated, “I usually feel it’s very bad. I feel very bad for youth who is living with HIV.” This statement upset the co-researchers more than most of the comments made by participants. One of the co-researchers, Jacob, during our reflection session noted with sadness that Elizabeth had not yet accepted her status. Similar feelings of shame were noted in the majority of our sessions.

Additionally, many participants were also struggling with the loss of their parents or family. Many expressed anger or grief and one young man began crying when this topic came up in our session. Our data on this issue was not enough to draw any conclusions, but we believe it is an area worth investigating in the future and certainly that programs serving young people living with HIV should take into account the needs youth might have around loss and grief.

Challenges with Disclosure

There was a wide range of experiences with disclosure. Most participants had not disclosed their status and expressed fear and anxiety around disclosure. In a follow-up session at the first orphanage, two of the young women reported that they would "never" disclose their status to anyone because the risk was too great. Pascal, 14 years, stated "I have never told anybody because I have never trusted anybody in my school." Another participant (Jonathan, age 17) explained in more detail his fear about classmates spreading rumors about his HIV-status:

> The people that surrounds me? They don't know my status. They are not aware of my status and I have not shared with them because I know if I share with them they will just start to think badly,… they'll just start to talk ... You'll see that they are just gossiping to other guys your status. So that's why I say that if you want to disclose, you have to disclose to the right person that you know and that will not fail you.

This quote illustrates the common fear attached to disclosure and delves into a second disclosure-related issue: establishing trust.

Students talked about testing the waters by joking, or by asking for general opinions about HIV before revealing their status to a freind. This is illustrated in a story shared by Christine, age 15:

> My friend knows. We used to stay with her in the same room. So when I found out that we were going to [the same] school, when we knew each other more and more – I trusted her. And I started asking her - what if she found out that she was HIV positive? And I told her as a joke, then later she went and believed it.

Christine, like many of the other participants, found ways to learn how her friend felt about HIV and AIDS as a way to establish trust before disclosing.

Others who had disclosed, shared both negative and positive experiences. Most of the negative experiences were not related to experiences of discrimination post-disclosure as feared, but anger at a lack of control over who had knowledge of their status. Participants reported instances of forced disclosure at orphanages and schools as Susan, age 14, explains: "Me, I never disclosed but the nurse who used to work here before is the one who disclosed to the people." In this example, Susan was describing an instance where the nurse at an orphanage would post a sheet of paper in her office that clearly listed the names of youth who were living with HIV. The sheet was posted in a place where anyone who came into the nurse's office could read it and the adolescents there were sure that this was how everyone on the campus knew their status.

This type of forced disclosure was not limited to residential institutions. Another participants, Geoffrey (age 17) shared:

> There is guidance and counseling at our school, but it's only that the teachers in our school- they are a bit talkative. They cannot keep a secret to themselves. So

> the only the guidance and counseling are for those, how can I say? The ladies. Yeah. But for us men if you go there, they can't keep a secret with them. Yeah.

William (age 17) described accidental disclosure when a fellow patient at his clinic turned out to also be a fellow classmate:

> According to me, I have not yet disclosed to anyone in school. But there is a girl in Form 1 in our school that also is the same as me. I am meaning that, we have the same status, I mean. I think she is the only one that knows about my status.

Many participants described seeing other patients in school or else where in the community. In each case, the other patient respected their privacy but the youth still expressed anxiety about others knowing their status without their consent.

A few participants had positive experiences with disclosure such as Brandon (age 14) who spoke freely and in depth about his experiences living with HIV in a group home for boys:

> One of them is Kelvin. I always meet him outside when we are at school. Even him is in Standard 6 West, but for me I am in Standard 6 East. So I told him why I was. When he looks at me, he think- oh, he seems to be weak. So I told him my first time. Then I told him. Because he was my friend I trusted him. I told him that I am HIV positive. . . . Yes. Even Will, Kelvin. And others. Even if they saw me with anything which they don't have, they just know that I am not like them. So, when I am having a milk, but for them they are not having. They know what I am facing. And I am taking drugs everyday. They not taking drugs. They know why I am taking that milk to help me with my drugs.

Brandon explained that his motivations for sharing his status with classmates was so that they would understand the special treatment and accommodations that were being made for him, and the reason behind his frequent illness. When other participants were asked about their motivations for sharing their status with others, participants reported that they wanted support and advice from their friends, as well as accommodations from teachers.

In one focus group the discussion around disclosure centered on feelings about how parents often delay disclosure to their children. Jonathan, age 17, recounted how he first learned of his HIV status:

> I asked my mom, ‘Mum, how did I get the virus?’ And the first day she did not reply back to me. The second day I repeated the same question, she told me that she is the one who gave birth to me and I get the virus through breastfeeding. So on that day I quarreled with my mom talking badly to her. Telling her those things that a child should not say. It was very painful, I felt hurt. …. Not only me that there are some guys, some other students that put the blame to their moms and dads for not taking care of them good, Yeah. I am not the first guy to blame my parents for that.

In response, Geoffrey, age 17, discussed how he did not blame his mother, but expressed disappointment that she withheld the information for so long and eventually forced him to confront his nurse to find out his status.

> I don’t have to blame my mother for infecting me with the HIV disease because it is meant for us human beings, not the animals. But what I blame my mother for is for not disclosing it to me earlier. I found out about my status when the drugs I was taking were being advertised on the television. I saw them and then I went and take my drugs and saw that they were alike. I go and asked my mom. She tried to deny it. But- I just, it was kind of paining me talking to her, telling her those things, so I just left it. But when I went to clinic on Thursday when my mother took the card to the doctor, I went to the nurse and asked her ‘why am I taking these drugs?’ The nurse told me. That’s when I knew about my HIV status. Then when we went back home I had some fight with my mom but all along, I don’t have to blame her for anything. That is all I can say.”

Although this subject was only discussed in one focus group, the research team found it to be very insightful. There is very little research on how adolescents respond after being disclosed to and yet the co-researchers report that the caregivers and parents they serve at the clinic often delay disclosure because they fear how the child will respond.

In our focus groups with older adolescents, discussion arose around the challenge of disclosing to romantic partners. Very few participants shared stories of actually having disclosed to a partner, but had concerns and thoughts about the subject. There were conflicting opinions with some like, Anna, age 17, suggesting that “maybe you have found a boyfriend and you feel shy to disclose to him.” Responding to Anna, Sadiki, age 17, said “I find it difficult to tell my girlfriend of my status because I don’t know how she will react.” Patrick offered “I am not afraid to tell my girlfriend about my status. If she love me, she will accept me.” Although there was no consensus on what, how or when adolescents should disclose to their partners, it was clear that this was a topic the participants were interested in discussing.

Disclosure is a complex term that covers a wide range of experiences from when a young person first learns of their HIV status to when their status becomes known to others. Participants discussed their fears about disclosure, as well as disappointments and what they saw as potential benefits as well. They shared instances of forced disclosure and their feelings about one day disclosing to future partners. One of the difficulties that emerged from non-disclosure was improper adherence to medical treatment.

Challenges with Adherence to Medical Treatment

Medical Treatment for most people living with HIV in Kisumu means that in addition to living a healthy lifestyle with good nutrition and exercise, patients must take daily anti-retroviral medication (ARV) in the from of pills and attend clinic appointments every two months to receive prescriptions refills, run lab tests and meet with healthcare providers. A majority of participants reported that they were adherent, scheduling to take one pill before school in the morning and one after school in the evening. For many students this offered the privacy and structure that lead to successful treatment. Other students reported challenges with adherence.

The first focus group was at an orphanage and participants complained that they needed watches so as to take their meds on time but that the administrators would not supply the watches. They relied on meal times to help them keep track of time, but as one participant pointed out: meals were often served late and furthermore, anytime he left the compound to visit family or go into to town, he had no way to tell time, and therefore took his pills late. The majority of participants reported being adherent most of the time, but expressed high levels of anxiety around keeping time.

In addition to the practical issues raised by the youth at one orphanage, other students reported stigma related issues being the biggest barrier. Since most participants had not disclosed to classmates, friends and even family, taking pills in front of people was not an option. Frequently participants would share comments like this one from Malcolm, age 14:

> The hardest part is when you are with your friends. You don't play with them much because you know sometimes the game can end up to even 6:50 and sometimes the field is too far from your home. So you have to leave the friends to come and take the drugs. And then you miss going to school to take your medication, and some friends will ask you. It's a bit challenging to tell them your status because then they can leave you.

For Malcolm, taking his pills on time became a restriction of his freedom and a burden on his friendships severe enough to invoke fear of abandonment. Jonathan, age 17, discussed skipping medications when he had visitors or friends over:

> Sometimes we find it difficult to take drugs because you find that one or two of your friends has come to visit you and time for taking drugs has reached, so you find it difficult to take because you have not disclosed to them your status. So, you just wait for them and when they will leave is when you will take your drug. So, you find that you have been with them almost an hour and yet you are

> supposed to take your drug, let me say at 7. And you have been with your friends for almost 2 hours. And your time for taking drugs has already past, and so you find it difficult to take the drug when such a friend have come to visit you.

Jonathan was not alone. Participants in many sessions discussed a lack of adherence due to a fear of taking pills in front of guests.

The biggest barrier to proper adherence, however, was school. Students reported having to hide at school, purposely being late or missing school in order to take their pills on time.

> But in the morning I get difficult coz I cannot take drug in school. But in evening there is no problem coz you find that in school – supposed to go to school at 6 and yet I am taking my drugs at 7. So, there is a big challenge for me there. There is a big challenge for me there in primary school. I used to hide when taking my drugs.

Students found ways to adapt. Some changed their medication time, others made up stories about having other, more socially acceptable diseases, such as tuberculosis or malaria, to explain their daily pill taking. One student began camouflaging his drugs so that he would be able to take them at school without others noticing:

> I can just say that to me, it really forces me to mix that drug with water, because sometimes when I know that I am going to be late for the morning class. I just mix the drug with the water and then rush to class and take it. No body will know what I am taking. But to me, I know what I am doing. The reason why I am doing that is to avoid questions. You know there was a time when I tried to hide but I was caught by a student, taking there. He started questioning me: 'What are you doing? And what are those pills you are taking?' I told him that these drugs are for TB.

Other challenges that were less frequently mentioned included fatigue, lack of knowledge and understanding of how drugs work, pills being too big, side effects, and feeling uncomfortable during clinic visits.

There were two primary reasons participants described that made them uncomfortable attending clinic appointments. The first reason was a fear of being seen by others entering the clinic, therefore effectively disclosing their status to the community. Sadiki, age 17, shared: “I think that is true because of the stigma that society relates with the HIV/AIDS. When you are seen coming to the clinic, even if you are not HIV-positive, you are branded as being positive.” The second reason youth want to avoid the clinic is to avoid having to answer the clinician’s questions about their sexual behavior. Many, participants, including Geoffrey, age 17, described his fear of being seen as well as lying to the doctor to avoid discussing his sexual behavior:

> When we go to see the doctor, the doctor will ask you such kinds of questions that can make you shy. For example, the doctor can ask you ‘Do you have a girlfriend?’ and she is a female doctor and she is insisting on her point. So according to me, to make the session go faster, I just tell her ‘No’ so I can go through. And when we go to get our drugs we’re always shy ‘cause you feel that someone might see you and go disclose your status to people outside. Yeah, so that’s the challenge that we face when we go there.

Unfriendly youth services and stigma mean patients avoid clinic appointments and sometimes provide healthcare providers with false information compromising the quality of their care. These challenges were further complicated for participants enrolled in unaccommodating schools.

Lack of Support in Schools

In addition to instances of forced disclosure and problems with adherence, most participants reported misinformation from teachers and a lack of accommodations leading to forced absenteeism. Adolescents enrolled in care at an HIV clinic are usually required to come to the clinic once every two months. As a result, students often miss school. Although most students reported their teachers excused them from class without challenge, some participants reported taking the whole day off of school rather than facing questions from teachers and classmates when they returned in the middle of the day. Finally, in every session, students reported teachers sharing false information about HIV diagnosis, transmission and treatment. This caused fear for some students such as Brandon:

> When I return back from the hospital ward I was coughing a little bit. Then I was afraid of coughing near my friends. Because even sometimes some doctors came to teach about AIDS. They say that if you are coughing for a long time that person may be having it. And sometimes he doesn't have it. Sometimes he has it. So they can think like that but don't tell them. So I was afraid of telling them [I have HIV].

Many participants shared examples, like Brandon's, of HIV lessons including false or inaccurate information about transmission, diagnosis or treatment. This caused a range of emotions in the participants including fear, frustration, and even boredom. Brandon's fear was echoed by George (age 13), "When they talk about [HIV in school, about] when people are going to die, I feel fear." Other students were able to recognize and cope with the misinformation such as Malcolm, age 14:

> In my school, I not telled anyone because when the teacher come into class, when she is teaching us she used to say that 'do not allow the boda boda [motorcycle drivers] to be your friends, they will make you pregnant and give you HIV. If they give you HIV, you will diarrhea and die.' But according to me you don't diarrhea and you don't die. You just living a normal life. It's not one teacher. Several of them, they use the same term.

Geoffrey, age 17, also shared:

> According to me, at our school we have prayer devotion. So we have a madam, with her, according to the HIV theme, she is always harsh on it. Even disclosing your status can even be difficult because the way she speaks about it, its as if its some thing big. Yeah. She says the medicines are always big. When she comes to class she can even discourage you in life. . . . When there's an HIV talk in class or in school, it is just fine. But the way the disease is being discussed by the teachers, they say it is something big. That if you get it – you just die the next day. Coz they say the medicines are always big, like when you take them, they can even remain on your throat. So, I always find it kind of boring...when am in HIV Class.

Inaccurate and false information taught in HIV lessons, whether it inspired fear or boredom, contributed to high levels of stigma.

Not just the teachers were contributing to an environment of stigma and fear. Participants also reported being harassed by their classmates. The examples of peer harassment ranged from persistent curiosity to outright discrimination. Malcolm (age 14) shared this story:

> Even my classmates, when it reach the time when I am not in school. Even before my CD4 was down, they were asking me 'why are you sick every time and you miss the classes?' And they just want to ask me 'you have HIV?' So, sometimes I am, I don't want to sit next to them, because they are just some pupils that keep on asking me up to now – 'what disease are you suffering from?'

Malcolm was not alone in reporting this type of behavior from his classmates. Jonathan (age 17) also talked about stigma among classmates:

> They say that when they heard of someone who is infected with HIV, they cannot be a friend to such a person. And also not to sit near that guy, so it really affects me...It really gives me a lot of stress.

Jonathan discussed the discrimination and violence experienced by some participants:

> I find that when there is an HIV talk, there is some student, student says that when they heard of a person infected with HIV, that guy should not be alive. He or she should be beaten to death because there is nothing that he or she is doing in this life. . . . When there's an HIV talk, you are listening to how they are talking. It gives me a lot of stress.

While it was unclear what motivated students to harass their classmates, it was clear was that teachers never intervened even when the harassment elevated to violent threats.

On the opposite end of the spectrum some student reported interactions with teachers who coddled students with HIV and, perhaps without ill intention, added to the experience of discrimination. Christine explains: "But sometimes they tend to treat you somehow different when they are too careful with you. They don't want you maybe to get upset, they just are too careful with you." This was also reflected when we approached a school to participate in the study. One co-researcher, Jacob, and I went to meet with the administration and were told that although students had personally disclosed to her, she would not bring up the subject of HIV with them for fear of stigmatizing them. We offered counseling and suggestions about how to speak privately to young people about HIV in a way that is empowering so that they can be connected to services, but the administrator was still felt it inappropriate. These actions seemed to be based on a lack of understanding of HIV as chronic disease, further supporting how a lack of accurate information leads to an environment marked by stigma and shame.

In addition to misinformation and stigma, some participants reported an inability to secure an excused absence from class in order to attend clinic appointments. Many participants who reported feeling safe enough to disclose their status to their teachers did not face barriers obtaining permission to miss class. However, as noted above, many participants felt school was not a place they could be open about their status and were therefore forced to lie about their whereabouts. This experience was shared by one of the co-researchers, Slichester, who described faking a different, more socially acceptable illness in order to be excused from school to attend her clinic appointments. But as Malcolm explains in this exchange with co-researcher, Jacob, this did not always work.

> Malcolm: So when I came back to school, I just came with a receipt and tell them I was sick. She [the teacher] keep on asking me. 'You become sick in one day?' <laughter> 'In one day?'
> Jacob: Ok. And she is not seeing you sick?
> Malcolm: So I keep dodging, dodging.
> Jacob: You dodge the teacher?
> Malcolm: Yeah.

In order to not be confronted about his HIV status, Malcolm chose to avoid his teacher. This is an ongoing experience for students who must return to the clinic every two months. Others who described teachers inquiring about frequent absenteeism chose to ignore their teacher, like Jonathan (age 17):

> When reaches my clinic day . . . I just go to clinic, then the following day I just go to school where I am doing my course. Then the person who is teaching there . . . starts asking my some questions: 'Where did you go yesterday?' and 'why were you not in the class yesterday?' I just tell him 'You know what? I was busy, I was doing something at home. That is why I was not able to come.' And he just continues asking some questions: 'What is it that you were doing at home?' I told him that I am the one who knows what I am doing, so there is not need for you to ask coz I am paying my school fees there. He's not the one who [pays for me]. I am the one who goes there. Yeah, so I told him just mind his business and let me do what brought me here. Yeah.

Other participants were not comfortable confronting their teachers in such a way and instead opted to miss the entire day of school rather than face questions from teachers and classmates:

> I always go back to the clinic on Thursdays, so on Thursdays I don't always go to school. Yeah. On Thursdays I don't go to school. And I don't even ask the permission. And when I come back to school, the teacher doesn't even care.

This kind of forced absenteeism even meant some students missed their national exams because they were "too scared of the teacher" to discuss their status and special needs with their teachers. National exams in Kenya are high stakes standardized tests that determine if and to which secondary school students will attend. Missing these exams or even study sessions for the exams can have severe and lasting consequences for the students' academic futures.

Lack of Substance Use

Drug and alcohol use among adolescents living with HIV was an issue of primary concern for the research team, particularly the young adult co-researchers and yet the adolescents we interviewed had reported almost no substance abuse. Walking down the streets of Kisumu it is common to see children sleeping on the corner with a bottle of glue in hand. However, when we asked our participants, only eight out 31 reported having ever tasted drugs, alcohol or cigarettes. With the exception of one older adolescent, the participants who had tasted alcohol or drugs reported only tasting the drug or alcohol once. They described, for example, having snuck a small sip of a beer that was left out by an adult. There was no evidence of substance abuse.

Participants were quick to identify the negative consequences of drug and alcohol use. Many participants discussed the adverse effects drugs and alcohol could have on their health and their future as a reason for abstaining. Brandon, age 14, for example, explained why he abstained from smoking: “I say ‘no’ because if I use it, it will affect my lungs . . . Drugs are not good in our body…” Another adolescent, Tobias, 13 years old, cited the adverse affects on his ARV treatment: “I have never used them because they can cure my [ARV] drugs so they cannot work.” Other adolescents would sometimes list negative consequences such a violent behavior or criminal activity that they associated with substance abuse. “Those drug takers, they think negatively. They think to go and steal and rape girls,” reported Sakina, age 13. For the most part, (2 interview sessions went on for so long that, based on previous data, researchers decided to end the session without asking about drugs) drug and alcohol abuse was either not reported not dicussed among the adolescents in our sample.

Coping Strategies and Hope

Despite reports of fear, stigma, isolation and a general lack of support at schools, participants expressed an immense sense of hope for their futures. Every participant expressed a sense of resilience and optimism, even those who also reported having experienced the most extreme forms of stigma. Some of this optimism seemed to be a result of the support youth receive from their HIV Clinics or other youth centers. When asked to explain why she liked to going to the clinic, Sakina, age 13, said "this is because we always have a group that encourages people. Where if you are HIV positive, you feel good."

Others find love and support from their family such as Geoffrey, age 17:

> All I can say is that the discrimination part is always there and you can't- there's nothing that can be hidden forever. So one day your status will be known in the community. So you just have to ignore that. So according to me, I don't care what they say, coz what matters to me is the support from my family. . . According to me, what I can say is you just have to live positive. Remain positive. Everything that you do, you just remain positive. Be a positive person in everything that you do.

Participants described various strategies, some previously mentioned, to help them cope with stigma. Malcolm helped his focus group keep perspective by stating, "I want to say that stigma is not only in Kisumu. Its worldwide." Others responded by avoiding people or places where stigma was rampant: "I handle stigma by avoiding those people who are negative, who are have negative attitude towards people living with HIV. I know myself and I have the information, so I avoid them." Others use humor:

> They say that if AIDS catch you, you die... Even in class 6, a teacher told us that when it catch you, you reach at the age of 20 and you die. But as I was taught you can live as long as you are taking your medication. So, even the pupils adopt those issues of the teachers. . . . And even if you ask them 'What causes the disease HIV?' - they will tell you the saliva. And you know in school people share

> one ice [snack], so I wonder <laughter> why don't they get the HIV? <laughter from the group>.

At the end of each interview or focus group youth were asked about what message they would like to send to other young people living with HIV. Participants offered words of encouragement like Abdul (age 13):

> I would like to tell the other youth that it's not your fault that you are positive. Even if it is your fault, just learn to accept it and have the will to live. Take your drugs as prescribed and life is just the same as the other person who is negative. There is nothing different.

Abdul's sentiment was echoed by almost every participant. Although the participants experienced fear, shame and anxiety, they also maintained hope for their future and the future of other young people living with HIV.

Our evidence suggests that collaboration between providers is important for youth health and well being, that adolescents who tended to be involved in activities with other HIV-positive youth had higher self-esteem. Based on our observations in addition to the transcripts, youth that were well connected to multiple agencies (schools, clinics, orphanages) with multiple points of support which included activities with other HIV-positive youth, tended to have lower levels of self stigma, anxiety and fear. Our study did not go far enough in exploring this notion and further research into the increased self esteem and health outcomes of adolescents living with HIV should be conducted.

Summary of Findings

Forty adolescents living with HIV shared their personal experiences with stigma, substance abuse and attending school. From their stories emerged six major themes that describe a community still struggling with stigma and the heavy burden adolescents face living with a closely guarded secret. Schools and clinics, meant to be places young people can feel safe, are often sources of anxiety and fear. And yet, the participants all shared a common vision for a hopeful future for themselves and their communities.

Actions

Through a process of reflection and discussion during our research meetings as well as debrief sessions after each interview or focus group, the team came up with three main actions to improve conditions for adolescents living with HIV in Kisumu. The actions were: (a) follow up with individuals and sites, (b) a Teacher Sensitization Workshop, (c) share the knowledge we generated locally and globally.

Follow up with Individuals

The research team began strategizing their action plan as soon as the first focus group was completed. There was a clear need for follow up with the individuals in the group with regard to helping them understand their ARV medications and also in communicating with the orphanage administration some of the issues brought up by the youth. This continued after each individual interview or focus group. The interviewer and observer would bring back their concerns to the reach team and we would reflect and decide a course of action as a team. Actions ranged from following up with their social worker, to making requests on a participant's behalf to the orphanage administration, to providing education sessions on HIV/AIDS.

Our first educational session was scheduled for a week after the focus group. The co-researchers who had conducted the focus group returned with me to the orphanage to provide a session on disclosure and ARVs. We gathered the participants and found a small, private room and led an open discussion about disclosure. Each participant took turns sharing experiences with disclosure as well as fears about how people might react upon hearing their HIV status. The participants were very interested in discussing the process of disclosing to their boyfriend or girlfriend. Their responses ranged from complete rejection of the idea that they would ever have a partner or ever disclose, to a more hopeful envisioning of the future with a family that knew and accepted their status. The participants asked if the researchers would share their HIV status. One of the co-researchers at this session was living with the virus and volunteered to share his experiences disclosing his status to friends, family and sexual partners. The participants were very engaged during this part of the session, but some still expressed doubt that they could also one day live as openly with the virus.

We returned a second time to the orphanage, this time to share with the group an educational video that explains how HIV attacks immune cells and how ARVs work to prevent the spread of the virus in the body. A co-researcher facilitated the session and provided the video that he had used in previous education sessions at the clinic. In debriefing with the co-researcher, we both agreed that that was most likely the first time any adults had tried to explain how their drugs worked and how the virus worked. We both also agreed, based on our experience working with young people living with HIV, that understanding how the medicine works helps keep patients motivated to take their pills.

Our final intervention with this orphanage was to send our recommendations to the administration. We suggested that watches be provided for the youth living with HIV, that the lists of who is living with the virus be kept private, even in the nursing office. I also shared local resources for the staff to educate themselves about HIV as well as connections to local organizations that could provide ongoing support for the youth. The nursing staff dismissed most of our suggestions over email, but the administration remains open to our return for future education sessions.

Our interventions at other sites were less robust as the youth expressed less immediate need for intervention during the session. The team, for example, would follow up with the social worker or clinician to make sure they were aware of issues that may have been brought up in the session. At another orphanage, the youth opted to participate in individual interviews, but upon reflection, the co-researchers realized that while one of the youth expressed severe self-stigma, the other, older one was well adjusted. We wrote to the director and suggested that he consider introducing the older boy as a mentor to the younger one. We offered our services to help with this since if done without care can result in forced disclosure and violation of trust.

Teacher Sensitization Workshop

At the final meeting, after discussing our findings and reflecting on the entire process, the team decided that the issue that disturbed them the most was the misinformation and maltreatment some students had experienced at school. The researchers also noted significant misinformation with the staff at orphanages and some reflected on their personal experiences as a student living with HIV. The team found inspiration in the words of the participants themselves: “Teachers should be counseled and given more information about HIV first because some does not know how to teach the topic” and “When HIV topics are taught, I feel like self-stigmatized and I think some teachers should be taught more on how to teach on the things that affect us as people living with HIV.” The team decided to design and offer a Teacher Sensitization Workshop that could also easily be modified for orphanage staff as well.

During our final meeting, the team discussed how they envisioned the teacher workshop and particularly how they eventually saw it fitting into a larger project with student workshops. The co-researchers began brainstorming a list of potential schools that would be open to allowing us to do such a workshop. Finally, we set a tentative timeline for workshop to be delivered in February 2014. Since I would not be in Kisumu to help facilitate the workshop, I took the responsibility to write the curriculum. I then submitted a draft to the team for review and incorporated their feedback. In April 2014, we had a completed curriculum packet with facilitator instructions, pre and post evaluations for participants, and an accompanying slide presentation, a copy of which is included in appendix A. We have also designed a draft of an interactive workshop for students. Two research team members along with another coworker piloted the teacher workshop in the end of April 2014. Although the workshop was only delivered to a small group of seven teachers, the workshop was well received and the teachers have asked for the presenters to return and continue to work with students and the other faculty on issues of HIV education and stigma.

This workshop and the accompanying curriculum for students has been well received by medical colleagues in the community as well. This interest from the medical community in addition to community education being an established part of the Sunshine program mean that this workshop will most likely continue to received support. The co-researchers have plans to continue to refine the curriculum and deliver it in schools in the community.

Sharing Knowledge

Finally, the research team decided that sharing this new knowledge with the community was important. Preliminary findings were shared with each of the participating sites through face-to-face meetings and email communication.

The team is also applying to various conferences, local and international. For example, Lucy and I applied to present at a major international AIDS conference and were both accepted to present at a poster session. Additionally, I was able to share our findings at the Comparative International Education Society's annual conference in Canada. We have also applied to other conferences and will continue to seek out audiences willing to dialogue about the needs of adolescents living with HIV.

CHAPTER V:
SUMMARY, DISCUSSION, RECOMMENDATIONS AND CONCLUSION

Summary

In 2011, 2.5 million people were newly infected with HIV, of whom 41% were young people (Masquillier, et al., 2012, Avert, 2012). As discussed in Chapter II, traditional research and response to the epidemic has largely failed in Sub-Saharan Africa, home to almost 70% of HIV cases on the planet (Avert, 2014). Responding to the failure to curb new infections or adequately meet the needs of young people infected with HIV, this study sought to explore the experiences of adolescents living with HIV in Kisumu, Kenya, using a Participatory Action Research (PAR) approach. PAR is a framework that challenges traditional research methods by placing value on contextualized expertise and by engaging those most affected by the research problem in the process of inquiry. For this study, four young adults were recruited to design and conduct qualitative research to explore the experiences of adolescents living with HIV. Through a collaborative process, the research team generated three categories of inquiry (stigma and discrimination, school, and substance abuse) and developed tools for data collection. Through interviews and focus groups, the team collected data from 40 adolescents living with HIV. The research team identified six major themes: (a) prevalence of self-stigma; (b) challenges with disclosure; (c) challenges with medical treatment; (d) lack of support in schools; (e) lack of substance use (f) coping strategies and hope. This chapter provides a discussion of these findings and the methodology as well as recommendations for practice and future research.

Discussion

Youth Agency

Our project began with the broad research question: What is the experience of adolescents living with HIV in Kisumu? We can now begin to describe the experience of adolescents living with HIV as one marked by fear and isolation, but also characterized by hope and resilience. Although enticing, we must resist the temptation to cease our analysis at this binary and flat conclusion. Chandler (2011) and Bajaj (2008) dismiss the common perception of African youth as merely victims or menace/risk-takers when it comes to understanding their experience with AIDS. Both authors also describe a more optimistic, yet equally simplistic popular categorization of youth as “the solution” or the “window of hope.” Instead, both authors call for a complication of the ways in which policy makers, researchers, and activists understand and describe youth.

Participatory Action Research provided a framework that utilized this concept of youth agency and encouraged the recognition of the complexity of our participants. Similarly, critical theory guided our approach and design, but also our analysis, encouraging us to critically examine the institutions included as research sites within this study.

Gill (2000) writes “our challenge is to find a meaningful way to hold together at once two or more irreconcilable positions and to do so without smoke and mirrors and without forced or too easy difference-denying solutions” (p. 451). Answering the call of Bajaj and Chandler to move beyond simple dichotomies, we recognize these young people comprise a complex and heterogeneous group, neither fully one nor the other, nor a harmonious compromise of the two, but existing in a dynamic tension consisting of many elements in complex relationship to one another. To understand and frame the complications and contradictions in our data, we move away from simple binary structures and choose to present youth as complex beings, living dynamic lives over which they exert some control. "Notions of 'control' and self-determination are important components of agency given the simultaneous construction of African youth as victim" (Bajaj, 2008, p. 3090). For example, the young man who spoke about mixing his pills with water is not a victim, and yet we cannot fully embrace him as an activist. We understand his actions and motivations as occurring within institutions and as him finding his own solutions, carefully crafting defenses and taking control of his medical treatment and his persona in school. Refusing to subject himself to ridicule, refusing to compromise his health, he forged a new path on his own. Within each example of oppression and victimization there are glimmers of control, defiance and self-definition. Most of our youth told stories of oppression, fear and isolation. And yet, it is clear that the will to thrive is in abundance among adolescents living with HIV in Kisumu.

Youth Driven Solutions

The participants in this study provided their ideas for solutions to two important challenges: the great number of adolescents lost to follow up and the high levels of stigma in schools.

This study was initiated in response to the high number of young people living with HIV who are lost to follow up at the clinics in Kisumu. According to the organization overseeing the clinics, 60% of youth fall out of care (FACES, 2012). In two of the focus groups, participants discussed friends or classmates who were lost to follow up, had stopped taking their medications and were no longer receiving care at a clinic. In both instances the participants were worried about their friends' health and wanted to help reconnect them to care. This is a significant finding. Recognizing adolescents as active members in the community with social networks that can be utilized to bring other adolescents back in to care has not been explored. Heeding the advice of Chandler (2011), we reject negative stereotypes of young people but do not remove responsibility from adults. Instead we suggest that we work in partnership and begin by incorporating their ideas and perspectives into programing. The fact that this potential solution was generated by the youth themselves provides credibility to PAR as a worthy endeavor capable of producing useful knowledge and realistic solutions.

The participants generated similar solutions to the challenges they faced at school. Schools are meant to be a place of learning and community. The adolescents we talked to described schools with hostile environments where false information was provided about HIV/AIDS. Through these discussions they demonstrated their agency and suggested solutions. In a community that places such high value on the words of elders, young people were not afraid to recognize when their teachers spread false information. Although they are not publicly defiant, they refuse to allow themselves to be defined by stories of diarrhea and death. When young people joke about their teachers' ignorance, they tell us stories of their oppression but simultaneously make statements of defiance. Kamau (2012) and Birungi, et al. (2011) both conducted studies on the experiences of HIV-positive youth in school and their findings were aligned with ours. Students experience stigma and discrimination at school that prevents adherence to treatment. Students report that HIV education is misleading and frightening. Bajaj (2002) found that HIV-negative students in Zambia also reported teachers often provided misleading and false information about HIV/AIDS. The participants in our study, as detailed in Chapter IV, provided the research team with ideas for action. The adolescents recommended that their teachers be provided with quality and accurate professional development on HIV/AIDS. Again, for this to be a successful remedy to the problems presented by our participants and in other studies, there will have to be a collaboration between youth and adults, but the practical and reasonable nature of the students' suggestions is noteworthy.

Disclosure

This study's most important contribution to the psychosocial aspects of pediatric HIV is found in the experiences and reactions of young people post-disclosure. Turissini et al. (2013) in their study on disclosure among children in Kenya reported that of the few children that were aware of their status, none reported experiences of depression or experiences of stigma post-disclosures. In their recommendations, they called for additional research that seeks to measure "stigma, social isolation, or discrimination experiences after disclosure" (p.141). Our research begins to fill this gap in knowledge by exploring post-disclosure issues among adolescents.

There is overwhelming research that shows parents and caregivers often delay disclosing to their children because they fear their children's reactions (Brown et al., 2011; Mahloko & Madiba, 2012; Madiba & Mokwena, 2012; Obermeyer, Baijal & Pegurri, 2011; Vaz et al., 2008; Vreeman et al., 2010). There is also research that demonstrates that young people are healthier and more adherent when they have a full understanding of their diagnosis (Brown et al., 2011). The participants in our study complained that their caregivers had waited too long to tell them their status. They also demonstrated through their stories and comments that they continually negotiate their acceptance; some embraced their identity as HIV-positive while others were still struggling. The majority also had questions about their health, treatments, and futures. They advocated for early disclosure, continued support, and education about their disease and its treatment.

Another reason often cited by parents for not disclosing to their children is fear that the children will tell other family or community members, which in turn can lead to discrimination (Vaz et al., 2008; Vreeman et al., 2010). Our findings show that adolescents closely guard the secret of their status and are very strategic about whom they share that information with, preventing opportunity for discrimination and giving parents less to worry about. Although there were instances of forced disclosure, many participants described how they asserted their agency by carefully strategizing about their disclosure process. Young people actively create meanings and define relationships, separate from what is presented to them by institutions and the adults in charge. When young people shared their stories of disclosure, they are in a sense sharing an act of defiance. They are risk-takers, but not in the sense they have been constructed to be – wild and hyper-sexed, refusing condoms as Chandler described (2011). The participants were strategic. Brandon did not share his HIV-status with his classmates by accident or on a whim. He chose to share his status in order to strengthen his friendship. He recognized that the accommodations made for him at the orphanage caused him stand out and could cause tension in his relationships. He prioritized his friendship and took a calculated risk.

The young people we interviewed self-defined in the face of false information and re-designed their treatment in order to accommodate their life circumstances that the adults in charge would not hear. Young people strategically map out how to negotiate relationships and dare to envision a future that defies what they are told in school. They have solutions already crafted and deserve to be heard. PAR provided the framework that allowed the research team to amplify their voices.

Reflections on PAR

The choice of PAR as an approach to explore the experiences of adolescents living with HIV brought some challenges, but also many rewards. Including local and contextualized expertise in the design and implementation of this study allowed us to explore new topics and have greater access to the population. The co-researchers themselves noted that they were not interested in asking the adolescents about their sexual activity because "that's what most researchers do." Instead they focused on a topic not in the literature at all: substance abuse. Although we didn't find drug use to be a significant problem with the adolescents we interviewed, our sample was very limited and only included adolescents living in or under the care of institutions. We hypothesize that youth outside of institutions are more likely to struggle with substance abuse and recommend further research into this issue.

Another benefit was that we were able to conduct focus groups and interviews with non-English speaking adolescents because most of the research team was trilingual. Although this was not tested, the team believes that the adolescents were more open and willing to share their personal experiences with the co-researchers who were close to their age, spoke their mother tongue and were from their community. The team felt so strongly about this that we decided that as an older, white American, it might be best for me not to observe all the sessions.

Working with a team of young researchers offers many moments of joy and brings energy and excitement to the discovery process. During a workshop the team was presenting at the clinic as a part of their regular work duties, one of the co-researchers leaned over to me while the participants were in a deep discussion about working with families affected by HIV. He whispered, “We should be recording this! This is good data!” Jacob had learned to recognize important data when he heard it! He also realized that we had not obtained consent and therefore could not just start recording, but as an educator and researcher, I was excited to see such enthusiasm in my co-researcher.

Duncan-Andrade (2007) argues it is “important to have the voice of practitioners be heard in the discussion” (p.618). Although he is writing about teacher effectiveness, this PAR study demonstrates the importance of practitioner participation in the discussion of effective youth development and health programming. Through the PAR process, the co-researchers, who were also frontline staff at HIV clinics, were able to infiltrate the conversation on adolescent care, a conversation normally dominated by foreign adult experts. This resulted in four important and interrelated outcomes. First, the co-researchers were able to form a better sense of where their work fit into the larger community. They observed and learned about other approaches to adolescent health through our site visits and meetings with administrators. They were able to understand the position of their work within the community and make comparisons. Second, engaging in inquiry allowed us to reflect on our own practice and encouraged us to critically examine our understanding of the issues we were working to combat. Third, working collaboratively with stakeholders offered opportunity to build a collective framework that helped us to more effectively confront issues that are bigger than just our program. Although their job description always included community education as part of their regular duties, the focus on schools in this study helped us to build better tools and expand our work. Additionally, the relationships we built at the research sites have continued and the team looks forward to collaborating with all of them in the future. The final result was increased confidence and higher self-esteem for the co-researchers. Realizing the quality of the programming they helped design was truly empowering. This came mainly through their observations at other sites. Interacting with young people living with HIV that had no knowledge of the virus or the medications they were taking upset the research team, but at the same time helped them to grasp the importance of the work they did with young people at the clinic. They felt good knowing that the youth who came through their program knew about their bodies, the virus, and their ARVs.

And yet, with PAR we run the risk of doing none of this. PAR does not guarantee enlightenment and transformation and comes with many challenges. For example, we experienced a great deal of trouble gaining access to certain institutions because the gatekeepers were unfamiliar with PAR. Additionally, as the lead researcher with the most academic training on the team, I expected my co-researchers to be interested in reading and writing activities. This was not the case. Instead, and in line with local tradition, my co-researchers much preferred in-person and face-to-face discussion and reflection. And although to me it seemed less rigorous and academic to analyze our data through dialogue, the results were nearly the same as when I reanalyzed with a more traditional reading/coding process. “Rigor panic” (Fine, 2007) had set in and it took a while for me to re-realize that knowledge *can* be generated through dialogue.

Although there were moments of joy, I also experienced a lot of disappointment and anxiety about whether I was doing PAR “right.” As I described in my journal at the very start of the project:

> There are a lot of crazy thoughts that go through your head when you don’t see the same enthusiasm you have for a project displayed on the faces of your potential co-researchers. This should not be a shock. Other scholars have pointed this out. But I was still emotional and disappointed and then started thinking what I would do if 2 years into this project and zero peer leaders wanted to participate!” (Sep 11 2013).

These feelings continued throughout the project and were especially acute when my research team expressed no interest in engaging with the readings or writing assignments I had prepared. I often wondered if I was failing as a facilitator and if our study was going to prove academically rigorous enough. Towards the end of the study, with little time remaining and still a number of focus groups to conduct, I sensed fatigue. Transcripts from the final interviews show that my co-researchers hurried through the interviews, missing opportunities to ask follow up questions and clarify, compromising the data.

And yet, as described in Chapter III, during our mock interviews, my co-researchers demonstrated their profound understanding of the ethics of research. Through their role-play scenarios, they acted out much of the theory I had been trying to coax them into reading. In reflecting on this moment, I fully understood PAR and the meaning of contextualized expertise. I needed to read these books and have anti-colonial theory explained to me. My co-researchers on the other hand, already understood the exploitation and disempowerment - they lived it. And they saw it play out daily in their clinics, with their youth, and with foreign researchers like myself. My rigor panic had in some ways blinded me to the very realities that inspired this PAR project in the first place.

Experiences like this also reinforced the power dynamics of our team. Although they were receiving stipends for their time and letters of recommendation that are valuable and difficult to obtain in Kenya, the benefit for me was much greater. While I worked hard to get them raises and scholarships and teach them skills that would be useful in their future careers, the benefits were not equal. At times it was clear by their side comments and attitudes that they were doing this for me. Especially towards the end of the project when they were tired and didn't quite feel the same sense of urgency I did, I could tell they were seeing the project through as a favor to me. We had been working together for more than 2 years when we started this project and had an established relationship, not one of equal power, but one of trust and respect and I believe that is the only reason we were able to complete this project in such a short amount of time.

Additionally, there are cultural considerations to examine when conducting international PAR. Although the power dynamics of the research team were generally marked by typical distributions of power along race, education level and country of origin there are notable exceptions when conducting projects internationally. At times, I was completely reliant on the co-researchers. I needed them to complete the project, but also to help in my daily survival living in a new place and new culture. Differences in culture also presented new opportunities for discussion, cooperation and compromise within the team. We were forced to find common ground on how we conducted and scheduled our our meetings, finding a place in between the American need for punctuality and the Kenyan need for flexibility. We found ourselves exploring new territory between

Western Academia and local values on oral traditions and dialogue as important forms of knowledge production. Conducting cross cultural research forces another layer of reflection on the research process and ultimately leads to greater personal growth on the part of the researchers in addition to strengthening the validity of the study.

PAR as a dissertation, if anything, stunts its potential. PAR should be a continuous spiral, a constant journey of action, reflection, education and inquiry. My co-researchers will continue in their daily struggle to ensure the health and well-being of young people living with HIV. With the research officially over, however, I do not expect them to continue with the same level of inquiry and critical reflection.

Like with our understanding of youth as complex beings, we come to the completion of this project with a complex understanding of PAR and its value. It cannot be The Solution, but as Koirala-Azad (2009/2010) writes, PAR is a tool to be used in the larger struggle to un-conceal marginalized realities, help us make sense of the suffering in the world, and than do something about it.

Recommendations

Research

Like Kamau (2012) and Birungi, et al. (2011), we recommend that teachers receive training on HIV and we add that experiences of young people living with HIV must be central to the development of the curriculum. We agree with Campbell and Macphail (2002) that “HIV education programs should encourage development of young people’s autonomy, and the capacity for critical thinking” (p.342). We argue that schools must become stigma-free zones if students are expected to thrive academically, socially and maintain their health. We further recommend that research be conducted on the experiences of teachers and administrators in relation to HIV and HIV education if schools are to become supportive environments for all students.

Our evidence suggests that collaboration between providers is important for youth health and well-being. Additionally, adolescents who tended to be involved in activities with other HIV-positive youth had higher self-esteem. Based on our observations in addition to the transcripts, youth who were well connected to multiple agencies (schools, clinics, orphanages) with multiple points of support which included activities with other HIV-positive youth, tended to have lower levels of self-stigma, anxiety and fear. Our study did not go far enough in exploring this notion and further research into the self esteem and health outcomes of adolescents living with HIV should be conducted. Additionally, instruments designed to measure self-stigma among adolescents in Sub-Saharan Africa should be developed.

Although we didn't ask any questions about violence specifically, violence – either in the form of rape, physical assault, or abuse was mentioned nine times in six out of ten sessions. The effects of violence on the psychosocial well-being of young people living with HIV in Sub-Saharan Africa should be further explored.

Finally, this study began to address the gap in literature concerning disclosure from the perspective of young people, but we advocate for continued research into this issue and for youth voices to become central in the discussion. Additional research on the experiences of children with disclosure is also needed.

Practice

Many participants were struggling with the death of their parents or other family members and expressed anger or began crying when this topic came up in our sessions. Again, our data on this issue was not enough to draw any conclusions, but we believe it is an area worth investigating in the future and certainly that programs serving young people living with HIV should take into account the needs youth might have around loss and grief.

As mentioned previously, adolescents who had multiple points of contact with supportive adults and HIV-friendly services were more likely to appear confident and had higher self-esteem. Agencies should continue to work together to provide holistic care for adolescents, coordinating information about patients/students and collaborating to provide accurate and effective care. Schools and clinics should work together on ensuring adolescents are able to attend clinic appointments and minimize their absence from school. Although it is popular in Kenya for schools to require students come to class on Saturdays, some clinics have found success retaining adolescent patients by offering services on the weekend. Clinics can also do their part by working to streamline the patient experience. It is not uncommon for patients to wait for hours for their turn to see the clinician. Students should be given priority to be seen first and then quickly sent back to school. Schools can also play their part and work with clinics to bring accurate information about HIV into the classrooms. Bajaj (2002) suggested that in order to address the issues of misinformation about HIV in schools, professional health care providers with expert knowledge of how HIV is experienced in the community should be encouraged to visit schools and provide supplemental information. Schools can also be more accommodating about allowing students to be excused from class without harassment.

Finally, we recommend that the participants' ideas for solutions should be tested. We started implementation of their recommendation for teacher trainings and recommend that this be continued in other contexts with youth input being built in along the way. Additionally, we recommend that clinics with high numbers of youth who are lost to follow up should work with young people to locate and re-engage young patients. Finally, we agree with Bajaj (2008) that "more inclusion of [youth] voices, experiences, and cultural forms could have a greater impact on promoting safer behaviors" among youth and recommend that youth be involved in the creation of HIV prevention messages and curriculum that promotes behavior change (p.324).

The co-researchers have helped design programs at their clinics to address disclosure. They offer counseling to parents and caregivers of young children living with HIV, providing advice and guidance through peer support groups on how to broach the subject of HIV with children. The co-researchers also facilitated their first workshop designed to encourage social workers and clinicians to work with parents on disclosure, focusing on supporting families through the entire disclosure process. Additionally, space for the adolescents to talk with each other about their experiences and fear around disclosure is offered. These programs need to be expanded, but also evaluated. I recommend that the disclosure programs be evaluated through longitudinal studies that examine the relationship between delayed disclosure and adolescent patients that become lost to follow up.

Conclusions

Chandler (2011) writes that there is not one monolithic “youth” that are either the solution or the victim and that stakeholders (parents, providers, funders) share responsibility and must work in partnership toward more effective programming for young people. PAR offers us a framework for engaging young people in the process of inquiry, knowledge generation and ultimately the actions, policy recommendations and program designs that can have a real impact on their health, education and well-being.

Harding (1987) argues “elite interests, have for too long, masqueraded as scientific objectivity” (as quoted in Fine, 2007). The very purpose of PAR is to un-cover realities through the recognition of contextualized expertise and give power to counter-narratives. Unconcerned with traditional generalizability and the search for Objective Truth, we are instead concerned with multiple and contradictory truths found within the local and immediate context. At the same time we refuse to deny that our experiences can offer insight or comfort to others in other contexts. Knowing that we are both and simultaneously global and local, that there are multiple truths that can offer enriched understanding our complex world, we hope that others will experience “moments of generalizability” (Fine, 2007) in recognizing the experiences uncovered in this study, but also be provoked to listen to the stories young people living with HIV have to share.

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APPENDIX A

Interviewer: Date:
Observer: Voice Recorder File Number:
NGO/Orphanage Name:

Focus Group GUIDE
GROWING UP WITH HIV IN KISUMU, KENYA: PARTICIPATORY ACTION RESEARCH WITH YOUNG PEOPLE LIVING WITH HIV

Introduction

Good day. I am………and my colleagues are…………. We are from………..and we are here to learn about the experiences of HIV-positive adolescents living in Kisumu. The objective of this study is to explore the experiences and needs of adolescents living with HIV. We have invited you because of your experience as an adolescent living with HIV. We will talk to you for about 1 hour. Participation in this discussion is voluntary.

In this discussion, every answer is correct. Every opinion is important and should be freely expressed. What we will learn from you today will be useful in the future in strengthening the interventions and programs meant for adolescents living with HIV. We wish to request permission to take notes and to tape record the conversation so as to ensure that we do not miss or misinterpret any of your views after the discussion.

This conversation can be conducted in any language you feel most comfortable in and you can always ask for clarification in another language.

Some of the things we will discuss are personal and private. We will keep your identities confidential and we ask that you all do the same. Please do not repeat anything you hear in this discussion. To help protect your identities, we ask that you choose a number to represent yourself. When speaking, its very helpful if you can say your number before you speak.

Confidentiality is one of the rules for this discussion. We also kindly ask that everyone respect each other. Please do not talk over each other. You can raise your hand if you want to add something. Please turn off your cell phones.

Today we will be asking questions about Stigma and Discrimination, Drug and Alcohol use, your families, and your experiences at school. Remember that you do not have to answer any questions that you do not want to and that you can always ask questions or for clarification.

Do you have any questions before we begin?

Interviewee	#1	#2	#3	#4	#5	#6
AGE						
Gender						

1. First, please tell me how long you have been living here at ________________________?

#1	#2	#3	#4	#5	#6

2. Can you each tell me a little bit about your families? (Probe for orphan status)

#1	#2	#3	#4	#5	#6

Thank you. Now we are going to talk a bit about your experience at school.

3. Are you currently in school? If not, why? If so, what class are you in? Or what was the last class you completed? Day school or boarding school?

#1	#2	#3	#4	#5	#6

4. How is or was your performance in school?

#1	#2	#3	#4	#5	#6

5. How did you find school generally? (How do you find school?)

#1	#2	#3	#4	#5	#6

6. Have you disclosed to anyone at school? Who are they and how did it go?

#1	#2	#3	#4	#5	#6

7. Was/Is there support for youth with HIV at your school? Are/Were there HIV Clubs?

#1	#2	#3	#4	#5	#6

8. Have you experienced stigma at school? Please describe.

#1	#2	#3	#4	#5	#6

9. How do you take your meds at school? At the Orphanage?

#1	#2	#3	#4	#5	#6

10. Are/Were you able to keep your clinic appointments when they are scheduled during school? Are/Were you able to get permission to leave? How did you travel to the Clinic?

#1	#2	#3	#4	#5	#6

11. Is/Was there peer pressure at your school? To have sex? Do drugs?

#1	#2	#3	#4	#5	#6

12. What happens(ed) if you become sick at school?

#1	#2	#3	#4	#5	#6

13. What is/was P.E. like at your school?

#1	#2	#3	#4	#5	#6

14. How do/did you feel when HIV is/was taught at school? Tell us about the lesson. What did you like about it? What would you change?

#1	#2	#3	#4	#5	#6

15. What are meals like at your school? Do you have access to special meals? Can you describe?

#1	#2	#3	#4	#5	#6

Thank you for telling me about your experiences at school, now we want to hear a bit more about stigma and discrimination….

16. Sometimes when adolescents come to the clinic, we notice them acting shy and like they don't want to be seen. What is this about? Is that true for you?

#1	#2	#3	#4	#5	#6

17. We spoke about how do you experience stigma and discrimination at school, what about at home? At church? In the community? Can you describe an incident when you experienced stigma or discrimination?

#1	#2	#3	#4	#5	#6

18. In general, how bad do you think stigma in Kisumu is? On a scale of 1-10? Do you think its getting better? Have there been improvements?

#1	#2	#3	#4	#5	#6

19. How has it affected you? (Do you think it makes taking your ARVs more difficult? Do you think it makes going to school more difficult?)

#1	#2	#3	#4	#5	#6

20. How do you handle stigma and discrimination? (Coping Skills)

#1	#2	#3	#4	#5	#6

21. Do you have a support system? Who?

#1	#2	#3	#4	#5	#6

22. How many people have you disclosed to? Who are they? What was there reaction?

#1	#2	#3	#4	#5	#6

23. What role do you think the media plays in contributing to or eliminating stigma?

#1	#2	#3	#4	#5	#6

Thank you for sharing about your experiences with Stigma, I would now like to ask you some questions about drug and alcohol use.

24. How you ever used drugs or alcohol?

#1	#2	#3	#4	#5	#6

25. If so, what kind? How much? How often?

#1	#2	#3	#4	#5	#6

26. When did you first use drugs/alcohol? What circumstances led you to try it?

#1	#2	#3	#4	#5	#6

27. How do you usually get drugs/alcohol?

#1	#2	#3	#4	#5	#6

28. If not, why not?

#1	#2	#3	#4	#5	#6

29. Do you smoke cigarettes? Have you ever? How many? How often?

#1	#2	#3	#4	#5	#6

30. Does anyone in your family use drugs or alcohol?

#1	#2	#3	#4	#5	#6

31. What role do you think the media plays in adolescent drug/alcohol use among youth? Adults?

#1	#2	#3	#4	#5	#6

32. What role do drugs and alcohol play in your decisions about sex?

#1	#2	#3	#4	#5	#6

Thank you so much, one more final question

33. What do you see for your future?

#1	#2	#3	#4	#5	#6

Thank you very much for your time today. Do you have any questions for me?

Once again, thank you!

GROWING UP WITH HIV IN KISUMU, KENYA: PARTICIPATORY ACTION RESEARCH WITH YOUNG PEOPLE LIVING WITH HIV

Interviewee	#1	#2	#3	#4	#5	#6
AGE						
Gender						

DESCRIPTIVE *describe participant, dialogue that is happening, the physical setting, notes from interview*	**REFLECTIVE** *your personal thoughts, feelings, ideas, reactions, impressions,*
Schooling	
Stigma & discrimination	
Drugs & Alcohol	

APPENDIX B

Teacher Sensitization Workshop:
“Understanding HIV in Your Classroom” (2 hours)

Summary: The purpose of this workshop is to give teachers access to accurate information about HIV and about how to better support students in their classrooms that are living with HIV. This is part of a larger project to help schools become Stigma Free Zones. Please see the accompanying Student Workshop for more information.

Note to Facilitators: A powerpoint presentation is attached as well as hand outs and activity supplies.

<u>Ice Breaker (10 minutes):</u>

Each person is given a card with question about HIV. The goal is to find someone in the room you do not know, introduce yourself and then ask the questions on your card. After hearing their answer (and allowing them to ask you their question!), switch cards and find a new partner.

After about 5-7 minutes, have everyone return to their seat. Ask if anyone was surprised about some of the answers they heard. Did they learn anything new or interesting? Did anyone know all the correct answers? Tell participants that we will be providing more information in this workshop a little later.

<u>Introductions (10 minutes):</u>

Introduce Sunburst Projects/FACES and presenters

Overview of workshop and motivations for our presentation

- Research conducted in October 2013 shows that many students with HIV experience discrimination in school. This supports other limited research on this topic.
- The purpose of this workshop is help teachers
    1. Get the FACTS on HIV
    2. Learn how to accommodate students living with HIV
    3. Learn how be an ally

Take a Stand Activity (20 minutes)

Place a sign that says YES on one side of the room, a sign that says MAYBE in the center and a sign that reads NO on the other side.

Have students all stand in the middle of the room. Tell students that you are going to be reading a series of simple questions. They are to answer the questions for themselves by moving to the side of the room that corresponds with their answer. This activity is done in complete silence with only the facilitator speaking.

Read the following statements aloud. Pause between each one and ask the student to look around and observe where their classmates are.

1. I know what letters in HIV stand for.
2. You can get HIV through unprotected sex with someone who has HIV
3. You can HIV by sharing food with some who has HIV.
4. You can if a person is very thin and coughing a lot that they have HIV or AIDS.
5. HIV can be passed from mother to child
6. Mother to child transmission can be prevented.
7. I would rather not sit next to someone with HIV.
8. HIV is a death sentence.
9. I have been tested for HIV
10. I know someone with HIV
11. I know someone who has died from AIDS related illnesses
12. I someone who has been discriminated against or treated badly because of their HIV status
13. I have felt lonely before
14. I have felt different, or like I don't belong
15. I believe that people living with HIV have rights just like HIV-negative people
16. Telling another person about someone else's HIV-status is wrong.
17. I have spread rumors about people with HIV
18. I am scared of AIDS.
19. If a friend or family members tells me that s/he has HIV, I would be nervous about getting HIV from them.

Thank the participants. Invite them to sit in a circle. Debrief the activity using the following questions or some of your own.

- How did you feel about this activity? Why?
- Were their some questions you found particularly difficult? Some that were easy? Why?
- Is it hard to be honest about some of these issues when other are watching your response? Why?

- What question do you think should be added to our list?
- What do you think the purpose of this activity is?

Understanding HIV Today: Stop the Pity and Stop the Fear! (20 minutes)

Use the slide show to go over the following sections:

HIV 101 – Get the facts
What is like to be diagnosed today?
What are medications & treatment like?

Understanding the experiences of HIV+ students (10 minutes)

Use the slide show to go over the following:

Share quotes from research

Understanding Disclosure and Your Role as an Ally (30 minutes)

- Discuss why disclosure is so hard.
- Discuss how to keep a secret and still support youth and help connect them to resources.
- Participants will get into 3-4 groups and a youth presenter will join each group. They will take turns role-playing scenarios (provided) about being an ally and being supportive if a student chooses to disclose to you.
- Intervening in bullying and discrimination

Questions? (15 minutes)

Resources/Handouts & Evaluations (5 minutes)

Questions for Cards

Print out the following questions and tape or glue to large index cards. You may also choose to provide answers provided below.

1. What does PEP stand for?
2. Approximately how many people are living with HIV worldwide?
3. What does PMTCT stand for?
4. How is HIV transmitted?
5. What percentages of adults who need HIV medications are receiving them in Kenya?
6. How can you tell if someone is living with HIV?
7. What does HIV Stand for?
8. What does AIDS stand for?
9. Is it illegal to discriminate against a person living with HIV in Kenya?
10. Where can you get tested for HIV in Kisumu?
11. What is the HIV prevalence in Nyanza?
12. What is the HIV prevalence in Kenya?

1. Post-Exposure Prophylaxis (PEP) involves taking anti-HIV medications as soon as possible after you may have been exposed to HIV to try to reduce the chance of becoming HIV positive. These medications keep HIV from making copies of itself and spreading through your body.
2. 34 million
3. Prevention of Mother-to-Child Transmission (PMTCT) of HIV
4. Through unprotected sexual contact with infected persons, mother to child, through sharing needles or blood with infected persons.
5. 72%
6. Only through HIV tests. People living with HIV can appear healthy.
7. Human Immunodeficiency Virus
8. Acquired ImmunoDeficiency Syndrome
9. Yes. The HIV & AIDS Prevention and Control Act prohibits discrimination against people living with HIV
10. A VCT near you
11. 15%
12. 6.5 %

Teacher Pre-Workshop Survey

Please Answer the following questions TRUE or FALSE be circling the correct answer:

1. Are there students with HIV in your school?
   TRUE FALSE

2. HIV can spread through saliva and sharing drinks should be avoided
   TRUE FALSE

3. People with HIV will usually not survive past 25 years
   TRUE FALSE

4. People with HIV should be hospitalized and removed from the community to prevent further spread
   TRUE FALSE

5. Women with HIV should not have babies since their children will be infected with HIV also.
   TRUE FALSE

6. I feel confident that I know a lot about HIV
   TRUE FALSE

One question I have about HIV and AIDS is:

Teacher Post-Workshop Survey

1. HIV can spread through saliva and so sharing drinks should be avoided
   TRUE FALSE

2. People with HIV will usually not survive past 25 years
   TRUE FALSE

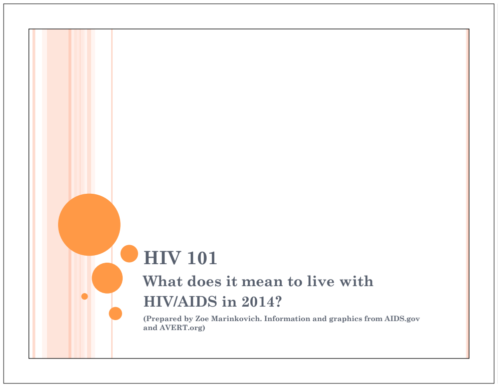
3. People with HIV should be hospitalized and removed from the community to prevent further spread of HIV
   TRUE FALSE

4. Women with HIV should not have babies since their children will be infected with HIV also.
   TRUE FALSE

5. I feel confident that I can help support a student with HIV.
   TRUE FALSE

6. I would recommend this workshop to others
   TRUE FALSE

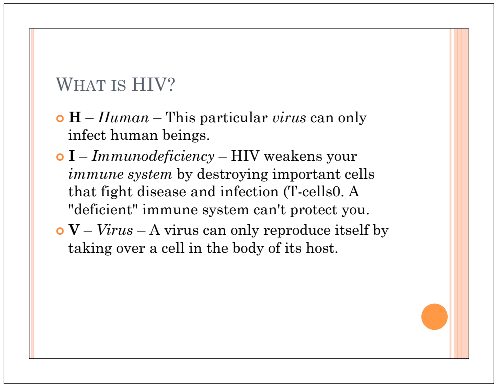
Please use the back of this form to share with us any comments, questions for suggestions.



HIV 101

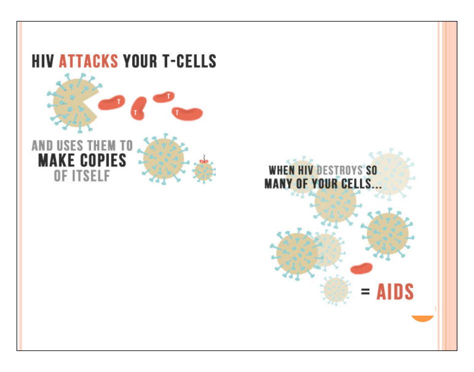
What does it mean to live with HIV/AIDS in 2014?

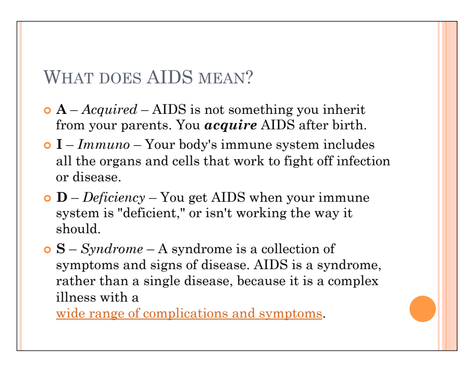
(Prepared by Zoe Marinkovich. Information and graphics from AIDS.gov and AVERT.org)



WHAT IS HIV?

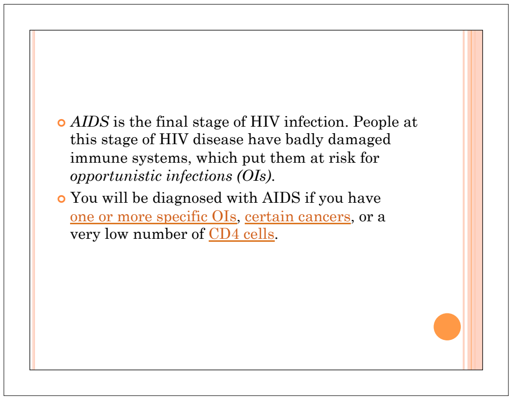
- **H** – *Human* – This particular *virus* can only infect human beings.
- **I** – *Immunodeficiency* – HIV weakens your *immune system* by destroying important cells that fight disease and infection (T-cells0. A "deficient" immune system can't protect you.
- **V** – *Virus* – A virus can only reproduce itself by taking over a cell in the body of its host.



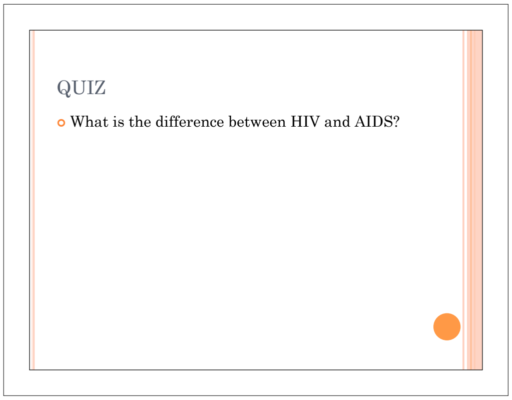


WHAT DOES AIDS MEAN?

- **A** – *Acquired* – AIDS is not something you inherit from your parents. You ***acquire*** AIDS after birth.
- **I** – *Immuno* – Your body's immune system includes all the organs and cells that work to fight off infection or disease.
- **D** – *Deficiency* – You get AIDS when your immune system is "deficient," or isn't working the way it should.
- **S** – *Syndrome* – A syndrome is a collection of symptoms and signs of disease. AIDS is a syndrome, rather than a single disease, because it is a complex illness with a wide range of complications and symptoms.

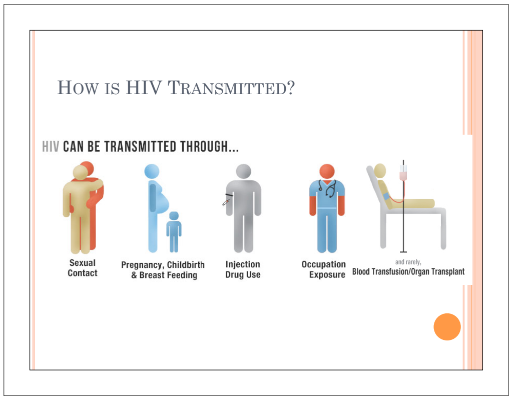


- *AIDS* is the final stage of HIV infection. People at this stage of HIV disease have badly damaged immune systems, which put them at risk for *opportunistic infections (OIs).*
- You will be diagnosed with AIDS if you have one or more specific OIs, certain cancers, or a very low number of CD4 cells.

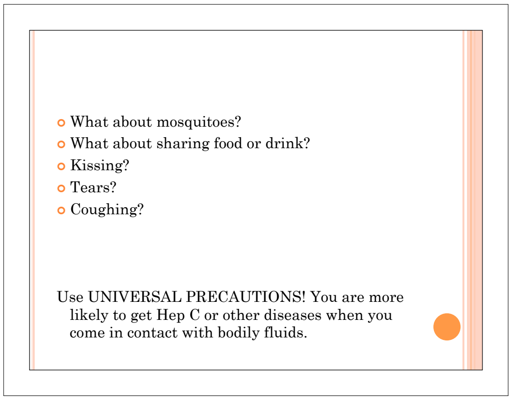


QUIZ

- What is the difference between HIV and AIDS?

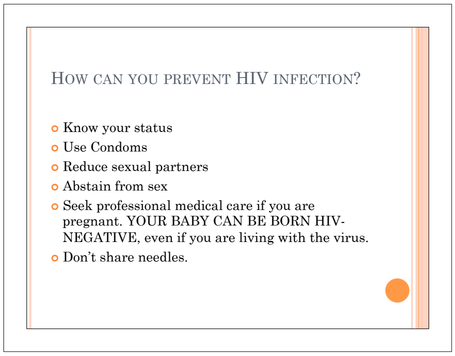


HOW IS HIV TRANSMITTED?



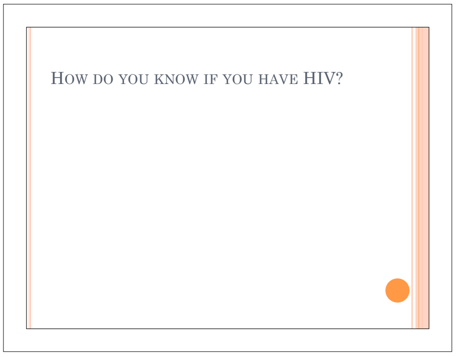
- What about mosquitoes?
- What about sharing food or drink?
- Kissing?
- Tears?
- Coughing?

Use UNIVERSAL PRECAUTIONS! You are more likely to get Hep C or other diseases when you come in contact with bodily fluids.

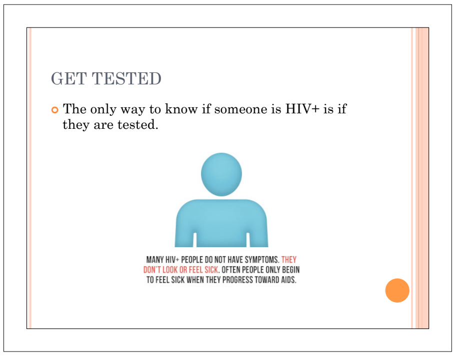


How can you prevent HIV infection?

- Know your status
- Use Condoms
- Reduce sexual partners
- Abstain from sex
- Seek professional medical care if you are pregnant. YOUR BABY CAN BE BORN HIV-NEGATIVE, even if you are living with the virus.
- Don't share needles.



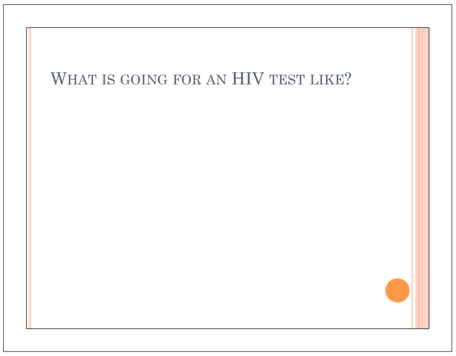
How do you know if you have HIV?



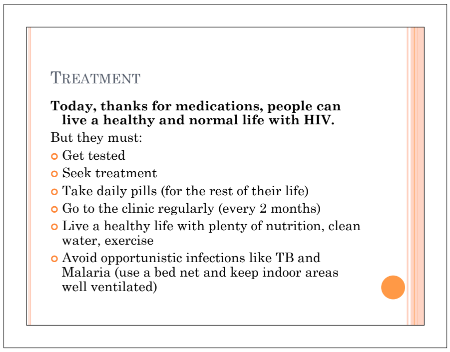
GET TESTED

- The only way to know if someone is HIV+ is if they are tested.

MANY HIV+ PEOPLE DO NOT HAVE SYMPTOMS. THEY DON'T LOOK OR FEEL SICK. OFTEN PEOPLE ONLY BEGIN TO FEEL SICK WHEN THEY PROGRESS TOWARD AIDS.



What is going for an HIV test like?



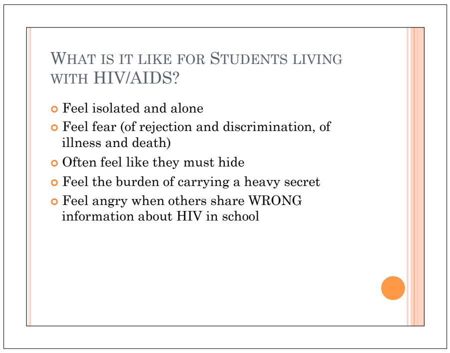
Treatment

Today, thanks for medications, people can live a healthy and normal life with HIV.

But they must:

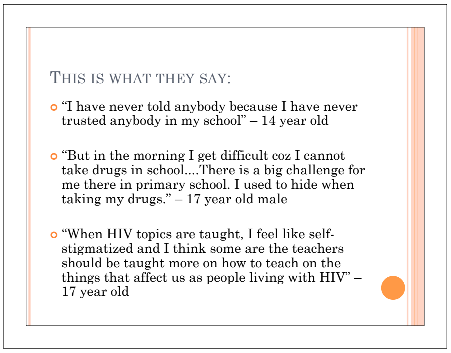
- Get tested
- Seek treatment
- Take daily pills (for the rest of their life)
- Go to the clinic regularly (every 2 months)
- Live a healthy life with plenty of nutrition, clean water, exercise
- Avoid opportunistic infections like TB and Malaria (use a bed net and keep indoor areas well ventilated)

Questions?



What is it like for Students living with HIV/AIDS?

- Feel isolated and alone
- Feel fear (of rejection and discrimination, of illness and death)
- Often feel like they must hide
- Feel the burden of carrying a heavy secret
- Feel angry when others share WRONG information about HIV in school



This is what they say:

- "I have never told anybody because I have never trusted anybody in my school" – 14 year old
- "But in the morning I get difficult coz I cannot take drugs in school….There is a big challenge for me there in primary school. I used to hide when taking my drugs." – 17 year old male
- "When HIV topics are taught, I feel like self-stigmatized and I think some are the teachers should be taught more on how to teach on the things that affect us as people living with HIV" – 17 year old

- “When it reach the meeting about HIV, they say that if AIDS catch you, you die. According to me, the virus is the one that cause the disease AIDS. But even the teachers, they used to say that if that, you diarrhea and you die. Even in class 6, a teacher told us that when it catch you, you reach at the age of 20 and you die. But as I was taught you can live as long as you are taking your medication. So, even the pupils adopt those issues of the teachers. . . . And even if you ask them, what cause the disease HIV, they will tell you the saliva” – 14 year old male

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- “I find that when there is an HIV talk, there is some student, student says that when they heard of a person infected with HIV, that guy should not be alive. He or she should be beaten to death because there is nothing that he or she is doing in this life. . . . When there’s an HIV talk, you are listening to how they are talking. It gives me a lot of stress.”

WHAT DO STUDENTS NEED?

- **Support!**
  - From Teachers, Administrators and other students
  - A safe person to talk to about their status. Someone they can trust with their secret.
- **Access to accurate information** and to know that the students around them also have access to accurate information.
- **Community** with others living with the virus
- **And an environment free from stigma**

WHAT CAN YOU DO?

- Refuse to participate in spreading rumors
- Refuse to allow others to share false information about HIV prevention, infection or treatment
- Let your students know that you are an ally
- If a student shares their status with you, respect their trust and keep their secret.
- Look for ways to support the student by privately letting them know about support groups or events in the community
- Be accommodating. Allow the student privacy to take their medications and excuse them from class to attend their clinic appointments.

LET’S PRACTICE

- Get into small groups of 4
- Chose one person to be the student and one to be the teacher. The other two people will observe.
- Role play the student disclosing his/her HIV status to the Teacher.
  - Think about:
    - What will the teacher say?
    - What will the student need to hear?
    - What do you think the student is feeling?

GREAT JOB!

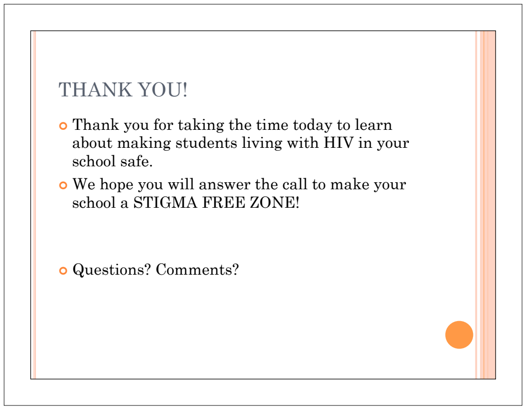
- Observers share your insights.
- What could be another good way to respond to a student?

ROLE PLAY #2

- 2 people in the group will be students that are making fun of another student who has HIV. One person will be the teacher who is intervening.
- Think about:
  - What can you say to stop this?
  - How can you protect the student living with HIV?
  - What do the students doing the bullying need to know?

GREAT JOB!

- Any Tips? Or Challenges? to share with the group?



THANK YOU!

- Thank you for taking the time today to learn about making students living with HIV in your school safe.
- We hope you will answer the call to make your school a STIGMA FREE ZONE!

- Questions? Comments?

EVALUATIONS