

Abstract

The aim of my case study was to examine and describe the methods of HIV/Aids prevention work that are used in Kabale district, southwestern Uganda. I will in this study discuss the importance of peer monitoring, education and reducing stigma to decrease the number of HIV infected people. I will use the theory of Pierre Bourdieu about the social, cultural and economic capital to try to give an explanation and a deeper understanding of why and how the prevention work is organized on a local basis.

I have used a qualitative method by interviewing HIV counselors and volunteers (peer educators) about their preventive work and also a quantitative method by handing out questioners about HIV/Aids prevention knowledge amongst primary and secondary pupils in Kabale. I have come to the conclusion that a combination of social, cultural and economic capital can well be used in the analysis of my collected material as to why and how the preventive work with HIV/Aids is organized in this area. I have also found that working with empowerment, reducing stigma and enhance the role of HIV infected people in the society is much important in the challenging work with preventing the spreading of HIV.

Key words: HIV/Aids prevention, Social capital, Peer educators, Stigma, Community mobilization

Acknowledgements

In the fall of 2011 – 2012 I spent approximately four months in Kabale, south western Uganda to do a case study about HIV/Aids prevention work. This is where I conducted my interviews and research material that is the base of this study. My time spent in Uganda was an interesting, informative and sometimes also an overwhelming experience and an experience I will treasure forever. In the meetings and interactions with people living with HIV and people working with HIV/Aids prevention in this area gave me a greater understanding and more knowledge about the life and struggles in a developing country.

I would like to thank everyone who participated in making this case study possible, the HIV counselors and the peer educators deserve a big thank you for taking their time to speak to me and I wish them great success in their future work with preventing HIV. I would also like to thank my supervisor at the university Lars Harrysson for guidance and support during the making of this thesis. Last but not least I would like to give my appreciation to the people of Kabale for their hospitality and kindness that have facilitated my work with this study and my stay in Kabale.

Republic of Uganda



Population: 34, 5 million

Capital: Kampala

Language: Official language is English, 40 different local languages of which Luganda and Swahili are the greatest

Religion: 80 % are Christians (the majority are Catholics), Muslims 10 % and other are Hindus and practitioners of traditional African religions

President: Yoweri K. Museveni

Government type: Republic, unitary state

Aid's share of state spending: 30 %

Major industries: Agriculture, food processing

Life expectancy: Women, 55 years, Men 54 years

(Source: Sweden Abroad, 2012-04-23)

Table of Contents

Abstract	1
Acknowledgements	2
Republic of Uganda.....	3
1. Introduction	6
1.1 Purpose.....	7
1.2 Questions.....	7
1.3 Delineation	7
2. Theoretical Framework	9
2.1 Pierre Bourdieu and the capitals	9
2.1.1 Social Capital	10
2.1.2 Economic Capital	10
2.1.3 Cultural Capital	10
3. Method	11
3.1 Choice of method	11
3.2 Limitations	11
3.3 Interviews.....	12
3.4 Survey	16
3.5 Reliability and Validity	20
3.6 Ethical matters.....	21
4. Previous Research	23
4.1 Behavior change.....	23
4.2 Public education	23
4.3 The youth and the future.....	24
4.4 Stigma related to HIV/Aids	24
4.5 Peer educators	25
5. Analysis	26
5.1 HIV/Aids prevention work in Kabale, Uganda.....	26
5.1.2 Peer educators.....	29
5.1.3 Stigma	33
5.2 Children and Youth	36
5.2.1 The knowledge about HIV/Aids prevention amongst pupils in a primary and secondary school in Kabale. A small survey	38
6. Summarize and conclusion	40

6.1 Research question number 1; HIV/Aids prevention work in Kabale	40
6.2 Research question number 2; Methods	41
6.3 Conclusion.....	42
7. References	43
Appendix 1; Interview guide	46
Appendix 2; Questioner	47

1. Introduction

My focus in this field study is to examine how the HIV/Aids prevention work is laid out locally in Kabale, Uganda. I have for a long time been interested in questions regarding HIV/Aids and during my internship in Kabale in spring 2011 I encountered the issue of prevention of HIV/Aids more up close than I have had before. Therefore I wanted to return to this area to speak to people working with HIV/Aids prevention and look into their methods in use.

I have spent approximately four months in Kabale where I have interviewed HIV counselors and volunteers (peer educators) in a total of five persons at three different organizations working with this issue about their methods for decreasing the number of infected and spreading knowledge about HIV/Aids. I will in the case study refer to them as organization 1, organization 2 and organization 3. I will also discuss the importance of education amongst people and nonetheless the children and youth about HIV/Aids prevention and what support is given to people infected with HIV.

The fight against the HIV/Aids epidemic is a huge challenge worldwide, creating fears that it would be too difficult or even impossible to achieve a large decrease in the number of HIV infected (Okware et al. 2001). The HIV/Aids epidemic is a widespread disease that has fatal consequences on the people affected. To my opinion it is important to look at this issue to see how to improve methods for preventive work and reduce the number of infected.

Uganda is one country that has demonstrated that an early, consistent and multisectoral control strategy can reduce both the prevalence of HIV infection amongst the population. Uganda reportedly only had two Aids cases in 1982 but at the end of year 2000 the HIV/Aids epidemic in the country had grown to about two million HIV infections. The Aids Control Programme was established in 1987 by the Ministry of Health and under the role of Uganda AIDS Commission they mounted a national response that expanded to reach other important sectors of Uganda (ibid).

Okware et al. (2001) further writes that the purpose with the national response was to bring in new policies, expanded partnerships, increased institutional capacity for care and research, public health education for behavior change, strengthen sexually transmitted disease management, improve the blood transfusion services, care and support for persons living with HIV/Aids and an observation system to keep an eye on the development of the epidemic (ibid).

After fighting the epidemic for a decade in October 1996 Uganda became the first African country to report a decrease of the number of infected. Further decreases in prevalence has been noted and in 2003 the number of infected was as low as 4% of the population, even though the rate has risen since then to about 6,7%. Repetition of knowledge, attitudes, behavior and program studies have shown to be positive changes in the prevention programs (Okware et al. 2001).

I have spoken to the HIV counselor and peer educators working with this issue in Kabale and examined how they are meeting the challenges organizing the preventive work against the HIV/Aids epidemic. I have mainly looked at how people are receiving the information and help they need to protect themselves from getting infected, to infect others and to get necessary information about the HIV virus. I have looked into how the subject of HIV/Aids is discussed with the people in the community.

The results I have achieved with this field study I am hoping to show how the work with preventing HIV/Aids with the people is organized locally in Kabale. I believe this information could also be useful for the organizations, researchers, the public and for the locals themselves to get an overview of the help and the work existing in Kabale with preventing HIV/Aids.

1.1 Purpose

My purpose with this case study is to describe and with help of theories and perspectives analyze how HIV/Aids prevention is organized in Kabale, Uganda. My specific focus is on the different methods used for decreasing the spreading of the disease.

1.2 Questions

What HIV/Aids prevention work is fulfilled in Kabale?

Which methods do different organizations use in their preventive work?

1.3 Delineation

I have specified my research about the success of reducing the number of infected with HIV in Uganda to Kabale and which preventative methods they are using for decreasing HIV/Aids amongst people in their region.

Jacobsson and Meeuwisse (2008) writes that learning about communities where you examine a specific geographical area can be one type of study and to examine organizations which can examine questions like the social structure of the organization, norms, decision making etc.

The reason for this delineation was to be able to get an in – depth look of the preventive methods in use with the matter of HIV/Aids prevention and to examine how the work is organized in this area.

2. Theoretical Framework

2.1 Pierre Bourdieu and the capitals

I have chosen to put an analytical perspective inspired by Pierre Bourdieu's theory about the social, economic, and cultural capitals in the analysis. With these capitals I am looking for to create a deeper understanding of the material I have collected in my study about the HIV/Aids prevention work in Kabale. These perspectives are factors which can help us understand the role groups, individuals and institutions play in a society. In my analysis I will use this theory as to try to better understand how influence on the issue of preventative work is laid out locally in Kabale.

Bourdieu's concept is linked with his theoretical ideas on class. He identifies three main dimensions of capital and each of them has its own relationships to class; economic, cultural and social capital (Bourdieu, 2008). In addition to these three capitals Bourdieu also identifies one other capital which is the symbolic capital. The symbolic capital is an extension of cultural capital and is the resources available to an individual on the basis of honor, prestige or recognition and functions as an enlargement of cultural value. Bourdieu used these capitals to expose the combination and dynamics of power and relations in social life and argues that class fractions are determined by the varying degrees of the three capitals and also teach aesthetics to the young (ibid).

One important factor of Bourdieu's theory is the thought of society as a diversity of social fields. The forms of capital (economic, cultural and social) are basic factors that are defining positions and possibilities of actors in any field of society. The main components of social resources describe the social position of actors which according to Bourdieu are economic, cultural, symbolic and social capital (Siisiäinen, 2000).

Bourdieu's theory of social capital puts the importance on conflicts and the power function within social relations that increases the ability of an individual to enhance her/his interest. From the Bourdieuan perspective, social capital becomes a resource in the social struggles that are carried out in different social arenas or fields (ibid).

I will mostly in my analysis use the theory about the social capital. I have been inspired by Sara Axelsson's (2011) case study where she also used Pierre Bourdieu's theory by describing the social, economic and cultural capitals in short:

2.1.1 Social Capital

The concept of social capital basically refers to connections within and between social networks. Social capital highlights the value of social relations and the role of corporation and confidence to get collective or economic results. Friendship, social contacts and networks are defined by social capital (Sokratis, 2008).

2.1.2 Economic Capital

The economic capital represents a type of power or status a person can attain in a capitalist society via a formal education or through social ties. According to Bourdieu's theory economic capital also reflects your socio economic belongingness (ibid).

2.1.3 Cultural Capital

Cultural capital acts as a social relation within a system of exchange that includes the accumulated cultural knowledge that confers power and status. It is forms of knowledge, skills, education and advantages a person has, which give them higher status in the society. For example parents provide their children with cultural capital by transmitting the attitudes and knowledge needed to succeed in the current education system (Bourdieu, 2008).

3. Method

3.1 Choice of method

To carry out this study I have chosen to use a qualitative method. A qualitative research is according to Bryman (2011) more about the understanding and what is said and analysis of data, rather than about quantity for gathering material. In this thesis I have chosen to visit three different organizations and I have spoken to five HIV/Aids counselors and peer educators working with this matter and look into the different methods that are being used for preventing HIV/Aids in Kabale, Uganda. A quantitative method on the other hand focuses on measuring and on gathering and analyzes of data and is also more objective (ibid). I chose to do a small quantitative survey among pupils in two schools, in primary and in secondary level about the knowledge of HIV/Aids prevention amongst children and youths. as a complement to my research questions.

Using a combination of qualitative and quantitative research is not always preferable, because many scientists stress that this combination is very difficult to put in work if it is even possible to do so (ibid). I have taken noticed of this and I have tried to make the two methods work together by using the survey more as a complement to the interviews.

3.2 Limitations

The debate over “What happened in Uganda” that led to a dramatic decrease in the number of HIV infected has led to many discussions about the methods that was and are being used to stop the epidemic (Green et al. 2006). In order to get in depths understanding about this I have chosen to make this study about Kabale, Uganda.

From the start I was meaning to do a study about HIV/Aids prevention work amongst the street children of Kabale, but reaching there I found out that there was no such specific work. I decided to enlarge my study to HIV/Aids prevention work amongst people in general of Kabale. I have had some help from my supervisor in field of contacting people for interviews, but for different reasons our relationship turned negative and I made most of the contacts myself with the help of friends and acquaintances in the area. Since this problem with my supervisor the situation and conditions I was given was not easy for me and I have tried to do my best considering this.

3.3 Interviews

First I like to stress the fact that it was difficult for me to make time with the interviewees for discussing their work, because they had much work to do and I saw their work as much unstructured. For example we could set a time together and when reaching the organizations the interviewees was not there, so I often had to reschedule which meant loss of time and energy. In total there were three interview occasions and the conversations took approximately 45 minutes to an hour. When taking the contacts with the persons I wanted to speak with I explained my intentions with the interviews and told them about my case study and why it would be of importance for me to speak with them. First after this information and their approval of participation I interviewed them. Amongst the persons I managed to contact no one said no to being interviewed. The interviews were held at the organizations where I interviewed five persons. I will refer them as organization 1, 2 and 3 in my presentation of the result. At organization 1 I interviewed one HIV counselor, at organization 2 I interviewed one HIV counselor and two peer educators and at organization 3 I interviewed one HIV counselor. The interview occasion at organization 2 where there was both an HIV counselor and two peer educators present I interviewed them at the same occasion.

Vetenskapsrådet (1990) has ethical guidelines to consider when carrying out scientific research and one of these is anonymity of persons participating in the research. Due to the anonymity of the organizations I cannot describe them very thoroughly, but I will make some descriptions to give a sense of what types of organizations they are. Organization 1 and 2 has their reception at hospitals and organization 3 is a center for HIV/Aids. At the organizations they provide with HIV testing services, counseling for people who are infected with HIV and for people that are in other ways affected by the disease, for example family members to HIV infected persons. They provide with health care recommendations and support groups for HIV patients. But the organizations are open for anyone who wants to come for information and counseling about HIV/ Aids and prevention. As mentioned two organizations are located at hospitals, one is located at a governmental hospital and the other at a private hospital. What I know about their funding of their activities is that the governmental hospital is funded by state funds and the private hospital is funded by private donations such as contribution to antiretroviral drugs to HIV infected. The third one is a center for HIV/Aids information, prevention and testing services. Their organization is also funded by the state and their organization is spread throughout Uganda, decentralized amongst the districts in the country, where Kabale is one (Notes, 2011-10-28; 2011-11-10; 2011-11-14).

I have been using semi – structured inspired interviews when meeting and talking with the HIV – counselors and peer educators working with HIV/Aids prevention in Kabale. Aspers (2011) writes that one type of an interview is the semi – structured ones, which means that the researcher has a number of questions within a specific field that he or she wants to discuss and the researcher are also able to follow up the questions that are being asked and discussed (Aspers, 2011). Before I visited the organizations that are working with HIV/Aids, I thought about the purpose of my study and therefore decided on the category of questions I needed to focus on (see appendix 1). Semi structured interviews also means that it is the researchers view and his or her questions that are being discussed and the interviewee is limited to lift their perspective (Aspers, 2011). The types of questions I used was about prevention work, how they reach out to people for information, what support they give to people infected with HIV/Aids and what struggles and challengers they may face in their work etc. This means, like according to Aspers (2011), for my interviewees they were asked to answer my specific questions of what preventive work they use instead of them freely telling me about it. This could mean loss of other aspects of their work than the intention of my case study.

The interviews were documented by taking field notes during the conversations, since I had no access to a recording device. I have referred to these notes with specific dates in my analysis. Aspers (2011) write that field notes do not have to be connected to the first order structure. It is therefore only parts of the field notes that represent what the actors say, thinks and does. The field notes consist largely of observations made by the researcher (ibid). I am well aware that taking notes can be less preferable than for example recording the interviews since notes is not a construction of the first order (ibid). It can also be difficult for someone else to read and understand the field notes due to the structure of the notes and misunderstandings can appear. Further the notes have to give an overview and a context to the purpose of the study (ibid). I have made observations of my own when visiting the organizations and interacting with people within the society of the culture and social life. I have considered this in my analysis, but this is my observations and my interpretations of what I have seen and heard.

As mentioned each interview took place at the organization of which the interviewees are working. Along the interviews we discussed the questions together and the interviewees described their work with their own words. I was able to ask follow up questions as we went on, this was preferable as to prevent misconceptions of what they told me (Bryman, 2011). The interview guide was followed but I made deviations from what the interviewees answered

and the questions about the financial structure of the organizations were often left out or not discussed closer. I did not encounter with language problems during the interviews since English is the second language in Uganda I did not use an interpreter.

Through participation and observation the researcher get knowledge about the field. But if the researcher spends time in a she cannot remember all of the events (Aspers, 2011). As earlier mentioned I was taking notes during the interviews of what the interviewees has answered from the questions and after the interviews I transferred my notes together with observations taken from the conversations more thoroughly on the computer and compiled and compared them with each organization. By doing this I have been able to see the many similarities between the organizations in which methods that they state they are using.

Coding the material means that the material is broken down into smaller parts (Aspers, 2011). In a combination with previous research and when compiling my material I was able to deduce five themes, which made me interested. By breaking the material into different themes that I saw as being important made my material easier to handle and easier to work with. I saw these factors as very important in the preventive work with HIV/Aids overall in Africa, but also from the interviewees. The reason of why I chose to deduce different themes afterwards instead of before I began my study was for me to be more objective when speaking to the HIV counselor and peer educators about their preventive work without having these themes on my mind, since I figured that it could affect my ability to take in the information they gave me if I had already had image of what they would tell me (Aspers, 2011). These themes are behavior change, public education, stigma and peer education. These themes are frequently shown in my case study and I have chosen to primarily write about the importance of peer education and reducing stigma in my analysis since these subjects came up frequently in my conversations with the interviewees.

I am discussing the term of stigma as a tool instead of a concept in my analysis because when interviewing the HIV counselors and peer educators my impression is that they are using stigma rather as a tool than a concept in their work for reducing the negative image and discrimination HIV positive person can face amongst the society. When arguing using stigma as a tool rather than a concept it is my interpretation of the HIV counselors and peer educators way of talking about stigma and working with stigma it is for them a way of reducing the discrimination and ignorance against the HIV positive population. By reducing the stigmatizing of HIV infected by education and knowledge about HIV/Aids prevention they

can also begin to control the spreading of the disease. When discussing about the concept of stigma I believe is more about defining stigma by explaining what it is and the meaning of stigma as a whole and it is discussed in a more abstract way, than what I have chosen to do in my analysis because of my interpretation of the meaning it has to the HIV prevention work within the organizations I have visited.

My purpose with these interviews was to develop a broader understanding of the whole picture of what is being done in preventing HIV infection in this area; therefore I decided to visit several organizations instead of just one. I realize that since I have a limited number of interviews and interviewees I get a somehow narrow image of the actual prevention work with HIV/Aids and which preventive methods that are being used in this area. When doing qualitative interviews it can be difficult to stay objective when you may enter the research with your own thoughts about what you may find and or other prejudices you may have (Bryman, 2011). I have tried to stay as open – minded and objective as possible also considering that my study is not to evaluate if the work is good or bad or whether the work is actually carried out. I entered this research project with thought of what I had heard beforehand about the issue of HIV in Africa and what is being done about it. Such prejudices included thoughts that it would be difficult to talk about the subject of HIV and preventive methods to people because of culture and religious views etc. But when starting the research I found that this was not a problem, people were very out spoken which they explained is because HIV now is such a “common subject” to talk about.

From the interviewees I also received handbooks containing guidelines they use in their work. I have chosen to use two of those handbooks as a complement to the interviews in the reporting of the result. I realize that the combination of using both interviews and handbooks can be problematic because there are two different materials, where the information can vary. I have used the handbooks mostly to make up for information I did not get out of the interviews for example questions about interventions and prevention about HIV/Aids amongst children and youth. Therefore they referred these handbooks to me as they contain guidelines for how they should and can handle when meeting with children and youths regarding HIV/Aids. They also contain guidelines about mobilization of the communities and how to handle problems with stigma and discrimination of HIV infected etc. These handbooks have been very valuable for me as a complement to the interviews when understanding their work in a more concrete way. The case of different strategies when meeting with children and youths were not brought up by the interviewees so from there I gathered the information of

how the handbook suggest the peer educators and HIV counselors should do when meeting these age groups. I will refer these handbooks as “handbook 1” and “handbook 2” in the presenting of my result. The handbooks are written and published by The Joint Clinical Research Center (JCRC) and the Ministry of Health Uganda. JCRC is a nonprofit organization that was founded in 1991 to address the challengers of HIV/Aids in Uganda. It is the largest research and treatment center for HIV/Aids in Uganda and overall in Sub – Saharan Africa (handbook 1). Ministry of Health is a government body set up with the mandate of policy and policy dialogue with Health Development Partners advising other ministries on health matters, coordination of health research and monitoring and evaluation of the overall sector performance on health issues (Source: Ministry of Health, Republic of Uganda, 2012-06-10).

My contacts helped to connect me with the HIV counselors and the peer educators for interviews and with guidance of where to search for people working with this issue. This meant I basically went to these places and took the first contact myself and asked if they would be willing to speak to me after having presented myself and my purpose of the case study. I made these contacts shortly after arriving to Kabale. I am conscious that using acquaintances and personal contacts can affect my selection in that sense I might only get a certain perspective of the preventive work that my contacts are choosing to connect me with. I have taking notice of this and when speaking to the HIV counselors and peer educators I have chosen to let them stand for what they are saying is part of their work with HIV/Aids prevention.

3.4 Survey

I have earlier mentioned that during my interactions with the interviewees I found that they did not have any programs or campaigns about HIV/Aids prevention that was directed specifically towards children or young people. I thought that it would be interesting to look into what the children and youth may know about HIV/Aids prevention in this area. My purpose with the survey was to try to measure their knowledge about HIV/Aids. I chose to use schools for my survey because school is the place where I would find these age groups. Due to the nature of limited conditions of making this case study as to where I did not have a supervisor in Kabale during this time, this survey is only meant to be a complementary segment to the rest of my result. The survey complements my research questions in such way that it can somehow answer on that there is preventive work regarding HIV/Aids existing among children and youths, not as a description of methods but as a way of finding out that

the preventive work with HIV/Aids is talked about and discussed with these age groups. I decided not to include this as a research question since my main purpose with the case study was to examine methods in how the HIV prevention work is carried out in this area and instead to have it as a segment on the section about children and youth. I had no chance to speak to the teachers about how they educate the children in this matter due to their busy educational program in school, they had no time to sit down and speak to me. According to Bryman (2011) handing out questionnaires is an easy and fast way to gather information. Therefore it was less time consuming for them and easier for me to get a picture of their knowledge about HIV/Aids by handing out this questionnaire. What I learned was that the knowledge about HIV/Aids was very good in these classes and that the knowledge they receive about HIV/Aids is mostly from education in school. When going through and compiling the questionnaires from the two schools I could not see any difference between them in how they had answered the questions. My purpose was not to compare the two schools in how the knowledge about HIV/Aids would appear. The reason why I chose to visit two schools was to try to get as many children and youths as possible to answer the questionnaire and thereby increase my picture of how the knowledge may be amongst this age group in this area.

When doing a survey there are many problems to consider. For example you cannot ask follow up questions in order to deepen the answer of the one filling in the form like when interviewing and it is difficult to ask many questions because there is a risk of people getting tired of the questions. There is also a risk of not getting all of the information needed when some of the questions in the form are not answered (Bryman, 2011). When constructing the survey I knew that I wanted to ask just basic questions about HIV/Aids prevention because I did not want to make it difficult for the students to answer the questionnaire. The questionnaire has 13 questions about HIV and Aids, where they get the most information about HIV/Aids, how it can be spread and regarding prevention. The questions are a result of important factors that have been and are still stressed as being of high importance in educational programs about HIV/Aids in Uganda. These factors are for example faithfulness, condom use, abstinence and transmission from mother to child (Slutkin et al. 2006). These factors may not be discussed much for example in Sweden when it comes to HIV prevention, but they are of importance in Uganda. For example the government has been trying to reduce the tradition of polygamy among the population, to reduce the risk of infecting each other and instead stress the importance of faithfulness and condom use (ibid). Therefore I decided to construct the

questions around these matters since it is pushed as being important for preventing and reducing HIV in this country (see appendix 2).

When I had constructed the questioner I went to the two schools and ask to meet with the principals to get an approval for letting the pupils answer them. I chose these two schools since they were the ones that still were running since other schools had already closed for holiday. I explained the purpose of my case study and why I wanted to this survey and they were able to look at the questions and approve of them. I only went to these schools and got a yes from both of them at once. I handed them out to two different classes as mentioned in a primary and a secondary school and picked them up when the pupils had filled them in after about 30 minutes. Before handing out the questioners I presented myself, the purpose of my case study and the purpose with the survey in the classroom. I told them that the questioner was completely voluntary and anonymous and it is also written on top of the questioner. To make myself as clear as possible the teacher of the classes explained what I had said in their native language. According to Bryman (2011) there are also some advantages in doing surveys comparing to interviews, which are that surveys are easier to administrate and you don't get the "interview effect". The interview effect means that the person performing the interview can be distracted from different factors like, gender, ethnicity and social background which can have an impact on the result of the study. But when doing a survey you do not know who has filled in the form (ibid). Since I did not know the children beforehand or had spoken to them before I entered the classroom I did not know about other different factors like their social backgrounds, age etc that could, like Bryman (2011) is stating above, have an impact on the result of the study and in my case the knowledge of HIV/Aids amongst these pupils. Therefore I avoided the "interview effect".

Since the schools had very little time for me due to their educational program my goal was to get as many pupils as possible to answer the questioner. As mentioned earlier I handed the questioners myself to the two classes and every pupil present in the classrooms filled the questioner. Therefore I had no loss. In total there were 68 pupils who filled in the questioner. I also handed out the right answers to the teachers so that they whenever they feel they had time could talk to the pupils about the answers, but none of the pupils or the teacher saw the questioner afterwards . According to Bryman (2011) the surveys should look less extensive and the researcher should make the survey easy to answer. The questioner is shaped to have yes or no answers except for three questions on the subject of where they have received the most information about HIV/Aids, which had four alternatives, school, friends, church or

other. The other question was if they were female or male and in which grade they were attending. I chose to leave out age because the students could be of different ages in the classes. I figured that the knowledge of HIV/Aids was not of how old they were but where they have reached in school. After receiving the filled questioners I compiled the responses and calculated the number of females and males that participated and also calculated how many pupils that had answered a specific question. I did this for each question and then converted the results in percent in order to get a more clear result. The internal loss was small, but there was some loss of 6 of 68 pupils in total, of both the primary and secondary school, that had not answered a specific or a few specific questions but these pupils had answered the rest of the questioner. According to Bryman (2011) the loss is mostly less when handing out questioners to for example the students that are present in a class room than to send it via e – mail. The questions not answered amongst these pupils varied between questions 1, 4, 7, 8 and 13. I figure that the reason could have been because of language issues or not understanding the question completely. I think the internal loss was so small that it did not have a great importance of the result of the questioner. I am also aware that since 68 pupils answered the questioner I cannot assume that the knowledge is like this amongst all pupils in Kabale or Uganda in general, only for these two schools.

Since the survey was directed towards children I understand there are different aspects for me to consider and Andersson and Swärd (2008) writes about the difficulties when meeting children in research since they may not understand the purpose of the study and the intentions of the researcher. As an examiner I have to think about the children's perspective and to be very clear about the intentions of my study. I was thorough regarding the design of the questioner and that the questions and language were not going to be difficult. As mentioned to be as understandable as possible the teachers of the two classes explained the voluntary and anonymous aspect and the purpose with the survey also in their native language. Andersson and Swärd (2008) further write about asymmetrical meetings and meetings with children. These types of meetings are asymmetrical because of the fact that children may have difficulty taking their own position on their own participation. It was therefore important for me to request for classes where the children were a bit older, especially in the primary school where I wanted the pupils to be between 10 and 15. It was important because I figured these age groups would be of an age where you would be able to decide for yourself if you would like to participate and to comprehend the purpose of the survey, also in case of language. When visiting the secondary school I knew that the pupils there would be teenagers so I

figured that age group would be able to comprehend the purpose and language issues, also that they would be able to decide to participate or not.

I also considered when discussing with myself about that the subject of HIV/Aids can be a sensitive subject to talk about. I thought about the possibility of that any of the children might have parents or other close relatives, friends etc that they had lost to Aids or that some pupils could be infected themselves. It would be impossible for me to know beforehand since I did not know any of them. I decided it was another reason for me to strengthen the voluntary nature of the study when it comes to the importance of children's autonomy aspects that Andersson and Swärd (2008) are stating and to ensure them that I was the only one to see the questioner. I do not sense that the questions are of a specifically sensitive nature and these are types of questions that I figured would have been a part of their education in school or elsewhere, or I figured they would not have been able to answer them. It is important when gathering material to keep the material confidential for others not to be able to recognize certain individuals in the study (Vetenskapsrådet, 1990). I figure this is especially important when it comes to children, since their reduced ability to take their own position in participation. I made sure to tell them that the answers of the questioners were only going to be witnessed and processed by me and since I had not encountered with any of them before I would not be able to identify any student. When answering the questioner I left the classroom so I did not see the students when filling them. I figure that this can have an impact on the validity of the survey since the students could help each other, but it is impossible for me to know how great importance that have had on the result.

3.5 Reliability and Validity

When doing a research it is important to look upon the reliability and validity of the data you have gathered. Many different factors can matter when doing a study and I am aware of the fact that my gender, ethnicity, age, social background and of course even my own opinions and values can affect the reliability of my study (Bryman, 2011). These are all factors that can be of importance of the reliability during the interviews because the interviewee's answers can also be influenced of how they experience me. They can as well see me as an intruder coming from the west and feel unwilling to talk to me. It can also effect on how much they are telling me about their work and how deep into the questions they go. Also the quality of the sources can be questionable, for example when they were telling me about what preventive work they have done for HIV/Aids it may not be correct of what is happening in reality. Because of this I have been very careful in informing the HIV counselors and peer

educators I have met that my purpose is not to evaluate their work just to find out how they are actually doing the work and the different methods they are using.

Validity is the question whether the result actually measures what it says it measures (ibid). With this in mind I am aware that the result of my survey amongst the students does not mean what children and young people in general knows about HIV/Aids prevention in Kabale.

3.6 Ethical matters

I have decided not to write names of any person or organization that I have met and visited. The reason is because Kabale is a small town and the organizations working with this issue are not many and are also small organizations. Identifying HIV counselors and peer educators would therefore be simple. According to Vetenskapsrådet (1990) when conducting research all information about identifiable individuals it should be stored, recorded and reported in such a way that individuals cannot be identified by others (ibid). Not writing and describing the organizations and my interviewees are because of the risk to reveal their identity and the right to anonymity. Other guidelines for scientific research are the information requirement and the requirement for consent for persons participating in the study (ibid). I have taking to great importance to have the interviewees consent to participate in the interviews by telling them in the purpose of my study and presenting myself.

Some problems I encountered when carrying out the survey amongst the pupils I figured that it was a problem that the pupils were sitting together and it might be difficult for one pupil to say no and instead fall for peer pressure if they did not want to participate. Basically what I did was to ensure the voluntary aspect of the participation. I had a premonition that the answers to the questions would be varying amongst the pupils due to school attendance and that might have been an issue if the pupils could see what an individual pupil had answered. But since the questioner was anonymous and the pupils' individual answers would not be seen by anyone else but me, I believe there is a very small risk that an individual pupil would be recognized. Since I had not met the pupils beforehand I did not know them and I could not recognize which of the pupils had answered the questioner when compiling and calculated the questioners together.

I have been very thorough in telling the persons I have met and interviewed in words discretion in my research and to first have their approval of being interviewed by me. I have always let these persons know that I will keep them anonymous in my study. Andersson and Swärd (2008) is writing that researchers with the intention to reach people in weak positions

or in vulnerable situations often depend on organizations, institutions, officials or individual social workers to get in touch with the field, to be let in or to get in contact with the people they want to talk to. When contacting and asking these persons for interviews and the two schools for the survey I wanted to be very clear towards them of the fact that my intention was not to come and study them and evaluate the work or the education about HIV/Aids, the purpose with the study was just to look into the methods in use by the organizations and to try to measure what knowledge the pupils may have about HIV/Aids. And that the purpose is only for my own. As Andersson and Swärd (2008) are stating ethics is therefore important and the researchers have to make sure to keep things confidential and not to disclose people in the field. I have not experienced any problems with confidentiality in my study because my purpose is only to examine the prevention work of HIV/Aids amongst people in general in Kabale.

4. Previous Research

4.1 Behavior change

There is a lot written about the success of Uganda's HIV/Aids program and also a lot of research has been done about the effects of the different methods being used to reduce the number of infected. I have chosen these five topics of what I have read about the HIV/Aids program in Africa in general and specifically in Uganda that I felt was linked to my case study in Kabale. Among these methods are such as trying to change the sexual behavior of people and through education and increasing knowledge on how HIV/Aids is transmitted (Slutkin et al. 2006)

Green et al. (2006) writes about the importance of behavioral changes amongst the people in Uganda such as reducing the number of sex partners, age of sex debut and the use of condoms to be the main factors in the decrease of HIV infected persons. But the authors also stresses that it is believed that HIV knowledge, risk perception and risk prevention eventually can lead to reduced HIV prevalence. Green et al. (2006) writes that there is a complex set of epidemiological, socio-cultural, political and other basics that more likely affected the course of the epidemic in Uganda, rather than only the factors mentioned above. They further discusses that many of these basics appear to be missing or less evident in those African countries that have not yet experienced significant national prevalence decreases, such as South Africa, Botswana and Malawi (ibid).

4.2 Public education

Slutkin et al. (2006) describes the different methods in which the reasons why these behavior changes occurred within the communities. They argue that a widespread distribution of information, increased importance for uneducated people to raise awareness, materials designed for groups at high risk of HIV and for families with Aids, effective networks for spreading written and illustrative information, communication skills, teaching training skills at district level, training packages, health educators and financial support to enable districts were all factors that led to a decrease of HIV infected people in Uganda. This was the main recommendation integrated into the 1989 – 1990 programs and was to be fully set and useful within weeks instead of months lead by the then and now president Museveni (ibid).

The authors further write about Uganda's health education program (information, education and communication; IEC) The main goals of this program were to mobilize all sectors of the Ugandan society, providing IEC material to all districts and to spread out information and

training to a district level. The main activities were to enhance and develop training packages and programs for all formal and informal sectors, development of public education materials and mass mobilization of districts and to spread the programs from one district to another, to train trainers from one district to be used in another and so on (Slutkin et al. 2006).

Like Slutkin et al. (2006) this case study also focuses on the different preventative methods being used for decreasing the number of HIV/Aids infected, although only in Kabale district, Uganda.

4.3 The youth and the future

Michielsen, Bosmans and Temmerman (2008) discuss the role of education in preventing HIV/Aids in children and young people in sub – Saharan Africa. Relative to the high number of HIV prevention activities in sub – Saharan Africa there is a limited number of scientific data on HIV-risk reduction programs for young people in this region. They further discuss that preliminary results show that many interventions have only a little impact on reducing sexual risk behavior, which they stress, can depend on the consistency and accuracy of information, the condition of life -skills, social support and access to contraceptives. Also the intensity and duration of the program and training of the facilitators can have an impact on the outcomes of the interventions and such as the age of the target groups (Michielsen et al. 2008).

4.4 Stigma related to HIV/Aids

Brown, Macintyre and Trujilloet (2003) write about the HIV/Aids pandemic and discuss that the epidemic has evoked a variety of reactions from nations and people. It has been emotions from sympathy and caring to silence, denial, fear, anger and even violence. They also stress that previous research has shown that stigma is an important factor in negative effects such as on HIV-test seeking behavior, motivation to reveal HIV status, also quality of health care received and social support provided (ibid). When talking to the HIV/Aids counselors and peer educators I found that decreasing stigma and discrimination against HIV positive people is a huge part of their work with preventing the disease.

Duffy (2005) also stresses that stigma related to HIV/Aids can have negative results for care and treatment but also have destructive consequences for prevention work and because of the long subclinical period of the disease preventive methods are very important for HIV/Aids.

4.5 Peer educators

I found that peer educators play a very important role in preventing HIV in Kabale district. Visser (2007) writes about peer education in *HIV/Aids prevention through peer education and support in secondary schools in South Africa*. This is a study done about peer monitoring in a secondary school in South Africa and peer education and support is about teaching and using people from the target group to educate and support their equal peers. Visser (2007) writes that interventions that include peer educators are based on the premise that behavior is influenced within social relations and that behavioral norms are settled through communication and interaction with others. The author discusses further on that by using peer educators as resources for information, knowledge and caring the social climate of communities can be improved. This means that it can therefore also improve the life for people living with HIV. Spokesmen of peer education have introduced the method as alternative or complementary interventions to other more individual based programs and peer education is growing as an attractive method especially for promoting behavior change in HIV prevention interventions (ibid). According to Visser (2007) previous evaluations from using peer education in developing countries shows that it did have an impact on behavior change in people and it added more awareness and knowledge about HIV/Aids.

5. Analysis

5.1 HIV/Aids prevention work in Kabale, Uganda

According to Parker (1996) over the years there has developed a growing awareness of the complex social, cultural, political and economic forces influencing the HIV epidemic and shaping theory and practice to respond and meet the needs of those who are most affected by the virus. My impression when meeting with the HIV counselors and peer educators of the HIV/Aids prevention work in Kabale in general is that it is seemed to still work accordingly to the HIV/Aids programs that was implemented by the government in the late 80's and 90's. The main goals with the programs were communication and public education about the HIV virus (Slutkin et al. 2006).

The result presented in the analysis is descriptions by the interviewees of the preventive work at their organizations. As mentioned I was also given additional handbooks by the interviewees, which are also descriptions of preventive work presented in the analysis. I found that all three organizations visited are using volunteers (peer educators) that are living with HIV themselves to connect with and give information about HIV/Aids to people in Kabale and in the villages around.

The HIV counselor at organization 3 answered this to question on how they are giving out information about HIV/Aids to the community:

“We give out information about HIV/AIDS through outreaches, counseling sessions, IEC materials, radio talk shows and through the trained peer educators”

HIV counselor 2011-11-14

The interviewee mentions outreaches in the quote above, outreaches mean that every month they visit villages around the district for counseling, provide information and sometimes even testing, where it can be difficult for people to physically get to town for information and where the health centers in the villages are not available to provide with the right services (Notes, 2011-11-14). IEC materials stand for Information, Education and Communication. This was a part of the Uganda's health education program which purpose was to enhance and development of public education programs and spreading of information to all districts (Slutkin et al. 2006) As also mentioned they also use radio talk shows to tell the public about their activities at the organization (Notes, 2011-11-14).

The relationships of the social capital are more or less really enacted and so maintained and reinforced in exchanges (Bourdieu, 2008). My thoughts about Bourdieus ideas of exchanges are that it can be applied to the work of peer educating, since what the peer educators do is basically to connect and create bonds with people. They exchange knowledge, information and counseling to help raise awareness about HIV and to strengthen the role of the HIV infected people in the Ugandan society.

My interpretation is that through exchanges of knowledge and experiences from the peer educators to the community it could give the community important facts and diminish myths about HIV/Aids by meeting someone who is infected by HIV. It can also mean that for other HIV positive people in the community to feel support and understanding of their situation from the peer educators.

When asked the question to the HIV counselor at organization 1 on how they reach people that are at risk of HIV infection the HIV counselor answered:

“We reach them through outreaches and through their peer educators.”

HIV counselor 2011-10-28

The HIV counselor continued saying that the peer educators have been asked and have agreed to work as volunteers and they have gotten refresh courses about HIV/Aids so that they will be able to provide the people with the right knowledge (Notes, 2011-10-28). My way of thinking considering the quote above when doing outreaches the peer educators with the community are bonding social networks. Social capital is about team spirit and social relationships (Sokratis, 2008). The theory of social capital can be applied to peer education since it is somehow about creating social capital by including people living with HIV into the community as a resource to enlighten and educate about the virus. In this way they are trying to gather the community together and make everyone involved in stopping the spreading of the disease.

According to my observations of the HIV counselors role their function is to mostly be open and available to communicate with people, counseling on questions regarding HIV/Aids health and provide with a good knowledge of how to protect yourself and others from getting infected. They have receptions at the organizations where people can visit them during the day for counseling. The HIV counselor at organization 1 said they try to also visit places like churches, schools etc for giving information about HIV/Aids prevention. They try to take

advantage of great holidays, such as Christmas and Easter where a lot of people gather and give out information by using information tents, about HIV/Aids, condom use and the importance of being faithful to your partner (Notes, 2011-10-28).

Handbook 1 stresses that communities and other patients' organizations often play important roles in supporting adherence through peer monitoring and home visits (ibid). Bourdieu's (2008) theory of the social capital means that social contacts, closeness with family and friends and networks are basics for collective results. According to handbook 1 social support from family, friends, and community and patients organizations is stressed to be very important for treatment preparedness and adherence for medication, which are factors that can result in good health outcomes for HIV positive people (ibid). This can well be applied by the theory of social capital whereas the idea of the community as a field of connections and social networks that can be used to create possibilities for people that are less fortunate, like HIV/Aids positive people.

It is further written in handbook 1 that the ability of patients to follow treatment plans can be affected in a negative way by a variety of factors; this includes stigma and discrimination against them and their families, treatment costs they cannot afford. Therefore handbook 1 stresses that intervention to ensure treatment preparedness and support adherence is very important. Adherence means loyalty for taking the medication which optimizes the effectiveness of ART and can minimize the development of drug resistance. Giving information, education and counseling is according to handbook 1 a major factor to enhance the ability for patients to follow health care recommendations.

The cultural capital we have when it comes to our education, skills and knowledge can be according to Bourdieu important for our pre – understanding and conceptions of things. Bourdieu states that cultural capital acts as a system of exchange, where this capital can be transmitted from parents to their children (Sokratis, 2008). As I understand by reaching and giving the community the proper information and knowledge about HIV/Aids prevention you can avoid misconceptions and myths that are often created around the virus. This could according to my opinion give people possibilities and right tools for how you can protect yourself and your loved ones from getting infected.

The HIV counselor at organization 3 describes the challenges that they may face in their work with HIV/Aids prevention:

“Stigma among the PHAs that hinders people from knowing their HIV status, community mobilization, funds to reach hard to reach places, drug abuse that hinders behavior change process.”

HIV counselor 2011-11-14

Challenges that the interviewee describes are for one physical difficulty. It can be problematic for them to reach people because of long distances and poor roads and therefore it is also difficult for people reaching them. As mentioned by the HIV counselor funds, as to economic resources, can also limit the preventive work. Another factor that the interviewee says can affect the prevention work is stigma, which I discuss more precisely on the section about stigma (page 33). Drug abuse is also mentioned as a challenge which according to the interviewee can affect behavior change amongst people (Notes, 2011-11-14).

5.1.2 Peer educators

As I have mentioned earlier the peer educators play an important role in the HIV prevention work in Kabale. Involvement and membership in groups and social networks, developing within these and the social relations as a result of arising from the memberships can be utilized in efforts to improve the social position of the actors in various fields (Siisiäinen, 2000). In my meaning what the peer educators are trying to do in the society to prevent HIV is also to strengthen the voice and the role of the people living with HIV in the society.

According to previous research and advocates of peer education and peer monitoring argue that it is more reasonable to target the community as a whole rather than the individual for changing behaviors. Peer education was first established as a response to more individual approaches, which were seeking to increase individual's health related behavior skills, rather than the community (Campbell, 2004). I can see the similarity when observing and interviewing the HIV counselors and peer educators about their methods and approach with what Campbell is stating about peer education and that it is more focused on the community as a whole rather than the individualistic approach.

This is how one of the peer educators described their voluntary work:

“We want to find the people who are infected with HIV and their families to make them feel that they are not alone”

Peer educator 2011-11-10

According to Campbell (2004) the theory on peer education is based on that peer educators have an important influence on people's health behavior and people would more likely to change their behavior if they see others that are known and liked by the community are changing theirs. My interpretation of the theory of peer educators that Campbell (2004) is describing is that by using peer educators you could more easily connect with other persons who are infected or affected in others ways by HIV as for the peer educators functions as a role model since having experience from living with HIV themselves. The development of social networks is dependent both on an individual subjective feeling like recognition, respect and communality (Siisiäinen, 2000). My impression is that the peer educators would be able to show that it is possible to turn a negative situation to a more positive one by educating the community and prove that it is possible to still have a quality of life with HIV. By giving something back that is connected to their experience of being HIV infected I believe can make them feel that they are making a difference for the HIV positive people in the community and thereby strengthen their role in society making their voices heard and prevent ignorance and discrimination of people living with HIV. And they can inspire other people living with HIV to do the same. Tengqvist (2007) states that one way to strengthen participation and agency is to focus on people's strengths and healthy sides. The HIV counselor at organization 2 also stressed the importance of teaching people with HIV "positive living". It is about to come to terms with the positive result and to change your negative feelings about it to be more positive and taking control of you own health (Notes, 2011-11-10).

At the interview at organization 2 a peer educator describes the work like this when given the question on what preventive work is to you:

"Giving information, condoms, care and support to PHAs, positive prevention, post test services. Actually all that we do is to reduce new infections among the populations."

Peer educator 2011-11-10

In handbook 2 I found six main tasks for the peer educators to handle when it comes to volunteering.

The main tasks for the volunteers are to:

- Help clients to follow the instructions and their treatment properly.

- Provide information and support for the community.
- Pass on medical help but they should not to give medical advice.
- Help the community to arrange support groups.
- Give the community education about HIV/Aids and ART treatment.
- Help clients set goals and give them a sense of achievement.

(ibid)

According to handbook 2 it is important for the volunteer to make time and to be devoted to the work, and that they are talented in working with people. Handbook 2 suggests that a work plan should be discussed with the volunteer by colleagues to give the volunteer a director of activities to do. It is also written that it is important for the volunteer to live a healthy lifestyle and that they should be of a gentle character so that they can interact and relate to the clients (ibid). Bourdieu's theory focuses on the consequences of sociability and cultural and economic aspects. By the inclusion of a group and the sum of possible resources create networks of people with mutual recognition and common attributes (Sokratis, 2008). The main function as I see it the peer educators function as a recognition factor for other people to recognize themselves in, which makes it easier for the peer educators to talk and get close to them, rather than for example a doctor or even the HIV counselors. Since the peer educators are living with HIV it is an advantage for them to get near to other people that are infected not to be afraid to speak up about their HIV status.

Askheim (2007) writes about the Brazilian educator Paulo Freire. Freire has a theory that empowerment can be an establishment of counter – power. In this version of empowerment you put the most importance in the interplay of the individual life situation and the structural relationships in the society. Freire stresses that the oppressed is oppressed but at the same time they are oppressed by themselves, they are engulfed by the reality that is oppressing them. I think the concept of empowerment can be applied to the preventive work the interviewees have described to me. My impression is that what they are trying to do is to encourage the HIV positive people to take control and change their own situation and inspire other people to do the same. This is close to the term of counter- power in the sense that the oppressed take control of their own situation, also to let the people infected with HIV play a role in changing the negative stigmatized image of them.

Handbook 2 describes the importance of community mobilization and getting people interested in things that affect them. This can therefore help them to make important decisions

for themselves. The handbook 2 encourage the volunteers in addition to helping people to follow health care recommendations to also provide with information about HIV/Aids to the whole community, because it can help to slow down the spread of the disease and raise understanding about HIV. Further the handbook 2 defines and describes the benefits of community mobilization like this:

- When giving information to the community information it can help decrease ignorance about HIV/Aids.
- Helping the community to work together as a team to solve problems means more can be achieved.
- Involving the community means that individuals receive more support and not get left alone with a problem
- If the community learns how a problem such as HIV/Aids affects everyone directly, they can also begin to take responsibility for it and for each other.
- Mobilization can also enhance people's ability to help and think for themselves. In this way the interviewees says they can also learn how to do things without waiting for charity or outside help.

(ibid)

Four different methods for mobilizing the community can according to the handbook 2 be arranged by 1, announcements through churches, mosques, schools and taking advantage of great holidays. 2, word of mouth moving from home to home. 3, arranging drumming and drama groups and 4, health outreaches in the communities. Social capital is formed more or less deliberately via integration into networks. It has no specific material form and it is not transparent, unlike economic capital. According to Bourdieu the amount of active or potential recourses are connected through a possession of a network of permanent relations and of inclusion into a group as a sum of individual action are not only endowed with common attributes but also tied with bonds that are useful and stable (Sokratis, 2008). Like Sokratis (2008) is stating my impression is that the social capital can be said to be the sum of individual action that together creates social networks and groups of people that are cohesive in the sense of mutual recognition amongst each other. As I see it mobilization of groups, like communities fighting HIV are integrations of people trying to gather together to find ways of stopping the spread. In this case I see this is what the peer educators and the HIV counselors are trying to achieve when for example doing the outreaches in the villages.

Rønning (2007) writes that empowerment can also be described as a mobilization of power which means that you transmit the power and strengthen a certain oppressed group. My thoughts are that it can therefore be important for people living with HIV in a society to understand that they are stigmatized and oppressed and as Rønning (2007) says it is also important for these groups to understand that it is not a state of nature and therefore put the power in their hands to change their situation and also take a responsibility of their disease. My interpretation is that they are somehow mobilizing their power as a stigmatized group to educate other people about HIV and make it possible to prevent it from spreading further on.

5.1.3 Stigma

Stigma and discriminations relating to HIV/Aids challenge public health efforts to take on the epidemic. As mentioned earlier aids stigma can affect preventative behaviors in a negative way, like condom use, HIV testing seeking behavior, care seeking behavior on diagnosis, quality of care provided to HIV – positive patients etc. Therefore decreasing Aids stigma is an important step in decreasing the actual epidemic (Brown et al. 2003).

Here is what the HIV counselor at organization 2 said:

“The number one key of stopping HIV to spread is to reduce the stigma and discrimination of those infected with HIV”

HIV counselor 2011-11-10

From the Bourdieuan perspective, the social capital becomes a resource in the social struggles that are carried out in different social arenas or fields (Siisiäinen, 2000). In doing this I see that the peer educators are very important in showing other people that it is possible to live a healthy and good life with HIV and giving them the right knowledge about the virus. According to Askheim (2007) to merge together with other people that are in the same socially disadvantaged situation is an expression of collective empowerment. As I mentioned earlier the handbook addresses stigma as to it can affect a person’s capability to take the ARV treatment because of fear that they will be recognized as having HIV. When getting a positive result there can be many difficulties, for example the handbook writes that stigma can cause negative feelings like guilt, shame and losing hope for the future (Handbook 2).

The HIV counselor at organization 2 said:

“It is important to remove the stigma, to demystify the disease to prevent ignorance and thereby spreading the disease further on. It is also particularly important to be honest and talk about your status to protect those you love from getting infected.”

HIV counselor 2011-11-10

My interpretation of the HIV counselor’s statement is that by preventing ignorance and demystifies the disease you can begin to control the spreading of the virus, as for people to come out instead of keeping it to themselves and make them aware of a responsibility they have not to spread it further on. In my view it is about to give them a sense of being in power of their own situation.

Handbook 2 addresses this problem by promoting openness to talk about sex and sexuality as a way to discuss the issues of HIV. Also to involve people with HIV, like the peer educators, in providing support and information to others people can see positive results of the ARV treatment. Further the handbook 2 states that reducing stigma in the community can be a challenge especially because of different cultural practices. These can be of varying things but handbook 2 addresses these to be mostly common: sharing women among relatives, early marriages of children, wife inheritance, traditional healers deceiving people Aids can be cured, witchcraft (witchdoctors sleeping with clients to cure them). These practices are according to the handbook harmful especially towards women and children (ibid).

The cultural capital of Pierre Bourdieu’s theory can consist of knowledge, experiences, way of talking, way of thinking and how you perceive things (Bourdieu, 2008). As to what I see all of these factors could affect the way people see HIV/Aids, in areas where people have a low level of education it affects how they receive information and their knowledge about the disease and about people infected with HIV which often results in many false prejudices. The cultural capital the adults bring to their children also affects their knowledge about HIV/Aids and the myths and presuppose continues to spread. This is where the HIV counselors and especially the peer educators come in to help reduce these misconceptions and prejudices about HIV/Aids and give support to the people who have HIV. The importance of education is also addressed as an important topic by previous research like Slutkin et al. (2006). The authors describe the public education as being a significant method in decreasing the number of infected in Uganda. According to my observations with interacting with people in Kabale

the educational level is not high amongst people living in rural areas which I think could affect their knowledge about HIV/Aids.

For the reason that Uganda is a country that depends much on voluntary organizations and donations for health clinics, education etc, the resources are often inadequate, which I think also could have an effect on the quality of the work that is being done. This can have an impact on how the conditions of social work are in Kabale but also in Uganda in general. According to my own observations while living in this area where you come from, how well educated you are and how much money you have are also factors that can depend on the quality of the aid you will get when you seek help for health issues. Bourdieu (2008) writes that in a capitalist society the economic capital controls a person's role and status within the general public. This can depend on the education and/or social ties a certain person has. My impression is that for people who support themselves by farming and are living far from the town where the hospitals and health clinics are situated often have problems to physically get there and the aids often also have problems to reach them. My impression is that is why the outreaches are an important task for the peer educators to reach people in the villages that are not as accessible for the HIV counselors. Handbook 2 suggests the peer educators to address this problem by holding meetings with groups that are at risk like young people, women and unfaithful partners to educate them on facts about HIV/Aids with the help of teachers, religious leaders and health workers (ibid).

When visiting organization 1 I met a doctor and happened to engage in a conversation with him about HIV/Aids work. The doctor said that during outreaches in the villages for testing they find that the HIV/Aids prevalence is much lower in the rural areas than in Kabale town, even though he said that the knowledge is much higher about prevention against HIV in town (Notes, 2011-10-28). This can of course have many reasons, for example that there are more people living in Kabale Town than in the villages and a higher flow of other people coming to town, which can increase the risk of the HIV virus to be spread.

I understand their efforts to work towards reducing stigma amongst people living with HIV is through education to understand more about HIV and it's transmission, raise awareness of stigma and discrimination, information about prevention and treatment and support people that are living with HIV. Tengqvist (2007) describes the central approach for the term empowerment as everyone is capable if they are given the right prerequisites, a focus on everyone's equal worth and rights, to give visibility and change power structures so that they

are expressing respect for every man's equal right and equal worth. For this I think the peer educators have a large role in changing the image of HIV positive people in the society by not hiding their disease and live in shame but to expose themselves and encourage other people to do the same. Also empowerment perspective value diversity and that we are all different. Tengqvist (2007) further writes that this means that you takes advantage of peoples differences in experiences and background and consider these differences as an asset. I see this as instead of hiding and blaming HIV positive people the society can use them as resources and focus on what they can contribute to the communities for having the experience of living with HIV.

5.2 Children and Youth

What is shown in previous research, for example in the study made in rural Masaka in northern Uganda by Kinsman et al. (2000) is that strategies to come to terms with the increasing problem of HIV infected people in Sub – Saharan Africa should include promotion of safe sexual behavior and other means for protection against the virus for adolescents and young adults. According to Kinsman et al. (2000) this is because this group tends to be at higher risk of infection than others and education for this age group can make people aware of the individual need to protect themselves (ibid).

My own thoughts about HIV prevention amongst children and youths are that it should be important to educate these age groups in how to protect yourself against getting infected, since these are the next generations coming. Therefore I figure it has to be a very important step in decreasing the epidemic by educating the younger generations how to prevent from getting infected by HIV and thereby reduce the number of infected in the future. I found when discussing and talking with the interviewees that they did not have much interventions and programs directly towards children and adolescents in their activities.

For example the interviewee at organization 3 answered this to the question on how they meet with children in their preventive work:

“Children are brought to the branch by their parents/care givers. We meet them in outreaches or through the organizations/SCOs which take care of them like compassion International”

HIV Counselor 2011-11-14

When asked the question if they have interventions for HIV/Aids prevention towards children the HIV counselor answered:

“Due to lack of resources we don’t have such program or interventions, but we would like to have in the future.”

HIV counselor 2011-11-14

Like the quotations above the answers I got when asking the question on how they meet with children was that they meet with children through outreaches and caregivers and because of inadequate resources they did not have programs directed especially towards these age groups. Therefore I did not get a good picture of how they are supposed to work with children and youths about this issue. As mentioned earlier I therefore decided to turn to school and hand out questioners about HIV/Aids as to try and examine what these age groups may know about this matter. You find the section about the survey on page 38.

Since I had no clear and comprehensive answers from my interviewees regarding HIV/Aids prevention for children that they are working with I have used information about preventive methods for children and youths from handbook 2. It contains suggestions and descriptions of what the peer educators and HIV counselors should do when meeting and interacting with these age groups.

When visiting families in the villages the peer educators meet with children and young people so therefore the handbook 2 provides with different strategies for meeting these groups. For reaching the very young children they are being advised to use playing games, telling stories, acting, singing, dancing, drumming etc. The handbook 2 stress that the non-verbal communication and friendly gestures to be very important otherwise the children can easily become reserved and it can be difficult to have conversation with them and therefore difficult to give them important information.

Handbook 2 also addresses the many problems that HIV infected children and adolescents can face in everyday life. Such problems can be feelings of low self-esteem and depression fearing that they will die, especially if their parents have died as the cause of Aids. It is written in the handbook 2 that these children and adolescents can be treated differently than others also by their families who can mistreat, neglect and blame them for bringing HIV into the family and that they are also sometimes being kept out of school. The handbook 2 stresses that as a result of this it can be a risk that many children develop slower than other children.

As earlier mentioned in the section about stigma the cultural capital is defined by that parents are transmitting attitudes and knowledge to their children (Bourdieu, 2008). Applying this to the importance of HIV/Aids education it is therefore imperative to educate adults, parents and caregivers in HIV/Aids to avoid stigma, discrimination and negative rumors and prejudices about people and children living with HIV. Doing this it might result in passing the knowledge further on to the next generation and so on and thereby increasing the role of HIV positive in society diminishing different myths and ignorance about the disease.

The handbook 2 brings the problems with older children and adolescents and that they can be of a different challenge as they are developing their own identity and independence, therefore the handbook 2 stress it is important not to judge this age group. The peer educators should instead aim to become their “trusted adults” who they can confide in (ibid). When applying Social capital to these ways of handling prevention and children and youths with HIV/Aids it is similar to the idea of creating social bonds and kinship to somehow form a context for these children and youths where they are not feeling alone or defines themselves as outcasts.

5.2.1 The knowledge about HIV/Aids prevention amongst pupils in a primary and secondary school in Kabale. A small survey

I decided on doing this survey since I wanted to get a picture of how the knowledge may be about HIV/Aids prevention amongst children and youths in this area. I was interested in this since the interviewees did not describe any work they do directed towards children and youths in their preventive work and I wanted to look into what they may know about HIV/Aids by doing a small survey amongst pupils in these two schools. As mentioned the survey does not describe any methods for working with HIV/Aids amongst children in Kabale but I figure it is a hint on that there is such work existing in Kabale and that it is fulfilled mostly thorough education about this matter in school. The result of the survey can answer somehow that questions regarding HIV/Aids and prevention are brought up with children but it does not describe how it is being discussed and brought up for example in the classroom, therefore it can be said to be a complement segment to my research questions that are aiming to discuss the methods in use on the matter of HIV prevention. As mentioned that is the reason why I decided not to include this as a research question.

There are currently no resources for having campaigns about HIV/Aids prevention that are directed towards young people, therefore I decided to do this small survey to try and measure how great the knowledge is amongst the youth about HIV prevention. To be able to do this I

decided to reach out to schools, where I figured I would find my target group.

I decided to do a small questioner with questions about HIV/Aids and about prevention. I chose two schools where I handed out the questioner. There were 13 questions for the pupils to answer voluntarily and anonymously. In total there were 68 pupils that completed the questioner, 45 (66.1%) were female and 23 (33, 8%) were male. The questions had a yes or no answer except for question number one that had four alternatives.

Overall the pupils had a good basic knowledge about HIV/Aids and about prevention against the virus. It also shows that the children receive most of the information about HIV/Aids in school. The pupils that had responded divergent on the questions specifically about basic knowledge about HIV/Aids were very few. This could have different reasons for example that they have had gaps in their school attending.

Many of the questions are interpretable for example question number 4 and 8 depends on how you experience it. Being faithful to your partner can protect you from getting infected by HIV if your partner also is faithful and HIV negative. If you chose to stay abstinence from sex you can reduce the risks of getting infected, but you can of course also get infected elsewhere than from having unprotected sex.

Question number twelve is also a question that you can choose to interpret in different ways because condoms are never 100% sure. For example a pupil had answered yes to the question but had written a comment besides the answer “if it is properly used”. This means that if the condom is used in a correct way it can protect you from getting infected.

What the questioner also may show is that it is very important for keeping the children in school for education about HIV/Aids. In Uganda education is not for free so it is very common that children have to leave school due to school fees that parents cannot provide for. It means that for some children there could be a large gap in their educational level on HIV/Aids education as well as other subjects. I think striving for free education in Uganda would be a great way for people to be able to have an education despite where you come from and it would mean more knowledge about HIV/Aids for people all over the country.

You find the complete questioner with the results on Appendix 2.

6. Summarize and conclusion

For this I was also inspired of Sara Axelssons (2011) section about the final summarizes of the case study. I figured this would sum up my questions in a good and comprehensible way.

6.1 Research question number 1; HIV/Aids prevention work in Kabale

What HIV/Aids prevention work is fulfilled in Kabale?

The HIV/Aids prevention work existing in Kabale district has much focus on education, reaching out to people and on counseling. For doing this work the peer educators play a large role in the society as well as the HIV counselors working at the organizations. Their purpose is to raise awareness about HIV/Aids and different ways to protect yourself and others from getting infected. Their center of attention is to find the people that are infected with HIV and the people that are at risk of getting infected.

They provide with support groups and counseling for people living with the virus and encourage them to step forward and not keep their disease to themselves. The idea is to somehow get people united in the fight against the HIV/Aids epidemic. Also reducing stigma and exclusion of people living with HIV is an important matter of decreasing the spread of the disease. Social capital is about networking and building groups within the society that can help neglected groups of people to regain strength and position in the general public (Sokratis, 2008). A sense of being included in a group and in a network to help raise awareness, reduce myths about the virus and education goes hand in hand in the fight against the epidemic. To bring the subject of HIV and education about prevention in the light can reduce the fear and ignorance of the virus and help to promote people to go and test themselves, be faithful and to use condoms.

The peer educators are creating social networks and relationships with the community to enlighten them with HIV/Aids education and prevention. The key factor for helping people that are living with HIV or are affected by the disease in other ways, like family members and relatives of infected persons, are to build up the status and positions of the people who is suffering from the disease. According to Bourdieu people can find that their expectations and ways of living are suddenly out of step with the new social position they find themselves in. But they are also actors making their own choices and their own history (Siisiäinen, 2000). By giving the people the right tools to relief themselves from the pain and the sense of embarrassment and disgrace that many people living with HIV are dealing with on an everyday basis. This can help to remove the stigma around the disease and to slow down the

spread of the virus. The HIV counselors and the peer educators are helping to educate the importance of taking their medication to try to prevent people from misusing and not taking their medicine. Also the adherence of taking their medication (ART) is very important for people living with HIV to stay healthy.

Ovrelid (2007) states that most important is to provide oppressed groups in society with support to create openings in situation that otherwise would have been perceived as closed. Support for HIV infected persons are very important for the processing of finding out that you are HIV positive and learning how to deal with the fact it is a disease that has to be carried for life. The most central of the support for people infected with HIV is the meetings and the hospitality of these people. It is for most people a life changing moment and many times it is the stigma around the virus that is most difficult to deal with.

6.2 Research question number 2; Methods

Which methods do different organizations use in their preventive work?

How they accomplish their work with preventing HIV/Aids in the communities are for one the outreaches. When doing the outreaches they can find and communicate with people that they normally do not meet mostly in the rural areas, because of difficulties to reach them and for them to reach to the HIV counselors at the hospitals in town. They also get invited to schools, churches and great holidays for example Christmas and Easter where a lot of people gather for giving education and information about the virus, by putting up information tents.

The peer educators engage themselves in community mobilization. Community mobilization means getting people involved and dedicated in the people living within their community. The peer educators give them tools for being in power of changing their situation for the better and education about HIV/Aids is the number one key for raising understanding about the disease and the people that are affected by the disease. Ovrelid (2007) writes that the individual has a responsibility for his or hers life. But it is also a role of the society to help and support the individual's initiative, where the individual has a co – responsibility. Since the peer educators are living with HIV themselves it is easier for them to connect with other people infected by the virus that often have feelings of shame and self – loathing. With support from the peer educators they can also be inspired to do the same and replace the negative feelings with a sense of responsibility and empowerment.

6.3 Conclusion

The capitals from Pierre Bourdieu's theory and especially the social capital has become useful for me in my case study for understanding the material that I collected from my time in Kabale, Uganda. By applying the capitals on the methods of the local work with preventing HIV/Aids in this area it makes the different roles, groups and other processes more transparent which is needed to get a deeper understanding of the society in general.

The capitals can also make us understand why the HIV/Aids prevention work is organized as it is. The capitals can also show the resources and in this case the lack of resources and how that affects the social work, than for example in a western country where the resources are not as limited.

The success of decreasing the HIV/Aids epidemic in Uganda is remarkable and as for my case study shows that the key factors of keeping the HIV epidemic in control is community mobilization, education and together reduce the stigma around the virus. By giving the community a sense of empowerment, possibility and giving those tools and support for changing their community and their family they can move towards a brighter future without HIV.

7. References

- Andersson, Gunvor & Swärd, Hans (2008) "Etiska reflektioner", in Meeuwisse, Anna, Swärd, Hans, Lappalainen – Eliasson, Rosmari & Jacobsson, Katarina (Red.) *Forskningsmetodik för socialvetare*. Stockholm. Natur och Kultur
- Askheim, Ole Petter (2007) "Empowerment – olika infallsvinklar", in Askheim, Petter Ole & Starrin, Bengt (Red.) *Empowerment i teori och praktik*. Malmö. Intergraf AB
- Aspers, Patrik (2011) *Etnografiska metoder*. Malmö. Författarna och Liber AB
- Axelsson, Sara (2011) "It's not what you know it's who you know" *A Minor Field Study about a Philippine cooperative*. School of Social Work, Lund University
- Bourdieu, Pierre (2008) "The Forms of Capital", in *Readings in Economic Sociology* (ed N. W. Biggart). Oxford, UK. Blackwell Publishers Ltd
- Brown, Lisanne., Macintyre, Kate & Trujillo, Lea (2003) "Interventions to reduce HIV/Aids stigma: What have we learned?" in *Aids care and prevention*, vol. 15, No 1. pp 49-69
- Bryman, Alan (2011) *Samhällsvetenskapliga metoder*. Malmö. Liber AB
- Campbell, Catherine (2004) "Creating environments that support peer education: experiences from HIV/Aids prevention in South Africa" in *Health Education*, vol. 104 Iss, pp 197-200
- Duffy, Lynne (2005) "Suffering, Shame and Silence. The Stigma of HIV/Aids" in *Journal of the associations of nurses in Aids care*, vol. 16, Iss 1, pp 13-20
- Green, Edward C, Halperin, Daniel T, Nantulya, Vinan, Hogle Janice, A (2006) "Uganda's HIV Prevention Success: The Role of Sexual Behavior Change and the National Response", in *Aids and Behavior*, vol. 10, No 4, pp 335-346
- Jackobsson, Katarina & Meeuwisse, Anna (2008) "Fallstudieforskning", in Meeuwisse, Anna, Swärd, Hans, Lappalainen – Eliasson, Rosmari & Jacobsson, Katarina (Red.) *Forskningsmetodik för socialvetare*. Stockholm. Natur och Kultur
- Kinsman, J, Carpenter, L, Nakiyingi, J, Kamali, A, Pool, R, Quigley, M & Whitworth, J (2000) "Evaluation of a comprehensive school-based AIDS education programme in rural Masaka, Uganda", in *Health Education Research*, vol. 16, Iss 1, pp 85-100

Michielsen, Kristien, Bosmans, Marleen & Temmerman, Marleen (2008) "Reducing HIV/AIDS in young people in Sub-Sahara Africa: gaps in research and the role of theory", in *Africa Focus*, vol. 21, No 1, pp 31-43

Ministry of Health, Republic of Uganda (2012-06-10) Available at:
<http://health.go.ug/mohweb/>

Parker, Richard G (1996) "Empowerment, community mobilization and social change in the face of HIV/AIDS", in *Aids*, vol. 10, No 3, pp 27-31

Rönning, Rolf (2007) "Brukarmedverkan och empowerment – gammalt vin i nya flaskor?", in Askheim, Petter Ole & Starrin, Bengt (Red.) *Empowerment i teori och praktik*. Malmö. Intergraf AB

Slutkin, Gary, Okaware, Sam, Naamara, Warren, Sutherland, Don, Flanagan, Donna, Carael, Michael, Blas, Erik, Delay, Paul & Tarantola, Daniel (2006) "How Uganda reversed its HIV Epidemic", in *Aids and Behavior* vol. 10, No 4, pp 351-360

Siisiäinen, Martti (2000) *Two concept of social capital: Bourdieu Vs. Putnam*. ISTR Fourth International Conference "The Third Sector: For What and for Whom?" Trinity College, Dublin, Ireland July 5-8, 2000

Sokratis, Koniordos (2008) "Social capital contested", in *International review of sociology*, vol.18, No. 2, pp 317-337

Sweden Abroad (2012-04-23) Available at:
http://www.swedenabroad.com/Page_____29622.aspx

Okware, Sam, Opio, Alex, Musinguzi Joshua & Waibale, Paul (2001) "Fighting HIV/Aids: Is success possible?", in *Bulletin of the world health organization*, vol. 79, No 12, pp 1113-1120

Ovrelid, Bjarne (2007) "Empowerment är svaret med vad är frågan?", in Askheim, Petter Ole & Starrin, Bengt (Red.) *Empowerment i teori och praktik*. Malmö. Intergraf AB

Tengqvist, Anna (2007) ”Att begränsa eller skapa möjligheter – om centrala förhållningssätt i empowermentarbete”, in Askheim, Petter Ole & Starrin, Bengt (Red.) *Empowerment i teori och praktik*. Malmö. Intergraf AB

Vetenskapsrådet (1990) *Forskningsetiska principer inom humanistisk och samhällsvetenskaplig forskning*. Available at: <http://www.codex.vr.se/texts/HSFR.pdf> (2012-06-01)

Visser, Mareth J (2007) “HIV/Aids prevention through peer education and support in secondary schools in South Africa”, in *Sahara J (Journal of social aspects of HIV/Aids)*, vol. 4, No 3, pp 678-694

(2011-10-28) Notes from interview with HIV counselor at Organization 1

(2011-11-10) Notes from interview with HIV counselor and peer educators at Organization 2

(2011-11-14) Notes from interview with HIV counselor at Organization 3

(Handbook 1) *Joint Clinical Research Centre. Lesson from designing, implementing ART adherence programs in resource limited settings. The JCRC experience*. Joint Clinical Research Center, Ministry of Health

(Handbook 2) *Joint Clinical Research Centre. Community Liason Volunteer. Handbook*. Joint Clinical Research Center, Ministry of Health.

Appendix 1; Interview guide

Description of organization

- Describe your organization.
- What are you doing for preventing HIV/Aids on a local basis?
- What are the resources and the local conditions that make it possible for you to work with preventing HIV/Aids amongst people?
- How did you decide on the specific structure of the organization?
- How does your financial structure work?
- Why did you choose to use that design?

Description of methods

- How are your work organized with preventing HIV/Aids amongst the people?
- How are you giving out information about HIV/Aids?
- How are you reaching out to people/children that are at risk of HIV infection?
- How are supports giving to people/children infected with HIV/Aids?
- What is preventive work to you?
- How do you make up your mind about what is a possible way of meeting the problem at hand?
- What is a good intervention in your view?
- What are the struggles and challenges you may face in your work?

Appendix 2; Questioner

Questioner: HIV/Aids prevention knowledge amongst Primary & Secondary students in Kabale, Uganda

Result of questioner

1. Where have you gotten the most information about HIV/Aids and how you can protect yourself and others from getting infected?

School : 72 %

Friends: 4,4%

Church: 2,9%

Other: 20,4% (divided between media, school & friends and school & church)

2. Do you think you know better about HIV/Aids prevention than your parents or other older persons around you?

Yes: 44%

No: 56%

3. Does the HIV – virus make a person more vulnerable to other infections?

Yes: 92,6%

No: 7,3%

4. Does abstinence protect you against being infected with HIV?

Yes: 94,1%

No: 5,8%

5. Is HIV a virus that causes Aids?

Yes: 98,5%

No: 1,5%

6. Is there a cure against Aids?

Yes:

No: 100%

7. Can you for example get Aids from sharing the same glass of water with someone who is HIV – infected?

Yes: 23,5%

No: 76,4%

8. Can you protect yourself from getting infected with HIV by being faithful to your partner?

Yes: 86,7%

No: 11,7%

9. Can you get Aids from sharing the same needle with an HIV infected person?

Yes: 94,2%

No: 5,8%

10. Can Aids be transmitted from mother to child?

Yes: 98,5%

No: 1,5%

11. Do you think you can see if a person carries the HIV – virus depending on how the person looks, dresses and/or acts?

Yes: 17,6%

No: 82,4%

12. Do condoms protect you from getting infected by HIV?

Yes: 73,5%

No: 26,5%

13. Can you live a long and healthy life with HIV/Aids with the right medication and healthy living?

Yes: 85,2%

No: 14,7%
