Children's voices about HIV/AIDS-related stigma in Uganda

A descriptive study of adolescents experience of stigma

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Abstract:

The aim of this study is to get an understanding of how children express HIV/AIDS-related stigma and the possible challenges it causes due to cultural factors that influence stigmatization in children in Uganda. In this study I also want to investigate if the Convention on the Rights of the Child is or can be taken into consideration in Uganda to protect children with HIV/AIDS from stigmatization.

The research questions are: How do children in Uganda with HIV/AIDS express their experiences about HIV/AIDS-related stigmatization? Which cultural factors in Uganda affect HIV/AIDS-related stigmatization in children? Can the Convention on the Rights of the Child (CRC) be used in Uganda to protect stigmatized children with HIV/AIDS?

Leininger´s Sunrise Model Enabler and the Convention on the Rights of the Child are used as frameworks. In the study Leininger's ethnonursing method as a qualitative research method was used. Data collecting has been carried out twice by group interviews with eight key informants and once by one-to-one interviews with three general informants. The data analysis was carried out using Leininger's Phases of Ethnonursing Qualitative Data Analysis.

The results show that for the informants stigmatization is the way society treats the children, stigmatization is when the church punishes the children, stigmatization is a lack of information and acknowledgment, stigmatization is a lack of resources and stigmatization is when the CRC is not used to protect the children.

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Titel och undertitel:

Barns röster om HIV/AIDS-relaterat stigma i Uganda

En deskriptiv studie om barns erfarenheter av stigma

Sammandrag:

Syftet med denna studie är att få en förståelse för hur barn uttrycker HIV/AIDS-relaterat stigma och de möjliga utmaningar som beroende av kulturella faktorer påverkar stigmatisering av barn i Uganda. Genom denna studie vill jag också ta reda på om Konventionen om barns rättigheter tas eller hur den kunde tas i beaktande i Uganda för att skydda barn med HIV/AIDS från stigmatisering.

Forskningsfrågorna är följande: Hur uttrycker barn i Uganda med HIV/AIDS sina erfarenheter av HIV/AIDS-relaterad stigmatisering. Vilka kulturella faktorer i Uganda påverkar HIV/AIDS-relaterad stigmatisering hos barn? Kan Konventionen om barnets rättigheter användas i Uganda för att skydda barn med HIV/AIDS från stigmatisering?

Leininger´s Sunrise Model Enabler och Konventionen om barnets rättigheter utgör studiens referensram. I studien har den av Leininger utvecklade kvalitativa ethnonursing metoden använts. Datainsamling har skett två gånger via fokusgrupp intervjuer med åtta nyckel-informanter och en gång via personliga intervjuer med tre allmänna informanter. Vid databearbetning har Leiningers Phases of Ethnonursing Qualitative Data Analysis använts

Resultatet av studien visar, enligt informanterna, att stigmatisering är hur samhället bemöter barnen, stigmatisering är när kyrkan bestraffar barnen, stigmatisering är bristande information och okunskap, stigmatisering är bristande resurser och stigmatisering är när Konventionen om barnets rättigheter inte används för att skydda barnen.

Nyckelord: Barn, ungdomar, HIV/AIDS-relaterat stigma, diskriminering, kultur, sjukvård, Uganda, Konventionen om barnets rättigheter.

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Chapter 1

Introduction

"There is no task more important than building a world in which all of our children can grow up to realize their full potential, in health, peace and dignity." (Kofi A. Annan, 2001)

To travel and learn to know people from other cultures has always been a big interest for me. Through this interest I have visited Uganda three times. During every visit I have met children infected with or affected by HIV/AIDS. These children are a vulnerable group. Mogwanja (2005) confirms that many people see HIV/AIDS as an issue that mostly impacts adults; nevertheless children are among the most vulnerable victims of AIDS in the developing world. Today there are about 150 000 children (0-18 years) infected with HIV/AIDS all over the world. An estimated 40 Ugandan children are newly infected each day. That means there are a lot of children at risk of HIV/AIDS-related stigma. Duffy (2005) maintains that HIV/AIDS is no longer merely a medical problem but a social and economic one that affects countries and their future. Focus is still on adults when it comes to testing, counseling and medication of HIV/AIDS.

Uganda with a population of 25-30 million is one of the countries worst hit by HIV/AIDS. Uganda is always mentioned as the country in Sub-Saharan Africa that has been a forerunner when it comes to prevention of HIV/AIDS. In Uganda the political support on HIV/AIDS-related questions has been strong since the early 1980s. Bertozzi, Padian, Wegbreit et al. (2006) maintain that people in Uganda have actively tried to fight stigma and discrimination and they have also tried to focus on youth.

Uganda ratified the Convention of the Rights on the Child on 17th August 1990. Because of that the Ugandan government is committed to protecting and ensuring children's rights and having the best interests of the child at heart. The CRC is the first legally binding international

instrument that incorporates the whole spectrum of human rights. The CRC stipulates that a child is a human being even below the age of eighteen with the full range of rights (Unicef, a). All countries in the world except USA and Somalia have ratified the CRC.

During my first stay in Uganda, 2003, I worked in a mobile clinic for children infected with and affected by HIV/AIDS. Those children were treated well, but still I experienced that many of the children among other things were emaciated, neglected, had no access to health care and several were affected by the ongoing war in the Northern part of Uganda. I also saw the problems that face the children's HIV/AIDS-status both in the clinic and with the families. Even though Uganda has been aware of the HIV/AIDS situation, I could see at grassroots level that there existed HIV/AIDS-related stigmatization. Several authors (Shonfeld, 2000; Strode & Grant, 2001) emphasize that there is a need for further research on the development of attitudes, fears and stigma in children and adolescence and that no original research exists on this subject.

Data for this qualitative study will be collected in the rural area in Uganda in one of the sub-counties in the Tororo district. As a framework in this study Leininger's (1991) Cultural Care Diversity and Universality Theory visualized in the Sunrise Model Enabler and the Convention of the Rights of the Child (Unicef, b) will be used. The research method will be Ethnonursing and, as a data collection method, I will use focus group interviews and one-to-one interviews. As a data analysis method, Leininger's (1991) Phases of Ethnonursing Qualitative Data Analysis will be used.

1.1 Scope of the study

Through the experiences of working in Uganda with children infected with and affected by HIV/AIDS I have seen as already mentioned that there are children having HIV/AIDS-related stigma at grassroots level. My intention with this study is to find out more about stigmatization of children with HIV/AIDS in a rural area of Uganda. By informing about the results of this study it will be possible to reach out with new knowledge and understanding for the children's situation and make stigmatizing factors visible. In this way it also will be possible to reach out and help the children to make their voices heard.

Through their work nurses have an excellent position in society and in that way good possibility to reach out to the children with HIV/AIDS. Nurses can play an important role in building bridges between persons with influence in the area of HIV/AIDS and to local people that enhance understanding of the contextual issues of children's lives. Duffy (2005) maintains that tearing down walls of misunderstanding, fear, stigma, and discrimination must be part of any health promotion effort, while building supportive environments that eliminate unnecessary suffering from AIDS. A helpful support for nurses in Uganda to build these bridges is to refer to the Convention on the Rights of the Child. The Ugandan government has ratified the CRC and in that way is committed to protecting and ensuring children's rights and having the best interests of the child at heart.

Even in the industrialized countries there are children suffering from HIV/AIDS-related stigma. For that reason another intention with this study is that the results could be a help for nurses in their work to gain awareness of the children's situation when they are taking care of them. Nurses in industrialized countries could also be helpful in building bridges and in that way provide understanding about children with HIV/AIDS-related stigmatization. In doing so nurses in the west could be helpful in showing that HIV/AIDS-related stigma in children is a worldwide problem and not just a problem for Africa and other developing countries.

1.2 Aim and problem definition

The aim of this study is to get an understanding of how children express HIV/AIDS-related stigma and the possible challenges it causes due to cultural factors that influence stigmatization in children in Uganda. Through this study I also want to find out if the Convention on the Rights of the Child is or can be taken into consideration in Uganda to protect children with HIV/AIDS from stigmatization.

Research questions:
1. How do children in Uganda with HIV/AIDS express their experiences about HIV/AIDS-related stigmatization?
2. Which cultural factors in Uganda affect HIV/AIDS-related stigmatization in children?
3. Can the Convention on the Rights of the Child be used in Uganda to protect stigmatized children with HIV/AIDS?

1.3 Organization

In the second chapter cultural and social structures in Uganda and in the Tororo district and the everyday life for children in Tororo are described as a background for the study.

The theoretical framework for Leininger's Cultural Care Theory visualized in the Sunrise Model Enabler and the Convention on the Rights of the Child are presented in the third chapter.

In the fourth chapter research related to factors that increase and reduce HIV/AIDS-related stigma are presented.

The ethnonursing method as a qualitative research method, data collection with focus group interviews and individual interviews are presented in the fifth chapter. Also the data analysis method, conducting of the study and ethical guidelines are presented here.

The sixth and seventh chapters respectively present and discuss the findings.

Finally, a critical review and conclusion are given in chapter eight.

Chapter 2

BACKGROUND

Children with HIV/AIDS living in Uganda and in this study specifically the Tororo district still live in conditions that are strongly influenced by the culture. Because Tororo is a rural area cultural values, beliefs and life ways are still strongly traditional. This implies that those children with HIV/AIDS risk becoming stigmatized. Strode and Grant (2001) maintain that it is frequently argued that stigma of and discrimination against children and youths infected with and affected by HIV/AIDS is a characteristic of the HIV/AIDS epidemic in many countries, particularly in the developing world. Most of the time, stigma and discrimination faced by children, youths and their guardians go unreported.

2.1 Cultural and social structures in Uganda and the Tororo district

There is no one Ugandan culture. In fact there are as many cultures as there are peoples. Nzita and Mbaga (1997) mention that there is no precise definition of culture but culture is the total sum of people's way of life. This includes norms and values of a society such as kinship, religion, education, health care, politics, economics and technology.

Tororo is one of Uganda's 56 districts and consists of 55 sub-counties. The major town is Tororo Town. The district comprises 560 000 people, of whom 500 000 live in the rural area. The main language in Tororo is Japadhola. In Uganda diverse cultural groups speak more than 33 languages but the main language is English. Uganda contains over 18 distinct ethnic groups and several religions. Life expectancy is 40 years for males and 41 years for females. (CRC/C/65/Add.33.5).

Uganda's economy relies heavily on rain-fed agriculture and constitutes the largest sector of the economy and a major source of income for over 80% of the people. In Uganda 44 per cent still live below the poverty line on less than US$ 1 per day. The main categories of people most vulnerable to increasing poverty in Uganda include people without land and widows and their families. (CRC/C/65/Add33.5; Unicef, c).

Only 42 per cent of Uganda's 5,152 parishes have any form of health facility. Problems seeking medical treatment include long distances to health facilities, transportation and negative attitudes of health care providers. (Garbus & Marseille, 2003). In Tororo there are 341 primary schools, 31 secondary schools, 6 technical institutions, and four teacher training colleges. There are seven health centers and two hospitals. One of the major problems of the district is water shortage. (Rwabwoogo, 2002). The average literacy rate is 54 per cent with only 15 per cent of the population having completed the fourth year of secondary education. (CRC/C/65/Add.33 5).

The above mentioned cultural and social structures in Uganda especially in the rural area of Tororo will have a big impact on the children's everyday life when it comes to HIV/AIDS-related stigma. The everyday life for the children will be presented in the following section.

2.2 Everyday life for children with HIV/AIDS in the Tororo district

The extract from an interview I did in Uganda in November 2006 with one of the general informants will best describe how the social situation in Tororo villages still causes the HIV/AIDS epidemic to continue and how kinship and social factors ensure that discrimination and thus stigmatization continue even in everyday life for children affected by HIV/AIDS.

> *Now like in the community here AIDS is spread in so many ways. One way is when people have parties somewhere, people will drink, get drunk and they forget that AIDS is there. Yeah, the youths are also like that, mostly the boys. When a boy knows that he is infected, he tends to infect every girl in the area. He says "I cannot die alone". They are many boys who are doing it, it's common. In funerals people come from different villages. They are sleeping outside there, some come with other intentions and they maybe have to get married. When youths have decided to get married there is no matter if the person is HIV positive or not and when they are ready to get married the youth will say "I never go for test three times". No they are never patient. (General informant).*

> *Another cultural thing that spreads HIV so much is when one's husband dies, other men around are there and they are coming to stay together. From there HIV is going to be spread. Another thing is circumcision; there are some communities which circumcise. They do it just culturally nearby. They have to use a knife and they don't paralyze the penis, they just cut. They can decide that they are cutting ten or twenty people. They will use the same knife for cutting all those people. It's common in Uganda even for women. Now there is also another cultural practice; they get a knife and they cut girls on the stomach. They cut to make some shapes and they can decide to take twenty girls in a day. That can also spread HIV. And they are removing the teeth. In some communities some ladies remove teeth from other females. Some of them are just around here. They are breaking ears here with the needles, they put needles in their ears and that can spread HIV. The women always seek advice and they always listen but the men just ignore. (General informant).*

It will be clear from the above extract that girls are especially exposed to HIV/AIDS-related discrimination. A number of girls initiate sex early and with older partners and therefore young girls are at a higher risk of HIV infection and more vulnerable. In Tororo polygamy is still common. Garbus and Marseille (2003) point out that about 32 per cent of married women in Uganda are in polygamy unions.

Another big risk for being discriminated and stigmatized in Tororo is the big number of orphans. Cabrera, Pitt and Staugård (1996) maintain that many orphans are looking after themselves. Such children have four destinations: a) staying on in their parents' house to look after themselves often with relatives living a short distance away, with the partial aim of protecting their rights to the house and land, b) going to grandparents or uncles and aunts, c) going to more distant relatives or to non-relatives or d) going into some kind of institutional care.

Many children in Tororo who have become orphans – due to their parents dying of AIDS - are being taken care of by relatives. Ugandan policy is that orphans should be taken care of by families instead of being placed in institutions. Garbus and Marseille (2003) maintain that orphan guardians are under considerable strain and many households do not have sufficient resources to take in more children. Many guardians are in poor health; some are HIV-positive. Child-headed households as a result of AIDS-related orphanhood are particularly vulnerable.

Some orphans may be vulnerable to sexual abuse, thereby increasing their vulnerability to HIV. Family-based sexual abuse of young children is often denied since there is very little scientific evidence. In part this is due to the stigma and fear of being labeled which may have a lifelong impact. In the late 1990s, HIV/AIDS-related discrimination, stigma and denial were declining, but it was still high, particularly in relation to family and community attitudes toward people living with HIV/AIDS. (Sengendo & Sekatawa, 1999; Garbus & Marseille, 2003).

Nevertheless it is important to point out that there are many families doing their best to take good care of their children with HIV/AIDS. Hartley, Ojwang, Baguwemu, Dbamulira, and Chavuta (2005) mentioned that there are many children with disabilities who are included, loved and cared for by their families in Uganda.

Religion is a part of people's everyday life in Tororo. Religion gives the people hope and security. Garbus and Marseille (2003) maintain that religious organizations have a long history of providing health services in Uganda and are highly influential. The early and significant involvement of Protestant, Catholic and Muslim leaders was crucial to combating HIV/AIDS. Catholicism is the major religion but people from different religions are living side by side in peace. The religions are strongly influenced by traditional beliefs that also influence the way people meet children with HIV/AIDS.

The primary education policy now allows free education for all children in each family including all girls (Unicef, c). The HIV/AIDS epidemic is still decimating the education system. Many teachers are becoming victims of AIDS. The Ugandan government points out the importance of education for these children who are HIV positive since they will live long enough due to antiretroviral drugs (ARVs) and remain healthy enough to be sexually active for many years (avert.org). Girls are the ones that often stay at home to care for sick relatives. A lot of children work and the majority are child domestic workers in urban areas. Cabrera et al. (1996) maintain that there is evidence of fostered AIDS orphans probably being removed from school on the grounds that there is no one supporting them. Evidence also suggests that the family structure, although under great pressure, can provide care although many families need some economic support to do so.

Uganda was one of the first developing countries to encounter HIV/AIDS (Okware, Opio, Musinguzi & Waibale 2001). In Uganda there has always been political openness and honesty about the risks of HIV/AIDS and how they might best be avoided. One of the first important responses to the AIDS crisis was the establishment in 1986 of the National AIDS Control Programme and the establishment in 1992 of the Uganda AIDS Commission. These have included among others: widespread HIV/AIDS education campaigns, care for children orphaned by the epidemic, provision of condoms. The government has enacted a national multisectoral policy on HIV/AIDS that stipulates that all Ugandans have an individual and collective responsibility to be actively involved in AIDS control activities (Monico, Tanga, & Nuwagaba (2001). The government encourages and supports all organizations and institutions that have put anti-HIV/AIDS programmes in place; this governmental support has born fruit (Tayeebwa, 1998). Since June 2004 all people with AIDS have been promised and expect to

receive free drugs from the Government by the middle of 2005, even children, with AIDS. Priority will be given to the poor (avert.org).

The culture in the Tororo district still seems to have a big influence on children's everyday lives and there are several cultural factors that could be stigmatizing for children with HIV/AIDS. At a political level in Uganda many preventive measures have already been put into action to try to reduce the risk of stigma and discrimination in children. At grassroots level there is still a big risk for stigmatization due to the HIV/AIDS situation.

As a part of the frameworks presented in the next chapter Leininger's (1991) Sunrise Model Enabler will aim to survey possible cultural factors that could be stigmatizing for children with HIV/AIDS in Tororo. The impact of the Convention on the Rights of the Child as a stigma-reducing factor and provider of support for children with HIV/AIDS will also form part of these frameworks.

Chapter 3

FRAMEWORKS

This study was done in a Ugandan culture and that is why it was natural to search for nursing theories about other cultures. I have chosen Leininger's (1991; 1997) theory of Cultural Care Diversity and Universality because the purpose and goal of the theory is to use research findings to provide culturally congruent, safe and meaningful care. Care is embedded in culture as an integral part of culture that challenges nurses to understand both care and culture together. It was in the mid-1950s while working with disturbed children that Leininger (1991) discovered the importance of culture in the care of children with different cultural backgrounds. Leininger (2002) and Leininger and McFarland (2002; 2006) write that the structure of the theory is visualized in the Sunrise Model Enabler. From Leininger's (1991) theory I have used this Sunrise model enabler as a framework (Leininger & McFarland, 2006) to survey possible factors that can affect children's HIV/AIDS-related stigmatization.

I have also used the Convention on the Rights of the Child (CRC) as a framework because the Ugandan government ratified the CRC immediately when it came into use. My intention is that I want to examine how the CRC potentially could protect the children in Tororo from HIV/AIDS-related stigmatization. In this study all key informants were within the CRC limits because they were all below 18 years. Through some of the 54 articles that the CRC is based on all key informants should have every possibility to live without being stigmatized in Uganda today.

3.1 Leininger's Sunrise Model Enabler

Leininger and McFarland (2002) state that, in general, the Sunrise model enabler is an invaluable guide to discover new knowledge or to confirm knowledge of cultural informants. "Let the sun rise and shine" figuratively means to have researchers open their minds to informants to discover many different factors influencing care in their culture with the meanings and ways they influence the health and well-being of people.

Culture refers to the learned, shared and transmitted knowledge of values, beliefs and life ways of a particular group. Closely related to culture is a sub-culture which can, for example, be persons infected with HIV/AIDS. (Leininger & McFarland, 2002). The children with HIV/AIDS in Uganda are a part of the Ugandan culture but they also belong to a sub-culture. In this case because the children have AIDS or are HIV-positive they are at risk of being stigmatized.

When using the Sunrise model enabler it is important to state that the researcher begins with her domain of interest or inquiry, so she may start the discovery process anywhere. The researcher can use the enabler with flexibility and in creative ways as one study and remain sensitive to the individual, group, family, culture, or community being studied. (Leininger, 1991; Leininger & McFarland 2002). In trying to understand different factors of the Ugandan culture that can influence stigmatization in children with HIV/AIDS I have chosen the top part of the Sunrise model enabler (Leininger & McFarland, 2006) in Figure 1, where Leininger describes important cultural factors for understanding different cultures.
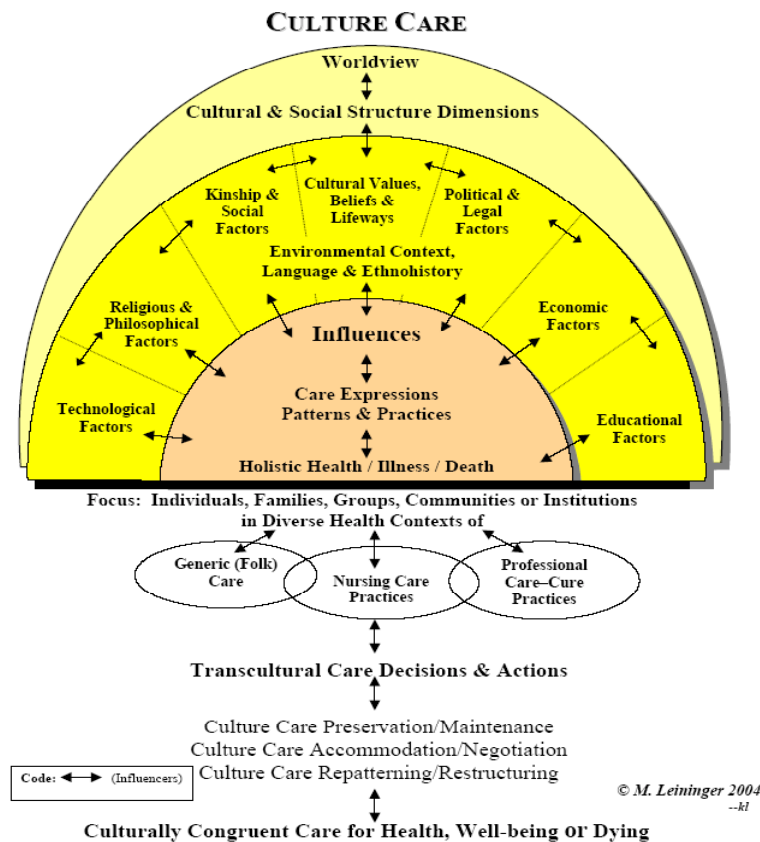

Figure 1. Sunrise Model Enabler to discover culture care. (Leininger & McFarland, 2006)

Leininger describes the cultural factors in the enabler as a) technological, b) religious and philosophical, c) kinship and social, d) cultural values, beliefs and life ways, e) political and legal, f) economical and g) educational factors. The enabler assists the researcher to get a holistic view of cultures, not just nursing diagnoses, symptoms and medical views. (Leininger, 1991; Leininger & McFarland, 2002). In using the enabler I try to grasp all the cultural factors that can affect children's stigmatizing in a Ugandan context and use these factors when developing the questions in the interview guide (see enclosure 1).

Leininger's method of generalizing her research findings by making lists of the cultural care values, meanings and action modes of each culture studied has been criticized by Andrews and Boyle (1999). First, it may result in a stereotypical view of a culture, which is not relevant if we consider the multiple realities existing in present-day cultures. Second, it does not consider the variation within cultures, including disability, socio-economic status, gender, age, religion or education, which influence the ways in which people express their cultural orientation. Third, every belief and behaviour has both cultural and individual determinants.

Andrews and Boyle (1999) continue by stating that transcultural nursing has been criticized for its definitive, theoretical and practical limitations. Colour, religion and geographic location are most often used to narrowly define culture and highlight cultural diversity, which is often portrayed as a minority or majority issue. Discrepancies in definition arise when you fail to recognize that every person has a cultural heritage. Transcultural nursing has also been criticized for embracing models based on the assumption that understanding one's own culture and the cultures of others creates tolerance and respect for people from diverse backgrounds. It has become apparent that the mere awareness of one's own culture and those of others is insufficient for the alleviation and potential eradication of prejudice, racial, ethnic or cultural conflicts, discrimination or ethno-violence.

Regardless of the criticism of Leininger's (1991) theory I have chosen to use Leininger's (1991) Sunrise Model Enabler because I find the model very useful for exploring and explaining different factors of the culture in Tororo that could possibly be stigmatizing factors for the children with HIV/AIDS.

In this study I was also interested in analyzing how the Convention on the Rights of the Child could be used to provide help to reduce stigmatization in children with HIV/AIDS. The fol-

lowing section gives a short presentation of the CRC and articles in the CRC that consider children with HIV/AIDS-related stigmatization.

3.2 Convention on the Rights of the Child

This is the most important international instrument on the rights of children and youths. The Convention on the Rights of the Child emphasize that every child, regardless of birthplace, race or ethnic group, has an equal right to become a productive member of society. The CRC is based on what are called the four basic pillars of children's rights: non-discrimination, survival and development, application of a child's best interests in all circumstances, and participation by the child. (Unicef, d).

The CRC does not specifically refer to HIV or AIDS but its provisions are broad enough to protect children and youths infected with and affected by HIV/AIDS. Strode and Grant (2001) mention that the UN Commission on Human Rights has recently passed a resolution stating that the term "other status" in international non-discrimination provisions should be interpreted to cover health status including HIV/AIDS.

Since ratification in 1990 Uganda has provided several reports for the Committee on the Rights of the Child. The Committee is concerned and recognizes in one report that discrimination against certain groups of children still exists in practice, particularly with regard to girls, children living in poverty and children infected with or affected by HIV/AIDS (CRC/C/UGA/CO/2). In another report (CRC/C/65/Add.33 5) the Government of Uganda has translated the CRC into national legislation. Various articles in the CRC concerning children with HIV/AIDS are presented emphasizing this national legislation.

In articles 2 and 3 it is stipulated that the children should be protected from unfair discrimination or punishment and that the interests of the child should be a primary consideration. The Ugandan government emphasizes the importance of taking adequate measures to guarantee the principle of non-discrimination and its full compliance and to adopt a comprehensive strategy to eliminate discrimination on any grounds against all vulnerable groups. Article 6 stipulates that every child has the inherent right to life and ensures the survival and development of the child.

Article 9 ensures that a child shall not be separated from parents against their will, except when such separation is necessary for the best interests of the child such as one caused by abuse or neglect of the child by the parents. The Ugandan government ensures that children may not be separated from their families or persons entitled to bring them up against the will of their families or those persons except in accordance with the law. Where the child is placed in an approved home or in a foster home the warden has the responsibility of ensuring that communication is maintained with the parents of the child.

In articles 12 and 13 it is stipulated that all children also have the right to be heard and that each child shall have the right to freedom of expression including freedom to seek, receive and impart information. The Ugandan government wants to ensure that children's views are given due consideration in families, schools and the courts. Children are also free to join associations and participate in peaceful assemblies. Many schools in Uganda today provide children with an opportunity to access information and to discuss issues of interest. Such opportunities are limited to children in schools, especially within urban areas.

Articles 14 and 16 stipulate respecting the right of the child to freedom of thought, conscience and religion and the child's right to privacy. The Ugandan government ensures that every person has a right to belong to any religion in society. Children in Uganda normally practice the religion of their parents. The need to respect the child's privacy to avoid potential harm which may be caused to the child by undue publicity is necessary and ensures access to child-sensitive and confidential counseling, without the need for parental consent.

Article 17 ensures that the child has access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health. Uganda has made an effort to increase the availability of, and access to, information and material for children for academic instruction, general information and entertainment.

Article 18 ensures that either parents or legal guardians have common responsibilities for the upbringing and development of the child. The best interests of the child will be their basic concern. In Uganda the law adequately endows parents with responsibility for their children. It is the right and duty of parents to care for and bring up their children in line with the best

interest of the child. The Ugandan government provides support for children through the local authorities in case the parents or guardians are unable to take proper care of their children.

Article 19 protects the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse. The Ugandan government wants to take the necessary measures to prevent child abuse and neglect and also carry out preventive public education campaigns about the negative consequences of ill-treatment of children.

Article 20 ensures alternative care for a child. Such care could include foster care, adoption or, if necessary, placement in suitable institutions for the care of children. In Uganda placement of children in institutions is considered a last resort as the family unit is the best environment for a child.

Article 24 ensures that each child has the right to enjoy the highest attainable standard of health by the provision of necessary medical assistance to combat disease and malnutrition and provision of adequate nutritious foods and clean drinking water.

Articles 26 and 27 state that every child has the right to benefit from social security and has the right to a standard of living adequate for the child's physical, mental, spiritual, moral and social development.

Articles 28 and 29 refer to a child's right to education which shall be directed towards developing the child's personality, talents and mental and physical abilities to their fullest extent. The Ugandan government recommends that greater efforts should be directed towards training teachers, improving learning and teaching facilities and the school environment, increasing enrolment and curbing school dropouts.

The framework for this study as described above is Leininger's Sunrise Model Enabler and the Convention on the Rights of the Child (CRC). The Sunrise Model Enabler and the CRC will be discussed later in chapter seven.

Increasing and reducing factors that will affect HIV/AIDS-related stigma in children with HIV/AIDS will be used to analyze interviews. In the following chapter literature concerning increasing and reducing factors will be presented.

Chapter 4

LITERATURE

In searching PubMed and Chinal with key words: children, adolescents, HIV/AIDS-related stigma, discrimination, culture, nursing, Uganda, Convention on the Rights of the Child, limited relevant hits occurred. This might indicate that research in this area about children and young people is almost non-existent. Several authors (Shonfeld, 2000; Strode & Grant, 2001) emphasize that there is a need for further research on the development of attitudes, fears and stigma in children and adolescence. Parker and Aggleton (2003) mention that internationally there has been an interest in doing research in HIV/AIDS-related stigma and discrimination. Much of what has been written about stigma and discrimination in the context of HIV/AIDS has emphasized the complexity of these phenomena. Stigma and discrimination are complex concepts that are often over-simplified, over-generalized and incorrectly utilized. (Parker & Birdsall, 2005).

4.1 HIV/AIDS-related stigma: increasing factors

There are factors that increase HIV/AIDS-related stigma and discrimination. Aggleton, Wood, Malcolm and Coram (2005) point out that a social environment, which promotes violations of human rights, may legitimize stigma and discrimination. In Sub-Saharan Africa, according to Kelly (2002) issues of gender as well as poverty, lack of economic opportunities, limited education, service and information, and traditional norms and practice increase stigma and discrimination. Abadia-Barrero and Castro (2006) did a study where the results showed that structural violence in forms of poverty, racism and inequalities in social status, gender and age fuels children's experiences of stigma.

Aggleton et al. (2005) point out that people are more vulnerable to infection when their civil, political, economic, social or cultural rights are not respected, for example where children cannot realize their rights to education and information. It is increasingly acknowledged that effective prevention and treatment strategies require an understanding of cultural frameworks, including stigmatization (Desapriya, 2004).

Brouwer, Lok, Wolffers and Sebagalls (2000) did research where they were interested in psychosocial and economic aspects of HIV/AIDS and counseling of caretakers of HIV-infected children in Uganda. The results showed that knowledge that a child is infected puts a heavy emotional burden on the mother. At grassroots level in Uganda, families care for AIDS patients with the great majority of the burden borne by women. Garbus and Marseille (2003) maintain that although standby guardians appointed by parents are predominantly male, women ultimately assume much of the responsibility for orphaned children. Brouwer et al. (2000) point out that the compliance of the mother also is largely dependent on her acceptance of the HIV status of the child. When a parent does not accept the child's HIV status, he or she will not be motivated to comply with the advice given by the counselor, nor recognize the need to give the necessary care.

Cabrera, Pitt and Staugård (1996) maintain that AIDS in a family member sometimes leads to tension between the household and neighbors, with the latter reducing their contact. In Uganda most families anticipate little help from the state or the neighborhoods and most of the sick turn immediately to their families, especially their blood relatives. The families' care system is tested not only by the demands of relatives they have known long but also by new infected babies born into the households.

Desclaux (2003) mentions that stigmatization and discrimination are general terms that cover a wide variety of practices and attitudes rooted in relations among social groups and between people. Stigma often relates to peoples attitudes toward others. Collymore (2002) points out that discrimination focuses on the actions, treatment, and policies that arise from such attitudes and which may violate the human rights of people living with HIV/AIDS and those close to them. Discrimination often results in a person being treated unfairly. Stigma and discrimination therefore form harmful thoughts (Strode & Grant, 2001). Even Parker and Birdsall (2005) maintain that stigma is largely related to ideas about others whilst discrimination involves some form of direct enactment of stigma which may be verbal or physical, and likely to be hurtful or harmful to the person to whom it is addressed.

Fransman, McCulloch, Lavies and Hussey (2000) did a study about attitudes of medical staff caring for HIV-infected children in Africa that showed that even the medical staff has negative attitudes to children with HIV/AIDS. The majority of respondents were not in favor of

routine testing for HIV among pediatric patients. Some of the reasons given were: "it creates unnecessary anxiety in the mother", "mothers should be routinely tested, not children". There was also one opinion that health care workers should have the right to refuse giving treatment to HIV-infected children. Some were unconcerned about needle stick injuries. Some expressed the concern that time and resources were being 'wasted' on these children who were going to die anyway.

Garbus and Marseille (2003) have found that some religious organizations have a "contradictory attitude" towards people living with HIV/AIDS. Some influential religious leaders are providing mixed messages about sources of HIV transmission and appropriate attitudes toward people living with HIV/AIDS.

Brouwer et al. (2000) maintain that counseling of caretakers at health centers should be an important element in care for HIV-infected children. During periods of illness of the child the caretakers are usually very anxious. Sometimes they express feelings of helplessness with the situation, for example when the child refuses to eat. Counselors fear that family members will not be able to take care of their children as they normally do, because of financial problems or because the children are not their own.

Wiener, Battles and Heilman (2000) maintain that an increasing number of children infected with HIV live to old age; the question of disclosure of the diagnosis to the child and to others becomes more crucial. Disclosure of a child's HIV diagnosis is a controversial and emotional issue. Marcus (1999) points out that for some caregivers it is not always easy to tell the children; the process is painful and traumatic. The result of one part in his study shows that one reason given for not wanting to tell younger children is that they would not be able to understand. Gilborn, Kambumbuli, Nyonyintono and Jagwe-Wadda (2001) maintain that it is too difficult to discuss the diagnosis and children may not be able to keep a secret. The children would be hurt and upset, and they could not benefit from knowing. Children should learn about their death from others. Children can see for themselves or come to know about death when they are older. In a study where the aim was to understand the factors that affect the process of disclosure and its consequences Wiener, Battles, Heilman, Siegelman and Pizzo (1996) indicate that the majority of caregivers do disclose the diagnosis to the child, usually with no ill effects, and that age is the most significant indicator of whether or not a child has

been told. But sometimes the HIV diagnosis must be kept a closely guarded secret. Wiener, Battles and Heilman (2000) maintain that one reason why families avoid disclosure is their fear of the negative impact on the child and family that the stigma associated with AIDS can bring.

At the other end of the spectrum Wiener, Battles and Heilman (2000) mention that there are families who choose to publicly disclose an HIV diagnosis. There are a number of reasons why a family may choose to go public with their child's diagnosis, although this has never been systematically assessed. Even Marcus (1999) points out that adults also believe that talking to young children about dying and death will help them manage their lives better when they do not have their parents to help them anymore.

Monico, Tanga, and Nuwagaba (2001, p. 22) write that "the gap between what, at one level, people do now and what, at another level, they may do, makes it possible for HIV/AIDS-related stigmatization and discrimination to continue."

4.2 HIV/AIDS-related stigma: reducing factors

The existing HIV/AIDS literature points to three antistigma strategies: information, making discrimination against people with AIDS a punishable offence and participation of local community members in antistigma efforts (Campbell, Foulis, Maimane & Sibiya, 2005). Katabira (1999) points out that health planning must be included in HIV/AIDS care to reduce stigma and discrimination.

The findings in a study by Kalichman and Simbayi (2004) suggests that HIV-AIDS awareness and education campaigns are a cornerstone in AIDS prevention and could impact stigmatization against people living with HIV. Gilborn, Nyonyintono, Kabumbuli and Jagwe-Wadda (2001) maintain that there are needs for relevant material in AIDS-affected households. Support for this can take the form of income-generation projects, vocational training, food, clothing, home repairs, and the payment of school fees.

In a study by Kouyoumdjian, Meyers, Mtshizanac (2005) they maintain the importance of an integrated approach to the treatment of children with HIV. The wider community and na-

tional programs for people infected with and affected by HIV should therefore be supported, including those which reduce stigma and those which improve the social, psychological and medical treatment of people with HIV. This study examines the complex issue of disclosure of HIV and illness status to children in the developing world. Children with HIV will only be able to realize optimal health if they are able to discuss HIV with their own families.

Gilborn, Kambumbuli, Nyonyintono and Jagwe-Wadda (2001) did a study about how to identify effective ways to meet the needs of children affected by HIV/AIDS before and after parental death in Uganda. The results of the study show that a parent's view on disclosure of HIV status to the children was that if children come to know the truth, they can avoid HIV/AIDS themselves and also prepare emotionally and practically. They also will know what to do when parents die. It is healthy for children to discuss illness but clinical experience and research indicate that this seldom occurs.

 MacNeil (1996) did a study describing and explaining care with regard to AIDS care for Ugandan women. Results of the study showed that for women as AIDS caregivers, culture care means responsibility, love and comfort derived from their kinship, religious and cultural beliefs and values. Culture care also means survival to help secure a future for the next generation.

In a study by Kalichman and Simbayi (2004) the results demonstrated that AIDS-related knowledge mediates much of the association between beliefs about the causes of HIV/AIDS and AIDS-related stigmas. Initially, there was a strong and consistent relationship between beliefs that AIDS is caused by spirits/the supernatural and AIDS-related stigmas.

Abadia-Barrero and Castro (2006) maintain that access to antiretroviral drugs (ARVs) changes the living experience of children, reduces stigma, and brings new challenges to AIDS care. Bikaako-Kajura, Luyirika, Purcell et al. (2006) did a study at an HIV/AIDS clinic in Uganda. Daily drug regimens were provided by the pediatric clinic. To ensure adherence to life-extending medications, findings underscore the need for providers to support caregivers to disclose and provide on-going support and maintain open communication with HIV-infected children taking ARVs.

Kelly (2002) writes that while the stigma and discrimination must be overcome, communities and governments continue to struggle to protect peoples´ rights and dignity. Duffy (2005) maintains that it is important to understand stigma with increasing political and social commitment at local, national, and international levels.

Several years of experience of the HIV/AIDS epidemic have shown that an essential component in preventing HIV transmission, protecting people from stigma and discrimination and reducing the impact of the epidemic, is the promotion and protection of human rights. (Strode & Grant, 2001).

There are many direct and indirect links between the HIV epidemic and lack of protection of human rights (Aggleton et al. 2005). One form of violence against a child's human rights is HIV/AIDS-related discrimination. Children infected with HIV/AIDS may suffer from violations of their rights, for example when they are denied good care or when nobody listens to them or discriminates against them. (Gruskin & Tarantola, 2002).

Violations of rights may worsen the impact of HIV. Ensuring the protection, respecting and fulfilling human rights is an important way of combating AIDS-related stigma and discrimination. The violation of human rights encapsulated in discrimination increases the impact of the epidemic on people living with HIV and those presumed to be infected. In several human rights instruments the term "or other status" should be interpreted to comprise health status, including HIV/AIDS. In that way discrimination based on HIV-positive status would be reduced. (Aggleton et al. 2005).

Gruskin and Tarantola (2002) mention that nearly every article of every document has clear implications for health and HIV/AIDS. Everything from information and association rights to social security rights or to the benefits of scientific progress and its applications has clear implications for HIV/AIDS and public health work.

But despite agreement that stigma and discrimination must be overcome to turn the tide on the epidemic, communities and governments in Africa continue to struggle to protect people's rights and dignity (Kelly, 2002). Aggleton et al. (2005) maintain that the stigma and discrimination are interrelated and that they legitimate each other. HIV/AIDS-related stigma causes

discrimination, which leads to violation of human rights, which in turn legitimate the stigma and thus it will be an ongoing process (Maluwa, Aggleton & Parker, 2002).

In the literature review it is clear that there are different factors that increase the stigma such as social factors, people's attitudes, disclosure of the HIV/AIDS diagnosis and a lack of information and education. Stigma reducing factors are available information, the importance of cultural care in the context of HIV/AIDS, religion and medications.

Chapter 5

DESIGN AND METHOD

This qualitative study with a descriptive design was done in Uganda. I wanted to enter the informant's world using Leininger's (1991; 1995; Leininger & McFarland, 2002; 2006) ethnonursing research method that is an ethnographic approach applied in nursing science. Ethnonursing was designed to fit Leininger's theory of Cultural Care Diversity and Universality and it is a natural and people centered method. Leininger's aim was to form a holistic picture of cultures and sub-cultures and she wanted people to teach her about culture care meanings, symbols and practices in their cultures.

As a data collection method I have chosen to do interviews with the informants. Interviews are widely used in qualitative studies. Hammersley and Atkinson (1995) maintain that interviewing can be an extremely important source of data; it may allow one to generate information that would be very difficult if not impossible to obtain otherwise. In qualitative studies, Polit and Beck (2004) mention that data collection is usually more fluid than in quantitative research and that decisions about what to collect evolve out in the field.

As a data analysis method it was natural to use Leininger's (1991) Phases of Ethnonursing Qualitative Data Analysis because it is an analysis method developed to fit the Ethnonursing method. Conducting of the study and ethical guidelines will also be presented in this chapter.

5.1 Ethnonursing

Ethnonursing refers to a qualitative and naturalistic open discovery and largely an inductive nursing research method for documenting, describing, explaining and interpreting the informants' worldview. The purpose of qualitative research is to discover the essence, patterns, symbols, attributes and meanings of human and related phenomena under study with informants in their natural or familiar environments. The Ethnonursing research method with enablers is unique in obtaining in-depth naturalistic qualitative data with less focus on the use of scales and instruments. (Leininger, 1991; Leininger & McFarland, 2002, Leininger & McFarland, 2006).

Leininger (1991) mentions that the ethnonurse researcher does not have "samples", "objects", "subjects", "cases" or "populations". The ethnonurse researcher uses key and general informants such as individuals, families and groups of people in diverse contexts. Leininger describes key and general informants as important in any ethnonursing research study. Key informants are persons who have been fully taught and purposefully selected to be most knowledgeable about the domain of inquiry of interest to the researcher. Key informants are held to reflect the norms, values, beliefs, and general life ways of the culture. In contrast, general informants usually are not as knowledgeable about the domain of inquiry, but do have general ideas about the domain. (Leininger, 1991).

Leininger and McFarland (2006) maintain that the selection criteria for the informants often include the informant being associated or identified with or belonging to the culture studied. The informant has to be willing to participate in the study and be interviewed. It is important that the informant speaks English or that the researcher can understand the language spoken and that the informant has lived in the community or country for at least five to ten years.

5.2 Data collection method

As a data collection method, focus group interviews and individual (one-to-one) interviews were used. Interviewing can be formal or informal. The formal interview must be related to the research question and the purpose of the study. Formal interviews involve some planning, such as making an interview guide covering a list of topics or specific questions that the researcher wants to explore with informants. In open-ended questions the researcher starts with general questions and then asks for more detailed material as the interview proceeds (Roper & Shapira, 2000; Polit & Beck, 2004). Open-ended interviews encourage the informant to share ideas, worldviews and information about the domain of the question under study (Bohay, 1991).

In addition to thinking about the types of data to be gathered, Polit and Beck (2004) point out that qualitative researcher needs to plan ahead for how data will be recorded and stored. Interview data, common to all qualitative traditions, can be recorded in two ways: either by taking detailed notes of what participants say; or by audio or video recording what they say.

Qualitative interviews should be recorded and subsequently transcribed, rather than relying on interviewer notes. Roper and Shapira (2000) maintain that interviews must be conducted in the participant's native language.

5.2.1 Focus group interviews

In Uganda, as in Africa in general, children and young people are taught not to talk to and disturb adults. For that reason a focus group interview is a good choice where the children as informants with similar problems and experiences have support for each other. Because of my short stay in Uganda focus group interviews were also time-saving. Stewart and Shamdasani (1990) point out that focus group interviews are a good method to use when children are interviewed. Focus group interviews provide data quickly and in less time than in ordinary interviews. Wibeck (2002) mentions that focus group interviews have been working well when talking to risk categories like people with HIV/AIDS about sensitive topics. Glesne (2006) writes that children often need to be together in a larger group to be emboldened to talk.

Focus group interviews allow the interviewer to study people in a more natural setting than a one-to-one interview. Participants are free to talk with other group members. Focus groups have a high validity, the idea is easy to understand and the results are believable (Marshall & Rossman, 1999). Stewart and Shamdasani (1990) point out that focus groups are designed to help understand how individuals conceptualize and categorize phenomena.

Wibeck (2000) mentions that the following three criteria characterize focus group interviews: a focus group method is a research technique that collects data for a research purpose, the method collects data through group interaction and the researcher has chosen the topic for discussion. According to Halkier (2003) focus group interviews are not the same as group interviews. In a focus group interview the informants will talk more to each other and participation from the interviewer is less than in a group interview.

Stewart and Shamdasani (1990) point out that one limitation of focus groups can be the small numbers of respondents. If one group member is very dominant and another more reserved it is a challenge to make everybody talk. Halkier (2003) mentions that some group members

will talk less even though the researcher is responsible for encouraging all respondents take part. Anything from six to twelve persons participating in a focus group interview is mentioned in the literature. (Halkier, 2003; Hansen et al. 1998; Stewart & Shamdasani, 1990).

5.2.2 One-to-one interviews

It is important to remember that an interview is a dialogue between two persons. The informant needs to feel that he is important and that he is allowed to talk to the end. The informant's information needs to be reliable and not affected by a number of irrelevant factors. The interviewer must give clear instructions to the respondent so that the informant will answer the questions with appropriate information. (Olsson & Sörensen, 2001).

The researcher's opinions and thoughts do not have to come up in an interview situation. In a research interview the intention is not to moralize or argue. The most important thing is that the respondent feels that he or she is important and that the researcher really is listening to what the respondent has to say. Enough time is important so that the informants feel that they can tell everything and that the researcher is not in a hurry (Dalen, 2004). It is important to leave time after the interviews for expressing your gratitude and for other informal talk. During such informal talk you, as a researcher, can learn even more after the interview (Glesne, 2006).

When using an interpreter this person has to have a good command of English and the informant's language. The interpreter must also supply questions to the interviewer from the informants. In addition, the interpreter has to be suitable for the interview situation; qualities other than just knowing the language are required. In some interview situations sensitive issues are discussed and the interpreter has to adapt a professional attitude and keep the information confidential. Some linguistic misunderstandings can come up if the interpreter is not completely familiar with the terminology used in the interview. Sometimes a problem can be that the interpreter gets too exited and starts to "take over" the interview. (Dalen, 2004).

5.3 Data analysis

Leininger (1991) developed the Phases of Ethnonursing Qualitative Data Analysis to provide a way to facilitate the research process as a part of the Ethnonursing method. The researcher uses the "four phases" of data analysis in a modified way because of the short stay in Uganda. The data is continuously processed and reflected on by the researcher at each phase.

According to Leininger and McFarland (2006) the two first phases of data analysis include recording of all grounded data along with specific code indicators. The third and fourth phases of data analysis require the researcher to identify recurring patterns and themes. The four phases will be described below.

In the *first phase* the researcher's task includes: recording interviews, collecting data from key and general informants, making preliminary interpretations, identifying symbols and recording data related to the phenomena under study.

In the *second phase* the data is coded and classified as relating to the domain of inquiry and sometimes the questions. Recurring components are studied for their meanings.

In the *third phase* the data is strictly analyzed to discover saturated ideas and recurring patterns of similar or different meanings, expressions, structural forms, interpretations or explanations of data relating to the domain of inquiry. Data is examined to show patterns with respect to meanings in context along with further credibility and confirmation of findings.

The *fourth phase* is the ultimate phase of data analysis, synthesis and interpretation. It requires analysis, configurations, interpreting findings and creative formulations of the data from the previous phases. The researcher's task is to abstract and present major themes, research findings, recommendations and sometimes theoretical formulations.

5.4 Conducting of the study

The study was done in the rural area of Tororo in Uganda in the context of children. The research process has been done as described in Figure 2 below.

Spring -06	- Plan the study - Literature review - Access to the field in Uganda in April - Submit the research plan, 8 June
Summer -06	- Write an interview guide in July - Start writing the theory section in July -Apply for permission to the National Committees for Research Ethics in Norway, 14 August
Autumn -06	- Apply for permission to Norwegian Social Science Data Services, in September - Continue writing theory section in September - Research in Uganda in October-November - Interview of key informants x 2 - Interview of general informants x 1 - Transcribe the interviews - Start the analysis in December
Spring -07	- Continue with the data analysis - Finish the study - Submit the study

Figure 2. The research process

The first contact with the field was taken in March 2006 by talking to the non-governmental (NGO) project director. I got permission by written notification to conduct the study and do interviews with children connected to the NGO-project. The project focuses on people living with HIV/AIDS. The selection of informants was done in cooperation with the project leadership. All children aged 13-18 years in the project were included in the study.

Permission from the National Committees for Research Ethics (REK) (2007) in Norway was applied for in August 2006 and granted in September 2006 (Enclosure 2). Permission from the Norwegian Social Science Data Services (NSD) (Nsd.uio.no) was applied for in September 2006 and was granted in October 2006 (Enclosure 3). After all formal contacts were done

and permission given I could start doing the research following the phases of Leininger's "Phases of Ethnonursing Qualitative Data Analysis".

According to the *first and second phases* data was collected, described and recorded, coded and classified. Data was collected through two focus group interviews with key informants (children) and one-to-one interviews with general informants (adults).

Related to Leininger´s selection criteria for key informants, my criteria were that: the children were from Uganda, allowed to be interviewed, spoke English and had lived in the community for several years. In addition they had to be HIV+, aged 13-18 and participated in the NGO-project. Nine key informants were asked to participate and all accepted. However, in the end eight key informants, all girls, took part in the study. It proved more difficult for boys to talk about this subject and was by far a cultural phenomenon. Seven of the girls were orphans. One of them had been raped and in that way she became HIV+. The other seven were infected mother-to-child. They had all known about their HIV-status in 2004-2006 when they had all been tested positive. The key informants did understand English but it showed that they were not used to talking about the topic so an interpreter was necessary.

Selection criteria for the general informants (adults) were that the persons were from Uganda, they agreed to be interviewed, spoke English, and had lived in the community for several years. In addition they had to be in close contact with the key informants. They were also supposed to know more about the community and how children with HIV+ status live in this area. They had to participate in the NGO-project and were well informed about the Ugandan culture. The general informants were very familiar with the key informants. They were teachers, counselors and relatives to the key informants. They had grown up in the community so they were well informed about the traditions and cultural phenomena. They were good in English. They fulfilled all the criteria.

Interviews were done in November 2006 in Uganda. The key informants (children) were interviewed twice by focus group interview. The interview guide (Enclosure 1) with open-ended questions was used. At first the researcher started trying to talk to the key informants but with no good response. After 10 minutes the decision to get help with interpretation was taken. The interpreter that came to help was talked to before and had promised to help if

needed. The interpretation was done word for word. During the interviews the interaction between the children was quite interesting. The first time it was stricter and they just answered the questions. When we met the second time to do some follow-up questions they knew me and so were willing to give even more information. During the interview the children where laughing a lot. One of the informants was sitting under the table and from there she talked about all the things I asked about. These children were really motivated to participate in the study. Some of the children had to walk two hours to come to the interview, and walked home again after the interview.

During the stay it also proved possible to interview general informants (adults). They were asking every day when they would be interviewed and they were really proud that someone wanted to listen to them. One-to-one interviews were done once with each of them. The same interview guide, as above, with some small modifications was used. The interview was done in English without an interpreter. Also the general informants were motivated to participate in the study.

Both key informants and general informants were really interested to be interviewed and they came with many important thoughts about the HIV/AIDS-related stigma problem. Also, to stay in the community for three weeks gave me more understanding of the culture and the problems.

Both focus groups and one-to-one interviews were recorded by minidisk in November 2006. The interviews were around forty minutes each and were transcribed word for word, 24 pages, to the computer directly after the interviews were done. Raw data was read through again and again and notes were made from the research questions. At first, data from key informants was coded and then data from general informants, so throughout the process it was possible to keep the informants' statements separate. However the data was categorized and presented together.

In *the third and fourth phases* major patterns, themes, research findings and recommendations were formulated from the research questions.

Descriptors were made visible and got their own colors. Then the descriptors were categorized into patterns. In the research findings the informant's original statements were maintained in the original version. From the patterns the final themes were formulated.

The method of presenting the results in Figure 3 (p. 43) in this study was inspired by Leuning, Small and van Dyk (2002) and their method of presenting their results in their Ethnonursing study.

5.5 Ethical guidelines

Researchers doing projects which are to be implemented in a developing country must fill out the form for ethical evaluation of research projects. If children below 18 years are included as in this study it is always necessary to gain permission from the National Committees for Research Ethics in Norway (REK) (2007). REK is well informed about everything concerning the law and the rules in ethical discussions. To get the permission to do new research studies it is important to have a good dialogue between the researcher and the committee. (etikkom.no).

The Norwegian Social Science Data Service (NSD) (Nsd.uio.no) is one of the largest archives for research data of its kind providing data to researchers. The main objective is to improve possibilities and working conditions for empirical research that is primarily dependent on access to data. Researchers at universities may request data from the NSD which assists researchers with regard to data gathering, data analysis and issues of methodology, privacy and research ethics. That means all information that can be connected to one person like name, social security number or other distinguishing features. A person will be indirectly identified if it is possible to recognize the person through background information, for example place of residence, gender, profession and diagnosis (nsd.uib.no). Because of the interviews with the informants I will handle personal information electronically in my study. That is why I have to report on and ask for permission to do the interviews for the Norwegian Social Science Data Services.

As in all other research a qualitative survey aims to produce valid and durable results. That has to occur in an ethically acceptable way. It is important to choose studies that have got

permission from ethical committees or studies where ethical considerations have been done carefully. The results that are presented have to be real for other researchers. Among other things cheating and dishonesty are not acceptable. It is unethical to just present articles that support the researcher's own opinion. Ethical considerations have to be made concerning selection and presentation of the results. (Forsberg & Wangström, 2003; Merriam, 1994; Polit & Beck, 2004).

Most disciplines have established their own ethical codes. The Northern Nurses' Federation (NNF) shows guidelines for nursing research in Scandinavia, based on international declarations, conventions and the law that concerns research. The ethical guidelines are based on the ethical principles that are manifest in the UN's Declaration on Human Rights and in the Helsinki Declaration. Care research is directed by the ethical principles of autonomy, doing good, doing no harm and doing justice. (Hoitotyön tutkimuksen eettiset ohjeet Pohjoismaissa, 2003).

The World Medical Association (1964), revised in 2000, has developed the Helsinki Declaration as a statement of ethical principles to provide guidance for doctors and other participants in medical research involving human subjects. An important aspect in the Helsinki Declaration is, among other things, that the researcher should be competent and very familiar with the current area, § 1: 3.

An ethical act for me is to take children seriously if I want their voices to become heard through my research methods. The National Committees for Research Ethics in Norway (REK) (2007) maintain that research about children and their lives is important and valuable. Their needs and interests are taken care of in a different way from those of adults. Children are in development and thus their needs change as they go through different phases. Researchers need to have enough knowledge about children so they can adapt the method and contents of the research to the age group of the children that will participate. The information that is given should be adapted to fit the child's age.

Ethical guidelines are important. Polit and Beck (2004) maintain that there are three aspects when talking about ethical guidelines: beneficence, respect for human dignity and justice. Beneficence means doing no harm. Many people may participate in a study to be helpful; the

researcher should as far as possible maximize benefits. Informants have the right to know about the risks and benefits so they can decide if they should take part in the study or not.

The fact that the key and general informants received information about the study and willingly participated was taken into consideration.

Polit and Beck (2004) mention respect for human dignity. That includes the right to self-determination and the right to full disclosure. Self-determination means that informants have the freedom to control their own activities, including study participation. Full disclosure means that the researcher has described the nature of the study, the informant's rights and the researcher's own responsibilities. It is important to point out to the informants that it is not a question of "right" or "wrong" but the informant's own experiences that are interesting. (Ejvegård, 1996).

The key and general informants were told about the study and also got time to ask about it. During the study the informants had the possibility to ask questions about the study and were told that they would have the right to discontinue participation at any time. Informants were told that it was their own opinion that was important.

According to Polit and Beck (2004) justice includes the informant's right to fair treatment and right to privacy. They should be selected on the basis of research requirements, not on a personal basis. Respect for cultural and other forms of human diversity is important. Informants have the right to expect that any data they provide will be kept in the strictest confidence. Dahlberg (1993) writes that the researcher should make clear to informants that everything they say is confidential because then the informants can feel freer to say anything they want.

The informants were selected on the basis of informant criteria. The researcher was aware of an informant's anonymity rights and that all data would be confidentially handled. The informants were also informed that the interviews would be recorded and published anonymously in this Master thesis and in articles.

Eriksson (1992) maintains that it is unethical not to search for knowledge, not to do research into situations where you face obvious problems, unsolved questions or something you do not understand. Research is not an end in itself. The knowledge received should be used to serve as many people as possible.

Chapter 6

FINDINGS

In this chapter the results of the research will be presented in the form of six major themes, patterns and descriptors with the aim of the research and research questions in mind. As a result of the first and second research questions – how do children in Uganda with HIV/AIDS express their experiences about HIV/AIDS-related stigmatization and which cultural factors in Uganda affect HIV/AIDS-related stigmatization in children – the themes are: stigmatization is the way society treats the children, stigmatization is when the church punishes the children, stigmatization is a lack of information and acknowledgment and stigmatization is a lack of resources. As a result of the third research question – can the Convention on the Rights of the Child be used in Uganda to protect stigmatized children with HIV/AIDS – the theme is: stigmatization is when the CRC is not used to protect the children.

The researcher has chosen not to disclose the informants' identity because the key informants are children and the study is done in a small community. The informants were promised that all data would be confidentially handled and published anonymously.

To make it more visible to the reader the six major themes, patterns and descriptors will be presented in Figure 3 (page 43) at the end of this chapter. In the following section the findings will be presented theme by theme.

6.1 Stigmatization is the way society treats the children

The key informants (children) expressed their experiences to a great extent about stigmatization in the way society treats them.

The stigmatizing patterns embedded in this theme were the community members' way of "pointing the finger" when telling about children's sickness, community members' negative attitudes, community members' psychological abuse of the children and community members' and children's mutual silence.

The way community members talked about the children's sickness made the children feel that it was very difficult. The most difficult thing for the children was when community members talked about them as sick, as a carrier of a disease, and that they would die at an early age. As one of the children said, "I have been told that I can die at an early age. It is very difficult for me."

Another child stated, "It's difficult because the disease is not shareable. It can't be shared." That shows that even if there are many carriers of the disease among the children in the community they feel very lonely in their situation. Even the community members' way of "pointing the finger" at the children causes a lot of difficult feelings like pain and anger in the children. It will also be difficult for the children to live in the community.

The children also related to community members' negative attitudes. Community members' negative attitudes may be partly due to their own lack of knowledge, partly due to the fact that they think more about negative effects of children's sickness than the best interest of the children. One child talked about negative attitudes as follows: "There was a time when we told our sister-in-law our disease. But that one started to tell us not to share with her the same cup that will transmit the disease to her. Then we stopped talking."

Community members' psychological abuse of children was very stigmatizing for the children. The psychological abuse of children in the family put a heavy burden on the children so that they felt useless: "Because the situation is that people are saying, 'you are poor, just staying here, you are eating and you are not working', such kinds of words." They are always treated differently because of the sickness. Even at school they are abused. One of the children says, "When I go to school and my friends are abusing me, that's when I'm crying."

Due to community members and children's mutual silence about the children's sickness it causes children to keep things to themselves which leads to feelings of pain and anger in them. As effects of the silence they stated: "I just keep the things to myself", "It's painful for me when I can't say anything." In society it is not common to talk about the sickness in families and schools and the children do not talk to other youths in the same situation either.

General informants (adults) had, to a large extent, the same view of community members stigmatizing treatment of the children. They said: "When a child is infected community members just say that the child is dead. So community members don't care about that child so much. Outside people don't care". As for negative attitudes against children the general informants stated: "In schools, maybe when most of the children know that a child is infected, the teacher will not let them talk to that child"; "Once there was a girl with HIV. When friends realized that she was infected, that she was HIV-positive, they started to desert her. They could not sit with her. Whenever she came to them they ran away, they left her sitting alone."

When referring to psychological abuse the general informants also mentioned that those children are not working, they are just eating, they have nothing to offer and they are useless. One general informant said, "I'm thinking in that way. I have realized that if someone is HIV positive or a relative sees that you have HIV, you are already infected, they start abusing you and tell you that there is nothing they want from you, nothing, so you are useless." The children were also abused in following way: "When they know that someone is HIV-positive they can even talk about you and laugh at you, you see, laugh at you and laugh at you. They can even abuse, they can even say 'that one is gone, that one has AIDS'"; "They don't think that the boy or girl has HIV and they don't say HIV, they say AIDS!"

The general informants also mention the mutual silence between children and community members but more in terms of children's silence. One general informant stated: "No, the child fears! He fears that people will know that he is infected so he wants just to say that he is not infected. That's why he has fear; he doesn't want to talk about it with his friends, or with adults. He comes here for treatment but when he goes home he doesn't tell his mother or his brother that he is infected"; "They don't want people to know what is happening to them. If someone realizes that he is infected, he just keeps quiet about it."

On the other hand the general informants mention the adult's way of neglecting children. Children did not mention it, maybe because all of them stayed in some families. One general informant stated about neglecting the child: "There are some parents who after realizing that some children are HIV-positive, they tend to neglect these ones, the HIV-positive ones." Another general informant said; "People fear to stay with such people who are HIV-positive; they say that those can die at any time. They may even fail to take the person for treatment if

he/she is suffering from HIV; perhaps he/she is going to die"; "And if somebody could fall sick and suffer in the house without any care, they don't give that person any food, they don't nurse, and even if the sick one informs them they don't clean him/her, they fear to touch that person because people fear that they will be infected."

6.2 Stigmatization is when the church punishes the children

Religion did not seem to have a big influence for the key informants. They mentioned it but only in terms of HIV/AIDS and the consequences of the disease as something they talk about in church. On the other hand the general informants saw the way the church punishes the children as very stigmatizing for the children.

The stigmatizing patterns embedded in this theme were the priest talking about HIV/AIDS as a sin and God's punishment because of sexual behaviour.

The general informants took the priest's allusion to punishment more seriously than the key informants, stating: "The priest always tells us… yeah it's a punishment, because it is wrong, it's a sin. People feel sorry and fear. Yeah, most people think it's a punishment"; "I think they take it as a punishment. Yeah, and that's why they are always sad, they feel bad in their hearts. Sometimes you see the kids start crying and you ask what is happening, maybe because of the thinking, that's why they start crying."

One general informant explains the priest's way of talking about God's punishment of them who get HIV through sexual misbehaviour: "Youths think it's a punishment. So if one is infected, God has punished him. They just think that they have misbehaved by maybe having sex, unprotected sex, or having sex before marriage and those who maybe have sex in an improper way. Maybe you have sex with someone not knowing that this person is infected. Only afterwards you come to know that he/she is infected. You may think maybe it's a punishment."

6.3 Stigmatization is a lack of information and acknowledgement

In findings it was clear that a lack of information and acknowledgement was stigmatizing for the children.

The stigmatizing patterns embedded in this theme were: drugs and diet controlling children's lives, difficulties to get to grips with hard feelings and misdirected knowledge about the future.

Drugs and diet control children's lives because in one way they are factors that keep the sickness under control. When it is about drugs one key informant explained: "The counselor always comes to my home, counsels me, helps me to take drugs and even my aunt tells me to take the drugs." Another child stated that it is a problem with everyone talking about diet, "They always tell me how to live positively, but the problem is that in most cases they tell me how to balance the diet, with nutritional support." One child mentioned that other things are overshadowed by all the talk about drugs and diet: "I change diets all the time. I have to stop thinking about other things that made me sick."

The lack of information and knowledge about things other than just drugs and nutrition makes the children have difficulties to getting to grips with hard feelings. The way they are talking about their situation makes clear that they do not understand what is causing these feelings. One child says, "It's my own feelings that are difficult." They even state that the sickness gives them strong negative feelings: "Most of the time I'm very angry when I'm sick"; "When I'm very ill I cry."

Misdirected knowledge about the future really puts a burden on the children. The key informants already talk about, for example, not wanting kids because they only see the importance of having the possibility to take care of their own lives in terms of medication and education, which in one way is positive. They stated: "I only want to take drugs and I don't want any kids"; "I don't want any kids because I think it's better to go to school than having a kid" As a child you should not have to think about not having a family in the future. As one child said, "I might produce children who might be infected already and die before their time" It seems that the children have not got information and knowledge about the possibility, even as HIV-positive, to have a family and children because of antiretroviral drugs (ARVs).

Even the general informants mentioned the misdirected knowledge as stigmatizing for the children. One general informant said, "They don't think about having their own family because they say, 'I'm already infected. I'm already dead so how can I think about marriage? It's just useless to me'."

General informants also expressed a lack of information and knowledge as stigmatizing for the children. However they expressed it in another way because general informants mainly saw the causes behind the drugs and diet control about children's lives and they talked about it only as an economic question. They also saw the causes behind children's feelings like losing their parents and children's loneliness. One general informant stated: "Those who are affected, like the orphans whose parents have died of AIDS, they just feel very sorry. Some children come out of class and start crying outside, others just become intolerable in class. The others tell them to stop and get out of class." The affected children don't want other children to talk about the situation: "Don't tell us. We have already heard that. We have lost our parents. We suffering; don't tell us that." Another general informant stated: "The feelings... sometimes, they feel so lonely, they don't want to come together where people are many. They get separated, you know. They feel so lonely"; "So you find that a kid becomes so sad and sits alone there thinking why am I like this? The kid feels so bad."

6.4 Stigmatization is a lack of resources

Even when key informants are expressing stigmatization as a lack of resources they focus on diet and drugs.

The stigmatizing patterns embedded in this theme were: lack of nutritious food for well-being and lack of food for best in-take of ARVs.

The young children's way of talking about lack of nutritious food both for well-being and for medication gives them a sense of hopelessness. The following statement from one key informant illustrates this hopelessness; "I've been prescribed ARVs. I'm an orphan. But at home there is nothing to eat. They give small, small scraps. I need a lot to drink and it's not there, so it's like a problem for me."

The general informants also mentioned a lack of resources as stigmatizing for children mainly in terms of money for medication. One general informant mentioned a girl who had a sister: "Her sister said to her, 'Those who are sending you to me to buy that medication, do they give me their money? Or have they given money for me to buy the medication?' So the sister just left the child like that without buying her the medication." Another stated: "They can't get it, the medicine. If they go and get medicines they can go with five hundred Uganda shil-

lings, every day they go for the tablets. So if they don't have the five hundred, they won't give them the tablets."

6.5 Stigmatization is when the CRC is not used to protect the children

The fact that the Convention on the Rights of the Child was not protecting the children was stigmatizing for children.

The stigmatizing patterns embedded in this theme were: no knowledge about children's rights, misunderstandings about children's rights and refusing children's rights.

None of the key informants had any knowledge about the CRC except one child who stated, "I saw the heading and read the paper, but it's now a long time since I read it so I have forgotten it." The general informants knew about the CRC but they thought that children's parents did not know, as one stated: "Children have their rights but parents don't know that their children have these rights." Even if general informants knew about the CRC it showed that there were quite a lot of misunderstandings about children's rights. The adults could not see the CRC as something that could protect the children. They saw it more as something that could be turned against them if the children got to know about it. One adult stated, "We have that right in Uganda here, but we don't implement it so much because our children are very stubborn, since implementing it will mislead the children." One adult gave an example of how children in general can use the CRC in practice: "A child has heard about the Convention on the Rights of the Child so when I tell her that we are going to dig, to wash clothes or to clean the house, she says that she will not because it's child abuse."

Because of all these misunderstandings the adults even tried to prevent children from knowing about the CRC. One general informant stated: "But we don't implement the CRC because the children can even beat us, they can imprison us, the teachers or their parents. So we try to avoid children's rights."

HIV/AIDS-related stigma descriptors	Patterns	Themes
• They always tell me about the sickness but it's not good for me. It's difficult. Because the disease is not shareable. It can't be shared. • It's difficult for me because they always tell me that I'm going to spread the thing, the virus. • It's difficult to live in the community because most people always tell us that we are sick and infected. People are telling us that we are going to die. • I have been told that I can die at an early age. It is very difficult for me. • I feel so angry with those who tell about it. It's painful to me when talking about it.	- Community members' way of "pointing the finger" when telling about children's sickness	Stigmatization is the way society treats the children
• There was a time when we told our sister-in-law. But she started to tell us not to share with her the same cup that will transmit the disease to her. • When I went to start school the teacher wanted to send me home because I was sick.	- Community members' negative attitudes	
• It's not good for me because the treatment is different. Because some friends abuse me… look at me and talk about it everywhere. • So they sometimes abused me about the sickness. Because the situation is that they are saying; I'm poor, just staying here you are eating you are not working, such kinds of words. • Even at home some of my young brothers and sisters abuse me, which is not good for me. • When I go to school and my friends are abusing me, that's when I'm crying.	- Community members' psychological abuse of the children	
• Nobody has told me about my sickness. We don't talk about it in the family. • In my case I don't tell the neighbors or friends. • I only told the relatives of teenagers of my age. Not the general community and youths. • I have not heard teachers talking. We are not talking about it in school. • I hide certain things from them. I just keep the things for myself. • I don't talk about it to anybody when I'm angry. • It's painful for me when I can't say anything.	- Community members' and children's mutual silence	
• The priest always tells us… yeah it's a punishment, because it is wrong, it's a sin. People feel sorry and fear. Yeah, most people think it's a punishment. (general informant)	- The priest talks about HIV/AIDS as a sin	Stigmatization is when the church punishes the children
• Youths think it's a punishment. So if one is infected, God has punished him. They just think that they have misbehaved by maybe having sex, unprotected sex, or having sex before marriage and those who may have sex in an improper way. Maybe you have sex with someone not knowing that this person is infected. After that you come to know that that he/she is infected, so he/she infects you. You may think maybe it's a punishment. (General informant).	- God's punishment because of sexual behaviour	
• They always tell me how to live positively, to take drugs well, but the problem is that in most cases they tell me how to balance the diet, nutritional support. • When we are discussing we always discuss it with our father. He only encourages us to take drugs. • The counselor always comes to my home, counsels me, helps me to take drugs and even my aunt tells me to take the drugs. It's a sort of counseling. • I have to take medications well. I have to take medicines without exception. • You change diets all the time. I have to stop thinking about other things that made me sick.	- Drugs and diet control children's lives	Stigmatization is a lack of information and acknowledgement
• It's my own feelings that are difficult • Most of the time I'm very angry when I'm sick • When I'm very ill I cry	- Difficulties getting to grips with hard feelings	
• I might produce children who might be infected already and die before their time. • I only want to take drugs and I don't want any kids. • I don't want any kids because I think it's better to go to school than having a kid.	- Misdirected knowledge about future	
• But always when I go home to tell mother they say that there is no money for changing the diet, to do it for the better.	- Lack of nutritious food for well-being	Stigmatization is a lack of resources
• I've been prescribed ARVs. I'm an orphan. But at home there is nothing to eat. They give small, small scraps. I need a lot to drink and it's not there, so it's like a problem for me.	- Lack of food for best intake of ARVs	
• I saw the heading and read, but it's now a long time since I read it so I have forgotten it. • Children have their rights but our parents they don't know that their children have these rights. (General informant).	- No knowledge about children's rights	Stigmatization is when the CRC is not used to protect the children
• We have that right in Uganda here, but we don't implement it so much because our children are very stubborn, since implementation it will mislead them. (general informant) • One child has heard about the CRC so when I tell her we are going to dig, to wash clothes or clean the house, she says that it's child abuse. (General informant).	- Misunderstandings about children's rights	
• No, most especially in village don't observe children's rights. (General informant). • But we don't implement them because the children can even beat us, they can imprison us, the teachers or their parents. So we try to avoid children's rights. (General informant).	- Refusing children's rights	

Figure 3. HIV/AIDS-related stigma descriptors, patterns and themes

Chapter 7

DISCUSSION

In this chapter the main findings will be highlighted and discussed in relation to the research questions and mirrored against the two frameworks and earlier research. The research questions are: how do children in Uganda with HIV/AIDS express their experiences about HIV/AIDS-related stigmatization? Which cultural factors in Uganda affect HIV/AIDS-related stigmatization in children? Can the Convention on the Rights of the Child be used in Uganda to protect stigmatized children with HIV/AIDS?

The biggest surprises of the findings are that the children, in answer to the first research question, really express so many experiences of HIV/AIDS-related stigmatization. The children are very young and it seems that they have lost a big part of their childhood. The answer to the second research question makes it clear and notable that the culture in Uganda still in 2007 has such a big impact on the whole HIV/AIDS situation for children. In answer to the third research question it was clear that knowledge about the Convention on the Rights of the Child is non-existent. Even misunderstandings about the CRC are very big among both key and general informants. It appears that breaches of many articles in the CRC are still common in the community. That means that there is still a lot of work to do to find out how the CRC can be used in Uganda to protect stigmatized children with HIV/AIDS.

The fact that people in the child's close environment – mothers, fathers, close relatives, friends and teachers – have very negative attitudes against the children, give the children a strong feeling of being lonely and different from others because they are carriers of a disease, they have the virus that can be spread to others. Brouwer, Lok, Wolffers and Sebagalls (2000) write that the compliance of the mother is largely dependent on her acceptance of the HIV status of the child. When parents do not accept the child's HIV status they will not be motivated to comply nor will they recognize the need to give the necessary care with the advice given by the counselor. It is best for the children to stay with their biological mother and father as long as they can. When children have to move to relatives because of their mother's and/or father's death it becomes more difficult for them, very often because of poverty and

lack of food. Since their relatives often have several children of their own these orphans will have a lower social status in their relative's family. Abadia-Barrero and Castro (2006) and Kelly (2002) write that structural violence, in the form of social status and poverty and lack of economic opportunities, fuels children's experiences of stigma.

Ever since the children were told of their HIV status they had known that they could die at an early age. Because of this the children are often neglected. These factors contribute to the unwillingness for testing. That in turn puts a burden on the child in the form of a feeling of hopelessness which causes them to think that they are already willing to choose not to have families and children of their own in the future. In this community where it is still common in families to have many children and where also polygamous marriages are common it is a very bad sign that the situation for the children is not handled in the best way. Wiener, Battles and Heilman (2000) and Kouyoumdjian, Meyers and Mtshizanac (2005) maintain that disclosure of a child's HIV diagnosis in the developing world is a controversial and emotional issue. One reason why families avoid disclosure is their fear of the negative impact on the child and on the family that the stigma associated with AIDS can bring. Marcus (1999) writes that one reason given for not wanting to tell younger children is that they would not be able to under- stand. For some caregivers it is not always easy to tell the children; the process is painful and traumatic. Kouyoumdjian, Meyers and Mtshizanac (2005) maintain that children with HIV/AIDS will only be able to realize optimal health if they are able to discuss the situation with their families.

It is common in this community to put your trust in God's hands; religion is important for the people. All the children under study were Catholics, but their religion was not something they had considered. Garbus and Marseille (2003) have found that some religious organizations have a "contradictory attitude" towards people living with HIV/AIDS. For example, some influential religious leaders are providing conflicting messages about sources of HIV trans- mission and appropriate attitudes toward people living with HIV/AIDS. General informants had an opposite opinion to key informants. The adults expressed the church as a big stigma- tizing factor for the children with HIV/AIDS. In their opinion the church sees HIV/AIDS as a sin and that the church punishes the children. Kalichman and Simbayi (2004) write that AIDS- related knowledge mediates much of the association between beliefs about the cause of

HIV/AIDS and AIDS-related stigmas. Initially, there was a strong and consistent link between beliefs that AIDS is caused by spirits/the supernatural and AIDS-related stigmas.

The fear of all the negative consequences of children's HIV diagnosis affects the unwillingness for not talking about the disease. When the children do not talk about their sickness they mention feelings like anger and that it is very painful when they cannot talk about their situation. Wiener, Battles, Heilman, Siegelman and Pizzo (1996) write that HIV diagnosis must be kept as a closely guarded secret. Research suggests that it is healthy for children with chronic illness to discuss their illness but clinical experience and research indicate that this seldom occurs.

In this study it became clear that the children and adults in the community have very limited or misdirected knowledge and education about the consequences of the children's sickness. That leads to an inability to handle the situation in a good and meaningful way. Monico, Tanga, and Nuwagaba (2001) point out that many Ugandans are aware of the facts about HIV/AIDS but this everyday action is not always effective. This difference between what people do and what people may do will cause HIV/AIDS-related stigmatization and discrimination to continue. Campbell, Foulis, Maimane and Sibiya (2005) and Kelly (2002) mention that the existing HIV/AIDS literature points to antistigma strategies offering practical information. Limited education and information increase stigma and discrimination. Kalichman and Simbayi (2004) suggest that HIV/AIDS awareness and education campaigns could have an impact on repulsion and social sanction stigmas against people living with HIV.

On the one hand children's lives are controlled by drugs and diet and that will be a serious problem overshadowing children's everyday lives which, in turn, lead to children losing their childhood. On the other hand antiretroviral drugs give children the possibility of a longer life. Abadia-Barrero and Castro (2006) write that access to ARVs changes the living experience of children, reduces stigma and brings new challenges in AIDS care.

If one begins from the children's way of expressing their experiences of HIV/AIDS-related stigmatization it is clear that all factors except technological ones in Leininger's (1991) Sunrise Model Enabler are represented which influence children's stigmatization. The absence of the technological element could be due to the study being conducted in a very poor, rural area

with no technological equipment, very often without electricity. The other cultural factors in the enabler are religious and philosophical, kinship and social, cultural values, beliefs and life ways, political and legal, economical and educational factors. Of these factors at grassroots level cultural values, beliefs and life ways, kinship and social factors are the biggest factors that affect stigmatization in children. The children are still young and many of them are orphans. The family is very important for these children. In the poor community economical and educational factors also appear as big stigmatizing factors for children. In the long term, religious and philosophical factors seem to be very stigmatizing for the children.

In one way political and legal factors will be the most stigmatizing for the children. The Convention on the Rights of the Child has been ratified by the Ugandan government so that could give the children the best opportunities. But the CRC is usually not taken into consideration at grassroots level. The implementation of the CRC has not reached the rural area of the Tororo district. Duffy (2005) writes that it is important to understand stigma with increasing political and social commitment at local, national and international levels.

Key informants do not know that the CRC exists. General informants show a great lack of knowledge and understanding about the CRC. The adults cannot see the CRC as something that could protect the children. They see it more as something that can be turned against them if the children get to know about it. Because of all these misunderstandings the adults try to prevent children knowing about the CRC.

It shows that the implementation of the CRC has not succeeded all over the country even if the government in Uganda has done a lot to integrate it with the best interest of the child in mind. Kelly (2002) writes that despite agreement that stigma and discrimination must be overcome, communities and governments continue to struggle to protect peoples´ rights and dignity.

Since children with HIV/AIDS are stigmatized to a great extent, the CRC could be used to enhance protection for those children. That could be done through more information and education about the articles in the CRC concerning the children with HIV/AIDS as they are presented in the framework. The most important thing is that the children should come to know

about the CRC. Community members should, in turn, receive information about the CRC to remove their misconceptions about children's rights. Aggleton, Wood et al. (2005) point out that a social environment which promotes violations of human rights may legitimize stigma and discrimination. Violations of rights may worsen the impact of HIV. Ensuring the protection and respecting and fulfilling human rights is one important way of combating AIDS-related stigma and discrimination.

Observing the articles on children's rights to be with their parents and not to be separated from their families is very difficult in Uganda because of the HIV/AIDS situation especially in the case of orphans. This is indeed no easy situation, bearing in mind the right and duty of parents to care for and bring up their children in the best interests of the child.

As there are still a lot of negative attitudes against children with HIV/AIDS it will be very difficult to avoid physical or mental violence, abuse and negligent treatment. It will also be very difficult to know how to accommodate the orphans, considering their situation. Because of widespread poverty it is hard to ensure the provision of necessary medical assistance, combat disease and malnutrition, maintain the provision of adequate nutritious foods and clean drinking water and give every child the right to a standard of living adequate for the child's physical, mental, spiritual, moral and social development.

As a result it is almost impossible in Uganda to follow the articles in the CRC because of the overall national situation. It is clear that children with HIV/AIDS are not protected from unfair treatment, discrimination or punishment and that the interests of the child are most unlikely to be a prime consideration in Uganda. Today ARVs are one of the best possibilities to ensure every child's inherent right to life and the survival and development of the child, but that will not be possible for all children because of poverty. Even the children's right to be heard and their right to freedom of expression, their freedom of thought and right to privacy are almost non-existent in Uganda.

It has taken a long time to implement the CRC in Uganda. Initially, more emphasis was put on children's rights than on their responsibilities. The long-standing conflict in northern Uganda has negatively affected the implementation of the rights guaranteed in the Convention. However, one positive aspect is that Uganda continues to work with CRC-

related questions which will be published in due course. Currently, a fifth periodic report for CRC issues in Uganda is being planned for November 2012 (CRC/C/UGA/CO/2).

Chapter 8

CRITICAL REVIEW AND CONCLUSION

8.1 Critical review

Leininger (1991) has developed specific criteria for qualitative investigations and maintains that since the purpose of ethnonursing research studies is to discover the nature, essence, attributes, meanings, characteristics and understanding of particular phenomena under study, use of qualitative criteria is imperative. The critical review in this study will be carried out using these criteria. The criteria are as follows: credibility, confirmability, meaning-in-context, recurrent patterning, saturation and transferability. These are criteria generally used by other researchers. The author has also developed the criteria: meaning-in-context, recurring patterns and transferability.

Credibility refers to direct sources of evidence or information from the people within their environmental context of their "truths" firmly held as believable to them (Leininger & McFarland, 2002). During three weeks in Uganda the respondent had time to get to know the informants better. Before the focus group interviews and one-to-one interviews were done the informants had received information about the study and its purpose. Focus group interviews were done during the respondent's first and last weeks in Uganda. In that way there was enough time to read the interviews and devise follow-up questions. One-to-one interviews were done at the end of the second week and the last week. At that time the respondent felt that she had come closer to the informants and had become a friend to them. The respondent gained the confidence informants who were willing to share their experiences with her. She felt that the answers by informants to her questions were honest.

Confirmability refers to documented statements and direct observational evidence from informants and other people who strongly and knowingly confirm and substantiate the data or findings (Leininger & McFarland, 2002). Due to the shortage of time available to finish this study and the distance to Uganda the respondent did not have the possibility to go back to the

informants to confirm the findings and their interpretations. However, the respondent felt that through the focus group interviews conducted twice, she could ask follow-up questions to the children the second time and in that way get a deeper understanding. Also, through the one-to-one interviews with general informants the respondent got a wider and more varied outlook of the subject. The data collection methods in the study provided a lot of information ensuring good confirmability.

Meaning-In-Context refers to understandable and meaningful findings that are known and relevant to the people within their familiar and natural living environmental context and culture (Leininger & McFarland, 2002). For the respondent it was a challenge to try to understand different cultural phenomena that were familiar to the informants. However, the fact that the respondent had stayed in Uganda before made it easier to face the cultural aspects. During the data analyses process the respondent kept informants' statements in their proper contexts.

Recurrent patterning refers to documented evidence of repeated patterns, themes and acts over time reflecting consistency in life ways or patterns of behaviour (Leininger & McFarland, 2002). Because of the respondent's limited time in Uganda and the relatively short time to finish this study it has not been possible to observe recurrent patterning first-hand. The informants, especially general informants, could describe recurrent patterning because they were Ugandans and thus very familiar with the HIV/AIDS situation in the country and the cultural context.

Saturation refers to in-depth information of all that is or can be known by the informants about phenomena relating to a domain of inquiry under study (Leininger & McFarland, 2002). Every informant's statement was original and yet you could see similar patterns in the statements. Both key and general informants participated in the study and that also gave more credibility to the patterns. The fact that general informants were adults answering the same questions as the children offered a better understanding and confirmed the patterns. Other children the same age as the key informants are not used to talking to adults in the Ugandan culture and not so good at English. That is why general informants were adults and not children. The focus group interviews conducted twice also give more credibility to the patterns. Also, the general informants and the one-to-one interviews provided saturation.

Transferability refers to whether the findings from a completed study have similar, though not necessarily identical, meanings and relevance to be transferred to another similar situation, context or culture (Leininger & McFarland, 2002). The findings from this study could probably be transferred to similar situations in other under-developed countries and other groups of vulnerable children. It might be difficult to transfer the findings to industrialized countries because the findings are specific to culture. However, in this increasingly multicultural world, the findings could well help nurses provide the best possible care for all children with HIV/AIDS, even in industrialized countries.

8.2 Conclusion

The aim of this study was to give an understanding of how children express HIV/AIDS-related stigma and the possible challenges it causes due to cultural factors that influence stigmatization in children in Uganda. Through this study I also wanted to find out whether the Convention on the Rights of the Child is, or can be, considered in Uganda to protect children with HIV/AIDS from stigmatization.

Through the research questions the aim of the study was achieved. It became clear how stigmatized the children really are by the way they were expressing their experiences about stigma. Also, several factors relating to local culture in Tororo still stigmatize children with HIV/AIDS. This would suggest that breaches of many articles in the CRC were still common in local society and a lot still needed to be done to protect children with HIV/AIDS from stigmatization.

Even if the results showed a lot of stigmatizing factors, key and general informants also expressed many encouraging factors, especially when parents and close relatives - despite the hardships - try to give the very best care to their children. Putting their hope and trust in God is important giving them the strength to survive. The children are encouraged to live as happy a life as possible. Through the confidentiality in counseling the children are willing to talk thus providing more openness and knowledge about the sickness. Knowledge about the life-prolonging ARVs will encourage more children to be tested for HIV.

My intention with this study was to find out more about stigmatization of children with HIV/AIDS in a rural area of Uganda and to inform about the children's situation. Since completing this study I have seen an urgent need to educate not only children but also adults in the children's immediate environment about the consequences of HIV/AIDS-related stigma. The results showed that the children's voices will not be heard. However, widespread information about these children will create a greater understanding of their situation and highlight the importance of reducing HIV/AIDS-related stigma. Information and knowledge about the CRC is also important to enhance the protection of children with HIV/AIDS.

Another intention with this study was to remind people that even in the industrialized world we have children suffering from HIV/AIDS-related stigma and the results from this study could help us to take more action to help children suffering from HIV/AIDS.

It would be interesting to see with further research how intervention programs could help to overcome stigmatization of children with HIV/AIDS. More research is needed regarding methods of intervention for improving the psychological status, knowledge and skills of carers for children with HIV/AIDS and for reducing the stigma associated with HIV/AIDS. Holzemer, Uys, Makoae et al.(2007) have developed the Conceptual Model of HIV/AIDS Stigma identifying areas suitable for developing stigma reduction methods of intervention which aim to reduce the burden of HIV/AIDS stigma. That could be an interesting model to adopt in further research.

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Focus Group interview guide for children with HIV/AIDS

Date_____   Names/code_____   Ages _____   HIV/AIDS status _____

1. Tell me if there are difficulties to be infected and affected by HIV/AIDS

      a)   Thoughts

      b)   Feelings

2. I am interested about how it is to live with HIV/AIDS in Uganda.

      a)   Technological Factors

            Health care

      b)   Religious and Philosophical Factors

            Religion

      c)   Kinship and Social Factors

            The treatment from family

            The treatment from the community

            The treatment in the daily life

      d)   Cultural Values, Beliefs and Lifeways

            To live in a rural area

            Rules, norms

            Rituals

      e)   Political and Legal Factors

            Children's Rights

      f)   Economic Factors

            Access health care and medicines

      g)   Educational Factors

            School attendance

            Knowledge about HIV/AIDS

3. Can you please tell me about your possibilities to talk about your situation of being HIV+

   Is it possible for you to talk to

      a)   Family

      b)   Friends, neighbours

      c)   School

      d)   Community

      e)   Health care

Enclosure 2

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Dato: 13.09.06

Deres ref.:

Vår ref.: S-06321b

S-06321b **Barns röster om HIV/AIDS relaterad stigma i Uganda**
      "Children´s voices about HIV/AIDS-related stigma in Uganda"

Komiteen behandlet søknaden i sitt møte onsdag 07.09.06.

Komiteen har ingen merknader til prosjektet, og tilrår at det gjennomføres.

Med vennlig hilsen

Tor Norseth

Leder

Julianne Krohn-Hansen

Sekretær

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

NSD

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Vår dato: 25.10.2006   Vår ref: 15363/JE   Deres dato: Deres ref:

TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 14.09.2006. Meldingen gjelder prosjektet:

15363	*Children's voices about HIV/AIDS-related stigma in Uganda. A descriptive study of adolescents experience of stigma*
Behandlingsansvarlig	*Universitetet i Oslo, ved institusjonens øverste leder*
Daglig ansvarlig	*Eli Haugen Bunch*
Student	*Sonja Carlson*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/endringsskjema. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://www.nsd.uib.no/personvern/database/

Personvernombudet vil ved prosjektets avslutning, 15.06.2007 rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Bjørn Henrichsen   Janne Sigbjørnsen Eie

Permission from Dr. Leininger

Dear Dr. Leininger,

I am a master degree student in Nursing Science at University of Oslo, Norway. To travel and learn to know about other people from other Cultures have always been a big interest for me. Through this interest I have been working as a nurse with children in Uganda. I have been visiting Uganda three times. During every visit I have met children infected or affected by HIV/AIDS.

Now I write my thesis 'Children's voices about HIV/AIDS- related stigma in Uganda'. I have done focus group interviews with 8 key informants and individual interviews with three general informants. As framework I use your theory of Cultural Care Diversity and Universality and the Sunrise Enabler and trying to understand different aspects in the Ugandan culture that can influence stigmatization in children with HIV/AIDS.

Now my question to you is if it is possible for me to use a copy of your Sunrise Enabler as a figure in my thesis?

Kindly
Sonja Carlson
Nurse, Master Degree Student at University of Oslo, Norway.

Dr. Leininger wishes you her best and grants permission to use her Sunrise Enabler in your work.
Thank you.
John Vanderlaan
Webmaster