

**“You Shall Be in the Future Someone That is Very  
Powerful”:**

The experiences of students with HIV/AIDS in rural, post-conflict  
Uganda

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## DEDICATION

For the students of Katakwi with HIV/AIDS: I hope your voices will be heard and you will continue to share your stories.

*Emuria Oliai: "Let it keep growing"*

## **ABSTRACT**

The roll out of Anti-Retroviral Therapy across Sub-Saharan Africa has given rise to a new generation of adolescents that previously would not have survived into their teen years. The aim of this research is to give voice to these young people, specifically HIV positive students, in the rural, post-conflict area of Katakwi, Uganda. Through the lens of empowerment, which focuses on participation, capacity building, leadership potential, and relationships, this research examines the factors in these students' lives that contribute to their empowerment, or the absence of these factors that then have the potential to disempower them. It considers the way the students themselves see both the protective and risk elements in their lives, and how they deal with stigma, school, and identity as a person living with HIV/AIDS.

The data in this work is collected through semi-structured interviews with sixteen adolescent students living in Katakwi. These sixteen students, a mixture of males and females, have varying levels of openness about discussing their HIV status. Additional interviews conducted with teachers, parents, and health care workers connected to students with HIV/AIDS creates a total of 25 participants.

The diversity of stories within the voices of these sixteen students makes it clear that this unique demographic is not a homogenous population, and the levels of empowerment vary based on gender, family support, means of infection, faith in God, relationships with peers and teachers, and age. While inconsistencies exist, school is a place these students want to be despite financial struggles regarding school fees, and the risk factors that exist within the schools themselves. Despite the various factors that work against these students' empowerment, the teenagers manage to find ways to succeed and maintain hope for futures that include education, careers and families.

Keywords: youth empowerment, post-conflict education, HIV/AIDS, adolescence in Uganda, stigmatization.

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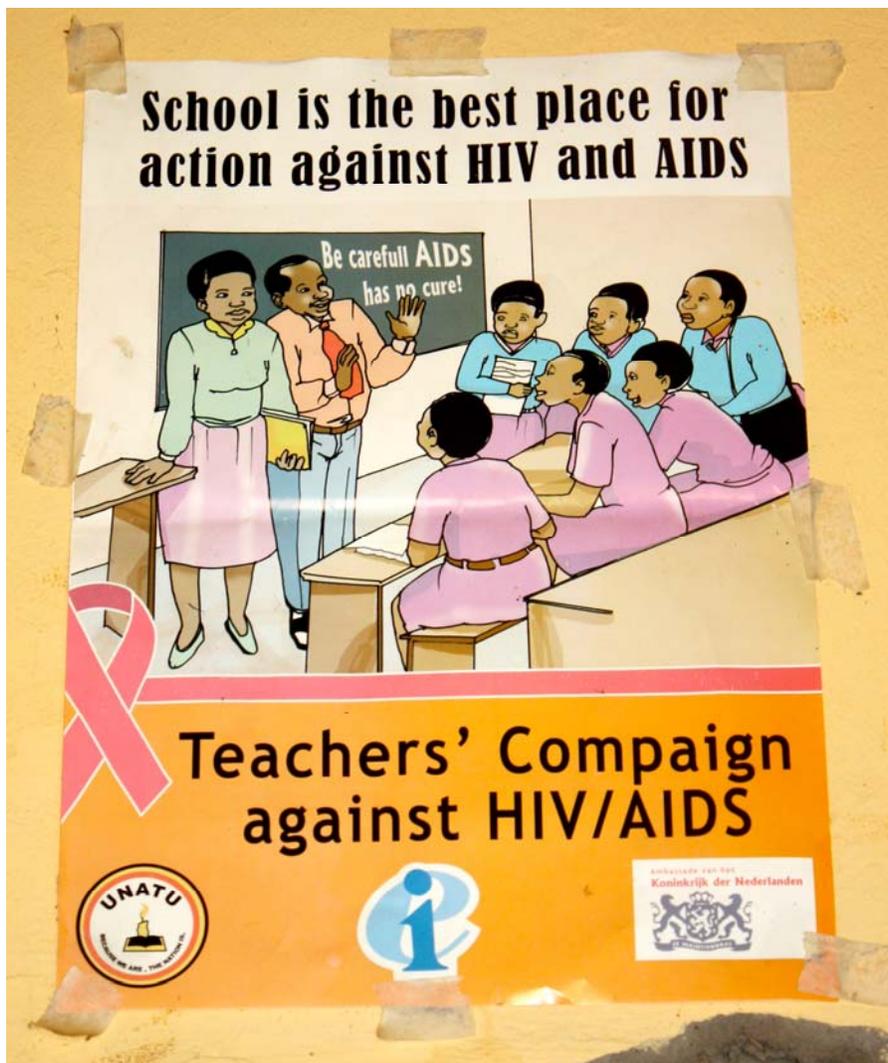


Fig 1: Poster in Ngariam Primary School (Source: Walsh)

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## **1. INTRODUCTION**

Anne was the first student I met that I knew had HIV. She was the first person I had ever met that I knew for sure was positive. When I reached out to shake her hand, I was ashamed to realize that I had a split second's hesitation, only the briefest of pauses, even though I knew I cannot get AIDS from a handshake. Or sharing a meal. Or a hug. Both of which would, in due course, happen. It was this moment of shame at my own behaviour that I realized that even with all the knowledge and work that has been done around HIV/AIDS, the fears and assumptions around this disease are close to the surface. It is these very fears that hinder those with the disease from coming out about their health status, and that must have a negative effect on how lives are lead with this sickness. How could these students, in particular, lead a life of achievement, success, and community living if they are dealing with the stigma of a chronic illness? And yet, as I was to find out, many of them do in their own ways. Their stories are diverse, of course, and contain both hardship and happiness, as all lives do. However, if I wanted to research students with HIV/AIDS in an effective way, empowerment theory was going to have to be the basis for this work.

My research explores the experiences of students with HIV/AIDS in a rural, post-conflict setting through the lens of empowerment. It is through this lens that the focus of adolescents with HIV/AIDS shifts from illness and weakness to wellness and strength. Through the voices of the students themselves, my research examines their school experience and questions what in their lives empowers them, how do they empower themselves, and what limits and hinders their ability to be empowered. In line with empowerment theory, this research puts the students' stories at the centre. Empowerment theory recognizes participation as central to achieving a level of empowerment, and even if the problems themselves are not solved, problem-posing in itself is an empowering act. As such, my work aims to take a "bottom-up" approach to looking at what school, and life, is like for adolescents growing up with HIV/AIDS. I am hopeful that the act of sharing their stories adds to their empowerment, and that this research can contribute to further research that takes their concerns and needs, as dictated by the students

themselves, into consideration. These students, experiencing varying degrees of empowerment, need to emerge from the periphery of the discussion around HIV/AIDS and be more than victims of this disease. Because this generation is the first of its kind, as previous generations of children born with HIV would not live into adolescence, (Cowan & Pettifor 2009, 288) it is the right moment to incorporate their voices into the fold of academia.

What follows will include a section on my methods, including how the topic came to be my focus, how the data was then obtained, the challenges and ethics related to this, what the data consisted of, how it was analysed, and general reflections on the process. Next, an overview of the region of Uganda in which these students live and study is addressed. This is crucial as it is part of the ecology of the adolescents themselves; it plays upon them and they act upon it in a dynamic relationship. The students' environment and its history adds to the culture in which they live, and highlights the unique experience of each student. Without the context, a full understanding of the students' experiences cannot be achieved. Even more than an overview of Uganda as a whole, details about the specific region add to our understanding, because a rural, post-conflict, environmentally damaged region creates a completely different set of challenges than if these same students were in urban Uganda. Beyond this, a section of my work is dedicated to unpacking and exploring empowerment theory in greater detail. A clarification of the terms and theory, as well as how it applies specifically to adolescents is addressed. All of these surrounding elements are included to add to a richer understanding of the students' experiences and to acknowledge the many layers that create their realities, and are included before delving into the interviews and the stories of the students themselves, as they explain it. Finally, the work ends with conclusions and possible areas for further study. These conclusions are, essentially, just more questions, and in no way "solutions" to any of the multifaceted challenges these students face. There is still so much more to explore within this topic.

## **2. RESEARCH TASK AND METHODOLOGY**

### 2.1 Choosing the Topic

Shortly after my arrival in Katakwi, the LWF staff took me for a courtesy call to the sub-county officials so that the local government was aware of my presence and were informed that while I was working with LWF. They were made aware that I was also in the region to conduct research for my Master's programme. The local chairpersons were quick to offer up regional concerns and issues that might be viable areas for research. The research topic evolved into learning and recording the stories and experiences of adolescent students living with HIV/AIDS in the greater Katakwi district. Not only did the community itself see this as an area of growing concern, there is limited research done on adolescents with HIV/AIDS that shares their personal stories. The original idea for my research had been related to schooling for female former child soldiers, and it was a topic that I had prepared myself to undertake due to a perceived research gap in regards to female soldiers specifically, as well as personal interest. Nonetheless, it was important to me to take on a subject that was integral to the community itself and would ultimately be seen as beneficial to the people whom I was working with. Above all, I was there to learn, and the idea of delving into my idea for research in a world I was only just starting to become acquainted with would have seemed both forced and unethical. I was, and remain, aware that my research, like that of others, is a double-edged sword in that "cultural descriptions can be used to oppress people or set them free" (Spradley 1979, 13). I was indeed a "positioned subject" in that every social location I occupied brought a mixture of insight and blindness (Grills 1998, 10).

While I was not familiar with Katakwi itself, I was all too familiar with the experience of being an "outsider". I had been to Africa, specifically Zambia and Zimbabwe, three times before this journey within a development capacity, working in the slums of urban centres with a youth centre. Because of these experiences, I was skilled in how to build rapport and mutual respect as a visitor to a community. Once in Katakwi specifically, I spent most of my time with the team at LWF visiting

the villages, following up on sponsorship projects, delivering seeds and seedlings for agro-forestry projects, and working with communities on participatory-based problem-solving activities. We also worked in many parts of the region on issues of health and water sanitation, after attending a training workshop. Because of the conditions of the roads and the long distances to travel, the hours spent in the vehicle listening were a great starting point for understanding the needs and concerns of the region as seen by other development workers. While I had been to Africa before, this had been mostly in an urban setting, and the needs and lifestyle in a remote rural community were clearly different. It was during these long drives that I was able to get a feel for the prevalent issues in the district and soon realized that I would need to change my initial research focus. I learned about the community's way of life, the major challenges for the people in the region, the work that LWF does, and future plans and development projects. I also learned about the everyday: the jokes, the families and stories from home from the staff, the gossip, anecdotes from Church, whose child was sick, which politician was making a scene, the neighbour's new hairstyle and on it goes. In all of this, rarely did the issue of child soldiers come up. My colleagues did mention the time when Joseph Kony and the Lord's Resistance Army were active in the region so I asked about how the returnees were treated. I was told that, "the Ateso are said to have short memories" and that unlike the neighbouring tribes of the Acholi and even the Karamojong, the Ateso people themselves and the other tribes in Uganda generally consider them to be culturally more gentle and forgiving (personal journal, July 2012). While this is somewhat of a stereotype, it does seem to be a cultural tendency and a trait that the people themselves are quick to assert and boast about. My colleague mentioned to me that during the previous week a child soldier had returned after ten years with the LRA and it was a reunion of much joy and celebration. I am sure that this returnee and others face undeniable challenges upon reintegrating into the community, but more importantly, this topic did not seem to be one that the community felt was a particularly relevant issue. In line with Spradley, I wanted to align my goals with the needs of the community, "one way to synchronize the needs of people and the goals of ethnography is to consult with informants to determine

urgent research topics. Instead of beginning with theoretical problems, the ethnographer can begin with informant-expressed needs..." (Spradley 1980, 18).

Because of this experience, I understood that it would be best to have a brainstorming session with the staff of LWF Katakwi on topics they might research if they were in my position. I explained that the topic had to fall under the category of education, so we took that time to explore all appropriate options. From there, the staff discussed the local issues related to these sub-categories. Finally, I asked each staff member to determine which one they would personally choose if they were doing research. At the end of this discussion, I put it to a vote of the staff and did not give myself a vote. It was from this that it was determined that the topic to explore would be to interview students in Katakwi who are living with HIV/AIDS and investigate what their school experience is like. This is not to say that the topic was not one that I felt passionate about. In order to do this work, I would need to feel strongly about the topic. I had seen the effects of HIV/AIDS in Zambia, and now in Uganda and so it was indeed close to my heart. The next issue to address was access to these students, and it was here that I relied very much on the LWF staff, their good reputation, and their community connections. In order to be successful, the elements of trust and developing relationships were crucial. My ability to move effectively in the field would be influenced by how others would perceive my interests, intentions, and identities (Grills 1998, 11).

## 2.2 Meeting the Students

The LWF staff granted me as much time as was required to gather my data, and also aided in making connections with the schools and the students. The initial process of meeting HIV positive students and the lack of privacy and protection in relation to their status for the teens was surprising to me. One of my colleagues would take me to a school, stop in to the principal's office, usually without an appointment, explain who I was, and ask if s/he knew of any students with HIV. Only one school had no one that they knew of with the virus, otherwise the principal or teacher would summon the children right from class. I also inquired about the need to talk to the parents of the children and was told on many occasions that the

school has full authority of the child when they are there, so talking to the parents was unnecessary. I struggled with this, but had to accept it and add it to my understanding of education and the role of the school in Katawki. While I reflected deeply on issues of privacy for the students, I have changed the names of the informants, though I also made it clear that ultimately, the interviews and field notes could be public record if needed. As Spradley discusses, changing names and identifying features are “minimal requirements of anonymity” and as a researcher there needs to be a “serious consideration” of ethical principals regarding the informants. (Spradley 1980, 24.) The interviews were always conducted in private, and while the local government was introduced to me and knew that I was conducting research, the topic itself was not general knowledge. Whenever I met with a child, their rights and anonymity were foremost in my mind.

After initially meeting a child, I would ask them to talk to their parents when they went home and if they were allowed to, visit the LWF office and have a chat with me. If they lived far away from the town, I would make an appointment to meet with them at the school or at their homes. It also became apparent that I needed to clearly state that I was not there to provide school fees or sponsor them after an early incident where a school nurse told the kids with HIV to talk with me because I might pay for their schooling. All of the students were still willing to talk with me even when they were aware that I was not going to provide anything for them.

The more challenging group to access were those students that had not disclosed their HIV status, and again I relied heavily on the staff’s connections in the community. One field worker in particular was crucial in connecting me with students that she had worked with in other contexts that were not open with their status, and she was able to contact the students beforehand, explain who I was, and then set up meetings if they felt comfortable. She also did this in a way that maintained their privacy and the meetings with these particular students were usually done at their homes, with the parents close by. This colleague was also often present at the interviews to help the students to understand my accent, to make

them feel more at ease, and to help them communicate their answers if they felt more comfortable replying in Ateso.

Beyond interviewing students, I also met with parents, teachers, health workers, a doctor, and a school nurse with the aim of covering all the elements that contribute to a student's experience living with HIV. I was pleased with how keen everyone was to speak with me, and despite not always knowing how honest interviewees are and what might be motivating them, the cultural context I was in as well as my general rapport with the community facilitated a successful research environment.

In the end, I was able to interview sixteen students living with HIV/AIDS, with varying degrees of openness regarding their health statuses. Of the sixteen, half were boys and half were girls. Half of the participants were from Katakwi town proper, and the other half from the surrounding villages. The way the participants contracted the virus varied. The majority were infected by mother to child transmission as babies, some were infected through rape, injection, caring for infected family members, and some did not know how they became HIV positive (see Appendix for full chart of participants and details about each student). Additionally, I supplemented my student interviews with those from two male teachers, one female teacher, the HIV focal person for Ngariam parish, a school nurse, the head doctor at Katakwi District Hospital, and two fathers of the HIV positive students.

### 2.3 Interviews and other sources of information

The interviews themselves were semi-structured and were based on an empowerment framework and principles of ethnographic research. While specific questions were not always asked, certain topics were always brought up. These included, but were not limited to, food, medication, transport, home life, stigmatization, positive living, hygiene, diagnosis, level of openness about having HIV, and I left time at the end for the students to ask me anything. It was challenging to pull more from the students than a "yes" or "no" answer because they were shy. I soon incorporated snacks or meal with my interviews, and that certainly

relaxed the students and allowed them to open up. As the interviews progressed and my skills as an interviewer grew, the discussions also became deeper and full of much more dialogue. Upon reflection, group interviews might have also been a good option.

While the topics generally followed those listed above, I used open-ended questions in order to give the students a chance to shape his or her own response, or even change the direction of the interview. One of the prompts that I would pose that generated a lot of “chatter” was, “tell me a story about yourself or your family.” The answers were often about the loss of a parent or family member, or in some cases anecdotes about a moment in class. Other questions that I would rely on were: “Describe a school day for me, from when you wake up to when you go to bed”; “Can you tell me some of your duties at school?”; or after a student would say inevitable say they preferred school to being at home, “Why do you like school more than home?”; or “What is your biggest fear?” The interviews were semi-structured; I did use a basic “interview schedule” and added to or subtracted from it in order to allow for easier comparison on the thoughts and ideas between each participant (Fife 2005, 99). Mostly, I went into each interview wanting to know the students’ stories and determine what was important to them.

For many of the interviews, an LWF colleague was there, especially if they had an existing rapport with the adolescent, and for those that needed assistance with the language. I purposely chose English-speaking students, but at times it helped them to be able to express their answers in their native tongue with translation from the LWF colleague. Instances where answers were translated have been identified in the text. Despite the interviews being conducted in English, the dialect and accent of the English in rural Uganda can be quite different from my own. However, while some of the quotes and sentences may not be conventional English, they follow the “verbatim principle” regarding that how something is said is crucial. If it is changed or altered by the researcher, important clues to the informant’s culture can be lost. Certain phrases can be used to generate ethnographic questions; a summary cannot (Spradley 1980, 67). This remains true even for the parts that had to be translated because the translators themselves were

from Katakwi and spoke with the same dialect as the students. The importance of the verbatim principle is evident in with the phrase, “playing sex” used by both the students and the adults. This particular phrase led to me questioning how sex itself is conceptualized and understood within this culture, and whether it is different from my own ideas, based on the way I would frame it as “having sex.”

Of course, the interviews were not without challenges, given my topic and the ages of the participants. As a researcher working with adolescents, the ethics surrounding my research weighed heavily on me. Ultimately, while the information gleaned from this topic could be integral to developing greater understanding of the AIDS experience in Africa, the priority was to prevent harm to the participants, whether that be from the community, or from the mental pain that can come up when reflecting on living with a terminal disease. As Montgomery (2012, 144)) puts it, “causing ‘harm’ may occur when participants are made vulnerable to perceiving failures in their lives and that those who take part in research ought to be able to live easily with the stories that they tell and not feel worse about any aspect of their life experience as a result of taking part in research”. Because of the ages of the students, this awareness of the pain that participating in an interview can bring up was probably not something they reflected on beforehand, and so I was cognizant to do this for them or with them. In the end, each interview lasted for about one hour, with some reaching up to two hours. I recorded the interviews on a small handheld digital recorder, only after asking the participants if they were comfortable with that. All of the participants, except the hospital’s head doctor, agreed to be recorded. Most of the students quickly forgot the recording device was there, and some were intrigued by it at the beginning because they had not seen one before. For the one interview that was not recorded, I took notes during the discussion and transcribed everything that was discussed once I left the hospital.

Upon finishing the interviews, I transcribed them for a total of over 300 typed pages. Each interview was played at least twice, with thoughts and notes jotted down for each. Eventually, general themes and trends emerged (such as positive living, stigma, home life, etc.), and each interview was encoded for each section related to the theme or topic. Each subtitle in the analysis contains the

comments, stories, and conversations that are related to that topic as identified by each participant. Ethnographic analysis, of course, is a search for patterns. Beyond recording what people say and do and making inferences from them, describing and understanding cultural knowledge requires patterns that exist within the data. (Spradley 1980, 85). The analysis of these interviews was indeed based on the identification of patterns and the categorization of them. In addition to the interviews, my data also included dozens of photos of school posters and campaigns, watering holes, latrines, where they treat sick students and the general school environment. Beyond these specific photos, I took daily of whatever it was I was working on with LWF or just daily life in Katakwi. Data also included copies of the local newspaper, and recordings of songs within the schools and villages. Also essential to the data was my daily personal journal. At the end of each day, I recorded all the events, my thoughts, feelings, quotes, questions and “notes to self” from that day. It also includes notes that were given to me, the handouts from a water, health, and sanitation training I took part in with the LWF staff, and photos that were given to me. This was all used to supplement the information gleaned from the interviews, and was clearly subjective, but as Blommaert and Jie (2010, 66) condense Pierre Bourdieu “it is better to be aware of it [subjectivity] and to question what you have seen, heard and understood from within that context, than to pretend that this context wasn’t there”.

#### 2.4 Being An Outsider

This journal and recording of my daily interactions leads to the topic of building rapport and trust, and doing so in a relatively short amount of time. This came from my daily involvement with the community. Beyond the day to day work with LWF, every Sunday I was at “Prayer.” I dressed in the local, sometimes traditional clothes, I spent time at the schools after work, and on weekends I was always wandering around the market, having coffee with different families, playing football with my neighbours, doing laundry with different women, loitering and listening to the radio outside of “shops”, and just being present. Every evening I spent time with the LWF guard watching the migration of the bats, and having

informal language lessons. By no means could I develop fluency in the local language, but I put every effort into learning as much Ateso as possible while I was there. My efforts to learn the language were often a source of humour, but went a long way in creating bonds. On one particular day I was walking through the town and a small girl climbing on an unfinished wall greeted me in the local language. I replied back in Ateso. She then decided to test me further and asked in Ateso where I was going. I answered back in her language, "to the village." Her surprise at my ability to answer her in Ateso literally knocked her off the wall upon which she was climbing. I ran over to her and we shared a good laugh. My efforts to learn the language, though feeble, incomplete, and at times embarrassing, were seen as a gesture of good faith in my desire to learn, value, and understand the community. Despite my best efforts to integrate into the community, I cannot claim to have full insider status in a few short months and without language fluency. In some obvious ways this is a weakness, but in other ways this strengthens my research because it allows me to view the data through multiple lenses and draw conclusions with these multiple viewpoints in mind. As Dutch ethnographers Blommaert and Jie (2010, 64) state, "reality is chaotic and complex, and this too, is reflected in your data. Your data reflect the different viewpoints from which social events can be (and are) viewed: they reflect positions in relation to topics, events, phenomena". The outsider lens of my research, while clearly unavoidable, did provide some benefits to this research. I was able to be privy to some discussion and topics that would normally be considered taboo, as people were able to let go of some of their culture restraints because I was not from their community or even their country, nor was I going to be staying for a very long time. With the other teachers, though we shared a common profession, being an outsider gave the teachers an opportunity to explain their challenges and frustrations. They wanted me to know about the lack of funding, the teacher to student ratio, their successes and disappointments. It was a chance for them to be heard.

My obvious outside status also came with limitations. Simply put, as a Westerner, there is the expectation that I come with money and power. This had an impact on all of my relationships and discussions. Speaking with students as

someone both older and wealthier, there is a power dynamic that cannot be ignored. I have to wonder if many of the experiences shared were influenced by the hope of some sort of support. I did clarify this in all of my interactions, but that cannot fully erase the hope. Both Stella and Akello told me the story about how, before they knew they were HIV positive, they had lied and said they were to a NGO that was at their school trying to determine how many students had the virus. They told me that they said they were positive in the hope that this NGO would provide some sort of tangible assistance. In the end, the NGO did not pay for schools fees or food, and Akello and Stella half-jokingly feel that they acquired the virus because they had, in some ways, asked for it. The fact that they revealed this story to me does show that they were being honest and open, but it also shows the undeniable power dynamic and desire for assistance from foreigners while living in poverty.

Through the research process, I came to understand that one of the core strengths of this research stems from the topic itself. This is a research topic that could not have existed even a decade ago. Many of the participants acquired HIV as infants, and before effective ARVS became available, they would not have survived into adolescence. The fact that this is a new demographic, and a new face of HIV in Uganda is one of the strongest aspects of this study. This is made even more unique by the fact that this research shares the voice of a unique cohort. In line with youth empowerment theory, giving the youth a real and valued voice is essential. It is not a literature review about adolescents with HIV, it is the students themselves sharing their experiences and their stories. Because of their voices, we can see that they challenge many existing stereotypes about youth with HIV, and even the literature itself, which tends to focus on the stigmatization of these people. The students speaking for themselves allows a fresh look at a group of people with incredible potential to change how HIV/AIDS is viewed, studied, and discussed. This work reframes a discussion surrounding a group that has typically been marginalized.

The principal limitation was time. Because I only lived in Katawki for three months, I could only scratch the surface of this topic and acquire the beginnings of a full cultural understanding. This is true for language as well. The students all learn English in school and sometimes at home, and the interviews were primarily in

English. For this topic to be explored in greater detail, fluency in Ateso would be an asset and would require more time immersed in the region. Moreover, each student was only interviewed once, and while rapport with the students was one of my strengths, several interviews with each student would have yielded more information and allowed the students to open up to an even greater extent. More time would also have allowed more students to be interviewed, and a more in-depth look at the topic could benefit from more students' voices. It would also be interesting to do a follow up with the students. Like all ethnographic studies, there is the problem of creating a somewhat static perception of the group of people studied. Of course, these teens have continued to live their lives and have moved forward and faced challenges that are not reflected in this work. I have remained in touch with many of the people in Katakwi. Because these events were after the interviews and internship, they are not part of the work. However, it is important to recognize that these interviews are only a snapshot of the lives of the students, and are not the end of their stories.

Finally, it was challenging to find a way to guide and address specific issues with the students while maintaining mindfulness in not leading the interviews in a way that reflected what I thought was important. Like most researchers looking to give voice to those that are otherwise considered peripheral, there is the constant awareness of the epistemic violence that results from this type of work. Gayatri Spivak questions whether or not the subaltern can ever really speak, in that western academic thinking is produced, with or without intention, to support western economical interests. Moreover, Spivak asserts that knowledge is never innocent and that it expresses the interests of its producers. Despite my best intentions, I am the producer of this knowledge, and I am the one that decides the material that is used and deemed important. As such, I struggle with Spivak's valid criticism that wonders how the developing world subject can be studied without cooperation with the colonial project. Ethnographic research, such as mine, is to some degree always colonial in defining the "other" as the object of study, and as something that knowledge should be extracted from and brought back "here". Regardless of how

authentic my efforts and relationships with the students, I am a privileged Westerner discussing and analysing the developed world “other” and in giving voice to them through my work, I cannot avoid the assumptions, ethnocentricity, and power hegemony that is innate in my global position. (Spivak 1988). As a researcher, one of the ways to overcome some of the power tensions that Spivak addresses is to include interviewees as co-participants of the research. By involving the community in identifying my research topic, I partially addressed some of those issues of power. Ideally, though, I would have liked to solicit feedback on my drafts during the writing process, and then share and discuss my findings with the community. This procedure would be enhanced if it could be done in the local language. I intend to share my work with the community, and hope they can use it for future projects, but with more time and funding, involving the participants more during an after the process would be beneficial.

### 2.5 Applying what I learned and staying connected to the community

The information from the transcribed interviews, the songs, photos, and personal journals amounted to a significant amount of data. As such, I did both a preliminary and secondary analysis of it. Much of the analysis was conducted during the fieldwork, as I tried to make sense of the world in which I was living and the information I was gathering. Upon return I conducted a basic method of coding: each set of data was poured over looking for preliminary themes that stood out. This was not a language analysis, or patterns of structural units, rather a search for topics, patterns, and theme, or rather “relevance units” (Blommaert & Jie 2010, 74). Moreover, I began with the information I judged to be the most basic or important and then considered the macro material in light of my completed basic analysis. This was more of a “ground up” approach in linking ideas and themes as I went, but remaining rooted in the words of the students and my written memories (Fife 2005, 120-121.) The interviews were always coded and analysed first, and then the other material was analysed with the themes from the interviews as a guiding framework.

The secondary analysis, my search for patterns, was an attempt to cement together the levels of data collection in order to form a larger conceptual framework

(Fife 2005, 123). This analysis moved beyond directly examining the notes and rather, looking for potential relationships between the data. Of course, fieldwork is never so tidy and patterns do not always exist. At times I was faced with contradictory or inconsistent evidence; for example, often what one student said about stigma was the opposite of what the next student said. This information was not disregarded. I included many of the inconsistencies and perhaps these can be used to both emphasize the diversity of experiences of these students, and as a starting point for more research and exploration. In due course, I came to realize that much of my analysis had to come from my experience and go beyond the exact words in the text. I had to trust myself to look beyond the sentences, knowing that the meanings people, and these students, produce are not always explicit.

At the core of my research was the hope that it would serve a purpose for the community. I chose a topic that was important to them, and want the knowledge gleaned from the research to then go back to Katakwi. One of my roles in LWF was to put together funding proposals based on fieldwork done by my colleagues. I am confident that the knowledge that both myself and my colleagues gained from talking to the students can be a source for new projects and funding for these projects. Two of my colleagues were with me at most of the interviews, and I know that they also gained the insight I did from interacting with these students. I will send this work back to LWF for them to use as a starting point for projects related to students with HIV/AIDS.

Beyond the hope that my research can be of some purpose, Katakwi is still a part of my life. I am in frequent contact with LWF staff members and every new email brings news of births, deaths, and updates of the students that have come to mean so much to me: Betty has dropped out of school and is now a mother, Anne's father has died and she is living with her mother, my LWF colleague has had a new baby and she named her after my sister, Ruth is happily at school and tries to call me but has not mastered the long distance consideration, and life, of course, continues. While my formal research is over, my connection to the community remains and I hope that it always will.

### **3. CONCEPTUAL FRAMEWORK: HIV/AIDS in SUB-SAHARAN AFRICA**

#### **3.1 Literature Review**

In many ways, young people are at the centre of the HIV/AIDS epidemic. In 2005, approximately half of the 4.2 million HIV infections occurred in those aged 15-24. For Sub-Saharan Africa, two-thirds of all young people are living with HIV/AIDS. This amounts to over six million young people with the virus. (Monasch & Mahy 2006, 16.) Because of this, young people are crucial to controlling the pandemic. As such, at the 2005 United Nations General Assembly Special Session (UNGASS) declared a goal of, “at least 95% of young men and women aged 15-24 have access to the information, education, including peer education and youth-specific HIV education, and services necessary to develop the life skills required to reduce their vulnerability to HIV infection by 2010” (Monasch & Mahy 2006, 24). Unfortunately, no country managed to reach that lofty goal, though six countries did achieve a 25% reduction in new infections. (Cowen & Peltifor 2009, 289). This is where Uganda is a special case. In six years, from 1992-1998, Uganda was able to reduce its HIV/AIDS rate from 17% to 6% in females and 4%-2% in males (Norton & Mutonyi 2007, 480). There has been much speculation as to why Uganda has been particularly successful, but also speculation as to why this rate of those with HIV/AIDS has started to creep up again in recent years. At the core of these conversations is the multi-sectoral approach, both nationally and locally, rolled out under Uganda’s President Yoweri Museveni. In 1994, there was a movement in the country to develop a skills-based health education and lifeskills programmes to address self-awareness, self-esteem, empathy, communication, decision-making, critical thinking, and coping. All of these elements are essential to empowerment. In 1997, these empowerment-based programmes translated into the Ugandan schools as the PIASCY programme. (Norton & Mutonyi 2007, 481.) This programme will be discussed in greater detail in the interview analyses section, but a summary of literature about the programme itself and its effectiveness is provided here.

### 3.1.1 HIV/AIDS Education

According to the World Health Organization, schools are a key setting for providing both the knowledge and life skills necessary to prevent HIV/AIDS. In fact, in Sub-Saharan Africa, 58% of primary school students, and 64% of secondary school students were exposed to AIDS education in school. (Monasch & Mahy 2006, 25-28.) Furthermore, in a 2003-2004 study school was cited as the *only* source of information identified as helpful in providing information about HIV/AIDS (Norton & Mutonyi 2007, 481).

In Uganda, HIV/AIDS education in school through PIASCY clubs and lessons vary in their delivery and effectiveness. However, they all have a patron teacher and equal numbers of female and male members. The general curriculum includes developing effective communication strategies around the virus, explaining the consequences of unprotected sexual activity, and the promotion of testing and counseling. This discussion is based on a Freirian peer-led critical pedagogy. As such, instruction should be based on drama, pop culture, community outreach and critical reflection. (Norton & Mutonyi 2007, 483-485.) However, whether this is an accurate reflection of how PIASCY plays out in each school will vary on many factors like available resources, staff training, funding, poverty and instability in the surrounding communities. Dramas are particularly effective in that they can visually address issues that are normally silent; they allow students to “perform the unsayable” and raise issues around sexuality and gender issues. Pop culture includes debates and discussions and has been shown to create a sense of ownership around the issue, and thus responsibility and comfort in addressing the topics. Finally, community outreach provides resources to other youth that are not able to attend school, and allows the students to visit and experience HIV/AIDS in a compassionate framework. (Norton & Mutonyi 2007, 485-487.)

In theory, PIASCY is virtually flawless, and in practice, it has been incredibly effective, though not without problems. In Katakwi there are limited resources, teachers feel over-worked, and the community outreach piece is non-existent, perhaps due to things like insurgency and transport problems. In line with Kirby,

Obasi and Laris, there are inadequate levels of training for the teachers, and many continue with didactic teaching methods. Moreover, Kirby et al. see the need to move from general knowledge to complex affective factors like values, attitudes, norms and the like. (Kirby et al. 2006, 104-106.) This is unlikely when staff is untrained and living in a remote and poverty stricken area like Katakwi. The interviews themselves will speak to the ability of the teachers to be effective in their delivery of the PIASCY curriculum. Regardless, this concern of a fact-focused delivery is echoed by Monasch and Mahy who say that while the youth may have general knowledge about HIV/AIDS, they may lack the real world skills to negotiate abstinence, reduce their sexual partners, or use condoms. Moreover, they may not have the skills to talk to their partners about sex even if they have the knowledge because of social norms and gender inequality. (Monasch & Mahy 2006, 31-32.) The students are not alone in their problems discussing topics of sexual health, as often the teachers can feel uncomfortable with the issues they have to address. These teachers, as well, can be abusive towards the students and may have HIV/AIDS themselves, adding another problematic dynamic to the situation. (Norton & Mutonyi 2007, 488.) In spite of these valid concerns, there is strong evidence that school-based interventions reduced the reported risky sexual behaviour (Cowan & Peltifor 2009, 289) and Uganda has been the poster child for reducing the rate of HIV/AIDS across the country.

### 3.1.2 Youth Living with HIV/AIDS

Education is fundamental in combating the scourge, but there are still the millions of adolescents that are currently living and dealing with HIV/AIDS. As Pienaar and Visser argue, the roll out of Anti-Retroviral Therapy (ART) for children with HIV has made living into adolescence and adulthood possible for the first time. The current adolescent population living with HIV faces distinctive challenges that affect the development of their identities and disease management skills. (Pienaar & Visser 2012, 66.) This generation of teens is truly unique in that they are the first to experience an adolescent life with the disease, and with hope for a long future. Medically, they are also unique in that perinatally infected children are typically

growth hormone deficient and go through puberty later than their peers. There is also research suggesting that the virus causes neurocognitive delay and is associated with behavioural issues and a high prevalence of mental illness. (Li, Jaspan, O'Brien, Rabie, Cotton & Naltrass 2009, 751.) Other research has determined that teens with HIV are particularly at risk for substance abuse, early sexual debut, and unprotected sexual intercourse (Petersen, Bhana, Myeza, Alicea, John, Holst, McKay & Mellins 2010, 970).

Beyond the distinct health concerns of adolescents with HIV/AIDS, their psychosocial needs also must be addressed. Like most teenagers, they do not want to be perceived as different from their peer group, and they have to balance their family and cultural roles with that of their school and peer group roles. This is, of course, an added challenge on top of their disease management. (Pienaar & Visser 2012, 67-68.) Other challenges these young people face include the worries about who will take care of them, particularly if they are orphans or have HIV positive family members. Generally, families that live in poverty have caregivers with a reduced ability to care for and protect these children. They are also burdened with concerns about future romantic relationships, disclosure of their status to others, and internalized stigma. (Petersen et al. 2010, 972-974.) All of these factors make it clear that these young people have distinct challenges in maintaining physical and mental well being. Petersen et al. claim that the psychosocial challenges of this generation with HIV/AIDS has a direct effect on their physical well being in terms of ART. Adherence to the drugs is difficult given the changing developmental stage, partial reliance on caregivers, interference with daily routines, and complex dosing regimes (Petersen et al. 2010, 970). It is no wonder, then, that UNICEF stated in 2011 that in general, adolescent health challenges are not properly addressed by pediatric or adult physician services and they made a call for adolescent friendly health care to address the needs of this unique group (Pienaar & Visser 2012, 67). This is particularly true for the adolescents that have HIV/AIDS.

Given the complex and important lives this generation of teens has, more exploration is needed to truly understand their experiences. Li et al. acknowledges that attention has been focused on these young people, "yet only a handful of studies

have considered the perspectives of HIV-infected adolescents themselves, and even fewer have done so in resource limited settings” (Li et al. 2009, 752). Li and colleagues found that the adolescents they spoke with generally identified HIV to be a negative aspect of their lives, and described it as physically and emotionally painful. They were fearful and angry, and some had considered suicide. Many of the youth in this study kept their status a secret because of the fear of stigma. Beyond this, they were preoccupied with problems at home: poverty, violence, crime, and drugs. Like my research, this study found that being hit at school depressed the students, but it was unclear if this abuse was related to their HIV status. (Li et al. 2009, 753.) Pienaar and Visser also explored the experiences of adolescents with HIV, most of whom were not open about their HIV status, and they found that the teens struggled with future disclosure of their status to others because of fear of rejection. They found that all the young people felt a conflict between being normal and being different. This was more pronounced in the older adolescents who had greater limitations in living with the secret of their status. (Pienaar & Visser 2012, 72.)

The subjects in the research by Petersen et al. stated that both the availability of the medication and the counseling helped them cope. Moreover, positive thinking and goal setting was helpful, as was instilling these ideas in others. The study also found that those with family and peer support coped better, and an extensive support network, like at the hospital, added to this coping. Finally, the research showed that being with other HIV positive children was particularly helpful. (Petersen et al. 2010, 974). These findings corroborated those of Li and colleagues, who also found that a strong family was important in feeling happy, as was friendship. Some teens even indicated that they were happy because they were grateful for the health that they have. In addition to this, going to school was generally viewed as constructive; that combined with clinics, schools are a positive source of support. Like Petersen et al., this study also showed that the medication helped the subjects stay positive. (Li et al. 2009, 754). However, in Pienaar and Visser’s research, some of their subjects expressed frustration with taking the medication. The subjects also found that the clinic visits took a long time, and that

they did not always know why certain procedures occurred. While they valued the counseling, the teens in this study found that formal interactions with healthcare providers were a barrier to disease management. (Pienaar & Visser 2012, 73.)

Finally, Li et al.'s study asked the adolescents about their futures and found that two-thirds of the participants felt positive about them. The teens wanted to be doctors or social workers, so that they could help others. While they felt positive about future expectations, they felt uncertainty on how to achieve their goals. The study found that the wellbeing of the HIV positive teens was dependent on many of the same factors that affect the general teen population, and argued that it is thus important to continue strengthening the broad spectrum health promotion programmes in schools and communities. The study did add that while the needs of all teens are similar, the effects of poor mental health on HIV positive teens have serious consequences for both drug adherence and risky behaviours: HIV positive teens do have distinct needs. (Li et al. 2009, 754-756).

### 3.1.3 Stigmatization

Most of the existing literature that explores the experiences of those living with HIV/AIDS, both adult and child alike, focuses on stigmatization. As medical advances have improved the physical quality of life for HIV positive people, a shift in attention has moved towards the psychosocial well being of those living with the disease. This focus is based on the 2003 UNAIDS definition of stigmatization, which is the process of devaluation of the individuals living or associated with HIV/AIDS. Discrimination is the action resulting from stigmatization. (Thupayagale & Tshweneagae 2010, 261.) The debate continues as to how this normalization of HIV/AIDS because of ART may impact stigma. Many people still see it as a "moral disease" which continues to undermine disclosure and voluntary testing, whereas others argue that it allows patients to resist and challenge stigmatizing attitudes. (Midtbø, Shirima, Skovdal & Daniel 2012, 261.) For many children and adolescents, the impact of stigma is two-fold because the discrimination they may experience can be based on their own HIV positive status, and that of their parents and/or caregivers. In fact, as Nattabi, Li, Thompson, Orach and Earnest (2011, 200) found

in Northern Uganda, there is a significant difference in stigmatization between those over 30 years of age, compared to those under 30. The over 30 group, particularly females, struggled much more with stigmatization. While this is encouraging in that it shows the younger generation is making steps to reducing stigma, it still has an indirect impact on the young people with HIV/AIDS. If caregivers are subject to stigma themselves, it can influence them to not tell their children that they are positive, or hold them back from seeking support (Midtbø et al. 2012, 262). This can also even affect the decision of a caregiver to even take their children to be tested in the first place. Non-disclosure to the younger generation can generate confusion, mistrust, compromising knowledge, and increased HIV risk through behaviour. On the other hand, disclosure is linked to good adherence to ART and fewer emotional problems in the long term. (Midtbø et al. 2012, 262.)

For adolescents in particular, most studies have shown that they do indeed experience stigma, despite the roll out of ART. This is usually in the form of verbal abuse and labeling. It is worsened by the teens' feelings of being gossiped about and potential rejection from friends and family. (Midtbø et al. 2012, 264.) This was also found to be true in Nattabi et al.'s research, but they also assert that not all studies document a reduction in stigma as a result of ART. They cite one study that found verbal abuse, negative self-perception and social isolation was actually associated with ART. They argue that this highlights the lack of privacy for patients in the delivery of treatment and therapy for HIV/AIDS. Their study also points to the role of internal stigmatization and feelings of worthlessness that can come with being HIV positive. This then impacts access to health care, drug adherence, disclosure, and prevention services. (Nattabi et al. 2011, 196-203.) Moreover, internalized stigma can lead to an inability to express distress (Midtbø et al. 2012, 262.)

In studies that actually interviewed and worked with adolescents, it was shown that the teens use a variety of methods to cope with stigma, and have diverse feelings in general about this stigma and about living with their disease. Even though some studies show that ART can increase stigma, teens in Botswana in Thupayagale-Tshweneagae's study (2010, 262) use adherence to the ARVs as a way to combat stigma because it keeps patients healthy and less visibly identifiable. This

was also true in Midtbø et al.'s work, as those adolescents cited the availability of medications contributed to their feeling of safety and was mentioned as being important in their lives. Moreover, they felt it helped them to live positively and maintain control of their lives. (Midtbø et al. 2012, 265-266.) Beyond adherence to medication as a way to reduce stigma, another common method was to keep their status undisclosed. The adolescents in Thupayagale-Tshweneagae's study (2010, 262) felt that by not telling others, they were protecting themselves from the community. The teens in Midtbø et al.'s research were advised by their caregivers to not tell others of their status. Despite this advice, some of the young people did disclose their status to people in their lives, and actually had positive experiences with this, particularly when they told their teachers. (Midtbø et al. 2012, 266.)

Positive social marketing strategies have emerged across Sub-Saharan Africa with messages about supporting and loving those with HIV/AIDS. Even so, according to Thupayagale-Tshweneagae, many people still do not talk about the disease and this exacerbates the belief that it is "bad." This may also contribute to why the teens in the study remained quiet about their status. (Thupayagale-Tshweneagae 2010, 263.) However, while the adolescents in Midtbø et al.'s research generally remained private about their HIV status, they did participate in support groups, which helped them not only cope but also thrive and decrease their self-stigma. These support groups served to enable meaningful social relationships and a feeling of unity as a group. Beyond acting as a source of knowledge and information, it created confidence in these teens. (Midtbø et al. 2012, 266-268.) Both studies were strongly in favour of the support groups, as they concluded that they allowed the adolescents to use the resources available to them, find community, and believe that they could overcome obstacles (Thupayagale-Tshweneagae 2010, 263; Midtbø et al. 2012, 268). Ultimately, this generation of adolescents with HIV/AIDS, despite experiencing stigma and other challenges, create a window of opportunity for changing the course of the epidemic (Thupayagale-Tshweneagae 2010, 263).

### 3.2 Empowerment

In keeping with this view of this generation's potential to be a powerful and positive force in the future of HIV/AIDS, I turned to empowerment theory as my guiding context for this research. I am not alone in this empowerment-based analysis: both Education and Development are somewhat notorious for shifting paradigms every decade or so, and current thinking tends to be towards an empowerment framework. Like most academic buzzwords, these concepts have a tendency to lose their substance as they become more ubiquitous over time. Empowerment runs the risk of becoming one of these cases. However, while it is clear that academia has a virtual overload of empowerment musings, it does remain an important concept in the reality of NGOs and their projects, programmes, and general goals and activities. I was especially struck by this while driving in the company vehicle to a remote village in Katakwi District and, as usual, the car was packed with field workers, interns like myself, take away lunches, and on this occasion, a teenaged girl that was with us to take care of one of the field workers' babies during the community participatory exercise. The car was a racket of chatting and laughing, but one fieldworker was teasing the teenaged girl saying, "This one is empowered! I see her on Sunday during Prayers, singing and swaying her braids back and forth!" Everyone laughed at that, but it made me wonder what exactly empowerment meant. Is it just the ability to be free at church and in the community? Or, more simply, is it just another word for confidence?

I was further intrigued by the concept of empowerment when a student in the town came to the office I was working at hoping that I would pay for his term's school fees. This was a common occurrence and one that was always rather awkward. I discussed with him the other options he had and we came to the conclusion that because he had a history of paying his fees regularly, perhaps the school would allow him to be late with his payment this time. He left the office to go to the school to discuss this possibility. About a week later he came back to see me to let me know that indeed the school allowed him a grace period, but what was more interesting was that he specifically told me how *empowered* he felt to have dealt with that situation and to have come to a solution that worked for him. Again, this concept seemed to be more than just confidence, and I was now on the path to

discovering what exactly it means to be empowered, how it happens, and what it means for quality of life for students in Katakwi living with HIV/AIDS.

### 3.2.1 Definitions

Influenced by Brazilian educator and philosopher Paulo Freire and his 1970's *Pedagogy of the Oppressed*, empowerment theory came to the forefront in the 1980s and 1990s through the writings of M.A. Zimmerman and J. Rappaport.

Empowerment emerged partly as an alternative to the approaches at the time that viewed communities and individuals by means of their weaknesses or deficits, the typical 'needs-based' approach. Empowerment, on the other hand, "links individual strengths and competencies, natural helping systems, and proactive behaviours to matters of social policy and social change" (Zimmerman and Rappaport 1988, 726). This approach, instead of a focus on illness, weakness, and needs, changes the focus to wellness, competence, capabilities, and strengths. (Perkins and Zimmerman, 1995, 570).

For Rappaport (1981), the appeal of an empowerment framework lies in its vision of a society that is participatory and where the people in a local setting are already handling their own problems. It requires that any intervention or programme must recognize the existing capabilities and thus foster changes that allow people to gain control over their own lives. Other needs-based models create a view of people as dependents in their current situation. Even advocacy or rights-based models, in Rappaport's thinking, still require some sort of expert or leader to come in and provide answers for a community or individual. Empowerment, however, suggests that people are active collaborators in their own problem solving. At the very least, it acknowledges that many competencies already exist or are possible. (Rappaport 1981, 15-16.) There is a core belief in the potential of people to direct their own futures.

In regard to what is seen as the problem or deficiency in any context, it is the poor functioning of a social structure and lack of resources that make it difficult for these existing capabilities to function. The key to empowering people or individuals requires that new capabilities be learned within the context of their community;

external programmes with an expert cannot just be inserted in artificially.

Furthermore, Rappaport argues that problems are divergent in nature and therefore have more than one solution. The recognition of a diversity of people with diverse experience allows for the possibility of a variety of local solutions. Rather than the usual 'top-down' approach from officials and donors, empowerment starts with the target community and works up to the officials, rather a 'bottom-up' approach.

(Rappaport 1981, 16-17.)

Overall, Rappaport states that, "...social problems require that experts turn to non-experts in order to discover the many different, even contradictory, solutions that they [individuals] use to gain control, find meaning, and empower their own lives." (Rappaport 1981, 21). The settings and situations for successful empowerment will differ in every context, so it is essential to foster the legitimacy of multiple ways to deal with problems. In doing so, empowerment makes it possible for people to obtain and control the resources that affect their lives. The alternative, or disempowerment, can result in learned helplessness, negative labeling, and a belief in the power of others rather than self. (Rappaport 1981, 18-20.)

Zimmerman (1995) furthers many of Rappaport's arguments and even quotes Rappaport in his definition, "empowerment is a process by which people, organizations and communities gain mastery over issues of concern to them" (Zimmerman 1995, 581) However, Zimmerman expands on the Rappaport's definition to make it a multilevel construct. Psychological empowerment of the individual, which is the most relevant for this study, includes intrapersonal, interactional, and behavioural components (Zimmerman, Israel, Schulz, Checkoway 1992, 708). There is not, however, one set of characteristics that show empowerment. To clarify, intrapersonal components are how a person thinks about their ability to influence systems that are important to them. This would relate to aspects of perceived control, self-efficacy, and perceived competence (Zimmerman 1995, 588). Interactional aspects of empowerment refer to one's ability to understand casual agents and gain a critical awareness of one's environment. This leads to both decision-making and problem solving skills and eventually resource mobilization. This interactional aspect of empowerment is essential as it connects

self-perceptions to actions. (Zimmerman 1995, 588, Zimmerman et al. 1992, 708). Finally, the behavioural aspect of empowerment refers to the specific actions one takes to exercise influence. This is largely through participation in community organizations and activities. (Zimmerman et al. 1992, 708.)

All of these components as listed above help to develop a more comprehensive definition of what constitutes empowerment, though it can be an elusive and fluid concept. In fact, Zimmerman explicitly states that an actual measurement of empowerment is difficult and inappropriate as it is an open-ended construct not easily reduced to a set of rules and definitions. Furthermore, “measurement of psychological empowerment may be especially difficult because (a) PE [psychological empowerment] manifests itself in different perceptions, skills and behaviours across people; (b) different beliefs, competencies and actions and may be required to master various settings; and (c) PE may fluctuate overtime.” (Zimmerman 1995, 583).

While measuring empowerment may not be a concrete, quantitative task, this is not to say that empowerment cannot be observed or studied. It is then important to differentiate between empowering processes and empowered outcomes. The former is where people are given or create opportunities to control their own future and have impact on the decisions that affect their lives. For this to be successful there, needs to be a setting that provides opportunities for shared leadership, skill development, and participation. It can be argued that the participatory processes are, at their core, empowering. Ultimately, empowering processes are ones that bring together a vision of goals, a sense of how to achieve them, and in doing so allow for greater access to resources and the ability to gain mastery over one’s own life. (Zimmerman 1995, 583.)

In contrast, empowered outcomes refer to the operationalizations of empowerment that allow us to study the results of the empowering processes (Perkins & Zimmerman 1995, 570). It is in this area that it becomes more difficult to define, as empowered outcomes may be situation-specific perceived control and resource mobilization skills, which can vary across settings and individuals. However, the basic components seem to be “participation with others to achieve

goals, efforts to gain access to resources, and critical understandings of the sociopolitical environment” (Perkins 1995, 571). Again, the challenge arises when trying to find a measure of empowerment because it has to be broad enough to encompass diversity, yet specific enough to allow assessment for a particular context. Thus, measuring empowerment may not be a realistic, desirable, or appropriate goal. Empowerment is a dynamic variable that fluctuates over time. Because of this, every person has the potential to go through both empowering and disempowering experiences and may become more empowered over time. It is likely that some individuals may be more empowered than others, but that is not to say that they are not going through an empowering experience or are on a path to their personal empowerment. Overall, then, it is key to keep in mind that “the development of a universal or global measure of empowerment is not an appropriate goal because it may not mean the same thing for every person, organization, or community everywhere”. (Zimmerman 1995, 586-587.)

In some cases, empowerment can be identified by traits that show its absence, for example, at times it may be easier to recognize alienation, powerlessness, normlessness, helplessness, and social isolation. However, in the spirit of the empowerment framework, it is more effective to look for positive characteristics. Again, it is not a hard and fast measure; many studies have explicitly looked at certain observed variables related to empowerment. These are: internal locus of control, chance control, belief in powerful others, control ideology, self-efficacy, sense of mastery, desire for control, civic duty, leadership, internal political efficacy, and perceived competence. (Zimmerman & Rappaport 1988, 729). Of these variables, at least three studies have shown that individuals that have greater participation in community activities and organizations that are associated with psychological empowerment. Therefore, individual empowerment can be described as, “the connection between a sense of personal competence, a desire for, and willingness to take action in, the public domain,” (Zimmerman & Rappaport 1988, 746). From this it seems that effective interventions are ones that give people genuine opportunities to participate. Meaningful participation helps institute empowerment as it helps with skill development, decision-making, and problem

solving. With this skill development, an individual can experience greater self-acceptance, social understanding, self-efficacy and many of the other factors that combine to form the single function of empowerment.

Finally, for Zimmerman, linked to individual empowerment is the concept of learned hopefulness, “the process whereby individuals learn and use skills that enable them to develop a sense of psychological empowerment” (Zimmerman 1990, 73). The concept is the empowerment approach to the theory of learned helplessness, where those that have that feeling experience motivational and behavioural deficits, and emotional withdrawal. Learned hopefulness, then, suggests that when experiences within a community provide opportunities to enhance perceived control, individuals are better able to cope with stress and solve problems. As previously mentioned, different aspects of perceived control are key pieces in the function identified as empowerment. Thus, empowerment is a product of learned hopefulness, and learned hopefulness seems to result from true participation in the community, whether that participation is through experience, observation, or modeling. (Zimmerman 1990, 73-80.)

In summary, the key elements of empowerment theory are a collection of characteristics, which include personality, cognitive, and motivational aspects of control and competence. Each of these contributes to the single function of empowerment. It is best to describe empowerment in positive terms, as it is more than the absence of helplessness, alienation, or powerlessness. (Zimmerman & Rappaport 1988, 746.) Empowerment is a dynamic and fluid concept, both a process and an outcome, and will vary between individuals or groups of individuals, but in generally includes self-acceptance, confidence, sociopolitical understanding, and what seems to be important according to empowerment studies, participation. Overall, empowerment can be described as “the connection between a sense of personal competence, a desire for, and willingness to take action in, the public domain.” (Zimmerman & Rappaport 1988, 746) It constitutes one’s beliefs that their goals are achievable, that they possess the awareness about the resources and factors that hinder or enhance the effort to achieve these goal (Zimmerman 1995, 583).

### 3.2.2 Empowerment Applied to Health and Education

The 'bottom-up' approach that is very much at the core of the empowerment framework appeals to many domains of academia and practice, but particularly applicable for this topic is how it has been incorporated into both health and education. This is especially true because many scholars working in health education see the importance of empowerment not only for the sustainability empowerment programmes can create, but because it is now acknowledged that powerlessness is linked to disease and conversely, empowerment is linked to health. Moreover, scholars are increasingly calling for health-related education to be based on Freirian empowerment in that it involves people in group efforts to "identify their problems, assess social and historical roots of problems, envision a healthy society, and develop strategies to overcome obstacles in achieving their goals" (Wallerstein & Bernstein 1988, 380).

Health issues go beyond their physical symptoms, and for those with chronic illnesses like HIV and AIDS, the emotional and social factors play a significant role in overall wellness. Sickness is not just biological, but also a socio-cultural experience in that it positions people within social roles and expectations (Crossley 1998, 509). As Wallerstein and Bernstein (1988, 380) argue, lack of control over one's life is a risk factor, stemming from the overburden of life's demands with inadequate resources to then meet these demands. Others have also found that there is a clear association between powerlessness, alienation, learned helplessness and one's mental and physical health status, and that control plays a role in modifying levels of stress and health and the relationship between the two (Israel, Checkoway, Schulz & Zimmerman 1994, 155). This is significant for the wellness of a community in that social support plays an important role on an individual's health. Additionally, the coming together of an empowered community to influence health related issues provides a more stable and stronger effect. As the Ottawa Charter for Health Promotion points out, health education needs to be aimed not only at individual behaviour change, but also collective action for social change, as many risk factors to

health are beyond any one individual's control. (Israel et al. 1994, 150.) This is particularly true for youth with HIV/AIDS in rural Uganda.

Across the world there is still the model of professionally driven solutions to problems in health, almost to the point where there is a release of ownership of one's body and its ailments to someone else to 'fix'. This giving up of one's power to a health expert can be particularly detrimental in areas that are lacking in both resources and qualified health professionals. In contrast to this illness model, empowerment applied to health is more proactive for the individual (Israel et al. 1994, 152) and embodies a broad process of prevention, community connectedness, self-development, improved quality of life and social justice (Wallerstein & Bernstein 1988, 380). An empowerment approach acknowledges that just the process of dialogue and 'problem-posing' as opposed to problem solving can be transformative and empowering. The collective questioning of critical health related issues and the chance for participation in a meaningful way encourages action to move beyond powerlessness and recognizes people as controllers of their own health rather than objects (Wallerstein & Bernstein 1994, 142-144; Romero, Wallerstein, Lucero, Fredine, Keefe, & O'Connell 2006, 392).

Specifically for programmes that target HIV/AIDS prevention and education, an empowerment approach utilizes dialogue and problem posing to work on issues as they are in a specific context. This framework allows for concerns like poverty, gender roles, cultural norms, limited education, and partner violence, among others, to be discussed and applied to health knowledge. Information alone is not seen as an efficient strategy in changing health behaviour practices. The empowerment model, through participation and dialogue, therefore brings to the surface other factors that influence health decisions and allows for the opportunity for solutions and the alleviation of powerlessness and learned helplessness. (Romero et al. 2006, 391; Levine, Britton, James, Jackson & Hobfoll 1993, 321-332). Again, while solutions may be beyond what one individual can control, the process of participatory dialogue is in itself transformative and achieves the empowerment ideals of "people gaining control of their lives within a context of participating with

others to change their organizational, social, and political realities.” (Romero et al. 2006, 392).

Education is clearly at the heart of empowerment. The goal of education, as Paulo Freire saw it in 1973, is that “...education should have as one of its main tasks to invite people to believe in themselves. It should invite people to believe they have the knowledge” (Wallerstein & Bernstein 1988, 381). This idea behind education, not just conventional education in the classroom proper, is that the entire process of learning is to allow for individuals to become empowered enough to fully participate in their social and political life: true learning requires taking action in the world. Freire’s ideas were based on the central premise that education is not neutral and needs the question of who education serves and for what purpose. (Wallerstein et al., 1988, 381-382).

Freire’s call for empowerment education has shaped the thought processes behind empowerment theory, and as such should be briefly summarized here, though most of his arguments are echoed and elaborated on by Zimmerman and others and will be discussed in more detail in the next section on youth empowerment. The basis, though, of Freire’s vision of education involves a three-stage model, of ‘listening’ to each other to identify problems, engaging in ‘dialogue’ to critically analyze the roots of the problems, and developing ‘action’ strategies for change. Like others that have written on the subject, problem solving is not necessarily the main goal here, but the process of problem posing and dialogue is in itself, empowering as it allows for the recognition of the complexities and long-term nature of individual and community change (Romero et al. 2006, 392). Furthermore, empowerment-based education recognizes the dynamic interaction between personal growth and participation in community change and action. It is the opposite of the traditional punitive environment where learners are treated as objects, best controlled through shame and fear. Essential components of education should be active listening and exploration to build self-esteem and participation. (Wallerstein & Bernstein 1988, 385.)

One study that combines all the elements of empowerment, health, education and HIV/AIDS. Boneh and Jaganath (2011) examined PACED, a performance-based

HIV/AIDS education programme in Ghana that, “shifts from using art as entertainment to conveying messages about HIV/AIDS towards more participatory, communal, and empowering approach made possible through art” (2011, 455.) Based on the ideas of empowerment, the performance group, composed of both HIV positive and negative actors, sets about to trigger discussions on HIV and AIDS within a community’s own context. This was in response to the perceived limitations of the Abstinence, Being faithful, Condoms (ABC) approach that neglects complicating factors such as culture, economics and power. The participatory aspect of the programme is that the audience determines the course of the discussion. Moreover, it is not until after the performance that it is revealed that some of the actors are HIV positive. This piece of the programme is intended to move away not only from the stigma that was created by the fear based approaches to HIV in the 1980s and 1990s, but even beyond the current ‘compassion’ approach. Compassion has increased the likelihood of care and has decreased isolation, but it has the potential to create dangerously uneven power dynamics. The person with HIV/AIDS is now the receiver of pity and mercy. PACED asks, “is it compassion that people with HIV/AIDS need from their families, the general public, and the government, or do they need the power to exercise their own human rights and not be dependent on the goodwill of others? Does the concept of compassion fuel the cycle of victimhood?”(Boneh et al. 2011, 456.) Overall, the performances are a gateway for topics not usually discussed, incorporates the empowerment approach of problem posing, participation and action with seeming success.

### 3.2.3 Youth Empowerment

As both Freire’s works and empowerment theory generally has gained a stronghold in academia, there has been the emergence of empowerment theory as it relates to youth. Recent years have seen a shift in researchers from viewing youth as problems to resources. As such, youth empowerment theory and programmes have abounded that attempt to build on young people’s strengths and involve them in issues that they see as important. However, the inclusion of youth in a meaningful way is still the rarity, rather than the rule, and most research related to youth is still

adult-centric and the experiences of the youth themselves are overlooked. (Wong, Zimmerman & Parker 2010, 100.)

Schools, being the central institution in most young people's lives, are integral to youth empowerment and have the ability to provide a safe, structured environment that can prepare youth for critical thinking, problem solving, and active citizenship. However, most schools still employ Freire's 'banking' concept of teaching, or Wong, Zimmerman, and Parker's 'vessel' concept. Both notions refer to students as passive receptacles in which teachers deposit information. Dialogue, in this instance, is limited and the development of exploration and understanding is eliminated (Pearrow & Pollack 2009, 46; Wong et al. 2010, 107.) Many schools and institutions are characterized by this type of education system, and at-risk and marginalized youth are particularly susceptible to learned helplessness and powerlessness (Pearrow et al. 2009, 47).

In response to the previously acknowledged issues that can arise in traditional educational settings, many researchers and academics have created youth empowerment models and strategies based on both Freire and other empowerment theorists. The shift, again, has gone from identifying youth as a source of problem in a community to embracing their potential to be active and engaged community members. In 1998 Chinman and Linney created the Adolescent Empowerment Cycle (AEC), based on both Zimmerman and Rappaport, aimed at preventing a sense of rolelessness and enhancing self esteem (Jennings, Parra-Medina, Messias, McLoughlin 2006, 34). Chinman and Linney argue that the elements of empowerment, active participation, awareness of socio-political surroundings, and the identification of strengths, are also important developmentally during adolescence. For AEC, the essential elements of youth empowerment are positive bonding to institutions through action, skill development, reinforcement and recognition. Adults play an important role in creating the empowering atmosphere and in providing the reinforcement and recognition for young people. An empowering environment fosters youth bonding to positive institutions, which leads to youth experimenting with positive roles rather than negative ones. Those who do not find a positive role in which to

participate are more likely to bond to negative institutions and engage in deviant behaviour. Overall, AEC can provide stability and offset a lack of purpose or direction for youth. (Chinman & Linney 1998; 394-408, Jennings et al. 2006, 34-35.)

In 2003, Cargo, Grams, Ottoson, Ward and Green discussed youth empowerment through their Transactional Partnering Model. This model is based on the premise that youth empowerment is a mutual process of transactional partnering between adults and youth. Adults create the welcoming environment to facilitate and enable youth, and incrementally give up responsibilities and decision making to the youth. Moreover, the interrelated concepts of engaging youth, actualizing youth potential, and cultivating constructive change help direct a youth-defined agenda. Like all other empowerment models, meaningful participation coupled with skill building is essential for keeping youth engaged and creating empowerment opportunities. For Cargo et al., youth empowerment requires a shift in programming from the traditional top-down approach to a partnering one where adults welcome youth and assume an active, enabling role as young people explore and navigate challenges and build their capacities. The ensuing youth participation and reflection can result in learning and empowerment. (Cargo et al. 2003, 66-78; Jennings et al. 2006, 36-37.)

Just as Paulo Freire was key in fostering empowerment theory, so too was he essential in youth empowerment specifically, given that his work targeted schools and the educational system in Brazil. According to Freire, empowering education is a process that involves listening, dialogue, critical reflection, and reflective action (Freire 1970). Thus, central to this theory is that the learners need to be active in their own education, and educators must have a fundamental belief in the learner's ability to learn. In doing so, teachers move from directing to facilitating, from talking to listening, and from doing to observing. (Timpson 1988, 63-64.)

Empowering youth moves away from the idea that students are empty banks in which to deposit information, and to a process that allows for meaningful activities to "learn skills, confront challenges, demonstrate success, and receive support and positive reinforcement..." (Jennings et al. 2006, 39). The challenging piece of Freire's ideas is that it requires the movement away from a set curricula because in

order to become empowered, the students themselves identify the problems, assess their roots, envision the change, and then create strategies for action. Obviously, in a highly bureaucratic system, this can be difficult to fully achieve, but the essential piece is student participation to learn meaningful skills not isolated from the learners' social realities. The ultimate outcomes of empowerment education, then, are self-efficacy, self-protective behaviours, socially responsible behaviours, and empathy. (Jennings et al. 2006, 38.)

Building upon the previous theories already summarized, Jennings, Parra-Medina, Messias and McLoughlin (2006) created the idea of a Critical Social Theory of Youth Empowerment in 2006, with the aim to “support and foster youth contributions to positive community development and sociopolitical change, resulting in youth who are critical citizens” (Jennings et al. 2006, 40). According to this theory, which recognizes meaningful participation as the common element among the other theories, the Critical Social Theory has six key dimensions: a welcoming, safe environment; meaningful participation and engagement; equitable power sharing between youth and adults; critical reflection on interpersonal and sociopolitical processes; participation in sociopolitical processes to effect change; and integrated individual and community level empowerment (Jennings et al. 2006, 41). While most of these elements are self-explanatory, it is important to touch on a few ideas in more detail. One of the more challenging elements is the concept of power sharing with adults, which can be difficult to not only achieve but also to maintain. It can easily lead to token participation by the youth, as the adults create and lead the activities and the youth have a minimal role. It is a balance between overt support and covert control, with the strategy of gradual transfer of decision making to youth over time. (Jennings et al. 2006, 45.)

Jennings et al. also emphasize the importance of critical reflection, and they assert that this is one element that is often overlooked. They draw upon Freire's idea that if people are not aware of the visible and invisible structures that make up social institutions, there is no room for empowerment. The Critical Social Theory then stressed the need for youth to fully understand their community, structures, and resources and reflect on the challenges that they create, in order to make

meaningful future actions, “without examining sociopolitical processes, youth lack the insight needed to become effective agents for altering the status quo” (Jennings et al. 2006, 50).

The benefits and outcomes of Critical Social Theory are all along the same lines as the other youth empowerment theories on which it builds: increased self-efficacy, self-awareness, positive identity development and bonding, interpersonal relations, and a sense of purpose. Beyond this, Jennings et al. also state that their theory provides the opportunities for adults and youth to spend time together in a partnership, and this allows for the recognition of each other’s strengths and assets. This, increases the community’s capacity to cooperate, compromise, and appreciate diverse perspectives and experiences. (2006, 51.) However, like Zimmerman and others, Jennings et al. also realize that a global measure of empowerment is not an achievable or a desirable goal. They too see empowerment as both a process and an outcome that is not experienced the same way by individuals, organizations and communities, rather, as a process, it is a series of experiences of engaging in collective action for change. (Jennings et al. 2006, 52.)

It becomes evident that in order to be effective, all youth empowerment theories require a great deal of youth participation. As Checkoway asks in 2010, what is youth participation? The Convention on the Rights of the Child (Article 12) actually lists youth participation as a protected right and affirms that youth have the right to participate in decision-making processes relevant to their lives. Moreover, they also have the right to influence decisions made in their regard, especially related to education and/or community matters. This Convention affirms that children are indeed full-fledged persons who have the right to express their views in all matters. (<http://www.unicef.org/crc/>) The acknowledgement of youth as competent citizens rather than passive recipients of services allows for youth to act as resources and provide valid input in goal setting, resource allocation, and programme implementation. However, the mere presence of youth does not constitute sufficient or proactive participation, nor is assigning token roles to children. Youth participation requires active engagement and real influence, with adult allies. As youth participate in meaningful ways, they grow in confidence,

develop practical skills, emerge as leaders, become aware and gain experience. This is particularly significant for Sub-Saharan Africa, and Uganda in particular given the percentage of the population that is under 15 years of age. According to the World Bank, in 2011 Sub-Saharan Africa had 42.3% of the population ages 0-14. For Uganda, this number is 48.3%.

(<http://data.worldbank.org/indicator/SP.POP.0014.TO.ZS>). Of course, this number does not include the large percentage of adolescents among the population. These youth have limitless issues and seem to very much care about schooling and education. It is essential to acknowledge youth as citizens, otherwise they are apt to accept the adult conceptions of themselves as deficits to the community.

(Checkoway 2010, 341.)

#### 3.2.4 African Youth Empowerment

Youth empowerment has clearly become an important sub-category in empowerment studies, development, and education. There is no shortage of empowerment studies and research in the developing world, but until recently, it is largely empowerment of women or generalized community empowerment (Mutuku 2011, 35). It is evident that adolescence is recognized as a period in life when relationships are formed, rules and norms are tested, risky behaviour can occur, and financial support shifts (Mohajer & Earnest 2009, 426). Youth empowerment programmes are aimed to address these aspects but there has to be an acknowledgement of what it means to be an adolescent in Africa, and that is often very different than in the global North. Expectations, roles, responsibilities, and levels of autonomy are only a few of the ways adolescents in an African context will differ from that of the developed world. Mohajer and Earnest refer to criticisms that see the entire empowerment model as a “manifestation of Western culture because it is brought through agencies and their own ‘cultures’” (Mohajer & Earnest 2009, 432). This is not just in developing countries, but also in reference to cultural minorities in Western countries. Beyond this massive oversight, Mohajer and Earnest also acknowledge that empowerment programmes traditionally overlook adolescent AIDS orphans. They argue that this demographic, representing about

11.8 million people between the ages of 15-24 in 2005, are less likely to receive skill training, reproductive health information, and are at a greater risk of exploitation. (Mohajer & Earnest 2009, 426). Clearly there is a need for youth empowerment research that acknowledges a model of youth empowerment that reflects the African adolescents' reality, especially when we see that youth empowerment programmes call for education and skills that are meaningful to the youth's life. This cannot be done if it is based on the culture and reality of a Western youth.

As Burgess (2005) notes in his work, "Introduction to Youth and Citizenship in East Africa", in the four years previous to his publication, four major institutes have hosted international conferences specifically on youth in Africa. He surmises that this new focus on African youth is because of the high birthrate and general youthful population of the continent. (Burgess 2005, vii). This large population of youth that face high unemployment and disengagement can be seen as a threat, as per the youth bulge theory. This theory identifies this unengaged demographic as a very real threat to durable peace. (Maina 2012, 12, 139). In the African context, young people are especially vulnerable because of AIDS, population growth, political turmoil and the like. As Burgess stated, "to be young in Africa [has come] to mean being disadvantaged, vulnerable and marginal in the political and economic sense." (Burgess 2005, ix.) However, in order to empower the young people of Africa, the lens through which they are viewed must be changed. Moreover, an examination of what exactly constitutes youth in the African environment is important.

In East Africa specifically, the twentieth century saw youth as a distinct phase with well-established understandings about characteristics and functions, but done so in relation to their elders. It was more of a "class" division than an age division. (Burgess 2005, xi.) However, different perspectives of youth reflect the various ways young life may be lived. This is inseparably connected to issues of power, authority, and gender, and therefore carries both positives and negatives. In this way, 'youth' is brought to the fore by circumstances that emphasize one generational category over the other. To fully understand youth, and, for this research, youth in an African context, it has to be examined in juxtaposition to the social contexts and situations that it is actualized in. Since the 1970s, for Africans,

youth have come of age in volatile circumstances and this has obviously shaped their collective lives. They are “a generation of people who have been born into social environments in which their possibilities of living decent lives are negligible and in which many have found themselves stuck in positions of inadequate life chances and bleak prospects...” (Christiansen, Utas & Vigh 2006, 9). This modernization and societal change undermined the stability of well-defined nations of youth in more traditional societies (Burgess 2005, x). Because of the precarious circumstance to which generations of youth are now born in to, there has to be a way to balance how young people see and interpret the world and the way they are positioned within it. There also has to be a recognition that youth states vary according to time and place and that they emerge out of languages and idioms: ‘youth’ are a constantly shifting population moving in and out of locally determined notions (Burgess 2005, viii). The Western notion of youth and youth empowerment cannot just be cut and pasted into the African context. This is even more important as young people in Africa have become a matter of global concern because of AIDS, famine, conflict, and disease. (Christiansen et al. 2006, 12-17.) Global research has shifted to this specific group, and which that shift the question of who is part of ‘youth’ and what is their role becomes central. There is a need to account for the modern and the traditional, and the global and local, in making sense of the social positions of youth in Africa. Currently, focus on youth is as a cultural entity in itself: youth in their own right and not as in comparison to another youth, child or adult. (Christiansen et al. 2006, 17-21.)

Mutuku laments the dearth of African specific youth empowerment studies in her thesis, “Youth Perspectives on their Empowerment” based in Kenya. She states that her work has “revealed that no research has been conducted to explore youths’ subjective views regarding their empowerment and integration in development efforts...No research has been published with a focus on listening to and identifying youth’s understanding of empowerment nor how they define their situation, challenges, and viable solutions to assist and equip them to reach and harvest their potential.” (Mutuku 2011, 43). At the core of empowerment theory is that the target community or individual is the one that should be given a voice and a role in taking

control of their own lives. How can youth empowerment studies genuinely make progress if those that are being studied have no say or no voice? It seems that Mutuku has exaggerated the deficiency of African empowerment studies, but her point remains valid that no real progress can be made unless the youth who are being discussed are given a voice.

Perullo is one such researcher that writes about African youth and their voice through hip-hop and rap. He argues that youth must be given a voice themselves, and rap provides a means for Tanzanian youth to do so. (Mutuku 2009, 37; Perullo 2005.) According to Perullo, African youth are seen by adults as social time bombs ready to explode in violence because of the pressures of living in the context that they do. He states that they are portrayed as a “caricature of youth as a ‘lost generation’ unable to deal with complex situations and find diplomatic solutions to adverse circumstances” (Perullo 2005, 76.) Many global perceptions fail to recognize youth as social and political actors. Unique to Sub-Saharan Africa and the developing world, however, youth as a whole are faced with issues of hunger, unemployment, corruption, and inadequate social institutions that are not addressed in contemporary youth empowerment theories from the global North. Perullo argues that by giving youth a voice through rap, they have become more empowered, “rap gives voice to many youth, often labeled as marginal, violent, or lost” (Perullo 2005, 97). Surprisingly, youth use their voice to address issues like AIDS, political corruption, failing schools, gender inequalities, and drugs and alcohol (Perullo 2005, 78.) Participation in rap is highly accessible and does not require traditional notions of literacy, thus it is a springboard for conversation, all of which falls in line with key elements of empowerment.

Ultimately, in order to empower the youth of Africa, or more importantly, have the youth empower themselves, the view of African youth needs to be challenged. Maina (2012) argues that young Africans have the ability to move the continent forward in a powerful and positive way. “This is the population that will change the face of Africa. This is the generation that will be held accountable for all the challenges that face the continent. The youth are our greatest asset, it is critical that we engage this youthful energy to create meaningful productivity for the

development of the African continent” (Maina 2012, 9). This statement has a very dissimilar tone to it in comparison to the ones that lament the troubles of African youth, and perpetuate the victimization of this generation. The question that remains, however, is how to mobilize this generation of young Africans and how to ensure their representation in a real and powerful way in society? It is not as if there have not been attempts, however feeble or unsuccessful, to do this. In Sierra Leone, for example, the post-conflict Poverty Reduction Strategy Papers promised to create an environment for youth that encouraged and enabled their participation in both social and economic measures. Unfortunately, a post-conflict government could not even begin to tackle this as the country struggled to rebuild. (Maina 2012, 22.)

For many in the international community, the answer to empowering and including African youth lies in education. The global policy of Education For All, as solidified in the Dakar Framework for Action in 2000, recognizes that any sort of sustained development cannot be achieved without a well functioning system of education. This education has to be effective and relevant. “Education is the *sine qua non* for empowering the people of Africa to participate in and benefit more effectively from the opportunities available in the globalized economy of the twenty-first century.” (Dakar Framework for Action 2000, 26.) I would argue that this education piece puts children and youth at the centre of social agency. This can only be a positive change if the education is effective in providing the younger generations with relevant skills and abilities that prepare them to become active citizens in their society. This is also the call of the Africa Commission, which sees Africa’s youth as a positive force for change, but only if skills and capital are available. From an empowerment framework, this Commission lays out how to realize the potential of this generation, and again education is key. Education in Africa, according to the Commission, must go beyond primary and has to be a fully financed priority. Secondary education needs to be more focused on the relevant skills of the private sector, and a push to improve vocational education with a stronger link to the job market is critical. (“Realising the Potential of Africa’s Youth” 2009, 16-52.) In addition to this, the voice of the youth themselves must be integral and not just a token gesture. The Youth Panel of the Africa Commission argues that

young people are largely excluded from the development debate in Africa (“Realising the Potential of Africa’s Youth” 2009, 17). Clearly, both education and voice are cornerstones to empowering the African youth, and while the debate rages on as to how to concretely establish that, whether it be national policy papers, local youth forums or some combination, it leaves no doubt that the voice of the younger generation must be considered. There has to be a shift from victimization of the youth in Africa to the recognition that we can contextualize their realities only through more explicit engagement with them. This research seeks to do just that by letting the voices of students with HIV/AIDS in rural Uganda be heard and contribute to the voice of their generation.

#### **4. UGANDA: CONTEXT AND HISTORY**

Given the above argument that the precise context in which a youth is living is essential in understanding what it means to be a youth in that milieu, as well as what is shaping the view of what youth exactly is, a specific look at Uganda is an important part in understanding the context in which the students with HIV/AIDS are living and studying.

##### 4.1 General Overview

Uganda, formerly a British colony with over 37 million inhabitants, lies in Eastern Africa. It is a landlocked country bordered by Sudan in the north, Rwanda and Tanzania in the south, Kenya in the west and the Democratic Republic of the Congo in the east (<http://data.worldbank.org/country/uganda>). With the exception of the semi-arid climate of the northeast, Uganda has a tropical environment with lush vegetation and many lakes and rivers. Because of its colonial history, English is the official language and is used for school instruction, legal documents and radio broadcasts. Swahili is the second official language, though Luganda is most commonly spoken. The major tribes that make up Uganda’s population are: Acholi, Alur, Baganda, Bagisu, Bagwere, Bakiga, Bakonjo, Banyankole, Banyoro, Basoga, Batoro, Itesot, Jopodhola, Karamojong, Langi, Lugbara, as well as a significant

amount of non-African groups. (Office of the Prime Minister, [www.gov.ug](http://www.gov.ug).) This research focuses on the Iteso people from the northeast.

Like many Sub-Saharan nations, Uganda has a high birth rate and relatively low life expectancy and adult literacy rates. The average Ugandan is estimated to live to be 51.59 years and have 6.74 children. Only about 70% of adults can read and write. About half of the population is below the age of 15, and the growth rate of the population is an average of 3.31%. Contrary to many African stereotypes, according to official government statistics, the average HIV/AIDS rate is just 6.4% (Office of the Prime Minister, [www.gov.ug](http://www.gov.ug).)

According to World Bank statistics, Uganda has been seen as quite a success story. However, “its continued economic prosperity requires sustaining macroeconomic stability while boosting economic productivity and integrating all regions into the development process. Equal access to quality social services, particularly education, health, and clean water, remains a challenge.” (<http://go.worldbank.org/8XKQR04V10>). Moreover, it notes that two of the most important upcoming challenges to its development are the fast-growing youth population and the newly discovered oil within its borders. The World Bank also notes that, “Perceived deterioration of governance and increased corruption threatens to tarnish Uganda’s image as a model reformer, and could challenge its future development efforts.” (<http://go.worldbank.org/8XKQR04V10>). Of course, the World Bank’s definition of Uganda’s success is based on ideas of pro-market policies and liberalization, and while it is congratulated for surpassing the UN Millennium Development Goals for poverty reduction, the regional disparities are significant. This will be discussed in further detail in upcoming sections.



Fig 4.1 Map of Uganda within Africa. Source: [www.nationsonline.org](http://www.nationsonline.org)

#### 4.1.1 A Brief History

Before Uganda became independent in 1962, the British influence and policies fostered ethnic and religious factionalism to the point that when the post-independence government was formed, it was an uneasy truce between the different factions. As a result, President Milton Obote suspended the constitution and ordered his army to chase his disputers out of the country in 1966 (de Berry 2001, 94-95.) In 1971, the now infamous General Idi Amin conducted a military coup that “sparked a trajectory of violence and mismanagement that reduced the country to a failed state and a collapsed economy”, (<http://go.worldbank.org/8XKQR04V10>). By 1979, Amin had finally toppled the Obote government and proceed to purge political opponents, especially those from the northern region, from which Obote came. The following years, 1979-1985, saw Uganda under the military dictatorship of an increasingly violent and paranoid Amin. Despite this, Uganda experienced successive coups including the disputed election of Obote in 1980 that led to civil conflict (de Berry 2001, 95.; <http://go.worldbank.org/8XKQR04V10>).

During the violent 1980s, Youweri Museveni's National Resistance Army (NRA) resisted Obote's forces. The NRA eventually defeated Obote in 1985. Museveni came to power in 1986 and remains the country's president today. For the regions that supported Obote, the succession of Museveni created apprehension regarding retribution. In the Teso sub-region, rebellion against Museveni broke out in 1987 when young boys and men took arms and fled into the bush to fight. This civil conflict did not end until 1992, and the years of insecurity opened the opportunity for the Karamojong warriors to attack the unstable region. For the Itesot people, they remain a threat (de Berry 2001, 95-96.) Additionally, the Lord's Resistance Army in the north of the country carried out a violent and destructive rebellion that did not end until 2006. This conflict also spread to the Teso sub-region in 2003 (<http://go.worldbank.org/8XKQR04V10>).

President Museveni's reign has been marked by protests and questionable elections. He was elected to a first term through a non-party election in 1996 and re-elected in a contested election in 2001. The constitutional amendments of July 2005 introduced multi-party politics, and Parliament lifted the two (five-year) presidential term limits. This act allowed President Museveni to seek a third term in office, which he won in 2006. On February 28, 2011 President Museveni was re-elected to yet another five-year term and the NRA secured an overwhelming majority in Parliament. Museveni has been in power for 26 years. The major source of opposition to Museveni is the Activists 4 Change (A4C) led by Dr. Kizza Besigye, despite the Ugandan Attorney General's banning of the group. Beyond this, civil society groups have initiated campaigns to restore the presidential term limits. (<http://go.worldbank.org/8XKQR04V10>.)

## 4.2. Education in Uganda

### 4.2.1 Universal Primary Education

In January 1997, Uganda was the first African country to introduce the Universal Primary Education (UPE) policy. This facilitated the abolition of tuition and other

costs, including parent contributions to teachers and/or schools. It sent a signal to the rest of the world about the importance of education in Uganda and its critical role in the reduction of poverty. (Higgins 2009.) Within this policy, as part of the greater Poverty Reduction Strategy Plan (PRSP), no less than 65% of the education budget must fund primary education. As a result, since the 1990s, the overall education budget increased from 1.6% to 3.8% of the GDP (Deininger & Okidi 2003, 481). The successful implementation of the UPE was to be led by the two measures: the elimination of school fees and participatory planning (Ekaju 2011, 40).

The specifics of UPE allow up to four children per household, two of who must be girls, to receive basic education for free. Along with the removal of tuition, the parents do not incur the cost of uniforms, textbooks, and any additional school expenses. Additionally, enrollment of girls in Uganda's schools has increased more than 300% from 1992/3 to 2002/3. Even in the more marginalized regions, such as the northern part of the country, there have been substantial female enrollment increases. In a broader context, primary net enrollment increased from 62.3% in 1992 to over 90% in the 21<sup>st</sup> century for both girls and boys. (Higgins 2009.) The increased student enrollment, particularly that of girls, is generally viewed as a step towards the reduction of wealth bias and the establishment of gender equality in Uganda, but the policy and its effects are not without criticism. The increased enrollment has put heavy strains on an already struggling system. The student to teacher ratio has increased exponentially, the school facilities are often not equipped to deal with the growing student body, and there are not enough qualified teachers to cover the needs of each school (Higgins 2009).

To further the above concerns, critics like Deininger and Okidi (2003, 481), argue that UPE and its following influx of students create a trade-off between broad access to and quality of education. Despite UPE and its lofty goals, only 22% of children enrolled in UPE in 1997 completed school by the 2003 school year. In northern Uganda, this number was 1.7% (Ekaju 2011, 40). Moreover, there are concerns that the UPE policy focuses too much on primary education and thus may not be the best path to the eradication of illiteracy and the attainment of lifelong learning. Some argue that by focusing only on primary education, a major portion of

the country is left out of opportunities to access education. To expand, at the World Conference of Education for All in Thailand in March 1990, the definition of “basic education” was discussed. The overall conclusions stated that basic education constitutes not just schooling, but formal, informal, and non-formal education together. Moreover, the primary goal of basic education is the creation of lifelong learners, which requires the partnership of governments and civil society. (Ekaju 2011, 39.) From this standpoint, UPE in Uganda has failed to meet these standards, though education in Kampala and the south seem to fare much better.

#### 4.2.2 President’s Initiative on AIDS Strategy for Communication to Youth (PIASCY)

Uganda has been touted as an African success story in the battle against HIV/AIDS, given that in 1992 the HIV/AIDS rate was 30% and by 2002 it had dropped to 6%. Recently, the rate has been inching up once again; currently, it is at 7.3%. There are many theories as to why the rate is rising, from criticism of abstinence-only education to the more widespread use of ARVs, which prolong life, thus reducing fears about the virus. (Uganda AIDS Indicator Survey 2011, Ministry of Health, August 2012). However, it is clear that the implementation of HIV/AIDS education in schools under the President’s Initiative on AIDS Strategy for Communication to Youth (PIASCY) in 1997 seems to be closely related to this drop. President Yoweri Museveni created the program as a way to break down the existing stigma that surrounds HIV/AIDS and educate the youth as much as possible. The general understanding was that parents would not talk to their children about sex and sexual health, but that teachers could and should. (Buonocore 2003, 51). Mandatory sexual and reproductive health education is part of the curriculum at all schools in Uganda, including the popular ABC programme (Abstain, Be faithful, use Condoms). Additionally, teachers are trained to educate the youth about these issues. Books are provided to advise teachers on messages to give to children and suggestions for teaching lessons. There are separate texts and guided lesson plans for Primary 1-3, Primary 3-5, and Primary 5-7. Each school is expected to discuss HIV/AIDS at least once a week within regular classes and to hold school wide assemblies weekly to discuss different issues surrounding HIV/AIDS. (Buonocore

52). In my visits to schools, many offered a PIASCY club in conjunction with the mandatory lessons. Discussions regarding the effectiveness and reception of the PIASCY curriculum will be addressed in a later section.

TARGET	ACTIVITIES	OBJECTIVES	RESPONSIBLE PERSONS	TIME FRAME	RESOURCES	REM.
• Pupils. • Teachers.	• Guidance & Counselling	• To reduce stigmatization & Discrimination.	• Mr. Enyodok. • Miss. Aleb. S. • Mr. Oluma. L.	• On going	• Stationery	
• Pupils • Teachers	• Drama.	• To develop Positive attitude towards HIV/Aids.	• Mr. Osi. A. • Mr. Ogestan • Mr. Onyuit. J.	• On going	• Costumes	
• Pupils • Teachers	• Role Play.	• To reduce Causes of early Marriage.	• Mr. Koinet. R. • Mrs. Kyai. S. • Mr. Enyodok.	• On going	• Costumes	
• Pupils • Teachers	• Debate.	To be faithfull to One Partner.	• Mr. Osi. A. • Mr. Opo. C.	• On going	• Stationery	
• Pupils.	• Skit.	• To reduce School drop out	• Mrs. Akokof. V. • Mr. Opo. C. • Mr. Onyuit. J.R.	• On going	• Costumes	

Fig 4.2: Photograph of PIASCY Work Plan in Ugandan School Classroom (Source: Personal Photo)

#### 4.2.3 Regional Inequalities

As a country, Uganda has experienced a significant overall reduction in its poverty rate. In 1992-3, the rate was 56% and by 2006 had dropped to 31%. This statistic is positive, however, what must be explicitly understood is that the reduction in poverty has not been experienced uniformly. For example, the region of Northern Uganda has had a decline in poverty by 17% in that time frame whereas elsewhere in the country the number has been closer to 60%. (Higgins 2009.) Poverty's effect upon the quality of available education, not necessarily access because of UPE, is clear.

While potentially the greatest barrier in accessing available education, poverty alone has not been the only issue related to schooling in the greater northern regions of Uganda. Decades of conflict have destroyed schools, materials, and resources, which were scant to begin with. The combination of present day poverty and the long history of conflict create inadequate educational infrastructures such as classrooms and latrines. Perhaps more significant, however, is the role that conflict and poverty in the north has had on the teachers themselves. Because the regions of the north are much poorer than the south, there is very little incentive for qualified teachers to move there. The teachers that are in these regions lack protective housing, have long commutes over dangerous roads, low salaries, and they teach many traumatized children. In Kitgum, for example, there were recently 500 teaching positions open, but only 210 applicants, and of those only 180 were deemed suitable candidates. The poverty of the students' families also means that they cannot supplement teacher salaries, as is common practice in the southern regions despite being contrary to the policies of UPE. Finally, the poverty of the region means that many of the students come to school without adequate food and thus their studies suffer along with their bodies. (Higgins 2009.)

There have also been problems in terms of administration and government efforts that have perpetuated the regional disparities in education. Although the government has taken action through Northern Uganda Social Action Fund (NUSAF) and has formed partnerships with UNICEF for campaigns, the resources remain limited and inadequate. Furthermore, central government financial transfers show that the north is not receiving additional transfers per capita to reflect the higher service delivery costs and the scale of needs. Finally, as districts continue to divide and decentralize, they become smaller. Smaller districts mean smaller transfers from the central government and less resource allocation to each school. Moreover, donor and NGO funding does not fully fill the gap regarding costs, particularly teachers' wages, further discouraging qualified applicants (Higgins 2009.)

## 4.3 Katakwi: The Case Community

### 4.3.1 Katakwi General Overview

My research is based in the District of Katakwi, part of the greater northereastern region of Uganda. It was carved out of a larger district in 1997 and thus named after its chief town, Katakwi. In July 2005, a new district called Amuria was then carved out of Katakwi. All of this is the result of the general trend of decentralization in many African countries, the rationale being that localized government is closer to the needs of each community, and as such is mandated to implement projects and manage the resources accordingly. ([www.katakwidistrict.go.ug](http://www.katakwidistrict.go.ug).)

The 2002 national census counts the population of Katakwi at 118,900 people, but the World Food Programme estimates the number to be closer to 145,300 in 2008. The annual population growth for the area is 2.8%, and 64% of the population live below the poverty line. The district has no electricity supply, thus almost everyone uses paraffin or firewood for lighting, and wood fuel for cooking. ([www.katakwidistrict.go.ug](http://www.katakwidistrict.go.ug).)

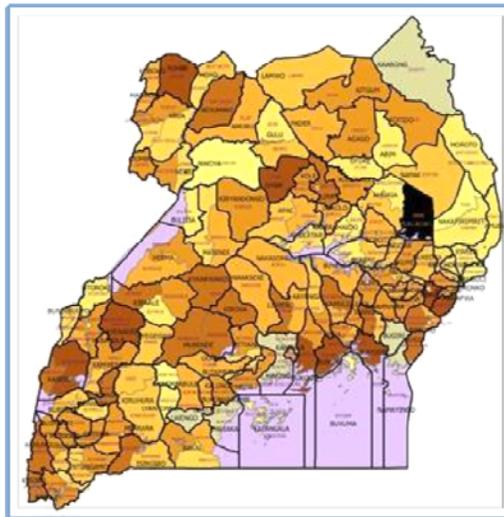


Fig 4.3 Map of Uganda with Katakwi District highlighted ([www.schoolguideuganda.com](http://www.schoolguideuganda.com))

Agriculture is the main economic activity of the district, with a full 95% of the population dependent on farming for livelihood. Of this number, 87.3% are subsistence farmers, though only about 40% of the land is currently cultivated. The

general crops grown are cassava, maize, sorghum, millet, sweet potatoes, groundnuts, simsim, cowpeas and a few other vegetables. Despite the focus on crop growth, livestock is the asset that determines wealth and status for the population. Due lack of safe drinking water for the animals and widespread disease and pests, such as foot and mouth disease, intestinal and liver flukes, bovine pneumonia, and ticks, the ability to keep livestock has been increasingly difficult.

([www.katakwidistrict.go.ug](http://www.katakwidistrict.go.ug).) Combine this with the years of cattle rustling from the Karamojong people and the situation for the communities is based on day-to-day endurance.

#### 4.3.2 A History of Conflict in the District

Katakwi, as part of the Teso sub-region of Uganda, has had a long history of conflict since Ugandan independence in 1962. After decades of military coups and dictatorships, when President Museveni and the National Resistance Army (NRA) took power in January of 1986, people from Teso feared retribution from the new president, as they had served in the army and police of the previous ruling party under Milton Obote. Their fears were well founded, as Museveni dishonourably discharged three quarters of police force, many of whom were Itesot people. To further aggravate the situation, the NRA also disbanded the local militia that was set up to defend the Itesot from Karamojong cattle rustlers from the east. (Jones 2007, 504.)

Seeing rebellion as the only viable solution, the Ugandan People's Army (UPA) fought the NRA in what was to grow into a civil war lasting from 1987-1992. In order to 'protect' the civilian population in the Teso sub-region, the NRA moved the rural populations into settlement camps. Anything outside of these camps was considered a fire zone. Within the camps, the conditions were appalling. The lack of sanitation and food security created widespread disease and starvation. Movement of the people was highly restricted. Many people were killed in the camps because of fighting or suspicions of rebel sympathy, and the girls were often raped and abused by the soldiers. Some were taken by the soldiers and trafficked to be companions for military commanders. (de Berry 2009, 45-46.)

The six-year civil war in the region overlapped with another ongoing struggle; the raiding Karamojong from the east, near the border with Kenya. Like the Itesot, the Karamojong people were historically pastoralists and as such, have a long history of movement and interaction in the Teso sub-region. Because of the harsh climate and the importance of cattle for marriages, alliances, and status, the Karamojong people have raided neighbouring regions as a survival mechanism. (Mkutu 2008, 100). The Karamojong people themselves are also subject to raids from other cattle rustling tribes in Kenya and South Sudan, having a domino effect and thus pushing the Karamojong to enter the Teso sub-region (Mwaita 2009, 141). The typical nomadic survival in the east of Uganda changed dramatically in 1979. After the fall of General Idi Amin, the Karamojong stormed the barracks and armed themselves with weapons, particularly AK-47s. This would be the first of many more opportunities for the arming of the Karamojong, with more weapons coming from Sudan, Ethiopia, and Somalia. (Mkutu 2008, 100.)

With the introduction of modern weapons and the instability caused by the civil war, the Karamojong warriors increased their cattle raiding practices, which escalated violence. In 1986 alone, 500,000 cattle were destroyed and/or stolen (Jones 2007, 504). Beyond the theft of cattle, the Itesot people were subject to looting, assault, rape, kidnapping, and the burning of huts during the raids. The Karamojong raids not only depleted the economic base for the region, but destroyed many social norms and traditions for the Itesot people. (Jones 2007, 505.)

After the end of the civil war in the region in 1992, Katakwi saw ten years of relative peace, though sporadic raids from the Karamojong continued. The government of Uganda has attempted solve this conflict with a series of nine disarmament attempts, both voluntary and forced, with the latest being from 2004-2007. Many have argued that disarmament has just created strong resistance and has not stopped the flow of weapons. (Mkutu 2008, 101-108.) The ten years after the civil war was a time of rebuilding for the Itesot people, but the uneasy calm was ended on June 15<sup>th</sup> 2003, when the Lord's Resistance Army (LRA) spread to the Teso sub-region. As with the attacks on the Acholi people, the LRA engaged in violence and kidnapping of children to use as soldiers. IDP camps were again established.

The war-fatigued Itesot people established a counter insurgency through the creation of Arrow, a group of young men and boys. Originally armed with traditional spears and arrows, Arrow banded together to combat the LRA. Eventually the government of Uganda armed the Arrow boys with modern weapons. (Castelein 2008, 27.) The LRA attacks came just as another disarmament attempt was made against the Karamojong, but the army was withdrawn to contain the LRA. Security was then left to the meek and meager home guards and local defense units (Mkutu 2008, 114).

Clearly, the Teso sub-region has had only short stints of peace, and the LRA is only the latest in a long history of violence, though it is this particular conflict that I will be focusing on in terms of how girls and their education have been affected by it. The year 2006 saw the end of the LRA attacks in Katakwi and elsewhere, but the Itesot people are still dealing with the Karamojong raids. The ongoing disarmament seems to be a slow process and many Itesot are still in fear of raids. As the effects of climate change continue to wreak havoc on the already harsh climate in the horn of Africa, flooding and droughts may again spur an increase in violence in the region, pushing the Karamojong once more into the Teso sub-region. Overall, the impact of the LRA conflict and the prolonged drought has hit the region hard, but it has particularly deprived women and children of any domestic support (Mwaita 2009, 143). They are the easy targets, and it is the role of education in this post-conflict setting that will be the subject of this research.

#### 4.3.3 The State of Education in Katakwi

The creation of the Katakwi district in 1997 also formed a Ministry of Education and Sports specific to the district. According to the local government's website, the district has 77 primary schools, 12 secondary schools, and one technical school. The schools, however, were mostly made in or near the IDP camps, and as a result many returnees do not have a school in their vicinity. The Ministry estimates that the average walk to school is 5 kilometres. Because of the dangers students may encounter along the way, many do not start the first grade until they are 9 or 10 years of age. Furthermore, by Primary 4 the students are young adolescents

without any reproductive health information and services. This leads to a high dropout rate for girls, around 19%, because of early marriage and pregnancy.

([www.katakwidistrict.go.ug](http://www.katakwidistrict.go.ug).)

CLASS	BOYS	GIRLS	TOTAL
P.1	67	76	143
P.2	26	27	53
P.3	38	26	64
P.4	44	36	80
P.5	26	40	66
P.6	21	12	33
P.7	11	07	18
TOTAL	233	224	457

Fig 4.4: Enrolment numbers in a typical Katakwi classroom (Source: Personal Photo)

The combination of lack of development in the greater northern region of Uganda and the influx of students from UPE has left school infrastructure and education quality inadequate. The 2010 student enrolment in Katakwi was 42,915 pupils, with 726 teachers. The Ministry requires another 250 teachers to match this enrolment number. Moreover, there is a 20% enrolment increase in primary school every year. The school structures themselves are also deficient to deal with the numbers of students. For example, the rate of pit latrine filling is five times the replacement rate. The current pupil-textbook ratio is 9:1, and the Ministry's recommendation is 3:1. There is an average of nine students per desk and a student-teacher ratio of anywhere from 102-153 students per teacher.

([www.katakwidistrict.go.ug](http://www.katakwidistrict.go.ug).)

Because secondary education does not fall under UPE, the enrolment is much less, though the quality seems to be no better. Of the 12 secondary schools, three are 'A' level, government aided schools, and one is exclusively a girls' school. In 2010, male enrollment at the secondary level was 2113 pupils, and girls numbered

1016. In 2003, however, only three students passed the Division I exam, and in 2010, only five out of the 685 registered for the exam passed. Furthermore, while 79 teachers are trained in special education, there is no individual programme established for students with special needs. ([www.katakwidistrict.go.ug](http://www.katakwidistrict.go.ug).)

As previously discussed, the regional inequalities in education in Uganda have resulted in poor infrastructure and education quality for those in the greater northern part of the country. As Higgins (2009) and others argue, the right of access to essential services, including education, remains unfulfilled in the northern part of Uganda. This also contributes to the difficulty in attracting teachers to the region. For Katakwi and elsewhere, the history of conflict combined with the lag in education and development results in education that is valued, but difficult to translate into reality for the peoples of the north. (Higgins 2009.)

## **5. ANALYSIS AND RESULTS**

### **5.1 Conceptualizations of HIV/AIDS**

Initially, my goal going into the interviews with the students that are HIV positive was to understand their experiences at school. It quickly became clear that in order to understand their experiences, I needed understand both how the students and their community members viewed their disease. This first struck me when interviewing the PIASCY teacher at one of the primary schools in Katakwi. She mentioned that one exercise she did was to ask students, “What does HIV look like?” The students would draw images, and she told me that there was a range of ideas, from funny monsters to “small, tiny people” (Asio Judith, 3). I was surprised at this, because in my mind, HIV is a virus. I had only thought of it in a scientific manner, forgetting that my concept of the disease was very different than the students’. From then on, I tried to remain aware of the ways in which HIV/AIDS was conceptualized.

While a thorough exploration of this topic is beyond the scope of this research, it is important to include. This facilitates a deeper understanding of the students' experiences, and it is also important to consider that any educational programme or counseling approach must take into account how people conceptualize this disease. For the most part, the virus is talked about as an anthropomorphized hunter. One song that the children in P7 sang for me explicitly calls HIV a monster. "Watch out everyone, wake up all day long to fight HIV. This monster is hunting day by day...HIV's a killer" (Apuuton Primary Song #1). This sentiment was echoed by the students themselves that are living with HIV. When I asked Stella how she felt when she was given her HIV test results she said, "HIV want to die [kill] me" (Stella, 3). It is interesting that she did not identify that she feared dying of the disease, rather that it would kill her. She would be acted upon. Ruth, 16, also externalized the disease, but discussed the different types of HIV and the danger of re-infection. "Even me, I don't know what type of HIV I have, that's why I'm fearing. If you have, eh, that lazy HIV and that one has a strong, and you play with this one, that one you can, you can add" (Ruth, 10). Conceptualizations of HIV as a human-like predator were also evident in my discussions with teachers. The Senior Man teacher at a local high school mentions, "I think, I think everybody now knows that HIV is part of life, ok? It is in the corner, that any slight mistake you make, is enough to what? To get a problem." (Ocom Matthew, 10). Moreover, the same teacher that conducted the drawing exercise explains, "eh, this HIV has not come to kill only one person, because we have today is me, tomorrow is someone else." (Asio Judith, 8).

The identification of the virus as an external and predatory force can create issues regarding empowerment. If the disease is thought of as external, a thing which preys upon them rather than a part of who they are, it can work against their feelings of control and autonomy, both key elements in empowerment theory. On the other hand, creating an external enemy can allow for something concrete against which to battle, something to become powerful in opposition to. The same song that depicts HIV as a hunting monster also reads, "...Together, we shall win". Another

student, Gideon, also told me many times, “but I know this disease will not take me. It will not take me very bad” (Gideon, 11).

Beyond anthropomorphizing the disease, there remains the common notion that one must appear sick to be HIV positive. Education programmes explain that anyone can carry the virus, but students specifically noted the reactions of others as examples that this misconception remains. Gideon, an 18-year-old student, discussed the reaction of his friends when he disclosed his status to them,

Shannon: what did they say when you told them?

Gideon: they were just advising me, and some of them were not accepting.

Shannon: ah, sorry

Gideon: yeah

Shannon: what did they say?

Gideon: they thought I was lying, I was deceiving them, like that

Shannon: ah

Gideon: but I showed the card, they were like, “sorry, sorry, ah”  
(Gideon, 7).

Ruth, 16, explains that part of the reason she has not disclosed her status is because she thinks people will not believe her because she appears healthy,

Ruth: ...one of a child at school, “they tell me, they say this one is living with HIV, but is healthy, strong. That one is lying us.”

Shannon: ah

Ruth: they don't, they don't accept HIV. They don't. They say...I am health also, I have health like me...Even my father, even my father, the nurses told my father, told, “your child is HIV”. They don't accept, “no, is not, she's not living with HIV”. Then he finished to test me from here, they, they come to test me at the clinic also, then at the clinic they get the same results. Then my father accept, but he didn't accept, yeah.

Shannon: so everyone thinks you have to be weak and sick to have HIV?

Ruth: hmmm

(Ruth, 11)

Furthermore, with the exception of only a few, students were not tested unless they displayed prolonged or repeated bouts of sickness. Even the students who had HIV positive parents usually were not tested unless they fell sick. When I asked Opio, 13, why his mother took him for an HIV test, he replied,

Opio: because I...ended a month when I am not feeling ok

Shannon: hmm

Opio: yes

Shannon: you were sick  
Opio: yes, every month, every month  
Shannon: sick again and again?  
Opio: yes  
(Opio, 1)

Opio's test was in 2009, when he was eight years old, even though his mother is HIV positive and was so during Opio's birth. His story is not unusual. Jeff, 15, was diagnosed in 2008 because, "I fall sick so much I would have going to begin to die....that is why the thing comes to be known" (Jeff, 3). Most of the students that I talked with shared the same experience of falling sick frequently, prompting a hospital visit, where the test is conducted. It was a rare story for a student to be tested without the presence of some illness, though there was a case of an HIV test at school for the general student body, or for local politicians to urge their community members to go for testing regardless of a family's health. However, as mentioned, these are the exceptions and the belief that one must look sick to be HIV positive remains.

## 5.2 Positive Living

Just as the theme of empowerment was evident within days of my arrival in Katakwi, so too was the concept of positive living once I had delved into the world of students living with HIV/AIDS. Unlike empowerment, the idea of living positively was not difficult to pinpoint in terms of both definition and, more importantly, what it means to those living in the context of HIV/AIDS. Moreover, positive living, as I came to understand it, seemed to be married to the idea of empowerment. It enabled people living with HIV to take control of their lives, their disease, and their future. According to The Aids Support Organization (TASO) of Uganda, positive living is a philosophy that "entails having the will to live, and embracing practices that enhance the quality and longevity of life and maintaining hope." This idea of hope is essential to empowerment, as empowerment is a product of learned hopefulness, and learned hopefulness seems to result from true participation in the community. This participation can be as simple as seeking advice from medical

professionals and counselors (<http://www.tasouganda.org>). For those that have HIV/AIDs, the practical implications of this philosophy means accepting the diagnosis and adjusting to it by seeking ongoing counseling. Furthermore, those with HIV need to seek “prompt medical care including Antiretroviral Therapy, ensure good nutrition, do adequate physical exercises and rest, avoiding compromising practices such [as] alcoholism and smoking, continuing to engage in productive work/employment and disclosure to significant others.”

(<http://www.tasouganda.org>) For adolescents, this would mean the continued pursuit of education with hope for a “normal” career after graduation.

Beyond the application of the philosophy of positive living to oneself, it also urges the care of others and the protection of them against the virus. Specifically, TASO promotes the use of condoms and practices that prevent mother to child transmission in utero. It was interesting that in all of my interviews I asked the students what they did to live positively and the role of their school in those practices, and none of them needed clarification on what I meant by that phrase. While the ability to live positively may vary from student to student, at the very least the concept has truly become entrenched in the vernacular and in the mindset of those affected by HIV. Micah, the HIV focal person in one of the sub counties, refers to positively living and the goal of those he liaises with to, “forget of the past, of your mind, live positively and become happy and joy, yeah” (Micah, 2)

While TASO and others in health care emphasize that living positively is a philosophy, a way of looking at life and taking care of oneself in the context of HIV and AIDS, the students themselves did not frame it in such terms. For them, it was more like a checklist of things to do to stay healthy, though it did often include overall wellness and mental health practices. Jeff, 15, when asked about what he does to live positively, focused on the practical ideas, “keep myself clean by bathing, bathing, washing my clothes, and...and getting rid of my drugs everyday.” (Jeff, 8). Similar ideas were shared by Gideon, 18, “mm abstaining from sex, and eh, by the time you learn to, to, to play sex or with your partner, you go for condoms. You, you, this drug wants to, to be eating something, after you have taken them, you take maybe tea like that...and you also do some exercise, but not much...And you are

advised to, to keep time (take medication on time)” (Gideon, 5). Betty, 19, also listed comparable practicalities, “yeah they told me I should abstain, that I should always sleep under a mosquito net, then I should take boiled water, should avoid boys” (Betty, 5). The focus on hygiene and medication was usually the first things that came to mind for many of the students, but what I found surprising was the importance of positive thinking. Most of the students talked about positive living as including keeping your mind busy and not thinking too much about the fact that they have AIDS. John, 16, went on at length about the importance of thoughts in staying healthy:

John: ok living positively, you need some exercises, yeah, to make your muscles normal what, stretch your muscles, and even you should not have, maybe, the fake ideas, yeah.

Shannon: sorry?

John: should not have some, some ideas about, maybe, thinking of some different things what can bring your mind back to this thing again.

Shannon: ah

John: yeah, so you should be free from those kinds of things, so that means maybe exercising yourself, maybe playing what, yeah you’ll be free from those certain kind of things

Shannon: easy to get maybe depressed?

John: mm, yes.

Shannon: or sad thoughts

John: yes, yes.

(John, 7)

Other students also emphasized keeping your mind busy, avoiding stress, and discussed how to do that. David suggested reading as an escape from negative thoughts, “Then sometimes you can go and you can start reading your books, eh, and you can also forget those things, forget those things.” (David, 8). This focus on positive thoughts and reducing stress is very current with contemporary empowerment theory as it relates to health. As Israel, Checkoway, Schulz and Zimmerman (1994, 155) and many others have noted, there is a clear association between powerlessness, alienation, and/or learned helplessness and one’s mental and physical health status. Control of this plays a role in modifying levels of stress and health.

Overall, the best summary of positive living was given by Apio, 13, who said that to live positively is to stay in a clean place, “and adhere to the drugs, attend school, reduce on thinking, to use a treated mosquito net, and drink clean water” (Translation. Apio, 7). While it is clear that all of the students knew what practices in life could make living with HIV/AIDS something other than a death sentence, the ability of each student to follow these guidelines was highly variable. Schools, then, have a clear role in enabling students to live positively. Not surprisingly, the schools are both empowering in some factors and detrimental in others.

### 5.2.1 Hygiene

With the exception of one or two schools, hygiene was a concern for the students. Of course, this affects not just those that have HIV/AIDS, but a student with an already compromised immune system is going to be particularly vulnerable to unhygienic environments. Interestingly, though, despite the students learning about hygiene and its importance in living positively, most did not specifically note that their schools were not providing a clean environment without prompting. For example, Apio, the girl that specifically mentioned staying in a clean place as important to living positively, was asked about school cleanliness:

Shannon: how clean is the school?

Apio: it is clean

Shannon: yeah, you have latrines?

Apio: yes

Shannon: and do you have a place to wash your hands?

Apio: they don't have

(Apio, 7)

Isaiah, 14, belongs to the Health Club at his school, a club specifically devoted to teaching others to stay healthy and clean. He was asked if the latrines at his school were clean. He replied that yes they were, and that there was place to wash hands after using the latrine. However, when asked if there was soap to be used at the hand washing station he laughed and said no, there wasn't (Isaiah, 8). Many of the schools had a place to rinse hands after using the latrines, but, with the exception of two schools, they did not have soap, “Like at school here there are no soaps” (Levi,

10). Even the schools that had water often found that by the afternoon the water was all used up and no one had gone to the borehole to refill. The two schools that did have soap would pour the liquid soap into the Jerri can, because the pupils would steal bars of soap. "Because some students are very stubborn, they can even go and take the...soap from the latrine and take to use" (Gideon, 15). Other schools, like Michael's, improvised and used ash as a soap alternative (Michael, 13).

When asked about the school's hygiene, some of the older students were able to assert that the schools were not that clean, but the younger ones did not link lack of soap to lack of hygiene despite education on the topic. The older ones, like Stella, 17, says, "uh sometimes the compound is not all that clean, the school is not generally clean, it's not slashed often, then also the hygiene in the latrines, if children don't come very early, it goes like that when it has not been cleaned."

(Stella, 10). Gideon, 18, also discusses the lack of cleanliness at his school:

Gideon: the hygiene is like ok, but it is not going very well because we have...only two latrines...it is three...one for teachers, one for girls and one for boys, and the one bathing room for boys. Is what we have.

Shannon: and they are not very clean?

Gideon: They are not very clean, they are not very clean

Shannon: mmm, and what about washing your hands?

Gideon: even washing, eh, the hygiene is not very, very ok. Because with some boys they don't even wash their plates they used, they used for eating, but they don't wash.

Shannon: but when you leave the latrines, do they have a place to wash your hands?

Gideon: no, it is not there....we just come out, you don't even go and wash the hands because there are no water. You'll just remain there, ah.

(Gideon, 14)

It should be stated that the schools are not negligent with hygiene because of lack of knowledge; rather it is the lack of resources that create the current situation.

Control over resources at hand is at the heart of empowerment theory, and while the resources for the schools are not easily attained, many of the schools and the students themselves with HIV/AIDS are going through an empowering process through community participation, problem posing and health education. Anne, 14, is a member of the AIDS club at her school, and part of the job of the members at the

school is to promote hygiene. When asked about the activities of this club, Anne said:

Anne: clean the compound, promote hygiene....and other things also

Shannon: yeah, how do you promote hygiene?

Anne: like drain stagnant water

Shannon: mm, cause that's where the mosquitoes are?

Anne: yes

Shannon: and do you clean the latrines?

Anne: yes

Shannon: ooh is that smelly?

Anne: yes (laughs)

Shannon: but it's important to have clean latrines?

Anne: yes

(Anne, 4)

Anne is not the only student that is part of a club that cleans the compounds. Initially, my reaction to having a student with HIV/AIDS doing the cleaning of latrines was that of concern. However, I realized that performing this duty was actually empowering for her. She and others are in a leadership role; they are using the resources that they have at hand, and they are educating others. Moreover, the club is a forum in which the students can problem-pose and engage in creative solutions. While the lack of soap and bathing rooms is clearly a worry, at least the students are able to participate in making the decisions about how to handle a situation that affects the entire school community. Finally, the students with HIV/AIDS that have an active role in the hygiene and health of the school are more likely to maintain the hygiene and health practices outside of school as well, something which clearly is important.



Fig 5.1: A 'tippy tap' hand washing facility outside a latrine block (Source: Fieldnote photo)

### 5.2.2 Exercise

Of all of the factors that are associated with living positively, perhaps exercise is the easiest of all to achieve for the students. Their daily life organically includes physical activity in that before they head to school, most of the students will be expected to work in the garden heaping potatoes, weeding and other duties. For example, Stella wakes at around 5am, "goes to the garden...does those kind of things, washing plates", all before she goes to school (Stella 9). Furthermore, all of the students walk to and from school and to and from the medical clinics for their medications and testing. What is important to note is that TASO and health care workers promote not only adequate exercise, but alongside that, enough rest. It is the latter part that the students may fail to receive in their lives, and it is also the idea of rest that is not mentioned by the students when referring to positive living. Many students specifically note the importance of exercise in leading a healthy life, but none of them actually mention getting enough rest, even though many of them wish they had more time for it. Justine, 16, mentions that her illness causes a headache that does not cease for up to one month; she "cannot even look at the blackboard". According to her, her mother does not understand this, and when Justine wants to rest, her mother, "begins shouting like she does not want to do work," (Justine, 6). For many of the students, school not only provides as place to

learn and be with their friends, but it also gives them more opportunity to rest and not be expected to complete chores.

On the other hand, some students mention that they, their teachers, and their peers see HIV positive students as weak, and they are often left out of sports and games. Micah notes that “most of them are sidelined, even teachers say ‘this one is sick’...so we should encourage them, whether or not you are sick, let’s give them play,” (Micah, 10). Jeff mentions that he dislikes football, “because I am weak, I can’t play football...I like just targeting,” (Jeff, 6). Despite these testimonies, most of the students mention their love of football and lament that they do not always get to play because many schools do not have the resources to allow the games to be played. Opio, like many of the boys, loves football, “but of football, I don’t play...because I like playing football, but the football is not there....you go there (to school) stay, talk stories, but nothing to play,” (Opio, 9). Clearly, the idea of physical exercise is important to a healthy lifestyle, but the idea of activity that is games and participatory sports has a much greater benefit than just exercise. Participating as part of group sport activities has a mental benefit for all children, including those that are living with HIV/AIDS. One former student, Gift, 17, also HIV positive, recently had to drop out of school because his family could not manage the school fees. He does his best to still live positively, but he misses school very much. He will do some exercise like “walking, riding, sometimes jogging around”, but the solitary condition of his life outside of school, and in sports, depresses him. He says, “...everything about school I miss,” (Gift, 7-8).

Another factor related to physical activity that is worth noting is the different experiences between that of the girls and the boys. As mentioned earlier, the boys are all keen to play football, and despite not always having a proper football, they improvise to create a makeshift ball and play the game on a regular basis. The girls, however, are almost never seen playing football. If they are included in any group sports, the expectation is that they will play netball or volleyball. These, unfortunately, include more equipment, and make it even less likely that the games can occur. Girls in Katakwi are only just starting to be seen as athletes in the same way as boys, and the resistance to their participation in sport is still present. Of all

the girls interviewed, only Ruth specifically mentioned that she plays sports at school (Ruth, 5). All the other girls included exercise in their lives through chores, playing the in yard, and/or commuting only. In this aspect, girls miss out on all the mental and physical benefits of group exercise and team sports that is very much in line with both living positively and the participation factor that is stressed in empowerment theory.

### 5.2.3 Medication

#### ***Adherence***

The rollout of ART (anti-retroviral therapy) in Uganda during the past two decades has revolutionized not only the management of the disease but also the ability of those infected with HIV/AIDS to lead a life that is socially and financially productive. Many have argued that ART has allowed patients to resist and challenge stigmatizing attitudes (Midtbø, Shirima, Skovdal & Daniel 2012, 261). Moreover, HIV positive teens have cited their taking of ARVs as an important factor in preventing stigma, as it allows them to appear healthy and to not show the signs of the disease (Thupayagale-Tshweneagae 2010, 262). However, even with the advances in medication, many studies contend that adolescents are among those least likely to adhere to ART. Thupayagale-Tshweneagae (2010) cites studies from 1997 and 1999 in Botswana that show adolescents generally lack adherence to the drugs. They also refer to a 2004 study that says stigma or fear of stigma contributes significantly to this poor adherence. Finally, the same authors refer to a 2002 study that shows that the younger the person is, the less like they are to stay the course of medication (Thupayagale-Tshweneagae 2010, 262-263). Petersen et al. also worry that adolescence is a particularly difficult age group for ART, “given their changing developmental stage, partial reliance on caregivers, interference with daily routines, complex dosing regimes etc.” (Petersen et al. 2010, 970). Despite all of these studies to the contrary, every student I talked to was on medication and felt strongly dedicated to maintaining their course of therapy.



Fig 5.2: Container and dose of Duovir-N which contains a combination of three antiretroviral drugs: nevirapine, lamivudine and zidovudine. (Source: Fieldnote photo)

Some of the students assumed to be most likely to stop taking medication were orphans, those that do not have parental support in adhering to the drugs, or those that are not open about their HIV status. In every case I encountered, these particularly vulnerable students still persevered with their treatment. Anne, 14, asked her mother to take her to be tested for HIV after losing her older brother to the disease. When the results came back positive, she “felt happy” because she knew she could take the drugs and feel better (Anne, 2). However, Anne’s father did not want her to take the drugs. “My father wanted to refuse me to take ARVS”, but she insisted and remains consistent with her dosages and check-ups (Anne, 1). I was able to interview Anne’s father later and he claimed that he only said he told her not to take them as a test of her attitude, “One time I was trying to test, eh, her attitude, that ‘I don’t want you to be taking these drugs.’ She cried, so I knew she had already accepted...taking the, the drug.” (Anne’s Father, 12). Most likely, the truth of the situation lies somewhere between the two accounts, but regardless of this, the

incidence shows that with or without her father's support, Anne was determined to take her medication.

Betty, 19, is also a student that based on existing research would be at risk for non-adherence to her drugs. Her uncle raped her while she was living in his household, and this was how she contracted the virus. Her father has vehemently denied that his brother abused Betty. He has also refused to pay for her to go to boarding school, like her siblings, because Betty's stepmother sees her as a waste of money now that she has HIV. Betty is also not open to those outside of her immediate family, with the exception of one teacher, about her HIV status. In order to receive ART, Betty has to travel to the next closest city but her father gives her money for transport sporadically, "when he's pleased he can give me, but when he's not on his moods, he will not," (Betty, 13). Despite all of these deterrents to treatment, Betty continues on her course of treatment and finds means to go the hospital every month.

Of the sixteen students interviewed, four are orphans. Many of the other students have lost a parent or have parents that are living with HIV/AIDS, but it is those that have neither parent that can be the hardest to keep on ART. Again, contrary to the research, all of the orphaned students I met with are strong in their desire to take their medication. Opio, who only has his mother and is the youngest of the students I talked to, told me, "HIV does not kill even. You take the drugs properly, take the drugs, follow the doctor's advice...you will grow and grow," (Opio, 11). Moreover, John, who has lost both parents, never forgets to take his drugs and does not need his teachers to remind him because, "for me always I know...cause I started taking them when I was still young so [I] grew up with that spirit" (John, 4). This seems in stark contrast with the above research that claims the younger the person the less likely they are to adhere.

The determination and commitment of all the students to adhere to their drugs does fall more in line with the work done by Midtbø et al., who found that the availability of medication contributed to a feeling of safety to their interviewees (Midtbø et al. 2012, 265) and also to the research of Li, Jaspan, O'Brien, Rabie, Cotton and Natrass whose participants all stated that ARVs help them to stay

positive in their lives (Li et al. 2009, 754). Many of the students' initial reaction to their diagnosis was sadness and depression, but it was the advice of the doctor that adherence to their drugs would ensure a long life that helped them come to terms with their disease. I interviewed David, 13, who had only been diagnosed one week prior to our meeting. When I asked him if he was shocked when he heard the news he said, "...no, not ...shock, I was fearing that I would die very early," (David, 3). Of course, I then asked him how he was already able to come to terms with his diagnosis in such a short time and he said, "...the advice, I got the advice [that] make me to be free, yes," (David, 3). The advice was specifically the importance of positive thinking and to take the drugs. David's best friend also responded with advice to take medicine, when David revealed his status to him, "but he advised me to go and get some more medicine, but I told him that I have some, mm," (David, 7). The sense of security that the drugs give the students is apparent. Michael told my colleague, who was present at the interview, about his fears:

LWF staff: what do you see, what do you hear that makes you scared?

Michael: HIV kills people

LWF staff: Hmm, it kills people who are what? Has it killed you now?

Michael: no

LWF staff: so when is it supposed to kill you?

Michael: any time

LWF staff: any time, when you don't do what? ...It means you are not doing what?

Michael: not taking medicine.

(Michael, 19)

Finally, the importance of taking the medicine so ingrained in the youth was most apparent in Gift and Apio. Before he had even gone for an HIV test, Gift suspected he had the virus and so began buying the medicine, "well I first suspected it but I was not sure so, basically, [I] put myself on a dose of cotrimoxil, then I went on it was just like two tablets in the morning, two tablets in the evening, everyday...buying and taking, buying and taking, like that, till just only recently when I came, when I got bold enough to test," (Gift, 2). Gift knew the importance of taking the medicine that he was willing to pay for the drugs and maintain the course of treatment on the chance that he had the disease. Apio, who had one of the most difficult situations,

specifically stated that drugs were her priority. All of the students I talked to had expressed their desire to stay in school, and every one of them told me they enjoyed school, but Apio sometimes has to choose between paying for school and paying for drugs. The drugs themselves are free but each patient needs a record book and thus has to pay a small fee for it, about 1000 UsH (.40 USD). In order to pay this fee, Apio will work for her neighbours in their gardens. Primary education falls under Uganda's Universal Education Programme, but again fees are involved for uniforms, supplies, and test fees. For Apio, this is about 4000 UsH (1.50 USD) per term. I asked Apio if she ever has to choose between paying for drugs and paying for school. She told me she does, and her choice is always the drugs first. (Apio, 12).

### ***Deterrents***

As the research has indicated, adolescent adherence to ART can be a challenge in the best of circumstances, so I was impressed with the commitment of the students to adhere to their ART. What became clear to me as the interviews progressed, however, was that there was no shortage of deterrents in these students' lives that could easily cause them to stop taking the drugs. Interestingly, in some circumstance, schooling actually contributed to the obstacles in their treatment. This is not to say that the schools were not supportive of the students with HIV/AIDS, as there are a few stories where a specific teacher was often the adult that kept the student's drugs and made sure that the student took the pills everyday. Asio Judith is the PIASCY teacher at one of the primary schools in the district. She told me that she is the one that keeps Opio's medicine:

“...it is us who monitor, it is me who has his medicine...yea, so every morning I call him and say, '[Opio], you take the medicine'...it is around seven, then in the evening, I call him and say, '[Opio] take the medicine' because at first for him, he feared, he had the heart of saying, 'I want to die, I'm useless in the world' so I had to encourage him, so we give him the medicine, we monitor...” (Asio Judith, 2).

However, Asio Judith seems to be the exception as only one other teacher was also in charge of a student's medicine, the rest were kept by the youth themselves.

While many of the students had a particular teacher that they felt they could

go to if they needed advice, and all of the students that were not open with their status did have a teacher that they had confided in, the teachers were not able to do much to support the students with their medication other than reminding them to take the pills daily. On occasion, a teacher would try to find food for the students to take with their pills, as most students go without meals while at school unless they have paid extra to have meals, if that is an option provided by the school. David's school has a feeding programme for orphans, but not those with HIV. However, he says that sometimes if there is extra the teachers will give him some food as well, "they also call me to eat, to take me the dinner and lunch time food...not everyday," (David, 6-7). The lack of food at school, which will be discussed in more detail in a later section, is an important connection to deterrents in adherence as the strong drugs taken by the students are best with food, and many of the students will vomit or feel sick when they take them on an empty stomach. Numerous students do not eat the entire time they are at school.

In order to monitor a patient's CD4 count, ARVs are given in one-month dosages, so that a doctor sees the student each month and monitors their weight, white blood cell count, and overall health. Unfortunately, this means that every month a student with HIV/AIDS has to miss school for at least a day to acquire their drugs. The distance to a health unit varied between each student, but for most the journey is long and they wait hours to see a doctor. The head doctor at the local hospital told me that everyday the HIV clinic sees 90-130 patients and it is run mostly by volunteers because the hospital is so understaffed. (Dr. Moroto, 2.) Once a patient finally reaches the hospital, the wait time can be all day, thus preventing the student from returning to school. Justine, through a translator, told me her routine for getting her drugs:

Shannon: Where do you get your drugs?

Justine: Katakwi

Shannon: How do you get there?

Translator: sometimes she rides her bicycle, she borrows a bicycle and rides

Shannon: hmm, how long does that take you?

Translator: when she leaves here at 8, 8, she reaches there at 9.

Shannon: and then you have to wait at the hospital?

Translator: hmm she has to wait for long.

(Justine, 7).

Apio, 13, has to walk once a month with her brother to Katakwi Health Centre, which is 15km away from her home. She stays for hours at the hospital and then walks 15km back. My colleague, who knew the family, told me during the interview:

“...sometimes when she gets her drugs late she sleeps just anywhere in the hospital, then she comes in the morning. You know, one day the mother came looking for the two of them, it had gotten rain, it was late, the mother looked for them for the whole day, so the following day they got them, they had slept in someone’s home.” (Apio, 4).

While this alone would be a deterrent to maintaining ART, unfortunately Apio’s school also remained unsupportive of this situation. During the interview with Apio, the only time she became emotional was when she told me that she is beaten at school when she misses the day to go to the hospital. Her teachers know that she has HIV, and that when she misses classes it is to go to the hospital, but when she returns to school she is beaten with a stick. After this statement, Apio began to cry and we had to take a break from the interview (Apio, 4-5). A few other children told me that they are beaten when they miss school to pick up their drugs, but the majority of the students said that their teachers are understanding and help them make up work from the day lost. Some students have their parents or even a teacher pick up the drugs for them, but in doing so they miss out on essential medical check-ups, like a CD4 count. As soon as the CD4 count is below a certain level, a change in drugs from Septrin to ARVs is crucial. If the student opts to stay at school and have someone else obtain the medication, it is much harder to monitor their health. On the other hand, missing a full day of school every month hinders academic progress, especially because with HIV/AIDS there are likely to be other days missed for health reasons.

Though unfortunate, the lack of food with which to take the drugs was not surprising because of the general conditions in the region. It was also not unexpected that travelling to the clinics would be a long and sometimes difficult journey, as the roads are in poor condition. However, after talking with Anne’s father, I was introduced to something that can be a deterrent that I had not thought

of: the pills themselves. Anne's father lost an older son to AIDS because he did not take his pills regularly. Part of the reason for this was because the pills are too big for a child to swallow easily, "They're too big, so even for my daughter as of no, we have to break it in two, then she is able to take, but taking one, even the other son of mine said, 'they are too bitter, too big'". Anne's father feels that there should be pills made that are easily consumed by children. It was something that I had not initially thought of but absolutely made sense to me. I shared with Anne's father that I also remembered how difficult it was to swallow a pill when I was young.

Finally, despite all the obstacles these students face to maintain their drug treatment: lack of food, absenteeism to pick up medication, large pills with side effects, cost of treatment, and lack of teacher and/or family support in treatment; most of the students stay focused on taking their medication daily in order to live longer. Unfortunately, despite this, there is still the problem of supply. Dr. Moroto told me that often they run out of the medication and have to turn to NGOs for extra supplies (Dr. Moroto, 2). Gift also talked of this problem:

Shannon: do they ever run out of the drugs?

Gift: yeah, the supplies...

Shannon: ah, what do you do then? You just wait?

Gift: yes, I have to wait. I have no option.

Shannon: do you get sick while you're waiting, do you notice a difference?

Gift: yeah sometimes, because I may withdraw

(Gift, 7).

Not only will this clearly have adverse health effects, the ability to concentrate and perform in school while withdrawing from strong drugs is unrealistic.

In line with Rappaport's assertions, empowerment needs individuals to find ways of gaining control and find meaning in their lives. One of the ways that this can be fostered is through recognizing diverse solutions to local problems and working with the resources in one's life. (Rappaport 1981, 21.) Despite all of the setbacks that these students experience, they all show varying degrees of empowerment. Indeed, empowerment does not equate to a problem-free life. Each adolescent has sought out various resources to help them in their situation, whether that is a particular teacher, a means of getting extra food, borrowing a bicycle for transport to the hospital, or simply drug adherence according to their own desires. It is easy

to feel that the students are in situations that can potentially work against their empowerment, but the counseling and education regarding positive living and the benefits of ART have contributed to a generation that feels hopeful and determined, despite factors working against them.

#### 5.2.4 Nutrition

Given the community in which these students are living, with ongoing issues of insurgency and subsistence farming in an area prone to flooding and drought, it is obvious that a substantial deterrent to any form of empowerment for any demographic in this community is the lack of a viable source of food. If time and energy must be spent trying to meet this basic necessity, empowerment is not a key concern, nor something that can be fostered. For students with HIV/AIDS that are already particularly vulnerable to health concerns and low self-esteem, the issue of proper nutrition is the foundation for everything else. Furthermore, the ARVs essential to keeping these students healthy need to be taken with food to be effective. When taken without food, the students will feel ill and often vomit, clearly creating a situation adverse to drug adherence. As Opio says, "...when I take drugs, [I] may be feeling to vomit when I have not eaten something," (Opio, 4). Life, health, and school performance simply cannot improve without basic nutrition. This is true for all students. While this seems to be a fundamental and obvious point, it is one that is often neglected within the school system in Katakwi, and yet one of the main requests of those working with the students with HIV/AIDS.

Micah, the HIV focal person for Ngariam parish within the Katakwi district, specifically noted that the one thing needed above all else to support students with HIV/AIDS is food.

Shannon: ...what do you think is needed to be able to support the students more?

Micah: oh, it's needed mostly one...provide them with food

Shannon: food, yeah

Micah: that's the first need to them because with this drugs they're having [needing] food.

(Micah, 9)

This sentiment is echoed strongly by Asio Judith, a teacher at one of the primary schools. Twice during the interview she emphasized the need for food in order to give these students a positive future and to keep them taking their drugs regularly,

“...my cry and my wish is if, if our government would take care of this children, this ones who are already HIV positive because some of this children come from very poor families and subjected to swallow ARVs...must swallow them with something...but they swallow at times with empty stomachs and they end up having upset, becoming weak in school here.”  
(Asio Judith, 8)

Moreover, Asio Judith recognizes that the quality of the food is an important piece in supporting and empowering these students. She mentions Opio specifically, that while he has paid for meals at school, he only eats beans and posho every day, and that there is no nutritional variety in his diet (Asio Judith, 9). Anne’s father struggled to provide a balanced diet for his daughter as well, coming to her school daily to give her something like bananas and chapati to supplement her diet and so that she has a snack when she takes her medication. When Anne moves to secondary school, he also plans to send extra money to the school to occasionally provide her with meat to keep her health up. He recognizes this is a wider problem that many families are faced with,

“Because of the poverty situation we have, eh? Children are dependent on one type of meal. Beans and posho, beans and posho. Even public holidays, beans and posho, beans and posho. And yet we pay at times a lot of money for school fees, but you can see this school don’t have a saving. Beans, posho, beans, posho, for ninety-seven days...” (Anne’s Father, 16)

Indeed, all of the students interviewed that were given meals at school received beans and posho for lunch and supper, and “porridge” for breakfast, which was just posho with hot water.

Out of sixteen students interviewed, about half of them received food at school. Some of these students managed to pay the meal fees along with their tuition, and a one was able to receive lunch because her school was supported by a local NGO that donated seedlings and other resources to create a school garden/feeding programme. The remaining students, however, did not eat when at school. In fact, they were often faced with the choice of staying at home in order to

have meals, or to go to school and not eat. Even at home, food may be scarce. David, who was diagnosed as HIV positive one week prior to talking with me, mentioned that the advice of the doctors is to have a balanced diet and to make sure to eat food when taking the medication. At school he does not eat, and at home there is only supper:

Shannon: ok and there's always food at home? There's enough?

David: but some days not

Shannon: so how often do you eat? How many times a day do you get to eat?

David: just once

Shannon: in the evening?

David: mmm

Shannon: so what do you have at supper time? What do you eat?

David: supper time, we eat green vegetables...that's dodo

Shannon: mhm

David: sometimes we will have corn...and also cassava, but now they are not now ready. We are waiting for the season.

(David, 6)

Akello, 14, who goes to school in Ngariam, eats only once a day when she is going to school and that is supper back at home. When she is on holidays or it is the weekend, she eats three times a day (Akello, 10). For her, and many others, school is seen as the path to a better future, but it comes at the cost of proper nutrition. Moreover, the ability to succeed at school is greatly hindered when students have not eaten all day, and being hungry has adverse effects on their ability to stay healthy and exercise regularly. This lack of food at school makes students particularly vulnerable to exploitation; as Akello points out, the soldiers on the road to school will often offer gifts, money, and especially kilos of posho and offer them to the girls in return for sex (Akello, 7).

Basic empowerment theory would suggest that success in school contributes to students feeling that they have control over their own lives, the ability to take on problems, and alleviates feelings of helplessness. For teenagers with HIV/AIDS in Katakwi, school is not only a good place to be, but also a universal right. Despite these positives, with lack of food, success in school is hindered. As Micah, the HIV focal person, asserts, it is not the stigma they may face at school that prevents them from going, it is the lack of food, and that those who have food seem to thrive:

Micah: Others tell me they don't enjoy school, why? Because of food...Most of them give us the reason, that's the biggest reason and the challenge, they lack food.

Shannon: So it's not finger pointing, it's not a stigma, it's food?

Micah: yeah food. Is what makes them...not have a good life, not to have school. But some of them, like that other boy Ocom, has got an aunt from Soroti who sends, ee, some food...So he takes food at a timely time, so he's saying he enjoys school learning.

(Micah, 4-5)

Interestingly, and not surprisingly, according to my colleagues at LWF, the schools that have the feeding programmes and gardens started by the local NGOs see a large rise in school enrollment and attendance (personal conversations/journal entry 2012). It allows all families struggling for proper nutrition a chance for their children to not only gain education, but it also eases the burden of providing food for them. It also frees the children from having to contribute to the work at home in the gardens, so that they can attend school and it does not have a negative impact on the home life.

### 5.2.5 Positive Thinking

Ultimately, all the factors that we know lead to empowerment of an individual or community can be present, but unless those individual(s) can adopt those factors and integrate an empowered mindset, the process will not be successful. TASO's philosophy of positive living specifically sites the importance of mental health and positive thinking. "For people living with HIV, the package of positive living entails having the will to live, and embracing practices that enhance the quality and longevity of life and maintaining hope. In practice this means among other things, accepting diagnosis and adjusting to it accordingly..."

(<http://www.tasouganda.org>). The key is the maintenance of hope and the will to live. As Micah, HIV focal person for Ngariam states, "And these kids now...they need the fresh mind, they need a happy mind, they need a joy mind..." (Micah, 2). He goes on to mandate that he has experienced effects of negative thinking in students and that when the students are stressed or depressed,

"she will not be herself...the next week, she will be sick and when she becomes sick, she will not all that do what you expect her to do at school, she

will either fail school or she'll be stressed and she will be every time having opportunistic diseases, these opportunistic diseases just come out of...stress...maybe they refuse to take drugs, say 'me, I want to die!' They now have that heart like, 'me, I want to die like my mother did, I want to die like my father did'...take two, three, four days, already they CD4 count is coming down...malaria will put you down, diarrhea will put you down, any other disease..." (Micah, 2-3).

For all of the students interviewed, it was obvious that their thought patterns and processes did indeed surpass all other factors in their ability to cope and/or thrive while living with HIV/AIDS. However, it is beyond the scope of this research to determine the psychology behind why some students are able to adopt positive thought patterns and why others cannot, though from the interviews and stories of the students themselves, we can see a clear continuum of those students that have maintained a positive attitude, those who have fallen into depression, and those in between. There are some identifiable factors that encourage ongoing positive thinking, like supportive home life, health care and counseling, peer group, and school environment, but ultimately it is incredibly dependent on the individuals themselves. As John told me when I asked where he gained such confidence and positivity, (despite losing both of his parents, having HIV himself, the ailing health of his guardian grandmother, and facing the fact that there will be no more money for him to continue school) he said, "ok, for me, when I grew up, I grew up (with) such spirits since I was still young..." (John, 13). In terms of empowering variables and factors in his life, there are few, yet he is one of the most empowered individuals with whom I spoke.

### ***Initial Reactions***

This section was specifically included because it was surprising to me how much variation there was among the students in terms of their initial reactions to learning that they were HIV positive. I assumed that universally, this news would have been devastating for the young people to receive. On the contrary, the initial reactions to the HIV test results varied almost as much as each of the student's personalities. Factors that seemed to influence this were the age of the child at

initial testing, the support they received during and after the test result, and method of transmission.

In terms of age, generally it seemed that the younger the individual, the easier the information was to receive and internalize. For example, Michael, who was infected through breastfeeding, was given ART in Primary 1 (around 6 years old) but was not told why he had to take drugs until he was in Primary 3 (around 8 years old). His father has been open about Michael's status ever since he was tested, and Michael cannot clearly recall a specific time when he received the news (Michael, 6). This is true as well for Opio. His mother, who is also HIV positive, took him to be tested in 2009 after he continued to fall sick repeatedly. When I asked him, "were you upset when you found out?" he paused for a few moments and then said, "I don't even remember," (Opio, 2). Beyond this, I was surprised to learn from some of the students that they were not particularly upset when they learned of their HIV status. Anne, currently in Primary 7, who lost her brother about one year ago to AIDS, shared with me that she almost felt relieved when she was diagnosed because she could now take the drugs to keep her healthy,

Shannon: Um, so when you found out that you were HIV positive, how did you feel?

Anne: I felt happy, I said, 'ah no, probably I can take what? Drugs'

Shannon: ah so you felt better that you knew

Anne: yes

Shannon: Rather than feeling sick all the time, you now had an answer?

Anne: yes

(Anne, 2)

Justine was eleven years old when she found out that she was positive. When I asked her how she felt when she received the news, an LWF staff member and friend of Justine, translated for me, saying, "...she did not feel any bad, she did not feel out of place and I was asking her why. She said because she knows everyone can get HIV and many people are sick" I probed further, asking if she felt scared at all and she replied that she did not. (Justine, 1-2). Ruth, now 16 years old, also surprised me with her reaction upon receiving her diagnosis,

Shannon: so when they told you you were positive, you weren't sad?

Ruth: no

Shannon: you weren't?

Ruth: mm mm

Shannon: were you surprised?

Ruth: no...those days, I am happy, I'm just praying God, God knows. I don't know where I get this disease, only...my father get shocked.

(Ruth, 3)

Even David, who I spoke with just one week after finding out he was HIV positive, was surprisingly comfortable with his diagnosis in such a short time. His initial reaction was fear, but within this one week he had already processed the news,

David: ...I was fearing I that I would die very early

Shannon: mmm, and now? How do you feel? The same?

David: no

Shannon: why? What changed?

David: the advice, I got the advice to make me to be free, yes.

Shannon: who did, who gave you the advice?

David: some are doctors, teachers, and my old, my elder brother

Shannon: mmm, and what do they tell you?

David: they told me if you be...you be thinking a lot you will die faster

(David, 3)

David was extraordinary in his ability to take the advice from his support circle, remove the fears from his mind and be open and free with his HIV status. It seemed that the fact that his mother, father, brother, and sister are living with HIV as well might play some role in his comfort level with the disease.

Of course, I spoke with many students that had a hard time with their diagnosis and responded with the expected fear, shock, and anger. Those that did not get the virus through mother to child transmission had a much harder time receiving the news. Betty, 19, was raped and infected by her HIV positive uncle while she was boarding with him. Her reaction upon receiving the test results was devastation,

Shannon: ok, um, what, how did you feel when you found out?

Betty: I felt bad

Shannon: yeah. You must have been angry

Betty: felt very bad, I was, I even committed [attempted] suicide.

(Betty, 2)

Akello, 14 was tested in June of 2012, and her reaction was told to me from an LWF staff member, "she used to fall sick often, almost every week she was on drip [I.V.

fluids]. Almost every week, so the grandie said to take her to test...is when she was told she was positive, and she broke down. She even fainted when she was told that." (Akello, 3). Akello is not sure how she became infected, as she is the only one of her siblings that is HIV positive. She did tell me that there are many soldiers on her way to school that offer gifts in exchange for sex, and while she asserts that she has not engaged, it remains unclear what has happened in some of her interactions with them.

Overall, most of the students I interviewed reacted initially with despair and fear when given their positive test results, but it is striking how effective the counseling provided with the testing is. While many will continue to worry about their health and quality of life, the next section will show that most of the students maintain positive thinking habits and actively engage in behaviours that encourage this. Most feel hopeful that they can remain healthy for many years.

### ***Current Thinking and Attitudes***

Like empowerment itself, positive thinking is not static or unequivocal. The students will fluctuate in their ability to maintain positive thinking, and this varies not only with the person's mood, but also depending on their current life circumstances. All of the students seem aware of this, and they know that resources are available to support them when they struggle to keep their spirits up. However, of all the students I interviewed, only about four really struggled on a daily basis to maintain a positive outlook. The remaining twelve seemed to generally feel positively and only had days or moments of sadness. In these times, they had a variety of methods to lift their spirits back up. An immense amount of credit has to be given to the counselors and staff at the health centres in the area. I spent a day with Dr. Alan Moroto, the head doctor at Katakwi Health Centre, and despite the overwhelming lack of resources and staff the support they are able to give members of the community with HIV/AIDS was, in a word, humbling. The clinic cares for 90-130 HIV/AIDS patients daily, and has a dedicated Youth Corner that is open to all youth regardless of their health status. Within this youth corner are youth leaders

that interact with those that visit the Youth Corner and can counsel them and/or bring them to the attention of other staff. I asked Dr. Moroto if he felt that this was an effective programme and he was emphatic that it is. He said that it allows for privacy, knowledge and counseling about topics that are not typically discussed at home. (Dr. Moroto, 1). The counseling and guidance given by all the health centres in Katakwi seem to be essential to the students I talked to for both their knowledge about the disease, but just as importantly, their ability to cope with the mental health issues that come with living with a chronic disease.

Gideon, 18, struggled when he was diagnosed two months ago, but it was the medical staff that counseled him and gave him the strength he needed,

Gideon: I felt, but, when they advised me, I just took it easy, yeah, because they told me, 'you will live for so long'. I also... I wanted to stop school even, but the doctors told me, 'no, continue, you will not die very fast'

Shannon: mmm, are you glad you remained in school? Are you happy?

Gideon: yeah, I'm happy.

(Gideon, 11)

Opio also takes solace in the doctor's counseling and advice, "HIV does not kill. Even you take the drugs properly, take the drugs and follow the doctor's advice...you will grow and grow." (Opio, 11) and he has been counseled that, "you shall be in future something, someone that is very powerful" (Opio, 9). Moreover, when asked what advice would they give to someone who was just diagnosed as having HIV, they all said to rely on the doctor's advice and the counseling at the health clinics. John's advice was this:

"...ok, I'll just tell them, 'you know what? It is good for you to be open, and maybe go and [to] any other counselor, eh?' And maybe... I will tell him to be open and that's the main fact, so that you will get help from trained people, cause when you are open there you get more, more things, structures that you will follow up, yes, and you get treatment first. Yes." (John, 14).

The advice from Justine is similar, "...to be confident, to relax, and follow what the doctors tell her" (Justine, 12) as is that from Jeff, "can tell him, don't fear, you are not alone, people are many, so don't fear, take your drugs freely...if he refused, I can take him to the counselor [at the hospital], who knows how to counsel people, yeah." (Jeff, 19).

Many of the students also referred to the importance of guidance and advice from teachers as well. Dr. Moroto also mentioned that at the health clinic they encourage their HIV positive students to seek out a special teacher (Dr Moroto, 1). For Ruth, it is only her father and two teachers at school that know she is HIV positive. The teachers are her main source of support when she is stressed, “they counsel me at school, they counsel me that...‘there are many people living with HIV, but we want [you] to take your drug and we want you to be happy at school, playing with other children, like that, love your friends’ mmhmm they tell me...they give me good advice,” (Ruth, 4). One of the teachers I talked to, Asio Judith, recalled a story about one of her former students that tried to commit suicide because of her feelings about her HIV status,

“I remember in 2010...there was a girl in P6, she was HIV positive...she wanted to commit suicide so she had to swallow some chemical that is used for, for animals. She swallowed it but before she swallowed that chemical, she came and told me, ‘teacher, I’m coming to tell you bye’ and I...said ‘you are telling me bye...for what?’ Then she said, ‘Teacher, I am telling you bye, I am going to die’ I tell her, ‘You are not going to die, Jesus is still with you’ She said, ‘No teacher, I am tired, you see somebody raping me and giving me HIV... if he had not raped me, I would not have got what? This HIV, so I am going to die’ Then I tell her, ‘No please, do not die for us’ ...and I talked to her at length...and she was rescued...” (Asio Judith, 5).

In this case, the role of the teacher was crucial in saving this girl’s life. Despite talking with the teacher, the girl still swallowed the poison, but because Asio Judith knew what was going on they were able to rush her to the hospital. Asio Judith has a number of stories where she has had to work closely with HIV positive students to help them feel that their lives are worthwhile even with this disease. I asked her why she thinks some many of the students seek her out specifically, and she replied, “cause when...they come to me, I encourage them to live positively, I give them support, I counsel them and guide them...I don’t tell anybody else...they trust me for that” (Asio Judith, 6-7).

What was surprising was that none of the students referred to getting advice from home, it was either the doctors/counselors or their teachers. It was only when I offered up a parent as a potential resource did the students agree that they could

possibly go to them for support. For example, when I asked Apio whom she goes to when she feels sad, she said she doesn't have anyone. I asked her if she could maybe talk to her mother, and she paused and said that yes, she could. For her and others, it was only with prompting that they would mention their parents as a place for advice. Furthermore, others said that they could not go to their parents at all. Ruth, as mentioned before, can go to her father, but he has advised her not to tell her step-mother about her status because the step-mother will not want to financially support Ruth if she knew. Betty, who was raped by her uncle, struggles to find support in her father because he denies that his brother raped Betty. Justine also relies on teacher support, Mr. James Peter, because she has a strained relationship with her mother. Justine talked about how her mother and her quarrel often because her mother will come home drunk and abuse her. This is not to say that the parents of these children are not supportive, many of them are, but they are often not the first place the students think of when they need advice and help to think positively.

Whether the advice comes from the doctors/counselors or teachers, the piece that is clear is the idea that the students are not alone. Having someone to talk with, regardless of whether it is a doctor or teacher, was important. The fear of being alone seemed to be one of the main causes of sadness for the students. Those that I talked to that struggled the most with sadness seemed to feel the most alone. Betty, 19, who tried to commit suicide when she first found out she was HIV positive, still struggles to keep her spirits up as she feels like she can't find the support or advice she needs, "I was feeling like getting someone who would counsel me...but I've failed to get...the friend which I used to have has been transferred, I don't know where she has transferred," (Betty, 10). Levi, who lost his parents and now lives with his uncle, has a history of fighting at school with the other boys. This may be linked to his feelings around his life and illness. He also mentioned that when he was first tested he did seek to speak with anyone about it, "but all the neighbours know...others told them" and these neighbours sometimes abuse the uncle for keeping a child with him that is HIV positive. I asked him whom he talks with when he is feeling sad,

Shannon: So when you are feeling sad, whom do you go and talk to?  
Levi: hoping my mother was still there  
(Levi, 4)

In this case, when I asked him if there is a teacher that he can talk with, he told me that only some are kind, but “there are those that like to abuse me [because] I am a big person but I am still in P7,” (Levi, 5). For Levi, the feeling that there is no one he can really talk to seems to have a negative impact on both his mood and his behaviour. Even Jeff, who seems quite upbeat most of the time despite being an orphan, does have the common fear of being alone in the world,

Shannon: are you scared of anything?  
Jeff: (pause) yes  
Shannon: what?  
Jeff: (pause) I feel like, eh, having something but when I look behind nobody can help me to get that thing.  
Shannon: hmm  
Jeff: yes  
Shannon: so you feel alone  
Jeff: I’m alone  
(Jeff, 10)

Justine has a difficult time coping, particularly because her mother seems to drink alcohol, and she frequently struggles with loneliness. In a translation by an LWF staff member, I was told, “sometimes at the school she begins crying, singing God’s songs and that relieves her, she sings and talks quiet, but of course at home she has no one...she just keeps quiet”. I asked who she goes to when she is having a hard time and she simply said, “no one,” (Justine, 6).

Interestingly, while the students feel much better when they know they have someone to talk with directly, just the knowledge that they are not the only ones with HIV seems to relieve them. As discussed previously, Justine was not even upset when she was given her test results because she knows that many people in her community also have the virus. In this way, she did not feel alone, despite the lack of outside support. Gideon specifically talks about how he felt when he saw other students at the HIV clinic getting their medication,

Gideon: it is only the first day [I] discovered I’m suffering is when I felt sad, very sad in my heart. But, but now I feel ok.  
Shannon: yeah

Gideon: yeah because there are very many people who are suffering, even the students, what, especially when I saw my friends also there, is when I felt that “eh, you’re also here?” and they said, “yeah”  
(Gideon, 12)

Clearly, the feeling that there is at least one person that they can go to can dramatically shift the students’ thinking into a positive mind frame. Some of these children may have people in their lives that they could talk to, but for whatever reasons, do not reach out. However, simply knowing that someone is there if they need support gives them strength. The belief that they are not alone buoys them, whereas the fear that they are in fact alone weighs heavily on them.

### ***Coping Behaviours***

Seeking out advice and guidance from counselors, doctors, and teachers is the main method used by the students to cope with their illness and its effect on their mood and thinking. It is also the one that seems the most effective for them, and also the one they recommend the most when asked what advice they would provide to others that were just diagnosed as being HIV positive. However, the students also had a few other coping behaviours that they relied upon. For David, and many of the others, the best coping mechanism is to keep busy, “sometimes I am hunting with friends...then sometimes you can go and you can start reading your books eh, you can...forget those things” (David, 8). David was emphatic about the importance of keeping yourself busy and said that school was the best place to do so, “because...you forget those bad times you have. Gives you advice...you can make your mind easy...sometime you can play with your friends, you can forget all your problems, yes” (David, 12). In a later section, school and its role for HIV positive students will be examined in more depth, but all of the students that mentioned keeping busy as a coping mechanism explained that the best way to do this was at school. Opio’s method of coping when things are bothering him was to simply go and play with friends, “...go and play and leave that thing, that which annoys me” (Opio, 6). For the older students, play turned to exercise, but the idea remains the same. As John states about his negative thoughts, “you should be free from those

kinds of things, so that means maybe to be exercising yourself, maybe playing what, yeah, you'll be free from those certain kinds of things," (John, 7).

Some of the students had a strong Christian faith, and for them, God and prayer is a source of strength and a way to cope with their status. Ruth mentioned God as giving her peace of mind even during her original status disclosure, and she continues to turn to Him, "you must pray to God, you don't know where this disease come from but...you must pray for God to help you" (Ruth, 4). Justine has a strong faith that gives her strength as well. She copes by "singing God's songs and that relieves her..." (Justine, 6) and while Anne did not mention her faith as a specific coping mechanism, she does put her future very much in God's hands. When Anne was asked what she would like to do for a job in the future, she replied, "[I will do] any work that God prepares for me," (Anne, 8). Gift also dreamed of his future career as an astronaut or archaeologist, but, "that's with God's help" (Gift, 10).

The link between keeping a positive mind and staying busy was identified by many of the students. The students also cited school as a good place to keep their minds busy. This is emphasized even more by Gift, 17, who recently had to stop going to school because his family could not afford the fees. He said that school kept his mind busy, and now that he cannot attend he gets depressed. To cope with this and to keep his mind busy now, he "listens to music...or when sometimes, I can't control myself, maybe...I'm forced to drink alcohol," (Gift, 8). He was quick to add that he does not drink alcohol anymore and so he tries to do things like, "walking, riding, sometimes jogging around" but that he misses school terribly and it depresses him. When asked what he misses about school the most, he said, "my friends, my studies...let's say everything about school I miss" (Gift, 7). The things he misses are also the things that kept his mind occupied.

The philosophy of positive living has become the guide to life with HIV in Uganda. It is from this value system that much of the counseling for those living with HIV is based upon, and it is also the "rules" that the students I talked with try to implement. While the ability to fully practice positive living varies between individuals; they all seem to at least know the principles involved and do their best

to live by them. It is clear that the philosophy is strongly connected to many of the principles we know about empowerment, for both an individual and a community as a whole, in fighting the disease constructively from a holistic perspective. Like effective empowerment strategies, positive living “takes account of practices, norms and conditions prevailing in our families, communities and institutions. In this aspect, positive living means creating systems and structures that take care of and support people living with HIV to lead meaningful, productive and happier lives while at the same time supporting people not infected with HIV to remain HIV free” (tasouganda.org).

### 5.3 Relationships with Teachers

#### 5.3.1 The Reality of the Teacher and PIASCY

Before a clear understanding of the relationships between students with HIV/AIDS and their teachers can be established, there needs to be a basic understanding of the school culture, curriculum and the role of teachers in Katakwi. Beyond the official reports and general overview from the section on education in Katakwi, interviews were conducted with members of the community and teachers themselves. Regular visits were made to many local schools to clarify and experience the education firsthand, with particular attention to PIASCY. Each school has a Senior Man teacher and a Senior Woman teacher that plays a special role in guiding the boys and girls, respectively, within the school. Moreover, they are the ones assigned to advise and counsel the other staff members and make sure they are behaving according to the professional code of conduct, as Senior Man Teacher at a local High School, Ocom Matthew told me,

“...the senior man teacher plays the role of advising, counseling the staff members in case someone has a problem ok?...we are supposed to be living an exemplar life, ok? Like, eh, it may not be good for maybe a male teacher to have sexual relationship with what? With girls at school, ok?...then also we are supposed to be seen teaching, ok? Yeah. So if someone is not following the code of conduct by dodging, ok, so that is misconduct...like if somebody comes to school when he is drunk, eh? So that will be the responsibility of what? The Senior Man teacher to talk to that person,” (Ocom Matthew, 1).

I asked both Ocom Matthew and Asio Judith, the Senior Woman teacher at a local Primary School, how they came to fill these roles and if they received any special training in regards to counseling. Both told me that they were just chosen for the job by the other teachers, and that they receive no extra pay or training to do the work. It is a role that is given to them because they are seen by their peers as being exemplary educators and fitting to do the job. Important to the role as Senior Man or Senior Woman is the Youth Corner, as special spot in each school where students can receive guidance privately. At Ocom Matthew's school, this was in conjunction with the sick bay, and was off one of the science rooms. The goal is privacy, but I noticed that if a student were to come to the Youth Corner, they would have to walk across the front of the science class to knock on the door of the Youth Corner.

The Senior Man and Senior Woman teachers also seem to be in charge of the PIASCY initiatives at each school. This was the case for all of the teachers I spoke with. I asked Asio Judith exactly what PIASCY is and she explained, "it was started by the President...so as to communicate to the children, to the youth, about HIV, telling them HIV is acquired through this, through sexual intercourse, sharing sharp piercing things, then eh, they encourage those ones that have HIV that, that is not the end of life but let's keep in what? Pushing on it..." (Asio Judith, 1). I also asked if they received training on how to teach in line with PIASCY construct and they do. PIASCY teachers are given one week of training by "coordinating teachers", those that are specially trained first and then go out to the communities to act as tutors for other teachers (Asio Judith, 3). Particularly in the rural, remote areas like Katakwi, coordinating teachers are positioned to assist other teachers. One teacher I spoke with, Asubu John, has been teaching since 1989 but failed to earn his proper licensing until 1997. In the areas where it is hard to attract teachers, community members without any education or teacher training are hired to fill the gap, and subsequently mentored by coordinating teachers (Asubu John, 1). Asio Judith discussed her training with me, "actually we had special training for one full week...Yes, because, even us we, we were very green about HIV so they had to train us, actually trained us, me in this school I was trained for 5 days...The person who

trained us was, eh, sent from State House, Provincial Office.” (Asio Judith, 3).

According to the teachers I spoke with, the training was a single event, and Asubu John said that refresher courses would be a significant way to improve PIASCY in schools.

The challenges the teachers face in Katakwi are numerous. Similar to the rest of Uganda, the teacher student ratio is often 1:100, the pay is low and often not received on time or at all. The teacher housing is shabby, and teacher training is minimal. A person in Uganda can become a teacher one year after completing grade 10, or, as in the case of Katakwi, the individual can be a community member filling a spot because recruitment is difficult. (LWF staff member 2012, field notes.) When asked what the biggest challenge is for PIASCY teachers, or teachers in general, they all responded with the lack of available resources. Asio Judith, like others, told me that the, “biggest challenges that we have is, at times, materials to be used...we have a challenge, cause if you want to draw something but in most cases the school cannot afford the manila paper, cannot afford the colours, the soap, that is one of the challenges.” (Asio Judith, 5). This also applies to materials for health and safety, “at least the school...should be equipped with necessity things for handling them...like gloves, like cotton, cause here we have accidents, and we don’t know whether a child is HIV positive or not, then we have parents who do not tell us about their children...” (Asio Judith, 10). Ocom Matthew also adds that he finds the added role of his job to be exhausting, “So I find that eh I get myself, I get myself overworked...cause maybe other staff members feel that is...your entire responsibility...so at the end of the day you find you get yourself exhausted” (Ocom Matthew, 12). Furthermore, Asubu John added that a hurdle for teachers is not being able to provide assistance to the students when they are sick. He mentioned the lack of nurses, money, and transport to take children to the hospital if needed. (Asubu John, 1). Asio Judith also felt that storing the students’ monthly medicine at the school would be helpful rather than the students commuting to the hospital, creating a break in their studies (Asio Judith, 10). Finally, Ocom Matthew also confided to me that he feels a challenge when dealing with the female students, who are supposed to go and see the Senior Woman teacher, “guiding girls; the opposite

sex. It is something so challenging...cause even I'm still asking myself why some of these girls bypass the right person who is supposed to guide them and they prefer coming to me, eh? And they don't want another person...to be there...I look, in fact, I look at it as a big challenge, maybe the temptation, but of course my, my work is to guide them regardless of the sex..." (Ocom Matthew, 13).

Despite the challenges, all the teachers were emphatic that PIASCY has been extremely effective in both educating youth about sexual health issues and reducing the stigma of people with HIV/AIDS. Specifically, I wanted to know what issues were addressed at school and how they were taught in order to create this success. Asio Judith said that communication works the best, "assembly talks...because we talk of drama and everything, we recognize they laugh and leave but when you talk to them directly, then you show them pictures of HIV, it works so much...the open dialogue." (Asio Judith, 8). When I visited the schools, I was able to take part in the general assemblies and watch a dance performance and song about HIV/AIDS. As well, I had a few girls from the nearby Primary School sing a number of songs about HIV/AIDS for me, and at one High School, Ocom Matthew gathered the students for me and proudly quizzed them on their knowledge of HIV/AIDS. Ocom Matthew also added that they try to have monthly debates related to sexual health as well. It was clear that despite the challenges, PIASCY is ingrained in the curriculum and is a regular part of school life, particularly through music and drama, as those require the least resources.

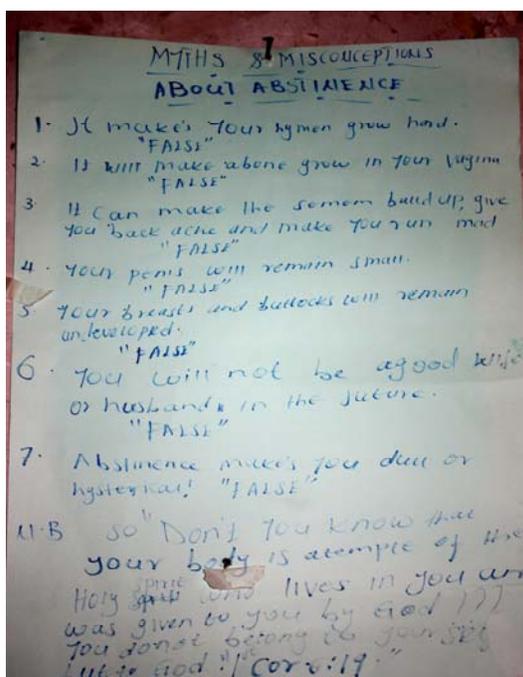
The specific issues that the teachers dealt with varied greatly, and differed between primary and secondary school. In primary school, the focus was more on preventing transmission of HIV through health care, rather than sex education. Asio Judith told me that they teach the students to take care of themselves and others, and to be open about their status, "like if...you're supposed to bathe that person and you have the cut and everything...you put on the gloves...then we encourage opening...up with HIV positive. We encourage them to come up so that we tell them what?...to be very free." (Asio Judith, 1-2). Moreover, the focus at the primary level is also against stigma and discrimination. The message is that, "even those who have HIV, they should love them also and show them care and show them love and

everything,” (Asio Judith, 2). In primary school, it is also the teachers that generally keep the medicine for those that are HIV positive, give this to the students daily and monitor their health. I visited a Primary School on one of the days where PIASCY issues were addressed in the general assembly. On this particular day, the boys and girls were separated; the female teachers discussed gender specific issues with the girls and the male teachers discussed relevant topics with the boys. While I was not at the session with the boys, and number of issues discussed with the girls stood out for me. General discussions included issues of hygiene and sanitation, and were excellent and clear in their direction. Next, the discussion moved into the topic of not putting too much attention into how one looks. The teachers advised the girls that there is plenty of time later to worry about perfume and smooth skin, but that while at school it is not appropriate. One of the reasons given for this was because it is not fair to the male teachers to have to work with female students if they are smelling nice, looking good and brushing up against him (Field notes, Thursday July 5<sup>th</sup> 2012). The fact that this was a topic seen as important enough to bring up at the general assembly indicated that it was not uncommon, and it was a sad truth that not only that it was an issue of male teachers having any sort of relationship with students outside of a professional capacity, but also because this was a concern at the primary level. Even more alarming was that this issue was taught as being the obligation of the girls to not tempt the teacher, not for the teacher to maintain the professional and ethical responsibility to resist. This discussion piece echoed the sentiment that Ocom Matthew expressed previously about his personal difficulties in guiding female students. Finally, at the primary level, PIASCY also addresses issues of self-esteem and self-worth among those with HIV. Asio Judith discussed that she often has to guide students away from their negative thinking, when they say things like, “teacher, as much as you are going to talk much about me, but I know I am a living corpse.”(Asio Judith, 5). She said that this is one of her challenges, but that the other students are usually excellent at supporting their HIV positive peers and will keep watch on that child’s health and even remind them to take their medication (Asio Judith, 6).

At the secondary level, the issues dealt with by the Senior Man and Senior Woman teachers and those that are in charge of PIASCY remain that prevention and care while dealing with those that have HIV are important. Stigma and discrimination are addressed as well. However, by the secondary school age teachers are dealing and guiding students on concerns that are more sexual in nature, and regarding gender issues. Despite some resistance from the community, the teachers work to realize the goals of gender equality. Ocom Matthew states,

“it is a new development in our country, whereby men and women are supposed to be treated equally, ok?...but you find that there is resistance in the community... ‘how can a woman be equated to my standard?’ ok?...that here at school, the other thing is that maybe our boys may be mistreating the girls...so all of these are the things we are making them discuss, that gender is not becoming a man or a woman, but only respect of rights” (Ocom Matthew, 4).

In terms of sexual health, abortion is also taught in classes. In Uganda, abortion is illegal and so young girls that find themselves pregnant may seek out illegal means of having an abortion. Ocom Matthew and other senior teachers, “encourage them that what? Abortion is bad and sex is, eeh, bad and dangers associated to...early sex” (Ocom Matthew, 4). Abstinence, then, is the main message at the secondary level, but teachers also advocate that condom usage is essential, “in case maybe the situation becomes worse, to the level you cannot control yourself. They should be having a decision to protect themselves,” (Ocom Matthew, 5). An interesting comment made by Ocom Matthew about abstinence was that it is the better choice, “much as maybe some people may be questioning your manhood, eh?” (Ocom Matthew, 5). When probed further, he clarified that virginity is valued in girls only, but that with boys and their sexuality, “they should be able to prove that he is a man and active, hmm? Like in our society, if a boy is seen maybe rating the girls, you will find that the father will be proud that... ‘mine is ok’” (Ocom Matthew, 5). He continued to say that is one of the messages the schools are trying to send, that “our culture allows boys to engage in...sexual affairs, but there is a danger in it. There is now AIDS, ok?...so it is up to now to control yourself, ok. Do not be taken by lust...”(Ocom Matthew, 5).



### Myths & Misconceptions about Abstinence

1. It will make your hymen grow hard - "FALSE"
2. It will make a bone grow in your vagina - "FALSE"
3. It can make the semen build up, give you back ache and make you run mad - "FALSE"
4. Your penis will remain small - "FALSE"
5. Your breast and buttocks will remain undeveloped - "FALSE"
6. You will not be a good wife or husband in the future - "FALSE"
7. Abstinence makes you dull or hysterical! "FALSE"

so "Don't you know that your body is a temple of the Holy Spirit who lives in you and was given to you by God??? You do not belong to yourself but to God" Cor 6:19

Figure 5.3: Myths and Misconceptions About Abstinence (Source: Field photos)

Finally, at both the primary and secondary levels, the teachers have taken a central role in encouraging students to get tested for HIV/AIDS. Micah, HIV focal person in Ngariam, says that teachers are essential to his role of testing and supporting those with HIV, "teachers who, mostly who teach sciences, are good friends, our good coordinators. When I have a visit at school, any programme...he [the teacher] says they are late, the other one was sick, the other missed school because he had a headache, I just saw he had a headache or malaria or typhoid, something like a water issue, she or he is taking" (Micah, 7). Ocom Matthew says that at the school, "we always organize volunteer testing and counseling, with the...hospital...they always come to the school to do it," (Ocom Matthew, 6). Due to privacy, the health staff members are not supposed to disclose the results of any of the students after testing, but Ocom Matthew recalled a story where the health staff tried to tell a student that she was positive and it did not go well, and so she asked Ocom Matthew to try and talk with the girl. He managed to talk to her, but she was too upset and ended up transferring schools. I asked if the health staff or school staff tried to contact her parents during this process and he said, "No, I have not met with the parents or the guardians of that girl...so we are just finding ways of reaching to

those parents and share with them....we have not taken a step to look for the parents, mmm.” (Ocom Matthew, 8).

In general, teachers at any school are given major responsibilities in educating the students on the curriculum, guiding them and counseling them as they make their way through life. Many times, issues of sexual health and reproduction are not addressed at home and thus the responsibility falls to the teachers to fill that gap. Particularly when the students are boarding at school, the teachers are monitoring and caring for the health of the student body, especially those with HIV/AIDS.

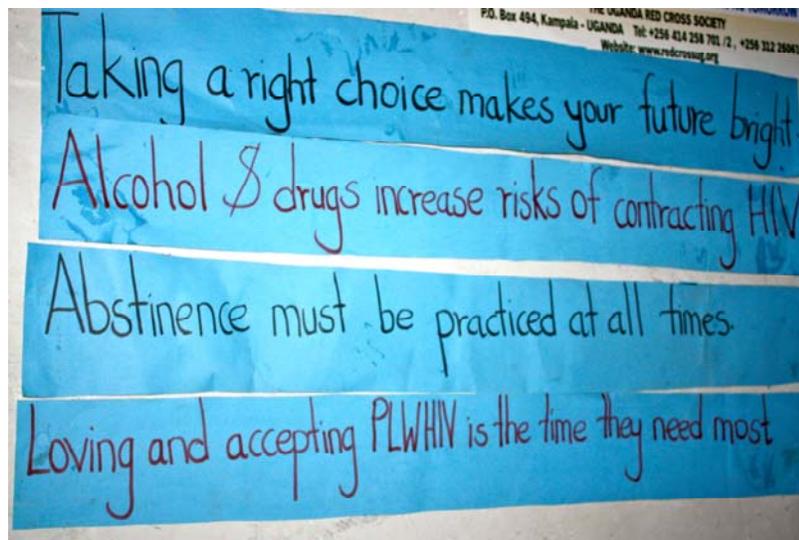


Figure 5.4: Poster Advocating Prevention and Acceptance. (Source: Field Photos)

As expected, the community varies in its response to PIASCY and sexual health education. I was able to discuss this with only a few parents and teachers, so further research is needed on this topic to gather anything concrete. It is interesting to add the responses from parents just to flesh out the understanding of general school culture and experiences of the teachers. Dr. Moroto had a discussion with me about attitudes of youth towards HIV/AIDS, and said that it depends on the family upbringing, but that mostly it is the adults who have fear and see the virus as a sin. He also said that very few parents actually sit down with their children and talk to them about sex and HIV, that it is not culturally common to discuss such subjects. Dr. Moroto told me that parents prefer to leave it to the schools to educate youth on

the topic. (Moroto, 2). In this respect, the parents and community are supportive of sexual education at school. Ocom Matthew also told me that parents tend to appreciate the efforts of the teachers to broach these difficult subjects; “you will find that even the parents are brought what? On board, so there’s no objection...and no in fact, they even appreciate what we are doing...cause some of them don’t have time to talk to the children, mm? They don’t have time. So the only source of information their children can get is...through the schools,” (Ocom Matthew, 11).

Conversely, Anne’s father had concerns with the sexual education that the schools are providing. As he says,

“when you look at the African syllabus, or Ugandan, some of this topics in the syllabus, they are tempting...even our bishops, the Christian fraternity, part of the syllabus, we’re condemning it, because it is in one way tempting the young generation to do things which are supposed to be done by adults...You can’t begin teaching at a young early age of a child who is at a lower primary, Primary 4, about the reproductive system. Then you tell them, even the real words for the...parts that make up the reproductive system. And then again you go deeper and the slightly deeper, so these children will want to explore” (Anne’s father, 17).

Michael’s father, Arthur, who is also a Primary School teacher, was also more in line with Anne’s father in terms of what exactly should be taught in the schools regarding sexual health. I asked Arthur what he felt about Michael ever having a girlfriend and he was adamant that Michael go through Senior Secondary without ever having a girlfriend. In fact, he wants Michael to become a priest. I asked if he ever talked to Michael about sexual relationships and he said that he rarely does, and when it is discussed the only message is abstinence. He said he tells Michael, “God will punish him for bad things” (Arthur, 2). I was interested to see that a teacher, trained to deliver the PIASCY content at school, was so conservative on the issue with his own son. It made me curious as to how he broaches this topic with the students in his classes.

### 5.3.2 Support from Teachers for HIV Positive Students

Overwhelmingly, every student I talked with identified that they loved school and all of their teachers. Even when school was challenging to the students in numerous ways, they all emphasized how much they wanted to be there. In fact, only one out of the sixteen students admitted that there was a teacher he did not like. He never told me the name of the teacher, and he seemed hesitant to even mention it. The remaining fifteen students, when asked if there was a teacher they did not like, told me there was not, but many did have a favourite teacher. My conversation with Ruth was typical of most of the interviews,

Shannon: so school, do you enjoy school?

Ruth: yes

Shannon: very much or only a little?

Ruth: very much

Shannon: do you have a favourite teacher? ...who is that?

Ruth: he, Okello Jimmy

Shannon: ...and do you have a teacher that you don't like?

Ruth: ah, I like all, heh

Shannon: really? All of them?

Ruth: mmhmm

Shannon: there isn't one teacher that you are fearing?

Ruth: (pauses) no.

(Ruth, 7)

While the vast majority of students said that there is not one teacher they do not like, part of those answers could have come from a fear of that teacher finding out they said something, and also the culture of respect for teachers from the students would not allow a student to speak ill of them.

For many of the students, the teachers are key resources for monitoring their health. Jeff told me that shortly after he tested positive he “went to them [the teachers] directly to tell them because if I fall sick there, they are the ones to help me” (Jeff, 5). He also told me that when he went to tell them about his condition, they were supportive, “they say ‘no problem, we shall stay. Shall help you in any way’” (Jeff, 5). Even the students that were afraid to tell their teachers, for fear of discrimination or abuse, generally found the teachers to receive them positively.

Anne was scared to tell her teachers that she was HIV positive, but knew it was important for them to know:

Anne: I was fearing but I said tell, now you see what's my body, I need to tell my teachers also first

Shannon: yeah, but you were fearing?

Anne: so that's. Yes. But I went with a, I went with a good heart

Shannon: mm

Anne: I told them

Shannon: yeah, what were you fearing?

Anne: I thought that they would laugh at me, say that 'that girl has HIV'

Shannon: mmhmm, you were fearing that they would point fingers at you

Anne: mmm

Shannon: yeah, but they didn't? your teachers were all good?

Anne: yes

Shannon: every one? And do they all know?

Anne: yes

Shannon: yeah, and are you able to go to them if you need advice? Guidance?

Anne: yes

(Anne, 2-3).

Furthermore, teachers are often the ones that store the students' medication for them and keep them on a schedule with taking them. Senior Woman teacher Asio Judith keeps Opio's medication for him, "it is us who monitor, it is me who has his medicine...then when it is a routine for going to the hospital, we tell them...So when he comes back with the medicine, he hands it over to me, then I take care of the medicine" (Asio Judith, 2). Apio's colleague, Madame Itiamat, also keeps the medicine for those that are in the lower primary grades (Asio Judith, 7). Justine's favourite teacher also keeps her medicine for her, both her ARVs and Septrin. (Justine, 4). Usually when the student is at boarding school, the teacher will monitor the medication, but in Justine's case, she is not boarding and her teacher still keeps the medications for her.

In some instances it is the teachers that notice the student's failing health and take them to be tested for HIV, or at the least, encourage the parents/guardians to take the students for testing. Akello, who lives with her grandmother, was actually taken to the hospital by her teachers. Through translation, an LWF staff member tells me the story, "she says there's a time, she used to frequently fall sick, so there's a time she fell sick from school here and they took her to the health centre, where

they give her treatment, she was put on drip, and um, from there they tested, just as a suggested 'we also have to test for HIV' because she used to frequently fall sick, so when they tested they found she was positive... the teachers told her, then she went, they told her to go and tell the grandmother" (Akello, 5). David had not disclosed his status to his teachers, but they had been noticing some signs and asked him about it, and when they learned he was indeed HIV positive, they took extra steps to care for him,

Shannon: ok, so how did your teachers find out you had HIV?

David: ...because some of the signs

Shannon: like what?

David: skin rash, and ee, every time being under sunlight...they discovered and then they asked me, then I told them

Shannon: mm, were you fearing to tell them?

David: no, I was not fearing

Shannon: ...how did they react?...

David: they also worried, they were, they were also worried

Shannon: but were they supportive to you, they were kind?

David: yes, but those other time, they also called me to eat, to take me the dinner and get lunch time food

(David, 6)

As noted previously, Micah, the HIV focal person, also said that the teachers play an imperative role when he comes to visit, as they report to him on the health of the HIV positive students, as well as if they have been absent or not receiving proper support at home (Micah, 7). Michael's father Arthur told me that Michael was moved temporarily to a different school because a teacher advised him that he was starting to associate with a peer group that had a bad influence on him. Arthur very much relies on the teachers to not only monitor his son's health but general well-being and social development. Referring to a specific teacher, Arthur said, "he will help me monitor that boy, his health, from there. Hmm" (Arthur, 3).

Moreover, it is at the schools that organizations like the Red Cross, with the support of the teaching staff, will come and test the student body. That is how both Ruth and others first found out that they are HIV positive. Ruth was tested just last term, in February, at school along with all the other students. Her results were positive and her two teachers are among the very few who know her status. They

have become strong allies for her, “those teachers are helping me from school. If anything done for me, if anyone want to abuse me or want to beat me, those teachers help me” (Ruth, 3). Ocom Matthew, as cited previously in the story of the girl that was tested positive at the school but then ultimately transferred schools, refers to the hospital staff coming to the school to test the students, “we always organize volunteer testing and counseling, with, with the hospital...they always come to the school to do it.” (Ocom Matthew, 6). The goal, as part of PIASCY, is to allow students to know their status as that is essential in receiving treatment and protecting others, or if negative, remaining so.

The amount that the students rely on the teachers for guidance and support varies from child to child. Michael finds comfort in his teachers. As he prepares to leave his primary school and begin secondary school, he mentioned that he hopes to be able to board at his next school. When asked why, he replied, “I want to be near the teachers...I want to stay with the teachers” (Michael, 10). Michael also said that it is the teachers that are the first people he would go to for help and comfort because they give the best advice and they are always willing to take the time to help him (Michael, 15-16). Even Betty, who is one of the students that I talked with that struggles the most with her HIV status, relies on one specific teacher. Betty has only told her family and this one teacher about her HIV status. When I asked why she told this specific teacher, she said, “I told her I am HIV positive cause I’m also a member in the Peace Club, so she told me that, ‘if you have any problems that is disturbing you, come and share with me’ So I went and shared with her” (Betty, 3). This teacher is important to Betty because she goes to her for guidance, but also when she has to leave the school to get her medication, she goes to this teacher to get permission to leave school and not get in trouble for doing so. For all of the students, having a teacher that knows of their status allows them to leave for the hospital with permission and not be punished when they return.

In general, the students included at least one teacher in their support circle, even those that are not open and free about their status. Teachers, as a source of guidance and support, are cited by almost all the students as one of the first places they would turn to with questions or problems specifically related to HIV. John told

me that if someone wanted to know more information about HIV/AIDS, the teachers would be the best resource: “go maybe to teachers, like cause we have a youth corner there, where they counsel, and we have a Senior Man teacher and a Senior Woman teacher, yeah, who counsels, if you have any problem you can go there and she or he will counsel you and you will know more what you want to discover, yeah” (John, 5). Isaiah, and others, also said they get much of their knowledge about HIV from the school (Isaiah, 11).

Finally, one of the ways in which the teachers are able to provide support to the students with HIV was in the disclosure of their own statuses. Opio has one teacher, his favourite teacher in fact, that is HIV positive and open about his health status. All of the students in the school know this teacher has HIV, and this alone helps de-stigmatize those with the disease. Furthermore, Opio has a special bond with this teacher because, “he is also suffering from it” (Opio, 6). Opio also told me that this teacher specifically checks in with him every Sunday to see how he is doing, and that this teacher does this with the other students that are HIV positive as well (Opio, 12). Unfortunately, this teacher falls sick about once a month, according to Opio (Opio, 6). Michael’s father, Arthur, also has HIV, and is a teacher that is open with his status to the community and specifically the students. When he told his fellow teaching staff about his status, they were told by the head teacher to support him; they reduced his workload, and gave him extra time to take both himself and his children to the hospital. This alone is excellent modeling for all of the students, but it is also particularly important for those with HIV to experience. The students themselves have stepped up to support Arthur as well, and they will help him in his garden heaping potatoes regularly. Asio Judith has two colleagues at her school that also have HIV and are open to the students about it. She says they are good examples for all of the students, and become quick allies for those with HIV. (Asio Judith, 7). The school and the role of the teacher cannot be underestimated in creating an essential community of support for those living with HIV.

### 5.3.3 Abuse from Teachers towards HIV Positive Students

There is a saying that I heard from LWF staff and other community members, and it is only a half-joke, that beating students with a cane is how, “the African child understand best,” (Betty, 12). While this is said in jest, it reflects the reality of the schools in Katakwi. Every student I spoke with said that beatings at their schools were a regular occurrence, even if they themselves are not beaten. The frequency of the beatings varied. In some schools only the most severe transgression warranted caning, but at other schools, it happened for small events like being late or doing poorly on a test. As Stella, a colleague of mine, told me, “here some schools really beat, private schools, better even government schools, but private schools the child is beaten 15 strokes...you cannot even sit for the next two days...you just look for a pillow” (Betty, 12). Despite the regularity of beatings, and the general acceptance of corporal punishment in schools, it is also cited by the students as one of the most upsetting things in their lives. During all of the interviews, it was only when the students talked about being beaten at school did any of them break down in tears or withdraw altogether. The students never cried when talking about the death of loved ones, their fears about dying themselves, the struggle to have enough to eat, or any of the other hardships they face. For a number of students that I talked with, beatings by teachers were the only overt source of anguish that I could see.

Caning in the classroom is obviously not solely a problem for students with HIV, it affects all students. Gift, who recently had to drop out of school, said he enjoyed school very much, but did not like Primary 6 specifically,

Shannon: Primary 6, it was not good?

Gift: yeah

Shannon: How come?

Gift: cause it was a lot of spanking

Shannon: ah. By the teachers?

Gift: yeah

Shannon: with a stick?

Gift: yeah

Shannon: on your bum

Gift: hehe, yes.

(Gift, 3)

Michael also said that he hates it when the teachers beat him. He was asked what makes him sad and it was the abuse from teachers:

Shannon: are you scared of dying?  
Michael: no  
Shannon:...do you ever get sad?  
Michael: yes  
Shannon: yeah, about what?  
Michael: (pauses) when the teachers beat me  
(Michael, 15)

Beyond the physical pain of the beatings, there is an element of shame involved, as the beatings occur either in front of the whole class to see, or in front of the staff. Ruth says, "...if you do bad thing, eh? Like abuse somebody...they take you from the office... the teachers are there, all, and beat you. But for me ah, ah, don't want. Don't like those things." (Ruth, 8). In my interview with Betty, two of my colleagues who are also peers of Betty's were there as well, and we had a conversation about students being beaten in front of their classmates,

Shannon: ah do teachers ever, ah, beat students here?  
Betty: they beat you when you do a mistake  
Shannon: Ah! With a stick?  
Betty: yeah  
Shannon: on your hand?  
Betty: hehehe, the bums  
Shannon: ah  
(laughter)  
LWF staff member 1: they tell you to lie down  
LWF staff member 2: lie down  
Shannon: what?!  
(laughter)  
Shannon: on the floor?  
Betty: yes  
LWF staff member 2: yeah  
(laughter)  
Shannon: in front of everyone?  
Betty: hmmm  
Shannon: how many times do they smack?  
Betty: it depends on what you do always, when you are always good they don't cane you.  
Shannon: yeah  
Betty: but when you do bad things they beat you  
(laughter)

(Betty, 11-12).

I was curious as to what “something bad” was exactly, so when I asked what some of the things were that students did to warrant a beating, there were a variety of answers. The most common response was being late/absent or failing a test. Anne said she is beaten, “because of failing” (Anne, 7) or John says he is rarely beaten, but others are, “if they come late what, yes...six strokes like that” (John, 10) and Levi is beaten for fighting with other students (Levi, 7). Mostly, the students said they are beaten for their mistakes. Jeff simply says, “beating, if I made a mistake” (Jeff, 12). The most severe beatings seem to result from students that have been caught fighting or drinking alcohol (Ruth, 8; David, 10).

For some of the students, having HIV actually protects them from being beaten, as the teachers are sympathetic towards them and will not beat them or let other teachers beat them. Others, however, despite the teachers’ knowledge of their status, are still beaten for missing school to pick up their medication. Justine says that only some of her teachers beat her, but “some don’t because they know she’s sick,” (Justine, 8). However, these same teachers that know she is sick will sometimes abuse her about being HIV positive, they will mock her saying, “hey for you, you have HIV/AIDS, you’re proud...you are proud now that you have HIV...” (Justine, 3). Conversely, for Isaiah, if he tells the teachers that he is being mocked by other students for having HIV, the teachers will actually beat those other students,

Shannon: you report them? Tell the teachers?

Isaiah: yes

Shannon: and what happens?

Isaiah: the teacher will beat them

(Isaiah, 5)

Unfortunately, there are stories of teachers that abuse the students despite knowing their health status. Levi has a teacher he particularly does not like, because he will explain to that teacher that he was absent because of his health but, “some day when I be absent at school, when I tell him my problem, he knocks me, I get beat” (Levi, 12). For Apio, telling me the story of how she is beaten when she has to miss school

to get her drugs actually made her break down in tears and we had to stop the interview temporarily,

LWF staff: when she goes, after missing, she goes to school and she is beaten for missing

Shannon: ah ah

LWF staff: hmm

Shannon: with a cane

LWF staff: with a stick

Shannon: ah, do the teachers know you are going to the hospital?

Apio: eybo (yes)

Shannon: do they know you have HIV?

Apio: eybo (yes)

(Apio starts to cry)

Shannon: is this too hard? Do you need to stop?

(Shannon hugs Apio and lets her cry before they continue)

(Apio, 4-5).

Overall, it was apparent how deeply affected the students are by the beatings at school. While some would laugh nervously when discussing it, many would withdraw after discussing it, and, as seen in Apio, it is clearly an emotionally difficult subject. Again, this topic is not specific to students with HIV/AIDS, but it is clear that it can deter them from going to the health centres to access their medication. It also negatively affects their overall wellbeing, which is a problem for these vulnerable students.

Even though the beatings at the school give the impression that the teachers must be particularly strict, some of the students actually felt like the teachers were, in several ways, apathetic. Apio told me that sometimes other students will deride her because of her HIV status, and when she goes to the teachers to help her with these other children, "sometimes the teachers get rid of them, but sometimes the teachers relax," (Apio, 6). This makes her feel like there is not a teacher that she could go to if she was having problems (Apio, 6). In a situation with Akello, she went to her Senior Woman teacher with her concerns about the soldiers that harass her for sex on the way to school, "but the Senior Woman teacher by that time was planning to, to call for a meeting, but she was transferred. So there was no action taken," (Akello, 8). Whether or not the teacher delayed in calling a meeting is

unclear, but the fact remains that the other staff did not take any initiative on this serious topic even after the Senior Woman teacher left. Akello also mentioned her fears about opening up about her HIV status once she reaches Senior Secondary because she thinks, “at the primary level, uh, discipline is tight, some laws are in place, like if they got others abusing somebody who is sick, the teachers are taken and discipline you. But in secondary...there are no disciplinary actions that are worth” (Akello, 6). Whether or not this is accurate, Akello is worried about teacher apathy as she progresses in school, which leads to disempowerment.

Furthermore, teacher absenteeism is an issue, particularly for those with HIV related health issues. Certain students are assigned the role of prefect or school speaker, and in this role they act as replacement teachers. David is the school speaker at his school in Ngariam, and when I asked him what that meant he told me his role is “to give them maybe work when the teacher is not there, to help them in the assembly when the teachers are not there, that’s my work,” (David, 16). I also recall a visit to another school in Ngariam (July 11, 2012) where students were digging in the garden, doing the hard physical labour to grow crops for programme to feed students. Each class has a turn in the field each day, but a student chosen from the Primary 7 class supervises. This student fills the role of teacher, but in doing so must miss their own lessons. In this case, it is not so much teacher apathy as lack of available staff and resources. This is also evident in the situation with Michael. He is a registered student at one Primary School, but his father had recently moved him to a different Primary School, where the father works, to monitor him and keep him from a peer group at the first school that was possibly being a bad influence. When I went to the school where Michael is registered to see him, the teachers said he was not there and that maybe he was sick that day. I was able to track him down at his father’s school, but was concerned that the staff at the original school seemed to have no knowledge that one of their pupils had been attending a different school for some time (Field notes, July 2 2012). For students with HIV/AIDS, it is excellent to see that they are put in leadership roles like other students, but somewhat concerning that an adult is not always around to supervise

and monitor both their health, particularly with hard physical labour, and/or social interactions when it comes to bullying, or general educational progress.



Fig 5.5: Primary School, Ngariam: P7 student supervising the P4 class working in the garden. (Source: Field photos)

It should be reinforced that the students spoke highly of their teachers and had many good interactions to share about them. Almost all of the students told me that their teachers are kind to them, and it is only a few that verbally abuse them. As mentioned previously, physical abuse is common, but only a few students said that some of their teachers are emotionally unkind to them. Levi said that some of his teachers insult him, though it is not about his HIV status, rather that he is older than the average student in Primary 7, as he is 15 years old. I asked him about his teachers,

Shannon: you trust them?

Levi: yeah

Shannon: are they kind to you?

Levi: yes

Shannon: all of them?

Levi: no

Shannon: what do some of them do?

Levi: there are those that like to abuse me

Shannon: how so? What do they say?

Levi: that I am a big person but I am still in P7

Shannon: mmm, do they abuse you about HIV?

Levi: no

(Levi, 5)

Conversely, Justine's teachers do abuse her in direct relation to her HIV status. When she is outgoing or achieves beyond another student, they say she acts like she is "proud" to have HIV, and that she is surpassing what she should expect from herself (Justine, 3).

Gift recently came to Katakwi from a big city near the capital city of Kampala, and he had concerns about some of his teachers' attitudes towards those with HIV/AIDS. Much of his experience could be influenced by the fact that he is struggling to come to terms with being HIV positive, and is afraid to open up about his status to anyone, as he has not come out to anyone except his brother. Gift felt like in the city the education about HIV/AIDS and health in general was much better,

Gift: ...this school, they basically do nothing, but back in [the city], used to be trained on life support and First Aid.

Shannon: ok

Gift: and they also donate blood

Shannon: hmm, and did they...teach about HIV and AIDS at the school?

Gift: yes

Shannon: what about here?

Gift: maybe they do

Shannon:...And do they teach about not discriminating against people with HIV?

Gift: yeah, but some do not actually mean it

Shannon: ah, how do you know?

Gift: ah, you can tell by the tone of voice

Shannon: mm

Gift: yeah

Shannon: the teachers?

Gift: yeah

Shannon: you think they are just saying it because they have to?

Gift: yeah

(Gift, 4-5)

Finally, the most alarming and worrisome relationships that the students have with teachers are those of a sexual nature. Of course, this is a major concern for all students, regardless of whether or not they have HIV, but for those that have HIV they risk not only spreading the disease, but also the chance of re-infection from their teachers with a different strain of the virus. Other students that are negative are also at risk, beyond the violation of having sexual relations with an authority

figure, for ending up with HIV/AIDS. I was horrified to learn that Micah, HIV focal person for Ngariam, said that the two main categories of people the girls have sex with are soldiers and teachers, “in post-counseling, one on one, we ask them, ‘have you ever had sex?’ they tell you, ‘yes, I had with him, I had with a soldier’. They will tell you with a soldier...they have sex with, they will tell you, a soldier or a teacher,” (Micah, 15). At all of the schools, there were many signs on the walls and the grounds giving messages about sexuality and HIV/AIDS, many of which encouraged students to avoid “sugar daddies”, and in a community that has many youth that are vulnerable because of poverty and insurgency, both soldiers and teachers are able to offer them support in the form of food or money. These types of adults are also the ones that students are most likely to encounter, as the soldiers are patrolling the areas en route to school, and the teachers are obviously at the schools themselves. Micah said that the girls are quite open to him about their sexual relationships with teachers, “They will be open to you, they will just...be open and tell you, ‘yeah I had sex with Sir, and even the last day I had...on Friday, I went to his place at night” (Micah, 15). Micah, and any other person I spoke with, did not mention that the boys are in these relationships with teachers as well, though it could be that these are kept even more secret. Stella confirmed Micah’s assertions when she told me about a former teacher of hers,

“...last year there was a teacher who used to disturb girls. Yeah. And that teacher used to be a drunkard, was the one who used to disturb even her. But no girl accepted, so what girls did was report to the Senior Woman teacher, who convened girls and got details and he was reported to the head teacher and was transferred” (Stella, 6).

It should be clear that this teacher was not fired, but transferred, and is still currently teaching at another school, according to Stella. It is encouraging that the girls are at least feeling empowered enough to speak out against these violations and use the resources at their disposal, but it is appalling that these students are even put in a situation where they have to deal with this.

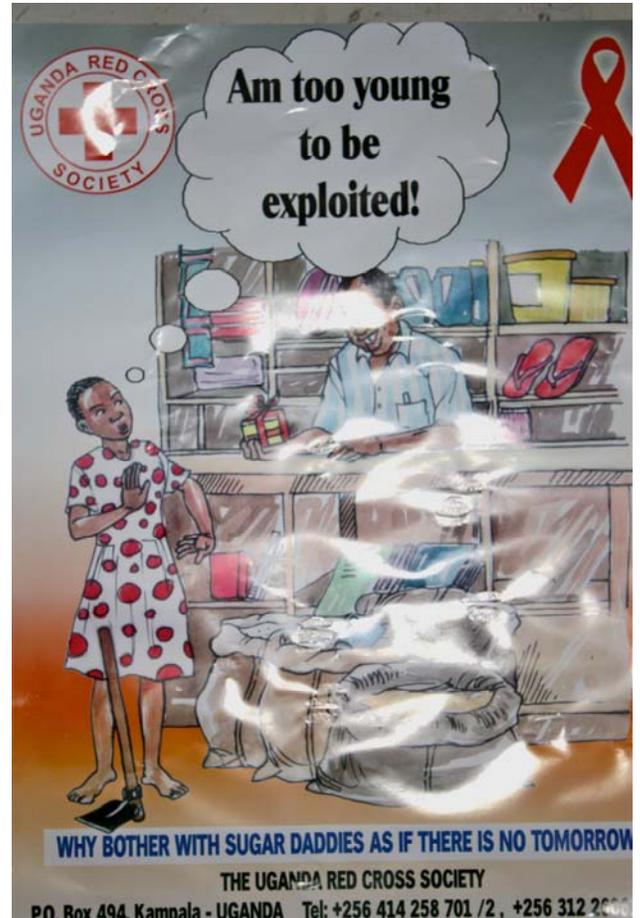
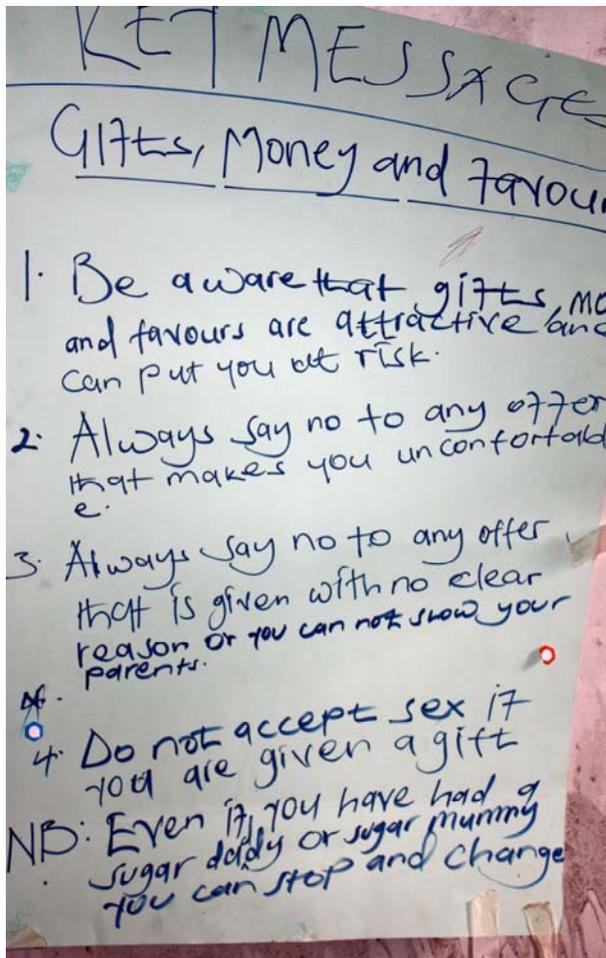


Fig 5.6: Informational posters placed around the school. (Source: Field photos)

Around the world, teachers play a crucial role in shaping a student's life. Depending on their interactions with any child, they can boost their confidence and well being as much as a parent. However, this role comes with the ability to exploit and abuse a student as well. In Katakwi, it is clear that there are instances of both types of teachers. Unfortunately, the teacher that can look out for and guide a student with HIV/AIDS can also be the same one to beat them or neglect them. It is important to show that the relationships that these particular students have with their teachers is as varied as the experiences these students have in every aspect of their lives.

## 5.4 Stigma and Discrimination at School

As the contemporary literature indicates, today's generation of teenagers in Sub-Saharan Africa are faced with unique challenges as they navigate their way through adolescence with a chronic disease. This is a disease that has undergone dramatic transformations from being a death sentence to a long-term chronic illness with the roll out of ART. This change has led to other changes in the virus's social and economic impacts on communities as children that are born with the disease can now live well past the teenage years. Today's generation of teens are some of the first to live into adolescence, and because of this, they are experiencing life with this disease in a whole new manner. The issue of stigmatization is of great concern. (Midtbø et al. 2012; Thupayagale et al. 2010; Petersen et al. 2010; Pienaar et al. 2012; Li et al. 2009). This issue is significant because of the link between stigma and delayed access to health care, reduction in ART adherence, and the negative effect on prevention of transmission (Nattabi et al. 2011, 194). I was surprised in my research to find how little stigmatization was cited as a major issue for many of the students, despite how much research and discussion there is surrounding this topic. In fact, only three of the students I spoke with felt that they were stigmatized at school. This in no way indicates that stigma does not exist for the rest of the students, rather that most of them have broad support at school from peers and teachers, and a small minority of their peers bully them. Many of the students seemed quite capable of rising above the bullying and used resources available to them to deal with any sort of verbal or physical abuse. What was more in line with the literature, however, was the presence of self-stigmatization, particularly for those students that were not open about their status. The fear of stigma was, for them, crippling. The issue of gender is also noteworthy in terms of stigma, and while this research did not specifically examine gender, some interesting points did emerge that could be starting points for further research, which also speaks to Nattabi et al.'s work.

### 5.4.1 Lack of Stigma

Midtbø and colleagues found that because of ART, those with HIV/AIDS have been more empowered and able to resist stigma because the distinction between “us” and “them” is less clear. Their health and success challenges stigmatizing attitudes. (Midtbø et al. 2012, 261). Opio, 12 years old, talked very openly to me about his school experiences, and throughout the interview I asked him about how the other students treat him. At varying parts of the conversation, and in different ways, I brought up issues of stigma and he was quite frank that it was not a problem for him. I asked him about fears people have about telling others about their HIV status, and he replied, “for me, I don’t worry. I tell them, we even play, nothing is wrong.” (Opio, 3) Later I asked him how the other students are towards him if he was injured or bleeding at school,

Shannon: and the other children are fine with it too?

Opio: yes

Shannon: they don’t run away from you?

Opio: Ah, they even go and get for me cotton...I tell them, ‘don’t touch the part that is bleeding or what, but help to tie it...’

(Opio, 8)

He later even referred to being at school with his peers as, “like a team, a supportive team, yes” (Opio, 12). Opio’s teacher, Asio Judith, confirmed this experience. When asked about students at the school being stigmatized, she said, “In our school here, they are not, they’re helped because if...one of them sick in the class, runs to us and say, ‘today, Opio is sick...’ Then we rush there” (Asio Judith, 2). She also mentioned that other students go and fetch water for Opio (Asio Judith, 6). Anne, who goes to the same school as Opio, shared a similar sentiment when asked how people are towards her at school, “they said, ‘let me help that girl, she is sick we need to take care of her’ so they took care of me” (Anne, 3). This is not just a Primary School experience. Jeff, who is in Secondary school, also said that he does not have a problem with stigmatization or bullying,

Shannon: ... have the kids at school, do they ever point fingers at you or anything because you have HIV?

Jeff: no, no, no

Shannon: they are good?

Jeff: yes  
Shannon: all of them?  
Jeff: yes  
(Jeff, 5)

David, 13, has not told many people yet about his HIV status because he was only tested and found positive one week prior to the interview, but he is feeling fine about opening up. I asked him if he had seen other students with HIV being discriminated against,

David: I haven't seen...no  
Shannon: mmm  
David: they are all loved by their friends  
Shannon: mm  
David: mm  
Shannon: that's good, so you are not fearing that people will discriminate against you?  
David: yes  
Shannon: ah that's good. How would you feel if one day the teachers said, 'David you have to stand in the general assembly and announce to everyone that you have HIV.?'  
David: I will  
Shannon: you will?  
David: yes...and I would advise them to abstain from sex.  
(David, 8).

My conversations with Michael (7,18), Akello (4-5), John (5, 11), Levi (5), and Gideon (7) were all along the same lines. Each of them told me that they have not dealt with any bullying or stigmatization because of their HIV status. I asked John specifically why he thought students are no longer stigmatizing those with HIV as much. He said, "...those things used to be like old days, those days people didn't know what to be done, like people feared like maybe if you sit like together, or else share things together you might contract HIV. No. So like these days they also know. Yeah, they also know" (John, 5). Later, he elaborated that teachers and students are now kind to those with HIV, "...they will be kind because they know that thing maybe come just by God, eh? It wasn't of your want, that you willed, you wanted to get it. Yeah. Also I never wanted this, it just came by accident, yeah." (John, 15). HIV focal person, Micah, also says, "...you know the stigma is not so much in our days. It has reduced. That is a fact. Because most of them are coming out saying 'we have'"

(Micah, 6). Asio Judith credits the change in attitude to the experiences of this generation with HIV/AIDS, “it was around 2000, 2001, 2002 and 3 there was a lot of finger pointing, but right now its not there, because each and everybody at least is affected, either their mother or their aunty, either the father or granny has ever died of what? HIV.” (Asio Judith, 7). She also felt that the country’s push to open up and discuss HIV/AIDS has had a great impact in a short amount of time, “the change is because of the things like PIASCY, then opening up when they, because talk shows and radios, yeah so it encourages people to say, ‘eh, this HIV has not come to kill only one person, because we have today is me, tomorrow is someone else” (Asio Judith, 8). Asubu John also attributes the efforts of the schools through PIASCY as changing the attitudes of students, as does Ocom Matthew “I think there is eh, mutual relationship, between the positive and these other students, eh? So to always support them, I always see them moving together...so they mix freely...it is because of the serious mobilization, mm...we tell them that being positive should not make someone to be condemned” (Ocom Matthew, 14). It was encouraging to see that not only has stigma at school been reduced, but students, teachers, and the school nurse also clarified this. When I asked her about stigma at school, she simply said, “...no, no, no, that is not there, mm” (School Nurse, 2). The collaboration of the stories was important because I thought the teachers might have inflated the positive experiences of the students in order to show how well the teaching staff was doing with PIASCY. The students’ echoing of their sentiments was heartening.

I was also curious to see if the stigma a student faced varied depending on how the student was infected. HIV/AIDS is still considered a “moral disease” in many ways, so it was unclear whether those that were born with the disease were less stigmatized than those who were infected later in life, perhaps through sexual intercourse. The answers were mixed. Senior Man teacher Ocom Matthew said that, “...a positive person is a positive person, eh? Regardless of how...somebody acquired it, mm?” (Ocom Matthew, 8). However, Jeff had a different view of this,

Jeff: they don’t talk because they know...I’m not the one who get it, it is my parents who  
Shannon: who gave it to you  
Jeff: yeah

Shannon: yeah. But if they thought that you got it from having sex, do you think they would be different to you?  
Jeff: they'll be different  
Shannon: it would...how come?  
Jeff: because they can say, 'you're the one who get it'  
Shannon: mhm  
Jeff: yeah  
Shannon: they would blame you  
Jeff: yeah, they would blame me, but by now they don't blame me because I'm not the one who got it  
(Jeff, 11)

This conversation with Jeff, however, is contrary to the one with John, cited previously, where he said people are kind because nobody wants HIV/AIDS, nobody asks for it. Though on the other hand yet again, Stella, who does experience some stigmatization, said that some of her classmates say about her, "she pretends that she got through sharing sharp objects yet maybe its through men that she got HIV" (Stella, 7). So while it is clear that stigma and discrimination at school has been reduced significantly, it is unclear as to what extent the method of infection plays a role.



Fig 5.7: PIASCY-funded signage at Primary School. (Source: Field photos)

Again, it should be emphasized that the overall message I received from the students was that most of them were not stigmatized at school, and it seems that

HIV/AIDS education in the schools has had a dramatic impact in only about a decade. With the exception of about three students, those that experienced stigma at school found it to be somewhat minor and not the general interaction with peers. This is not to say that those that have been stigmatized have not been effected by the abuse, nor is it in any way undermining the pain that comes with bullying, but it is important to celebrate the positive changes that are happening in the schools in Katakwi, the compassion that this generation is learning to show, and the larger implications as all of this generation of students complete school and become more powerful members of the community with the knowledge that stigmatization of those with HIV/AIDS is not acceptable. However, it should be noted that I interviewed students, and as teacher Asubu John told me, those that are in fact stigmatized are more likely to drop out and lack the will to continue (Asubu John, 2). This is significant because teenagers that are not in school might have a different story to tell about stigmatization. Asubu John and the other teachers, though, did say that in their careers, the reduction in stigma for students with HIV/AIDS has been dramatic, mostly because of PIASCY and sexual health education.

#### 5.4.2 Stigmatization at School

While many of the students explained that stigmatization is not part of their experience, some also told me that they were occasionally verbally abused due to their HIV status. Interestingly, it seems like this is related to when the students with HIV are excelling or breaking out of the victim role. The compassion piece has been implemented within this generation of students, but perhaps that keeps those with HIV in a less than empowered role. When these students reach above their accepted role, verbal abuse occurs. For example, Gideon talks about how he will be mocked for doing well in class, and will use his HIV status as a way to bring him down, “they will abuse me because they see I’m active in class...there are some of them are, are jealous” (Gideon, 8). It was interesting that Gideon was able to see the mocking as jealousy, and in no way did it shake his confidence. Justine also had a similar experience, though she certainly struggles to stay happy when it occurs. As mentioned previously, Justine’s teachers will put her down if she is active in class, or

excelling beyond a male pupil. An LWF colleague helped explain, “sometimes in class the teacher can tell her, ‘hey for you, you have HIV/AIDS, you’re proud’ because now...maybe if you are a girl...” She says that many students, “they abuse her, they hate her...[so] she just keeps quiet” (Justine, 4). Stella has also dealt with some mocking because of her HIV status, though she seems to have found a way to not let it bother her. Through translation she told me,

“there are boys who like playing, so as they play, of course its rough play, and when she tries also to revenge...the boys who want to play tell her, ‘don’t, don’t give me your HIV, don’t touch me and give me your HIV’ and she used to cry but now at least she’s fine. When her new status she used to cry when they tell her that.” (Stella, 6)

In this case it seems like Stella is not so stigmatized that she is not included in school activities; in fact, she is the class prefect and in a leadership role. The students that abuse her are few, but she is scared to report them. She worries because “some of those boys are big and when they learn she has reported they might again fight her” (Stella, 7). Apio also tells me that the other students “abuse her because she’s positive,” (Apio, 5) and when I asked her if the teachers stop them she says, “...sometimes the teachers get rid of them but sometimes the teachers relax” (Apio, 6). More upsetting is the fact that when she misses school to obtain her ARVs, the teachers beat her upon return (Apio, 7). It is unclear, however, from both Justine and Stella’s stories, and to some extent Apio’s story, as to whether it is their HIV statuses that are the root of the abuse, or rather HIV is just used as the weapon, but the real issue is related to gender. In fact, Isaiah was the only boy to tell me that he has dealt with any mocking because of his HIV status, and in his case, Isaiah says that only a few students will bully him,

Shannon: do the other students know (about your HIV status)?

Isaiah: yes

Shannon: all of them? And do they point fingers at you and say, ‘this one has HIV’?

Isaiah: no

Shannon: they are good to you?

Isaiah: yes

Shannon: all of them? There is not even one person that is mean?

Isaiah: only some

Shannon: and how do you react? You report them? Tell the teachers?

Isaiah: yes  
Shannon: and what happens?  
Isaiah: they teacher will beat them  
(Isaiah, 5)

For Isaiah, he does not seem to be upset by the mocking, and obviously feels supported and comfortable enough to seek out the teachers as a resource.

The link between gender and stigma is an interesting one, and while this research does not have a broad enough group of interviewees to really explore the issue, there are some significant findings. Micah, HIV focal person in Ngariam, spoke about the issues with gender, opening up about being positive, and stigma. He said, “more girls are open than boys, that one is reality. Because we are finding, girls just come by themselves, for testing. And they can even tell you the last day they had sex...the boys are not so good, boys go and hide...even the boy who goes fears to get his results, yeah” (Micah, 15). When asked why he thought the difference in gender existed as such, he replied, “...the difference is because boys...are not skilled to be open. That’s the first thing, and two, these boys are not put...to believe in themselves, are not told that. And three...they are loved, boys are loved generally, because he’s going to be heir, he’s going to be a very big man in the home” (Micah, 16) meaning that for a girl to have HIV it is not seen as such a loss as compared to if it was the first born son. While Micah seemed to have recognized a gender discrepancy, my discussions with students found the opposite of his thoughts. The boys that were open about their status faced less discrimination and were more confident and forthcoming in their discussions. They chatted longer and had more self-assurance to address the topic. The girls, on the other hand, were slower to open up, and their stories showed more stigmatization and abuse. I agree with Micah that the boys are “more loved”, but I think this actually allows them to be freer with their status, and more self-reliant in the face of verbal abuse.

Ultimately, while the issues of gender and discrimination lead to many more questions, what was unmistakable was the suffering because of self-stigmatization. The students that I spoke with that had told only a select few about their HIV status were struggling the most. The fear of others finding out and the anticipated ridicule has to be the most damaging part of this disease for them. Similar to the research by

Thupayagale-Tshweneagae, some young people choose to remain quiet because they believe they are protecting themselves from the community (Thupayagale-Tshweneagae 2010, 262). However, Michael's HIV positive father, Arthur, said it best, "that stage of hiding kills a lot. You stigmatize yourself...denial life kills a lot of people and it is a terrible stage," (Arthur, 2). This was evident in the students I spoke with that were in this stage of hiding. Gift, 17, has yet to tell most of his family, let alone his peers, that he has HIV. Only his brother and father know his status. He has also had to drop out of school because his family could not manage the fees for this term. As mentioned previously, his depression caused him to start using alcohol. In his mind, he feels that his sisters and his peers will not support him when they learn of his status. I asked him why he is afraid to tell people. He said, "...mmm this country of ours has a lot of stigmatization, so it's really hard to tell" (Gift, 3). I asked him why he felt this way, what gave him this impression, and he mentioned that the teachers follow the PIASCY curriculum but that they do not seem sincere, "you can tell by the tone of voice" (Gift, 4). Given the other students' experiences, Gift might be more supported than he imagines, and he is still working through his fears. This is impacting how he sees the world around him, especially since his father and brother that he has told are kind and supportive of him.

Ruth is also not open about her status, and both her father and her teachers have advised her to remain private about it. They have warned her that people will treat her poorly if she opens up, "the teachers tell me, 'don't go tell other children, they can disturb you'" (Ruth, 6). In some ways, she struggles with this because she has to lie to her friends about why she goes to the health clinic every month (Ruth, 13) and she says that the girls often share razor blades with each other and she has to find a way to not share with the other girls (Ruth, 11). However, she feels this is a better choice than being open because she is worried about what people would say, she fears, "they can laugh at you, 'Eh, this one's finished, ah, what's the use of that one, its finished!'" (Ruth, 11) and even more so she fears that no one will want her, "they don't admire me...with HIV" (Ruth, 6). Betty is also fearful of disclosing her HIV status to people other than her family. She feels that, "when I tell them, like when I tell one, she will go and spread the thing over the whole students, then they

begin laughing at me” (Betty, 4). This particular fear comes from the story of one of her classmates that transferred schools, and Betty believes this is because her peers belittled the student due to her HIV status when she made a mistake in class (Betty, 4). However, Betty does admit that she has no real reason to think that she would be abused for having HIV, because she teaches other students about it through a school club she belongs to:

Shannon: um, and do you find that students, when you are teaching them about HIV and AIDS, they have a good attitude?

Betty: yeah, they have it

Shannon: yeah

Betty: hmm

Shannon: so, there’s nothing that makes you think they would be finger pointing

Betty: no

Shannon: it’s just your own fear?

Betty: hmm (in the affirmative)

(Betty, 9)

Some of the other students that are open about their HIV status do have fears that it will be different for them as they enter Secondary school. Akello is in Primary 6 and is open at her current school, but she does not think she will tell anyone when she moves to Secondary school because, “...senior level is different when, uh, when they get to know that you’re sick, they disturb you, when you tell they’ll disturb you. At least people are told that.” (Akello, 6). This fear is even greater for Akello because her uncle wants her to go to a Secondary school in the neighbouring district, which is inhabited by a different tribe. My colleague explained Akello’s fears, “ok her, why she doesn’t want to go to Karamoja is, eh, that she can’t manage the lifestyle in Karamoja, and also the other is, uh, because it is boarding is sharing all the things exposed, is when she is swallowing her drugs they’re seeing and they’ll begin stigmatizing her.” (Akello, 9). The perception of Secondary school as less understanding about HIV/AIDS seems to be a common conception. Anne’s father is trying to find medicine to help Anne’s rash that results from her ARVs, so that her classmates in Secondary school will not find out she is HIV positive, “but you know, this children, others, they can disturb her. Supposing she joins Secondary school, eh, then when they look at, you know, heh, these children are very crazy and they can

try to make her and abuse on the child and it gets her mind disturbed.” (Anne’s father, 13). Anne herself, however, feels comfortable and intends to let people in Secondary school, next year, know that she has HIV,

Shannon: are you fearing going to Secondary school?

Anne: yes

Shannon: you are? How come?

Anne: cause I want to learn

Shannon: hmm, are you going to tell your teachers there that you have HIV?

Anne: yes

Shannon: yeah, are you scared...

Anne: no

Shannon: ...of telling them?

Anne: no

Shannon: no. Do you think the students will also be kind?

A: yes

(Anne, 9)

For those that are in Secondary school and have not struggled with stigmatization, I asked them why they think other students might be afraid to be open about their own HIV positive statuses. John said,

John: you know, some of them, they are scared maybe if other students know that they might be maybe, you know, maybe laughing at them, what and what, yes.

Shannon: but you don’t think that would happen?

John: yes

Shannon: so it’s just in their head?

John: yes, they assume of it, yes

(John, 11)

Gideon has a different theory as to why other students, like the ones he sees at the health unit but that are not open at school, may keep quiet. “It’s like they want to, to make love with boys what, because most of them are girls, yeah, they want to make love and even to transfer the disease...some of them, yeah, some of them say that they want to die with more, more people” (Gideon, 8).

From the students’ fears, it often seems to be based on the advice they receive from other adults in their lives, and it would make sense that the older generation may still have the fears and experiences with discrimination that was rampant before the roll out of ART. If these are the ones that advise the students, it

is easy to see why they would adopt the assumptions of potential abuse from peers. Michael's father, Arthur, discussed with me that many adults are hiding their own status and so also deny their children drugs, to protect the family from stigma. Anne's father also talked about this inherited denial, "I have talked of stigma, eh. Some parents, eh? They take their children but they don't tell the other administrators what is surrounding a child's life. You keep quiet and you may think that you're helping that child a lot. Nothing." (Anne's father, 16). Asio Judith has also had to deal with parents' fears of stigma for their children. One time a student injured himself and when she came to help him he told her not to touch his blood because he had HIV. She called the mother of that child to confirm this, and the mother said he did not have HIV. Eventually, the school found out that the child was indeed HIV positive, and the mother confessed that she had lied. "She told us the reason why she didn't tell us, that we would reject the child from school, eh, but we told her we can't reject that child." (Asio Judith, 11). As Dr. Moroto told me early on in my research, he feels it is mostly the adults that have the fear of HIV, and they are the ones that see it as a sin and make it damaging. He also sees that the youth are the ones that are changing this perception, and they can actually be an excellent entry point for knowledge and understanding for the rest of a family and community. (Dr. Moroto, 2).

The panic for the students that have not opened up about their HIV status is valid and real. Coming to terms with their disease is a process, and can be made easier or more difficult by those around them. The ones that have been able to be open and free about their statuses generally have good experiences. For all but three of them, verbal abuse is the exception, not the norm. This finding was actually one of the most surprising and inspiring parts of my research. In such a short time, the shift in attitude towards those with HIV/AIDS is dramatic, and while more progress is still to be made, one generation has reduced the social pain of this disease. It should be clarified again, that this section is the students' experiences with stigma at school, and that their stories of stigmatization may differ in other environments like their homes and villages, as will be apparent in the next section.

## 5.5 Home or School?

One of the goals of my research was to show the diversity of stories for students living with HIV/AIDS, to make apparent that there is not a single story of a teen coping with this chronic disease. However, what is clear is the universal desire of these adolescents to be at school. Regardless of what their lives are like at home, every single student expressed their preference of being at school rather than at home. This is the one piece of the story that was unanimous amongst all of the students interviewed, and it is significant because even those that deal with abuse, bullying, lack of food, and unhygienic conditions at school prefer to be there. Those that also have a supportive family and comfortable home life also prefer to be at school.

### 5.5.1 Why is School Good?

When asked why school feels better than home, the answers varied, but one sentiment that came up a number of times was the feeling of being free at school. Gideon says, “when I’m at school, I do read my books very well, I’m not, I feel free being at school, but if I’m home, there’s too much work. At home...there’s no time, you can’t read your books, yeah.” (Gideon, 12). Ruth also used this same phrasing, “...at school I am free. Mmm...I’m happy...but from home, huh, somebody can come to abuse you, that’s why.” (Ruth, 8). Micah, HIV focal person, elaborated on why school provides a feeling of freedom for these students,

“...we encourage them to go to school, so that they...cannot be stressed at home...that one helps to not be segregated or isolated...they should not be stressed, it encourage them to take drugs and they feel, ‘I’m the same with this other one who is negative.’” (Micah, 2).

This concept of being stressed at home prompted me to ask Micah and the students what the stressors are at home that they avoid when they are at school. For Stella, school allows her to escape the men in her village that harass her for sex or marriage. “It’s better being at school than home. Home, the disturbances is because of men, most of them soldiers...so there is a lot of disturbance for them girls of the village.” (Stella, 7). She also said that these men are there on the way to school,

which is worrisome, but once she arrives at school she is safe, and that if there are boys at school that harass her, she can at least tell the teacher (Stella, 6). Moreover, Stella says that some of the boys in the village have dropped out of school, perhaps because they have HIV. "Some of the boys are sick, so they want to spread. They want to give to all the girls in the village." (Stella, 5). Akello also worries about the soldiers in her village and en route to school, and so prefers being at school and would actually prefer boarding school even more because then she does not have to do the dangerous commute. She recalled a story when, "on time is when the soldier came on the way to wait for [me], but [I] was moving with other people, other friends, so it became hard for him..." (Akello, 7). An LWF colleague further explained that for Akello,

"boarding is better cause during the day as she moves is when the other ones can disturb her most because they can access her, as you move they abuse you and they begin disturbing her...boarding again would be better."  
(Akello, 9).

Justine also feels that school is better than home because at home, "there are very many men who are interested, but [I] may get a man who will re-infect [me]" (Justine, 14) and Ruth says the men in her village, "they are asking me...at home" (Ruth, 9) but that she wants to finish school before she thinks about having a husband (Ruth, 10).

School also provides the same function of safety for the boys. Gideon had a girlfriend in his village and they had engaged in sexual intercourse once, but without a condom. He said that being in school makes it easier to stay abstinent. "It will not be difficult to abstain because I stand an advantage that I'm at school, there's no way I can tell, attempt to such things like playing sex...the school will keep me busy." (Gideon, 9). Michael's father, Arthur, is adamant that his son will not have a romantic relationship and that being in school supports this. He wants Michael to become a priest, although Michael told me he wants to be a lawyer. I asked him how he would react if Michael came home and told Arthur that he had a girlfriend. Arthur said he would show him those that have dropped out of school because they chose relationships instead. He also said that in the village there are "those that can

spoil [ruin] him”, and he wants his son to stay focused on education and not romance. (Arthur, 2).



Fig 5.8: “Education is Better Than Marriage” Primary School Sign (Source: Field photo)

Staying busy and surrounded by positive influences are also reasons students cite school as a more comfortable place than home. This busyness is essential for keeping their minds off their HIV status, which is part of living positively. For Gift, since he has had to drop out of school, he has struggled to with depressed moods and to keep himself occupied. He simply said that he misses everything about school, “my friends, my studies” (Gift, 7) and it, “kept my mind busy” (Gift, 8). David prefers school, even though home is fine, “because it...give to you to forget those bad times you have. Gives you advice, you can take a lot of time when you are resting, you can make your mind be easy...sometime you can play with your friends, you can forget all your problems, yes” (David, 12). In contrast to school, at home David says, “at home you can sit...you can’t sit with friends...at home you can miss too much friends,” (David, 12). Friends and peer support are also part of keeping their minds pre-occupied. Jeff articulates, “...because when I am at school, my friends are there, we play with them, they share with you ideas, they also give me ideas, good advices

you cannot get me, get me to problems,” (Jeff, 4). Akello, through an LWF colleague, discusses that the social aspect of school is important to her, “school is better because she has lots of friends who counsel her, whom she moves with, rather than home. Home’s far away, so she has not much attachment to it. It’s in the village. She has to go back, do work, there is no time to socialize,” (Akello, 4). Dr. Moroto supports this positive social interaction at school and also talks about the generational differences when it comes to HIV/AIDS. He asserts that school is a good place for the students, particularly regarding the support the students get at school in comparison to at home. He said that peer-to-peer interactions tend to be supportive, but that the youth-adult interaction can be a problem, “home is not that supportive.” (Dr. Moroto, 2). Most of the students see their interactions at school as enjoyable, as Jeff says, “schools teaches you good manners, even teaches you to be kindly to people, yeah” (Jeff, 17).

Given that these children see school as a supportive and positive place, it could be assumed that home is therefore negative. However, many of the students did say that their home life is fine; there is nothing particularly wrong with it and they love their families. Regardless, it is at school that they feel they can create a better future for themselves. The students’ dreams ranged from becoming a nurse to an engineer, a lawyer, teacher, bank manager and even a candy confectioner, astronaut or archaeologist. Even without these lofty dreams, for Michael, he likes school better than home because he worries that when his parents die (they also have HIV), there will be no hope for him unless he can concentrate on his schooling (Michael, 15). Gift continues to hope that he will be able to return to school, “well, with God’s help, possibly I will be able to go back to school, hopefully complete my studies, yeah, and then maybe I can think of a better future” (Gift, 9). Justine wants to be a nurse one day and feels that school will be the way to facilitate this (Justine, 7). Apio has yet to decide on her career path, but an LWF colleague told me, “what she knows is that when she is at school she’s going to read and she will get a job, so that’s what makes her be at school, and she hopes for a better future.” (Apio, 12). Despite Levi’s pension for fighting with the other boys, he also chooses school as a better place simply because, “I want to get a[n] education” (Levi, 11).

### 5.5.2 Home Can Be Difficult

It is important to reiterate that not all of the students have a home life that they do not enjoy. In fact, many of the students are able to have more meals when they are at home than they can access at school. However, home can still be a difficult place for many reasons, and this contributes to the preference of all of the students to being at school. Micah, who interacts with both schools and the communities in general, said that home is actually the hardest place for the teenagers. He said that the surrounding community, despite those that are exploitative, can be supportive and will keep an eye out for children that have HIV or that are sick, especially when the parents are neglectful,

“At least the community has got concern...I love it. Because they all stop (and tell me), ‘in my village somebody’s hiding, I’ve noticed, I haven’t seen this girl for two weeks and I am told she is inside the house and I know I don’t want to go there so you try and go there and advise, because (of) the young one’ so they tell you...so the community’s concerned.”(Micah, 13).

Micah did relate to me that the community treats those differently that acquired HIV/AIDS through means other than mother to child transmission. He spoke of a boy in one village that left and came back with HIV, and the people in the community stigmatized him. “People don’t introduce him, don’t tend to be with him, they say, ‘you went red for HIV instead of going to school’ so that one...he’s not all that in the community...so he’s ever alone” (Micah, 14).

In general, stigmatization appears to be worse in the villages and at home than in the schools. Levi now lives with his uncle because both of his parents and one brother died from HIV/AIDS. He told me that when his uncle and neighbours quarrel about cattle, his neighbours verbally abuse the uncle. “The day my uncle calls on the neighbours, they said, ‘even you are keeping a child who is HIV positive!’” (Levi, 4). Arthur also related a story of stigmatization in the villages against his son. He told me that one time, Michael went with his uncle to another village, and that night one of the cousins refused to sleep with Michael because of his HIV. Michael was forced to sleep elsewhere without a mosquito net and ended up getting malaria. (Arthur, 2). Stella has also experienced stigmatization in the village

that is much greater than what she experiences at school. She recalls a story, through an LWF colleague, of when her dad sent her at night to get cigarettes

“one time when the father sent her in the night to go buy cigarettes in the centre, when she came...on a bicycle, she found men at on the way who were trying to stop her, and she was resisting and they grabbed the bicycle, she jumped off of it and went home. So they were abusing her, ‘you who has HIV, we are telling you to stop and negotiate’ so she went home...she says there are a lot of disturbance at home” (Stella, 8).

At home in the villages there are a variety of people with little education, particularly about HIV/AIDS, because it is a relatively recent initiative in schools. Because of this, there is bound to be more discrimination by the surrounding communities. However, it is important to note that by all accounts, overall stigmatization of those with HIV/AIDS has reduced.

According to Micah, the community as a whole can be both supportive and cruel, but the family itself can be the place of the most hardship faced by these students. The stories from some of the students themselves as to why school is better than home substantiate this claim. Micah’s experiences have shown him that the students with HIV/AIDS that struggle the most at home are those that are staying with guardians and not biological parents. He says that the students become upset because, “the guardian has to abuse you, the guardian has to talk ill about you, remind you of parents...”(Micah, 2). Furthermore, he says that, “they are segregated at the time of sleeping, even the time of eating sometimes, yeah” (Micah, 7). Micah also finds that he sometimes have to chase students down to find out why they have missed their CD4 count and ARV refill at the health unit,

“I see you two, three days not coming, I have to come to you home, why? I go to school or I come to home, I say, ‘why haven’t you come?’ Then he or she tells me the problem, ‘they never brought me because there was no bicycle’, ‘my uncle went for grazing (the cattle)’, ‘my uncle went to, was drinking.’ It gives me that so I...attack the uncle, indirectly, because if I directly, he will also come back and punch the...kid, which is not good.” (Micah, 10).

Ruth now lives with her father, stepbrother, and stepmother, who she refers to as “mother.” She and her father have decided it is best not to tell the stepmother that Ruth has HIV. Without knowing her HIV status, Ruth says that her stepmother

already abuses her and makes her do the work around the household, “cooking and even washing clothes of my father, but she there, she sit” and refers to her as having “bad manners” (Ruth, 2). Both her father and Ruth know that if the stepmother and stepbrother were to find out that Ruth was sick, “they can come to me and if I get a problem they can abuse me, ‘this one’s living with HIV, we don’t want you’...they say, ‘this one is...finished’” (Ruth, 9). Betty also has a similar struggle at home with her stepmother. When I asked what her stepmother says to her that is painful, Betty replied, “she talked of wasting money, wasting money on someone who is affected...that I should stop schooling, they are just wasting money” (Betty, 7) This argument caused Betty to run away and stay with her sister for a few months before returning home. Akello lives with her grandmother and her story was translated for me,

“she stays with the grandie, and the grandie has been concubined by some man. So they like drinking so much, ah she doesn’t provide for her clothes, she has to keep telling her other uncles, to provide for her clothes. Then even up to now her exam fee is not paid, she told the uncle...so he has not yet sent the money. And she has to go back to cook and when she comes back from school, they grandmother just goes to drink in the centre, she comes back home late, drunk...” (Akello, 3).

On the other hand, Levi lost his parents to HIV/AIDS and now stays with his uncle and cousins, and he says that his uncle treats him just like his other children, but that he prefers school because at home, “there are lots of job to do...fetching water, some days I am the one who cooks the food” (Levi, 11).

It is not just the guardians that can make home life difficult and school preferable; some of the parents themselves can be neglectful. Micah explains that for many parents in this region their children are not their priority, “because the first priority is other things than the kid...grazing, is the first of all, then after grazing they also go for farm work, garden work. After garden work they also have small small business, and they go and drink...” (Micah, 10). He summarizes that, “they are not given that care. That parental or love care, really, that the patient...should feel” (Micah, 6). Apio lives with her mother, and while affection is given, home is difficult because she, “doesn’t have clean, clean place to sleep, doesn’t have a treated

mosquito net...does not have time to boil [my] drinking water” (Apio, 8). Justine, however, seems to lack the care to which Micah was referring, an LWF colleague explained,

“she says she’s almost finished a month where she has a headache, and when she has head pain she cannot even look at the blackboard, but the mother does not understand. That sometimes when she has pain, she wants to lie, but now when she goes to sleep the mother begins shouting like she does not want to do work...and of course she drinks, she comes back drunk, and she begins quarreling her” (Justine, 6).

For many children in this region, whether or not the love from the parents is present, the economic situation that the communities are in does not leave time for things other than getting through each day. The children are expected to come home from school and contribute to the running of the household. Stella says that at, “home you are not allowed to read, every time, if you read, if you are to get books, you are told, ‘you are from school, what reading do you need? Put books aside and begin...work’” (Stella, 7-8). Jeff and his younger brother live with their grandmother, and life at home is also hard work. He tells me how after his parents died,

“they left us with my grandmother while my grandmother was still having some energy, to help us cook, because we are also young, can’t cook. Until P5, P6, P7, and entered senior and now my grandmother has gone blind...we are now there just alone now, protecting ourselves, so when we when we tried to maybe have something, like to construct a house, like me I am weak, the other one is young, we cannot manage alone.” (Jeff, 19).

For the reason of intense chores alone, students prefer school because, “there, life is easy” (Levi, 14). This must also play a factor into why the students prefer boarding school to day school.

### 5.5.3 School Fees

For so many students in the Katakwi region, regardless of their health status, managing to find money for school fees is daunting. This is particularly true for those that I interviewed that are orphaned, or those whose guardians feel that paying school fees for someone with HIV/AIDS is a waste of money, such as Betty’s stepmother. Even though Uganda has UPE and USE, there are still costs for

uniforms, supplies, exam fees, development fees and the like. This is not an issue just for students with HIV/AIDS, but because the students themselves mentioned the importance of it for them, it should be addressed briefly.

As previously mentioned, Betty's stepmother feels like paying Betty's school fees is a waste, and while her siblings are all in boarding school, she remains in day school because after she was raped by her uncle, she dropped out of school for a time. Because of this, Betty told me that her dad said, "he cannot waste his money on me, so he told me that, 'if you want school, you can be going for day school, but if you don't want, you stay home'" (Betty, 8). While Betty has chosen to continue in day school, she struggles to stay focused because she is unsure of if her fees will be paid, "like right now, there are somethings I have not completed, like fees...so that thing keeps on disturbing my mind, like today they just went to chase me home because of some balances, so that thing keeps on disturbing my mind, I don't concentrate on books very well." (Betty, 10).

Jeff has been supported in his education by an organization that sponsors orphans, but they only pay for schooling up to Senior 4 and, "the organization is paying just school fees so when the books get finished, again, I want to look for the books, again, to look for the sugar...which I cannot manage...and that discourages my education." (Jeff, 10). Many of the other children have similar sentiments, such as Gideon, who says, "I feel very proud to be at school cause when it's class hours, I'm very active in class, but now, one thing which is discouraging me is the, well, the paying of my school fees. Is the one which is discouraging me" (Gideon, 11).

Students with HIV/AIDS are particularly vulnerable to dropping out of school because they cannot afford the fees, and because many of them are orphaned, or will become orphaned, money from families have to go to medical costs when they fall sick, the stigmatization from neighbours that families can incur when supporting children with HIV/AIDS. Additionally, the sentiment that there is no point to support a child's education when they are sick also acts as a deterrent. Stella has a plan that if her family cannot afford to send her to Secondary School, and that is "she will come back and repeat P7, cause there is not much money which is paid in primary...she will keep repeating if she can't cross over" (Stella, 8). This seems to be

a clever plan, but the desire to stay in school also puts her, and others, in a vulnerable position. I asked her about the soldiers on the way to school that harass her for sex. I asked her what she would do if a soldier offered to pay for her school fees in return for sex. She told me she would not, because she may give him the HIV virus, or he might re-infect her. I asked her would she do it if the man promised to use condoms. To my despair, she said she would do it. (Stella, 9).

It is not the goal of this section to lay blame on the families for their struggles regarding their children, nor is it the goal to argue that school is indeed the best place for them. Both places have many challenges and risks for the students, but also many positives. It is important to emphasize that despite the problems in their education system, every student interviewed prefers school to home, and there are a multitude of reasons for this, not always because home is a “bad place”.

## 5.6 Preventing the Spread of HIV/AIDS

I spent July 5<sup>th</sup>, 2012 at a local High School interviewing the Senior Man teacher, watching the PIASCY club practicing their dance performance about being faithful to a partner, talking with the school nurse, and watching the students gather to show off their knowledge about HIV/AIDS. The Senior Man teacher assembled the students in a large room and would ask a PIASCY-related question out loud and then toss a pen. Whoever caught the pen had to answer the question. I was impressed with the knowledge that each student had, as there was no study time or previous warning that this was going to occur. Despite this, I was struck at the rote memorization of most of the answers given. This is not to say that the information is not ingrained deeper into these adolescents, but it did prompt me to reflect on the questions I wanted to ask the students I interviewed, and to encourage them further with their responses regarding how HIV is spread, how to live positively, and how to show compassion to those living with HIV/AIDS. I was curious as to how much they genuinely apply their knowledge about HIV/AIDS, and what their plans are for the future, particularly in terms of sexual relationships and preventing the spread of the

virus to others. If abstinence is the main message they are receiving, how does this realistically apply to their future?

Every student was able to list for me how the HIV virus was spread, and their answers were almost word for word the same as each other: through unprotected sex, sharing sharp objects, and mother to child transmission through breastfeeding. Only Michael forgot the last source of infection, but then we laughed because that was how he himself acquired HIV (Michael, 22). Given that he is one of the youngest students interviewed, I wanted to see how much his particular knowledge was rote memorization in comparison to critical understanding, I asked him specifics,

Shannon: how is HIV spread?  
Michael: through unprotected sex  
Shannon: ah that's it? Just unprotected sex?  
Michael: sharing sharp objects  
Shannon: sharp objects, like what? A pen?  
Michael: no...razor blade  
Shannon: razor blades, ah, anything else?  
Michael: ...  
Shannon: what about a needle?  
Michael: needle  
Shannon: yeah, should we share needles?  
Michael: no  
(Michael, 21)

I also asked him what are some of the signs of HIV and he told me a red mouth. I asked him, then, if I should assume that someone is HIV positive if they have a red mouth, and he told me that you can never know until the doctor checks your blood (Michael, 22). Later in the interview, I asked him how, as the eldest brother, he could protect his HIV negative siblings from becoming infected, and how he could support his young sister with her HIV positive status. Through an LWF co-worker, his role is as follows,

“he has been supportive for the other one, the young sister who's also living with HIV by sometimes parents are not at home so he's the one who helps to give the drugs, at the right time. And uh, he has also tried to...sensitize these young ones to be careful as they play with him... to be cautious of the wounds, and any cut and also to avoid any sharp things they pick at home, because they have tried at least to keep their instruments separate, mostly not sharing the razor blade, each of them has separate razor blade and kept well so that the other ones don't access it...” (Michael, 25).

As the student's age increased, their knowledge and authentic understanding tended to advance. Ruth, who is 16, was able to clarify to me the issue of re-infection between two HIV positive people. "Even if you get a husband, the husband has HIV/AIDS, he don't know what type of HIV is in that...person, eh? Even me, I don't know what type of HIV I have...If you have that lazy HIV and that one has a strong, and you play [sex] with this one, that one you can...add" (Ruth, 10). Justine is also well aware of the risk of secondary infection, and that is part of the reason she has avoided the men in her village that are interested in her (Justine, 14). At 18 years old, Gideon is one of the oldest students interviewed, and accordingly, he did seem to possess the most advanced knowledge on the subject of preventing infection in the future. He discussed with me the options surrounding safe sex, "I keep myself abstaining from sex, for a long time and if, by the time I wanted to...start, alright to play sex like, that I go for...condoms from the hospital. They give me, they teach me how to, how to use and till right now I've already know cause we learn at school there." (Gideon, 5). Gideon also told me that even with just one sexual encounter the virus can be spread, "But it is very easy to get it. The moment you push your penis inside...even one like this is enough, you have got it. That's why nowadays they advice people to, to get circumcised...to remove the foreskin which can carry that, which can get that fluid easily." (Gideon, 9). What was significant about my conversation with Gideon was that beyond his knowledge about HIV/AIDS, he was comfortable to talk to me about sex, sexual organs, and condoms. It was telling of this generation that has grown up talking about things that were taboo for the previous generation.

In general, the students had a clear understanding of how the virus is spread and how to protect themselves and others from infection; their knowledge went beyond a simple list. However, there is some concern about their knowledge, mostly based on the fact that abstinence is the key message they receive. Most of them had not thought about how they will manage to have a family in the future and be able to keep that family HIV negative. This differs from Petersen et al.'s findings, where their subjects were found to have considered their future romantic

relationships (Petersen et al. 2010, 973). Anne, 13, answered my question about whether she would like to be married one day with, "I don't know" (Anne, 6) and when I asked her if she would like babies when she is an adult, she paused and said nothing. (Anne, 6). Isaiah does want to get married one day but plans to never tell his future wife that he has HIV, and he will keep her protected by using condoms. I asked him how will he have children with this future wife and he just nervously laughed and then could not answer. (Isaiah, 10). John and some of the other boys also plan on having a wife one day. I asked John how he would protect her from HIV. He said, "I know she'll be protected...cause I had some instructions from the people at TASO, thing that maybe protect your wife, there is a way they can manage, yeah so that your wife won't...get what? HIV. And even the child won't get HIV. Yes." (John, 12). Gift also wants a family, and when I asked him if that is a problem because he has HIV, he said, "eh no...it's possible." (Gift, 10). However, neither boy told me exactly how this is possible, just that it indeed is.

Some of the students had plans to remain abstinent forever. This plan is in line with the plans of some of the parents I spoke with as well. Anne's father has no plans for his daughter to get married. "Ah she cannot get married...She should stay with me, I'm the father. There's no need to say that she gets married, no, she should stay with me..." (Anne's father, 19). Michael's father has similar plans for his son, as he wants Michael to stay abstinent and become a priest (Arthur, 2). Michael himself, despite wanting to be a lawyer, says that he will stay abstinent and never get married because he does not even like girls (Michael, 16). Ruth is afraid to ever have a husband because of the issue of re-infection, but she also has been told that not having sex will keep her healthy, "they say...not to do bad things like sexing, you can, you can have health" (Ruth, 4). Jeff currently has a girlfriend but they are both choosing to not have sex right now and he indicated that he wants to wait until he is married to have sex (Jeff, 14).

The messages that the students receive at school are to remain abstinent for as long as possible, but if they do engage in sex to use a condom. One of the issues with this, however, is that schools do not provide condoms (Ocom Matthew, 5) and as Micah tells me, the health clinics also run out. "We have out of stock of them, and

even condoms, we have out of stock,” (Micah, 8). When I drove throughout the district, certain households were designated by the Red Cross as a place to obtain condoms, but it seemed like if abstinence before marriage is the highly valued behaviour, students would not freely go to their neighbours to seek out condoms.



Fig 5.9: Amuria Parish: “Free Condoms Available Here”. (Source: Field photo)

Gideon is now in the situation where he is obligated to inform his one sexual partner that he has HIV and that she needs to be tested as well (Gideon, 9). Because abstinence is the message at school, there has been no education on how to address these issues with sexual partners, no skills taught in terms of communication around sex. As Monasch and Mahy noted, youth often lack the skills to negotiate abstinence and may not want to talk to partners about sex because of issues surrounding gender roles, social norms, and individual risk (Monasch & Mahy 2006, 31-32). Gideon said, “I told her, one day when I went for school fees, that ‘you go and test’ but I didn’t tell her that I’m, I’m suffering from the disease....cause, eh, she might be surprised, like, ah, she might even faint...it is very difficult” (Gideon, 9). Stella is also in a situation surrounding sexual behaviour that is hard to navigate through, and in which she does not have the skills to address. Her education at school does not teach her how to deal with the soldiers that harass her for sex on the way to school. When they bother her, she tells them, “I’m finished, just leave me alone” or “I’m a gone case, try elsewhere” (Stella, 5). When they persist, she has tried

to talk to the local council chairperson, but she says it was done without result and so, “she has to be keen, she has to keep running when she reaches some spots” (Stella, 5).

Notwithstanding the real and serious problems students face in terms of preventing the spread of HIV/AIDS, this generation is largely well educated and proactive with the disease. Current research shows that it is not the teenagers that are at the highest risk of contracting or spreading HIV, it is actually highest among married couples (Uganda AIDS Indicator Survey 2011). I asked Micah why he thinks the younger generation is more successful in the management of HIV/AIDS. He referred to the youth being more faithful to their partners because,

“the message the youth are perceiving it and seeing the parents gone...the guardians gone, HIV, they are seeing it, they’re witnessing it...this very youth are taking care of their parents who are sick...so for them they stick on ‘my parents, I don’t want to be like my parent, I don’t want to die like my parent.’ The parent dies in pain and suffering, really...so whenever you go, or she goes off for sex, at least she will have some flashbacks of ‘ah my father died in pain’ and maybe use a condom.” (Micah, 9).

He also emphasizes the importance for this generation to receive “continuous teaching” as opposed to just one session or one lesson, so that it will, “stick in their mind and really we have got their behaviour change.” (Micah, 6).



Fig 5.10: High School Youth Corner Poster 1. (Source: Field photos)

All of the students have concrete plans for their future. They do not view their disease as a death sentence, and they are keen to move ahead with their lives and even to educate others. Naturally, they experience times of fear and doubt, but they all seem to feel the responsibility of their generation to stop the spread of this disease. Many of the students have taken on leadership roles within their schools in the battle against HIV/AIDS. For example, Betty, as part of a club, talks with other students about HIV/AIDS. "I always encourage them to abstain from sex, like if they have, like, like some of them who have boyfriends, they should use condoms" (Betty, 9). David loves his membership in the journalism club. "Sometime we give advice when we are writing newspapers, sometimes we put those cartoons...to show the sick they can go to any health centre to get medicines, and some can get advice from their elder brothers and sisters" (David, 11). This younger generation of students is also keen to take the steps necessary to reduce the spread of HIV/AIDS. Dr. Moroto told me that groups of teen boys come to the hospital daily to be circumcised, so much so that he often cannot keep up with the demand. They have found that circumcision can reduce the chance of transmission by 60%, and this young, educated generation has fully embraced this practice, (Dr. Moroto, 3).

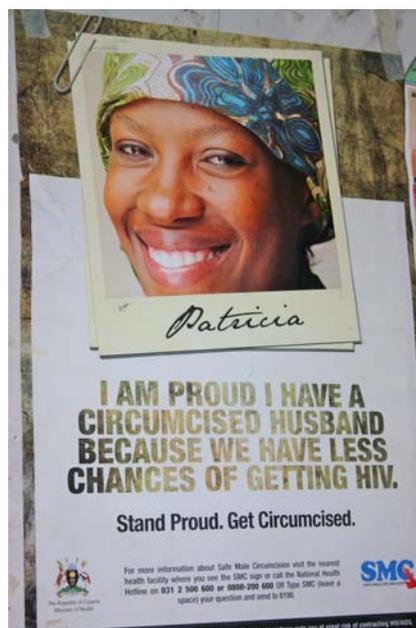


Fig 5.11: High School Youth Corner Poster 2. (Source: Field photos)

Overall, the clear empowerment of this group of students I spoke with, even among their individual differences, is evident. Education and support around HIV/AIDS has allowed them, and many of their generation, to emerge from shame. Like the teens in Midtbø et al.'s study (2012, 267), they all have a vision for their future that includes careers, loved ones, and the possibility of happiness. As teenagers, they are bound to experience angst, and living with a disease that has no cure weighs on them heavily in moments of sadness. Despite this, they still look forward to the future. Gideon asserts, "I know this disease will not take me." (Gideon, 11). Like those in Midtbø et al.'s study, the students actively accessed and used the resources available to them, they are able to apply their knowledge to their lives, and they have developed strategies to cope with hardships like stigmatization (Midtbø et al. 2012, 268). I think the students' attitude is summed up best with Opio's advice he would give to those that have just learned they have HIV. He tells them not to worry, and that they should "Learn. You shall be in the future...someone that is very powerful" (Opio, 9).

## **6. DISCUSSION**

My research is to make the voices of the students living with HIV/AIDS heard within the context of Katakwi, Uganda. Moreover, the conclusions reached from my work should be a starting point for further study, and the conclusions reached are merely basis upon which more exploration is needed. I cannot stress enough the importance of recognizing that each student has a unique experience living with HIV/AIDS; a different set of needs and varied levels of empowerment. To view them as a homogenous cohort is to rob them of the dignity of the individual experience. There is not a single story of the student with HIV/AIDS in Uganda. Furthermore, the level of empowerment of each student is not static, and will fluctuate over the course of each student's life and in different situations and relationships. Summarizing a blanket set of needs, conclusions, or solutions as to how to empower these students would defeat the purpose of sharing each of their distinct stories.

However, there are a several points that should be mentioned for both clarity and points of reflection and inquiry.

1.) **The Core Importance of Food and Nutrition:** The most evident need that can be drawn from this work is that of food. It was probably the most surprising finding from my analysis, and yet it makes the most sense. No progress can be made; no empowerment can happen if the most basic human needs are not met. We tend to think that these complex and multidimensional issues in development and education need complex and multidimensional solutions, but in overlooking the basic needs of adolescents we actually stifle their ability to thrive. The adults in the lives of these students clearly told me time and again, that what these students need more than anything else is an adequate supply of food. The students often have to choose between staying at home and having enough to eat, or going to school without proper nutrition. This is true for many of the students in Katakwi, but it is that much more crucial for students living with a chronic disease. Their medication is to be taken with food to be effective, and their general health and wellness requires proper nutrition. Further research could explore school feeding programmes targeting those with HIV/AIDS, the effect of proper nutrition and food diversity in the diet of young people with this virus, or even the reduction of stigma for those with HIV if they combat the expectation that those with HIV are weak and emaciated. As seen in the field and as told to me by my colleagues, school feeding programmes, or school gardens, already increase school enrolment of the general student body. Some schools also have feeding programmes specifically for those students that are orphans. While the issue of stigmatization could increase in a feeding programme just for students with HIV, general feeding programmes, while benefitting all students, could significantly help those with this chronic disease.

Simply put, the most significant need of these students is having enough food and a variety of food in their diet. This lack of one of the most essential pieces to survival – food and clean water - calls into question how valid empowerment theory can be in any context if basic needs are not met. Is empowerment achievable only for the privileged? Can empowerment happen despite basic needs not being met? I

reflect on this more when I recall Abraham Maslow's hierarchy of needs and while not without criticism, his basic premise is that a person cannot pursue the next need until the currently recognized need is satisfied (Gawel 1997, 3). If a student cannot achieve the basic physiological needs or, often in this context, the safety needs, how can we realistically aim for empowerment as it is understood in much of the surrounding literature?

**2.) From Compassion to Empowerment within AIDS Education:** Beyond this, my research has brought up questions surrounding AIDS education itself. The PIASCY programme, as well as the positive living philosophy, is very much based on the concept of empowerment, but has a few gaps. The progress made in turning people with HIV/AIDS from outsiders to be feared into people in need of compassion is extraordinary and should be praised. It has had a quick and effective impact on shaping how those living with HIV/AIDS are viewed and interacted with. To move from compassion to empowerment, however, is a more significant step forward. Viewing people with HIV as in need of love, care, and support still victimizes them. There is not a balance of power between those infected with the disease and those that live and work with them. The young people I spoke with have the potential to become powerful adults, and many are already in leadership roles.

This also ties in with empowerment theory's further integration into AIDS education and support. Empowerment theory calls for youth led education and the process of problem posing, not necessarily problem-solving. The students I spoke with had comprehensive and age appropriate knowledge of their disease and how to prevent spreading it. However, each student experienced situations when they lacked the appropriate skills with which to negotiate it, specifically telling others about their status. This is in line with Pienaar and Visser's research that also concludes that adolescents with HIV need help in learning how to disclose their status to not only romantic partners, but also to family and friends (Pienaar & Visser 2012, 74). While the schools implement PIASCY into the curriculum in a variety of ways, there could be the opportunity for peer led counseling and problem posing within this context. Midtbø et al. (2012, 268) also highlight the benefits of group

therapy and support. They found that these support groups created meaningful relationships between the students and increased confidence and mental strength. None of the students I worked with had a support group; their counseling, while helpful, was one on one with the health care worker. Moreover, the students did, at times, express that they felt better when they saw some of their peers at the clinic picking up their medication. Adolescence is a stage when peers become particularly important and thus, this should be incorporated into their overall HIV/AIDS therapy. My conclusions here echo those of other researchers, that peer support and group therapy would be beneficial for the students in not only removing stigma and the sense of being an outsider, but insofar as this could also allow for a balance of power between those that are HIV positive and those that are negative.

**3.) The Role of Faith and Religion:** One surprising finding of this work is that, even with the understanding that empowerment is not an “all or nothing” concept, there are certain boxes that can be checked off, and that when a number of the “must haves” are present, students are more likely to describe themselves as empowered. However, a number of the students I spoke with seem to have none of the required elements to be empowered, and yet they not only were coping, they were in many ways thriving. In particular, Justine felt stigmatized by both teachers and students, and then discussed how much she quarreled with her mother, especially when the mother came home drunk. Despite this, Justine was one of the most determined and fearless of the girls to which I spoke. She, like others, credited her strength to God and the importance of God in her life. For many of the students, their faith in God was an incredible source of strength and comfort. Further research into the role of faith for students with HIV/AIDS has potential to explore aspects of both support and empowerment.

The role of religion is also significant in terms of AIDS education. The current standard message of ABC (Abstinence, Be Faithful, Condoms) does acknowledge the importance of using protection, but the general lesson given to all students is that of abstinence. Sex before marriage is not discussed or approved of, despite its regular occurrence. This creates a culture of shame around the topic, and decreases the

likelihood of a girl or boy purposely and confidently choosing to use condoms. Moreover, the ability to discuss issues like sexual health and pregnancy with a sexual partner is diminished if it is shameful and the students are not taught the skills to have these conversations. These young people are not given the ability to make healthy sexual decisions if they are only taught abstinence. This is particularly true for girls, as their virginity is expected to be preserved and often praised. The boys receive a more contradictory message, as they hear the importance of abstinence, but are also expected to “prove themselves” as men. The teaching of abstinence only, not only creates a culture of shame, but it also increases the rates of infection because youth do not have easy access to condoms. Condoms are not available at the schools and students do not have the education on how to use them, unless they visit the health centres. The health centres and the schools, in some ways give contradictory messages, largely because the latter is based upon religion. While Uganda may not be ready to do a full review of its programmes to combat the spread of HIV, to be more effective, the schools and health units at least need to align and work together on youth AIDS education to create a consistent message.

**4.) Giving Families More Skills to Support HIV Positive Students:** While my research specifically looked at the school experience of these adolescents, the role of family in these students’ lives, both in terms of their success in school and in their overall well being cannot be stressed enough. Like all adolescents, family support during the challenging teenage years is a determinant of future success as adults. Family, of course, in this context extends beyond the parents and siblings and often involves aunts, uncles, cousins and grandparents as central figures. As Petersen and colleagues conclude, the importance of family support for adolescents with HIV cannot be underestimated, and those without it tend to engage in risky behaviour (Petersen et al. 2010, 976). This was true from my findings as well. The students that had a supportive family that was accepting of their HIV status seemed to have a stronger sense of identity that was not wrapped up in their disease. Those families that still saw the value in sending these students to school despite their disease helped to shape the students’ identity into more than an AIDS victim. Even when it

was only one family member that knew their status, having that extra support buoyed the students. On the other hand, those students whose family either did not know, or knew but were not supportive, struggled much more with mental wellness and self-stigmatization. This compromised the students' ability to stay in school. Moreover, I surmise that if there is stigmatization at home, the likelihood of the student disclosing status to teachers, friends, or sexual partners is greatly diminished.

Family also played a role in terms of the grief the students carried because of the loss of a family member. Petersen and colleagues discuss the emotional challenges of their participants in dealing with the loss of a family member; the loss of a biological parent “emerged as a key emotional challenge that amplifies the stress experienced by HIV+ children in South Africa...Further, a sense of loss at not being able to lead a normal life as well as a perceived foreshortened future was experienced by the majority of youth” (Petersen et al. 2010, 975). While this was indeed true for many of the students I interviewed, I would argue that this loss also had a mixed effect on how the student reconciled their own health. For example, Anne lost her brother as a result of HIV complications. For her, this solidified her desire to take her medications despite her father's objections and increased her determination to lead a healthy life. After my research, I learned that Anne's father also passed away, and while I do not know what effect this has had on her ideas about her own health, I do know that she continues to attend school and do well there. Family, then, is a crucial piece to the overall well-being and success of the students, and as such, along with the physical and mental health treatment these students receive, there perhaps needs to be a family component as well. These students do not live and learn in isolation, and in order to provide effective support for them, families should be brought into the fold of overall therapy and skill building. Not only does this support the students, but it also has the potential to bring support and skills to the family members, not just parents, that live with an HIV positive adolescent.

5.) **The Importance of Acknowledging How the Disease is Contracted:** Other similar studies discuss that most of their participants felt hopeful about their futures. They state that the adolescents in their study all had ideas to finish school, have a career, and raise families. (Li et al. 2010, 755.) While the students I spoke with also had this same sense of hope, how each student contracted the virus played an important role in this. The students' senses of hope varied depending on their outlooks on their illness and, subsequently, their future. This outlook was largely dependent on their support systems, as mentioned in the previous discussion of family, but also particularly the way in which they had contracted the virus. In line studies done by others, those students I interviewed that were infected from mother-to-child transmission and learned of their status early on seemed to adhere to treatment more successfully and displayed feelings of hope, despite the expected frustrations and doubts (Pienaar & Visser 2012, Li et al. 2010, and Midtbø et al. 2012). However, the students that I spoke to that were infected later in life through rape, injection, or unknown sources, or learned of their status later in life, struggled more with both disclosure and self-stigmatization. They were less open to others about their status, even within their families, and they worried more about what others would think if they were to disclose. The treatment they received from the health care units did not address the trauma of contracting the virus through other, sometimes violent, means. In contrast, the adolescents that have known of their disease since their early years, and have grown up with that knowledge were generally more comfortable with their status and the routine of the therapy. As many of the students in the situations commented, they did not know any other reality. Additionally, they were able to relieve themselves of any guilt associated with the disease because they could be confident in not feeling like it was their fault. This was not the same for those that contracted the disease by other means. Because of the difference within the teens regarding when and how they became infected, treatment and therapy also needs to be different. Positive living recognizes the overall well-being of people living with HIV/AIDS, and in order to empower all adolescents living with the disease, mental well-being has to be included as a staple in treatment. Again, the need for unique therapy for teenagers should by now be

obvious, but within this work needs to be done reconciling those teens with how they were infected and how they can move forward as capable and confident youth. Additional support needs to be given to those who contracted the disease later in their childhood or from traumatic means.

**6.) The Contradictory Nature of School:** School and education is often thought of the best place for young people to be, and there has been a global push for universal primary and secondary education for all children and adolescents that echoes this sentiment. While I do fully agree with the importance of schooling and education, it is essential to reflect on its contradictory nature in this context and in regards to these particular students. Every student, despite encountering abuse or stigmatization and often a lack of food, wanted to be at school. For them, it was a source of hope and the best way they saw of making a better future for themselves. Many of the students took innovative approaches to ensure that they remained in school even when money was not available. Not only was it a place to learn, but many of the students referred to the sense of freedom and peace they had when they were at school. It was there that they could forget about their worries, especially their disease, be with friends, and focus on their goals and dreams. Moreover, the students all loved being a part of a school club. There was a deep satisfaction gained from being involved and contributing to the school community. PIASCY clubs (and others) in Katakwi also create positive and progressive school environments, which may be in stark contrast to the views and behaviours of people in their homes and villages. While not all members of the student body may adhere to the ideas taught in PIASCY, it does set the tone and create a safe place for students with HIV/AIDS to be, knowing that compassion is being taught and expected. Finally, because much of PIASCY education is performance based, it creates many opportunities for the students to participate in a meaningful way, which is a key component in empowerment. School and PIASCY in particular, allow for the students to find leadership within themselves.

School, however, is not always a safe place. The walk to school is threatening for many of the girls, and poses a real danger to their safety. Once they arrive at

school, these threats are often exchanged for new ones. Many of the students did not experience stigmatization to a great extent, but it did seem apparent that using HIV/AIDS against these students was close to the surface. When the students were getting along fine with their peers and teachers, it was never mentioned. However, for some students as soon as teasing between peers begins, insults quickly included comments about them having HIV or by becoming infected through promiscuity. This was also not the exclusive tactic of other students, but teachers at times also were willing to chastise a student and use their status against them. Of the students in this study, they all had varying techniques for coping, and some were able to dismiss these insults better than others.

**7.) The Role of Teachers:** Surprisingly, though, while the abuse the students received about their HIV/AIDS status was hurtful, it was the physical abuse from the teachers that demoralized them the most. Beyond this, the teachers also posed a threat to the girls specifically as sexual predators. The girls in my study could all relate a story, personal or from a friend, of a teacher that would attempt to have sex with the students. This was also confirmed at the health centres that stated girls that contract HIV do so almost exclusively from either soldiers or teachers. For many students that so desperately want to complete school, it is often an abuse they are willing to endure in order to have access to education.

Of course, many of the students spoke highly of their teachers. Very few ever said that there was a teacher they did not like. In fact, most of the students had a teacher as one of the few people in their lives to whom they had disclosed their HIV status. The teachers were crucial in supporting the HIV positive students not only emotionally, but physically as well. The teachers were often the only person in charge of making sure the student took their medication on time and with food. The importance of this role and of having a teacher that is aware and supportive of an HIV positive student cannot be underestimated.

Clearly, school is both a protective and threatening force in the lives of students with HIV/AIDS. While the threats are both physical and mental, the protective factors do make it a better place for adolescents than not being there.

The threats they face at school, while real, are not eliminated when not at school. In the villages, the same threats of verbal, physical and sexual abuse are still present and even magnified depending on the community. Thus, despite the threats at school, it is a place that enhances empowerment and provides the conditions to support these students, even though the long-term effects may be tenuous at best. School needs to be a safe place, not just because of the ethics surrounding this, but it will also increase enrolment and the willingness of families to send their children to school if they know they will be safe. There needs to be some sort of monitoring and prevention of teacher-student sexual relationships. Currently the onus of this falls to the girls to “not tempt” their male teachers. When a teacher is reported, what follows is usually just that teacher being transferred. Perhaps it needs to fall to the community to set up a watchdog programme, but ultimately the government must make this a priority as part of the Ministry of Education, and the schools themselves need more than a Senior Man or Senior Woman teacher to carry this issue themselves. Above all, it is the one thing that every student I spoke with agreed on: school is where they are happiest and where they want to be. No other issue of discussion raised such a unanimous pronouncement.

**8.) Varying Levels of Maturity Within Adolescence Needs to Be Addressed:** Age, or perhaps more specifically grade level, is an important factor in the lives of these students with HIV/AIDS. Both Pienaar and Visser (2012) and Li and colleagues (2010) call for the study of older adolescents in the African context, to add to the knowledge of teenagers with the virus, as they focused more on younger adolescents. My research included students that ranged from 12- 19 years of age and indeed there was a marked difference between the older students and their younger counterparts. As would be expected, the older students had a more sophisticated and complex view of what life is like with HIV/AIDS. They are more able to think critically about their futures and see the complexities that arise for them, specifically regarding sexual partners and family, surrounding the disease. The younger students, often, had not thought much about being married or having a

family. They also still had a certain level of naivety surrounding issues like disclosure to others.

One clear concern for the students was the transition from Primary School to Secondary School. The students in Primary 7 were quite open about being HIV positive, but were hesitant and unsure about whether they would disclose their status once they reached Senior 1. They feared that bullying would be an issue in the older grades, and to some extent this is a valid concern. The students in the younger grades often, but not always, did not experience stigmatization from their peers. In fact their fellow pupils were cognizant of helping and even protecting the students with HIV/AIDS. In Secondary School, some of the students continued on without problems related to stigma, but many more were aware of the potential for abuse and the questioning of their morals and sexual behavior because of their status. The education piece around HIV/AIDS also changes and is not always age appropriate when older teenagers are still in Primary School. Indeed, adolescent health care is a unique realm and needs to have unique approaches to work with and support this demographic. Within this, there need to be guidance for the teenagers as they transition from early adolescence to young adulthood. Even within the realm of the teenage years, the challenges for students are dynamic and change between Primary and Secondary School.

**9.) Gender is Crucial to Understanding the AIDS Experience:** Finally, my research included an equal number of female and male participants and did not specifically address the issue of gender. However, gender is the biggest contributing factor to the experience of a young person living with HIV/AIDS. There was a clear divide between the girls and the boys in terms of confidence, resilience, determination and ability to finish school, and general safety. The girls that have HIV experienced more stigmatization from their peers and were mocked for having the disease because of their sexual behaviours. The families of the girls were more hesitant to pay for school fees for the girls, and this led the girls to become particularly vulnerable to soldiers and teachers that would pay their school fees in exchange for sex. The boys had much less experience with stigma. Their struggles at

school came more from difficulties in paying fees, as all the students experienced, but their sexuality was not a topic for comment. Moreover, the boys were more often in leadership roles, whether in clubs or as class prefects. This is in no way to say that the boys did not struggle and suffer from having HIV, but it is one of the most obvious findings despite not being one that I specifically set out to explore. It is beyond the scope of this work to truly delve into this issue, but it also is one that is perhaps the most significant to facilitate future progress in this area. Bringing gender into the exploration of the topic can look specifically at the role gender plays in AIDS education and messages of abstinence, relationships with teachers, and/or opportunities for leadership roles within schools. In line with ideas of group therapy and participatory education, an examination of gender specific clubs or therapy groups could be fruitful. Moreover, the recognition that girls as much as boys will have pre-marital sex needs to work its way into the culture surrounding AIDS education and discussions. However, girls in particular need to be empowered to have a voice in their sexual health, as they are the ones most likely to be infected with HIV/AIDS. How this shift can realistically be made remains to be seen.

Because empowerment is complex concept influenced by multiple internal and external factors at various levels and scales, it seems that a multi-level analysis would be required to truly understand the dynamics of the empowerment process in this particular demographic. Interviewing teachers, students, and parents is one part of the puzzle, but more funding and time to truly explore this topic is perhaps the next piece. What now becomes essential is to look at how government policies, religious groups that urge abstinence, and other macro-level cultural institutions contribute to how empowered these HIV/AIDS-infected youth can possibly become. In other words, the danger of limiting analysis to students, teachers, and families is that it deflects responsibility away from governments and institutions that have the power to change school curriculum, fund HIV/AIDS prevention, and shift cultural values and expectations. While reducing the HIV/AIDS transmission rates seems to have slipped from the political priorities as Uganda's reputation is restored because

of its success, schools, families, students, and communities are left to their own devices to continue to make any progress. At least for now. The HIV/AIDS rate is rising again in Uganda, and perhaps this, if anything, will bring the issue back to a place of proper funding and a re-examination of policies. Most importantly, the inclusion of the students themselves in meaningful ways to the discussion and policies around HIV/AIDS and where to go from here not only empowers them as individuals, but shifts the culture of how this disease is thought of and talked about. Moreover, they become leaders within their communities and advocates for so many people in Uganda that live with HIV/AIDS or that love and care for someone that has this disease. Empowering these youth by giving them a voice, can only bring about effective and positive change.

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## 8. APPENDIX

Table 1: Summary of Student Participants

Age	Sex	Source of Infection	Open with Status?	Experiencing Stigma?	Beaten at School?	Orphan?	Fed at School?	Membership in Club?	Medication?
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<del>Emmanuel</del> <del>Levi</del>	15	M	unknown	yes	minimal	Yes	Yes	No	Fair Pen	Septrin
<del>Dennis</del> David	13	M	MTC	Somewhat (diagnosed only one week ago)	no	No	No	No	Fair Pen	Septrin
Gift	17	M	MTC	no	n/a	N/a yes	Father only	n/a	N/a Yes	ARVs
<del>Josephine</del> Apio	13	F	injected	yes	yes	Yes	Mother only	Yes	no	Septrin
<del>Ocon</del> Michael	13	M	MTC	yes	no	Yes	No	Yes	WASH (prev. school)	ARVs
<del>Emmanuel</del> John	16	M	MTC	yes	no	No	Yes	Yes	Patriotism Club	ARVs
<del>Calvin</del> Opio	12	M	MTC	yes	no	No?	Mother only	Yes	Yes (general)	ARVs
<del>Isaac</del> Isaiah	14	M	MTC	yes	some	Yes	No	No	Health Club	Septrin
<del>Katherine</del> Akello	14	F	unknown	yes	no	No	Yes	No	GEM	ARVs
<del>Harriet</del> Betty	19	F	rape	no	n/a	Not this term	No	Yes	Peace club	Septrin
<del>Cosmas</del> Jeff	15	M	MTC	yes	no	Yes	Yes	Yes	No	ARVs
<del>Annette</del> Anne	14	F	MTC	yes	no	Yes	No	No	PIASCY	ARVs
<del>Josephine</del> <del>HStella</del>	17	F	MTC or care?	yes	yes	No	Father only	No	No	Septrin
<del>Ben</del> Gideon	18	M	Car accident?	yes	no	?	No	Yes	PIASCY	Septrin
<del>Rita</del> Ruth	16	F	care	no	n/a	No	No	Yes	No	Septrin
Justine	16	F	MTC	yes	yes	Yes	Mother only	yes	No	ARV & Septrin

Table 2: Summary of Adult Participants

	Occupation	Parish	Other
Asio Judith	Senior Woman Teacher	Katakwi	
Asubu John	PIASCY Teacher	Usuk	
Anne's Father	Local Government Employee	Katakwi	Child with HIV (Anne)
Arthur	Teacher	Katakwi	Child with HIV (Michael)

Alan Moroto	Doctor	Katakwi	
Micah	HIV Focal Person	Ngariam	