HIV-related Stigma in Karamoja

Master in International Health (MIH)

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Utrecht, 20th of august 2009

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Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ARV	Anti Retroviral
CBO	Community Based Organisation
HBC	Home-Based Care
HIV	Human Immunodeficiency Virus
ICF	International Classification of Functioning, Disability and Health
ICRW	International Centre for Research on Women
IMR	Infant Mortality Rate
INF RELEASE	International Nepal Fellowship RELEASE Project
KDDO HC	Karamoja Diocesan Development Office Health Centre
NGO	Non-Governmental Organisation
NUSAF	Northern Uganda Social Action Fund
PLWHA	People Living With HIV and AIDS
S&DIWG	Stigma and Discrimination Indicator Working Group
TFR	Total Fertility Rate
UDHS	Uganda Demographic and Health Survey
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing

1. Introduction

HIV is already for several years an immense problem for the world, especially in Africa. Tremendously amount of people died because of HIV and it orphaned an immense group of children. The pandemic of HIV expanded not only because of the occurrence of the disease itself; it is also a highly stigmatized disease. HIV-related stigma can cause that people do not change sexual behaviour, do not go for HIV testing, and exclude people which they think they have HIV. It harmed the People Living With HIV and AIDS (PLWHA) and their families, even in Karamoja.

In 2005, when I worked as adviser for primary health care with the Church of Uganda in Karamoja we started to support PLWHA. We were surprised that people came for testing of HIV and they came for the meetings when they were found HIV+. They started to share experiences and recovered visible from the distress. The PLWHA told stories about exclusion by their communities and families. Some were pushed away from the central and lived on the sideline of the village. They were not allowed to eat together with others. When they were sick, the food was pushed with a stick. They feared to come near to them. After such experiences, most of the PLWHA decided to move to Kotido Town to find another way of living.

This phenomenon was interesting started and I started to read about stigma and found out how stigma can be measured. The International Nepal Fellowship RELEASE (INF RELEASE) had developed a scale to measure Participation and International Centre for Research on Women (ICRW) made questions based on indicators of stigma. I developed two questionnaires based on the stigma indicators and used the Participation Scale: one for the community members and one for the PLWHA.

Even during my study in 2006 for the Master in International Health, people told me about the increasing number of PLWHA that came to the Home Based Care (HBC) activities and lived in Kotido Town. What is exactly happening in the villages? What factors cause that the Karimojong exclude those HIV+ members? Although the HBC program is doing well in giving support, but what can be improved so that the quality of life of PLWHA is sustained?

In preparation on the field visit, I send the questionnaires for translation into Karimojong to Kotido. In Karamoja, I trained two research assistants and during the six week of fieldwork, they did the verbally interviewing.

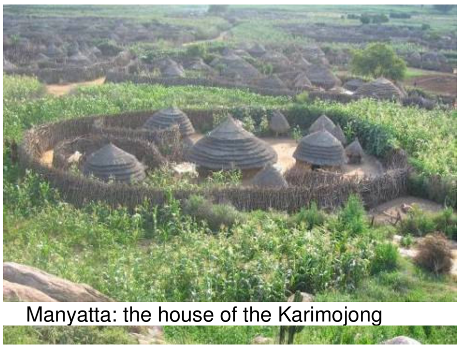
After being back in the Netherlands, it took a while to get used to the statistical analysis using EPI info. During the analyses, I used the variable social participation, fear, blame, shame, enacted stigma, and internalize stigma. I compared it with factors as age, sex, marriage, village, income, education, knowledge on HIV prevention, knowledge on HIV transmission, experiences of disclosure, disclosure by PLWHA, and health condition of PLWHA. Finally, I got the result of the study, studied again the theories around stigma and I wrote the thesis.

In the thesis is explained the theories of stigma and the dynamics of HIV. The next chapters are about the background of HIV in Karamoja, the objective of the study and the methods used. In the chapter of the results, linear regression and descriptive tables are written down based on the variables. On the end of the thesis the discussion, conclusions, and recommendations are described.

Although the result of the study is just a reflection of what is real happening in HIV-related stigma in Karamoja, it gave a more reasonable insight in how HBC programs can be designed. The objectives can be more precisely defined and activities can be done more appropriate in order improve quality of life for PLWHA and to prevent the spread of HIV.

2. Karamoja

Karamoja is situated in the northeast of Uganda, bordering the countries Sudan and Kenya. In Karamoja lives the tribe Karimojong that is divided in different sub-tribes. Related tribes live even in the neighbouring countries. People who call themselves Karimojong share the same language. They understand partly the languages of the neighbouring tribes, but not all.



Manyatta: the house of the Karimojong

Although the Karimojong come from the same tribe, most sub tribes live in conflict with each other, because of cattle raiding. In the 1970s, the Karimojong started acquiring guns in large quantities. This deteriorated the problems and caused many dead people and cows. This has been a problem for many years and has seriously increased the insecurity at times.

The Karimojong are a semi-nomadic cattle-herding tribe. The men move with their cattle looking for pasture and water. That means that during the dry season the cattle with the men are away from the Manyatta[1]. During the rainy season, the cows are back in Karamoja and they start with digging and preparing the land. Agriculture is mainly done by the women as well as the building of the Manyatta and keeping the household. Karimojong men are polygamist. The survey of Northern Uganda Social Action Fund (NUSAF) indicates that 22% of the people lives polygamous. The wealth of a man is seen on the number of cows he owned and the number of wives he has married.

The climate in Karamoja is hot and dry. There is only one rainy season a year, but because of the erratic rainfall, most of the harvests do not yield enough food for the whole year. The vegetation is mainly savannah grassland with thorny bushes. The total population of Karamoja is 669.000. In the north of Karamoja, Kotido, where the research took place live 424.132 people where the research took place. (NUSAF, 2004)

2.1 Development in Karamoja

According to the Uganda Demographic and Health Survey (UDHS) and NUSAF report, Karamoja is the least developed area of Uganda. The comparison with the figures of national level and the level of Karamoja is remarkable. The education level in Karamoja is the lowest in the country. The rate of population that is illiterate is 79% and 59.5% of the people older than 6 years have never attended school. (NUSAF, 2004) Only 43.3% of the primary school age children (6-12 years) attend school. (Uganda 85%) (UDHS, 2006)

The majority of the population is poor. 82% of the population lives under the poverty line. Their main consumption per adult equivalent is below 20.000 Ugandan shilling. (NUSAF, 2004) The common type of housing is a grass roof hut with mud with unburned bricks. Almost all households are affected by traumatic evens as rebels destroying their house and kill community members, raids of cattle or drought and famine. (NUSAF, 2004)

2.2 Health indicator

In line with the other indicators, even the health indicators are also poor. In Karamoja, the average distance to a nearby health centre is the longest in the country: 5 km. Only 54% has access to safe water sources (See Table 1)

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[1] Housing of the Karimojong

Indicators	Uganda	Karamoja
Infant Mortality Rate (IMR) per 1.000 live births	76	105
Under Five Mortality	137	174
% children 12-23 months with all basic vaccinations	46	48
Total Fertility Rate (TFR)	6.7	7.2
% using any family planning method	24	1
% of birth with assistance of skilled birth attendant	42	18
% children < 5 years stunted	38	54
% children < 5 years wasted	6	11
% children < 5 years underweight	16	36

Table 1: Health Indicator Karamoja (UDHS, 2006)

2.3 HIV and AIDS in Karamoja

The prevalence of HIV in Uganda in 2004 and 2005 was 6.1% and has risen slightly in 2006 and 2007 to 6.4% The prevalence of HIV in Karamoja was reported to be 0.7% in 2003. At that time, there were no HIV test facilities and even now, there are fewer facilities. The numbers for this prevalence figure came from the women who came for antenatal care in Matany hospital in the south of Karamoja. The percentage HIV+ varies strongly from 7.6% in 1994 to 0.0% in 2005 and 5.9% in 2006. In Kaabong, in the north of Karamoja, HIV positivity among women who came for antenatal care was 0% in 2005 and 12 % in 2006 (Annual Health Sector Report 2007/8). Therefore, it is difficult to estimate the real prevalence of HIV in Karamoja.

However, there are signs that HIV is a prominent problem among the Karimojong. The Church of Uganda started a HBC program on small scale in 2004 with 15 PLWHA. During the research carried out in 2007, 300 PLWHA came for the meeting and the support of the HBC program.

3. Defining stigma and discrimination

To investigate the effect and existence of stigma we need to understand the concepts of stigma and it manifests. As almost literature on stigma, we return to the definition of stigma by Goffman (1963). He describes stigma as 'an attribute, trait or disorder that is deeply discrediting' and results in the devaluation of a person or group 'from a whole and usual person to a tainted, discounted one'. By considering 'others negatively, an individual or group confirms their own 'normalcy' and legitimizes their devaluation of the 'theirs'

Based on the criticisms that the stigma concept locates the 'problem' in the individual and tends to focus on cognitive processing of information rather than on the discrimination and exclusion that a stigmatized person experiences, Link and Phelan (2001) widened the definition of stigma, 'Stigma exists when the following interrelated components converge. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labelled persons to undesirable characteristics to negative stereotypes, in the third, labelled persons are placed in distinct categories so as to accomplish some degree of separation of 'us' to 'them'. In the fourth, labelled persons experience status loss and discrimination that lead to unequal outcomes. Stigmatization is entirely contingent on access to social, economic and political power that allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories and the full execution of disapproval, rejection, exclusion and discrimination'.(Link and Phelan, 2001)

Link and Phelan (2001) explain the above components as follows:

Labelling: The vast majority of human differences (e.g. finger length, preferred vegetables) are not considered socially relevant. However, some differences, such as skin colour and sexual preferences are currently awarded a high degree of social importance.

Stereotyping: In this component, the differences is linked to undesirable characteristics in the minds of other persons or the labelled person either him- or herself. The person or group to be stigmatized has to be indentified. They must have some characteristic that can be used to stigmatize them.

Separating: The third aspect of the stigma process occurs when social labels imply a separation of 'us' from 'them'. When this separation is thorough, members of a stigmatized group may accept stereotypes about themselves and view themselves as fundamentally different from and inferior to other people.

Status loss and discrimination: When people are labelled, set apart, and linked to undesirable characteristics, a rationale is constructed for devaluing, rejecting, and excluding them resulting in poor life outcomes of stigmatized persons. This can happen in several ways on an individual level, but also on a structural level. The stigmatized person is distanced, disempowered, excluded, or controlled by the stigmatizer. Inherent in this process is a change in interaction and relationship.

Emotional reaction: The emotional responses are critical to understand the behaviour of both stigmatizers and people who are recipients of stigmatizing reaction. (Link et al, 2004; Gilmores and Somerville, 1994) For instance, stigmatization can inflict intense emotional pain. It may well be that those on whom such emotional pain is inflicted are not regarded as suffering from it is in the same way or to the same extent that we would do. (Gilmore and Somerville, 1994) It is important to realize that stigma is not just an attribute in the person.

Parker and Aggleton (2003) clarified that stigma is a constantly changing process, which devaluates relationships, rather than a fixed attribute. The focus should not be only on stereotyping, but also on the structural conditions that produce exclusion from social and economic life. Social psychological analyses have often transformed perceived stigma into marks or attributes of persons.

In that way, stigma comes to be seen as something *in* the person stigmatized, rather than as a designation that other attach *to* that individual. (Parker & Aggleton, 2003)

3.1 Stigma as an exercise of power and domination

As said already, stigma needs to be conceptualized as a social process. Power en domination is central in the reality of stigma. Power stands at the heart of social life and is used to legitimize inequalities of status within the social structure. Socialization places individuals as well as groups in positions of competition for status and valued resources and helps to explain how social actors struggle and pursue strategies aimed at achieving the specific interest. (Parker and Aggleton, 2003) In this exercise of power and domination, stigma is not an isolated phenomenon; an expression of individual attitudes or of cultural values, but is central to the constitution of the social order and regimes of power. (Parker and Aggleton, 2003) Stigma plays a key role in producing and reproducing relations of power and control. It causes some groups to be devaluated and others to feel that they are superior in some ways. Stigma is entirely dependent on social, economic, and political power. Groups with less power may label, stereotype and cognitively separate themselves from groups with more power. (Link et al. 2004)

Therefore, stigma is linked to the mechanism of social inequality and requires us to think more broadly about how some individuals and groups are socially excluded and about the forces that creates and reinforces exclusion. (Parker and Aggleton, 2003)

3.1.1 Stigmatization and marginalization

Stigma has a strong relationship with power and domination. It explains why some people with the same condition in higher positions do not face stigmatization in the same severity as people in lower positions. Stigmatization devalues people, and people who are devalued, for whatever reason, are more likely to be stigmatized, thereby reinforcing or augmenting their pre-existing devaluation. This double devaluation, permits people to distance themselves from those whom they stigmatise, and so makes the stigmatizers much less sensitive to the harm, pain and suffering they inflict on the persons they stigmatize. (Gilmore and Somerville, 1994) For instance, many PLWHA are members of groups that are already socially marginalized, such as sex workers, homosexuals, and the poor. HIV and AIDS is used to justify further marginalization of such people and further establishing deeply rooted prejudices. (Nyblade et al. 2003) On the other hand, because HIV and AIDS is associated with marginalized behaviours and groups, all individuals with HIV and AIDS are assumed to be from marginalized groups and some may be stigmatized in a way that they were not before. This can cause men to fear revealing their HIV status, because it will be assumed that they are homosexual. Women may fear revealing their serostatus because they may be as ‘promiscuous’ or ‘sex workers’ and be stigmatized as such. HIV and AIDS worsens the stigmatization of individuals and groups who are already oppressed and marginalized and gives people fear to disclose their HIV status or even to go for HIV-test.

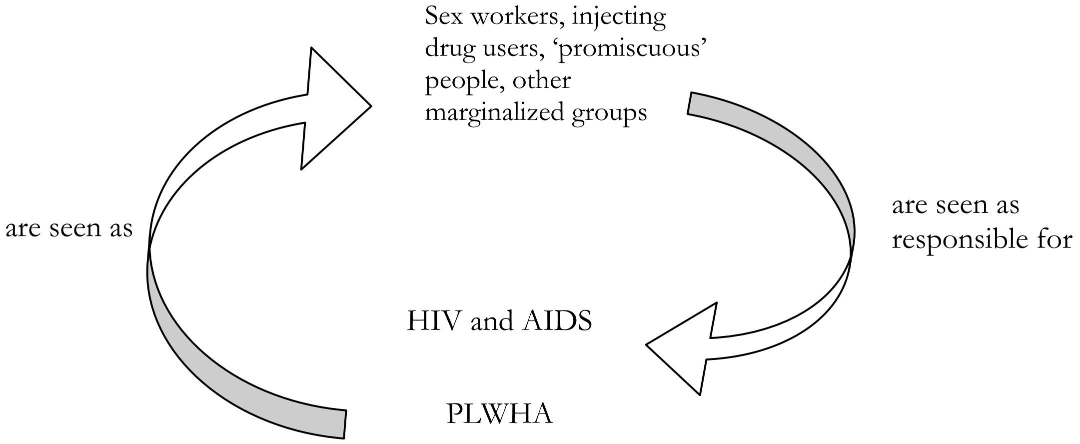

Figure 1: The circle of stigmatization and marginalization. (Parker and Aggleton, 2002)

3.2 Circumstances and existence of stigma

Stigma is a dynamic process and thus depends on the circumstances and the conditions. It does not manifest every time in the same way and with the same intensity. The circumstances where stigma exists can be very different and this has an impact on the severity and intensity. It makes sense if there is a possibility of exposure or if somebody can be associated with the people who are infected or exposed to the infection. When the spread of infection is rapid or uncertain, the threat may be worse. When social norms or public safety and order are challenged, the sense of danger increases. The risk of stigma is extreme if the law supports activities that stigmatise people as being criminal. Media coverage, especially of an alarmist or exaggerated nature also contributes to the existence of stigma. (Gilmore and Somerville, 1994; Link and Phelan, 2001)

3.3 Purpose of stigma

The reason why people stigmatise others may be very different. Gilmore and Somerville (1994) described a range of motivational actions. Stigma can be used to protect life, health, and property. It can be a response to risk and danger. Especially when the threats are open and prominent, overriding values. It can be also a means of strengthening or homogenizing a community and its values by excluding the unwanted, undesirable, or unproductive traits. Stigmatizing can be also a means of social control of both the persons stigmatized and those who are not; by marginalizing people from the community or by making they fear this. It is important to recognize that the use of stigmatization raises complex ethical issues concerning the justification of both the means and the results. If flight is not a realistic or desirable alternative to the problem, then the 'blame' the victim' or 'kill the messenger' response may be used. In that way, it offers the community a blemished and ineffective way to remove and destroy the problem. The community 'purifies' the community values, to promote its own identity and to reduce variance and provoke conformity among community members. Exclusion can enhance homogeneity by eliminating differences. However, this loss of diversity is not without its costs: very recent scientific research on biodiversity confirms this same phenomenon at a biological level. The greater the biodiversity of an ecological environment, the stronger its capacity to survive catastrophic events and the faster it can regenerate. (Gilmore and Somerville, 1994)

3.4 Stigma and consequences for health

Stigma is not without any consequences. It harms the people affected and those around them. It can prevent people from accessing prevention and care services. They hesitate to come for treatment and try to cope with the disease and the circumstances. Exclusion can even increase vulnerability to being exposed to the infection or become infected because precautions cannot be used or practiced. (Gilmore and Somerville, 1994) Discrimination tends to instil fear and intolerance. It creates a climate that interferes with effective prevention by discouraging people from coming forward for testing and seeking information on how to protect themselves and others and to adopt safe behaviour. (UNAIDS, 2000)

Stigma affects even the activities on prevention of HIV and spreading of the disease. The fear of stereotyping can cause activities for prevention of diseases to fail. Instead of dealing with the risk and fear, a stereotypical stigmatizing response replaces this risk and the fear. Precautions that would reduce the risk of being exposed are not used with everyone, but only with those who are stigmatized. 'Nice' people like 'us' are not seen as risk, whereas 'those' people are. Such redistributed risk does not prevent transmission, but rather increases the risk of spreading HIV. (Gilmore and Somerville, 1994) Discrimination may engender a dangerous complacency in individuals and groups that are not targeted and therefore assume that they are not at risk. (UNAIDS, 2000)

3.5 Characteristics of HIV and AIDS

Not all diseases or medical conditions are stigmatized. Depending on the way in which conditions or diseases behave stigma may be higher or lower. Stigma related to medical conditions is greatest when the condition is associated with 'deviant', socially improper behaviour or when the cause of the condition is viewed as being the responsibility of the individual. This is especially true when the illness is associated with religious beliefs and thought to be contracted through morally sanctionable behaviour. Stigma is also more evident when the condition is unalterable, incurable, severe, degenerative and/or leads to readily apparent physical disfigurement or to undesirable and unaesthetic death. (Nyblade et al. 2003)

Keeping this in mind, HIV and AIDS has a high risk of serious stigmatization. The way HIV and AIDS manifest has a considerable influence on the stigma. It is associated wit heavily stigmatized medical conditions. First, HIV is primarily transmitted by intimate contact. This means that the behaviours responsible for the transmission are private and intimate. Being infected with HIV brings about public disclosure of such private and intimate behaviour. This is a serious threat for most people.

Second, carriers of HIV are seldom recognizable when they are contagious, so that for someone to avoid sexual exposure requires abstinence, disclosure of HIV status or other precautions. Stigmatization can cause people to feel they do not need to take precaution, because they avoid sexual contact with the stigmatized group.

Third, sexual activity is a biologically and socially constructed behaviour, which reflects and can challenge public and private religious, cultural, and political norms and values. Those who are seen to embody such can be seen easily as 'polluted', morally corrupt or promiscuous. (Gilmore and Somerville, 1994)

Fourth, AIDS is incurable, degenerative, often disfiguring, and associated with undesirable death. It is also often incorrectly thought to be highly contagious and a threat to the community at large. (Nyblade et al. 2003)

3.6 Stigma and discrimination in relation to human rights

Stigma and discrimination can have serious negative consequences for a population. It can exist in a certain extent that it is considered as violation of human rights. The principle of non-discrimination, based on recognition of the equality of all people, is protected in the Universal Declaration of Human Rights and other human rights instruments. These texts prohibit discrimination based on race, colour, sex, language, religion, political or other opinion, property, birth, or other status. Furthermore, the United Nations Commission on Human Rights has resolved that the term 'or other status' should be interpreted to include health status, including HIV and AIDS', and that discrimination on the basis of actual or presumed HIV-positive status is prohibited by existing human rights standards.

Stigma violates the fundamental human right to freedom from discrimination. It leads to the violation of other human rights, such as the rights to health, dignity, privacy, equality before law, and freedom. (Gilmore and Somerville, 1994) To protect human rights among PLWHA it is important to involve legal institutions. The law is among the most important institutions in society, including in terms of its symbolic impact. This includes a powerful role of prohibiting discrimination, protecting people who are vulnerable to this and providing remedies for those who are subjected to it. (Gilmore and Somerville, 1994)

3.7 Domains of stigma

To measure the impact and existence of stigma there is a need to know how stigma works among groups and individuals. There are signs and symptoms that indicate the severity of stigma and discrimination.

3.7.1 Fear

Fear is one of the most prominent domains of stigma. There is fear of transmission of the disease, but fear of getting pain of disfigurement and even going to die is cause of the fear. It can happen that people do not want to have physical contact like shaking hands with PWLHA or sharing a meal with a PLWHA because of fear to contract the virus. There is even fear to have contact with PLWHA. The underlying cause of this fear can be very diverse. It is possible that there is lack of knowledge about prevention of transmission, but it is also possible that people have misconceptions about transmission. People have spread rumours about a person and this has brought him into disrepute. There is fear among people to be excluded as well, if there interact with this person. (USAID, 2006)

3.7.2 Blaming and Shaming

The moral- or value driven stigma is an important domain of stigma and discrimination. Assumptions and judgments about how PLWHA contract HIV are manifest in stigmatizing attitudes. (USAID, 2006) PLWHA are stereotyped as promiscuous people and as responsible for bringing the disease to their community. HIV and AIDS is expressed as punishment of God or as result of bad behaviour. Gilmore and Somerville describe blaming as 'scapegoating'. Blaming someone who is innocent of causing this 'evil' – considering them 'guilty' is what is understood by scapegoating. Duality is also intrinsic, namely that the scapegoated person is at once seen as innocent and guilty: human and dehumanized: identified with the persons undertaking the scapegoating and disidentified from them. The scapegoated person must be human enough to be identified with and to carry the 'sins' of the community. And they must be able to be dehumanized in order to be blamed, isolated, hated, or in some way separated from the community in order to expel those 'sins' and for the community to justify doing this to them, but not to others. (Gilmore and Somerville, 1994)

3.7.3. Self or internalized stigma

The result of stigmatisation may be that the stigmatized person accepts the view that he is bad or devaluated person. According to Weis, internalisation refers to a process in which person with a stigmatized condition accepts perceived exclusionary views of society and self-stigmatises him or herself. Personal experiences and childhood associations may be responsible for stigmatizing social norms. Recollections of stigmatizing behaviour produce fear of an anticipated social response. (2008)

Gilmore and Somerville describe this phenomenon of felt or internalized stigma as follows. One of the difficulties with labelling is that people so often tend to react according to labels. People learn to react according to certain labels in their childhood from their parents and attitudes and behaviour regarding other labels may be acquired later in life. They are not aware about this process. Since the public community has defined both him and his group as bad. He and the group are threatened, punished, counselled, and even committed to institutions to force them to conform. Ultimately, the person acts as the community thinks he should act. He becomes loyal to groups in which membership consists of persons like him and finds himself accepted if he follows the group's norms

To understand why it is that those who are stigmatised and discriminated so often accept and even internalize the stigma, there is a need to understand the context and complexity of struggle for power and domination that lie at the heart of social life. The stigmatised people are subjected to an overwhelmingly powerful symbolic system whose function is to legitimize inequalities of power. (Gilmore and Somerville, 1994) Although people are trying to be loyal to the group, fear of rejection will have serious negative affects on the person him or herself. One of the most tragic consequences of stigma is the loss of self-esteem. Affected people conclude that they have failures or that they have little to be proud of. It is undoubtedly threatening and personally disheartening to believe that one has developed an illness that others are afraid of. (Link and Phelan, 2001)

3.7.4 Discrimination or enacted stigma

Discrimination and stigma are often mentioned in one sentence. Discrimination and stigma are interrelated and not separated from each other. Discrimination is the negative acts that result from stigma and that serve to devalue and reduce the life chances of the stigmatized. It is the end-result of the process of stigma, so-called 'enacted' stigma. (UNAIDS, 2006) (Nyblade et al. 2003) Those who stigmatise others may do so directly or indirectly. Stigmatizers may actively engage in the process of exclusion to discriminate unfairly, excluding, or actively troubling someone who they regard to be unacceptable. Others who do not actively engage in exclusion may *endorse* it. Justifying and supporting exclusion despite the fact that they themselves have outstanding legal or moral constraints. Still others may disagree with the stigmatizing behaviour, but do nothing to stop it. They *accept* it without endorsing it, either because they feel powerless, or because they feel vulnerable to stigma if they identify themselves with the interests of other who are victimized. (Weiss, M, 2008)

3.7.5 Disclosure

Disclosure is often considered a proxy measure of stigma and discrimination. The way disclosure take place among the PLWHA relates to the existence of stigma. It is assumed that, where stigma and discrimination is low, disclosure will occur more often and among a wider group of individuals. The number of people who discloses their HIV status may capture valuable information about stigma. (USAID, 2006)

3.7.6 Participation restriction

People with stigma have, most of the time, also challenges to participate in daily live. They fear to interact, to communicate with others and therefore it is frightening to go to meetings, to the markets or for travelling. They are restricted in their participation compared with others and risk isolation from the community, friends, and family. Participation is a person's involvement in a life situation. A life situation refers to a person's interaction in wider aspects and areas or normal living or community life. Stigmatized people face participation restrictions in various domains of life. Participation restriction refers to social, economic, civic, interpersonal, domestic, and educational domains of daily living most of which concern every person, regardless of their health, age, gender, or caste. (van Brakel, 2006)

4. Problem statement, research questions, and objective

4.1 Problem statement

Since Voluntary Counselling and Testing (VCT) became available in 2004 in Karamoja, the first People Living with HIV and AIDS (PLWHA) were introduced to the Home Based Care (HBC) program of the KDDO HC (Karamoja Diocesan Development Office Health Centre). They conducted monthly meetings with them and they shared there experiences about living with HIV and to learn from each other experiences. It gave them comfort, love and understanding. PLWHA talked about the way their relatives treated them. A major problem for most of the PLWHA is HIV-related stigma. Some PLWHA still lived in their community with their relatives, but a large group has left their village. The members of the community feared sharing eating utensils and eating with them. PLWHA went to the traditional healer and to the clinics, but no cure was obtained. Nobody was willing to help, as most people feared PLWHA. The community sends them and their children away. They went to Kotido Town, rented a room and try to get some income. Some PLWHA told stories of people who became sick and were kicked out of the house by their landlord. He was afraid that nobody would want to live anymore in his house after someone has died in that place. Approximately 200 PLWHA are living in Kotido Town lacking support of their family.

The Church of Uganda helped a large group of PLWHA in Kotido Town in many ways. They visited them at home, giving them supplies such as blankets and bed nets. They received medical treatment and training on agriculture and received even some seeds and tools to get harvest. There are also still PLWHA who live in the community, but their wellbeing and the degree of HIV-related stigma was unknown.

There are several reasons why PLWHA are sent away from their community. It is possible that the community cannot afford the costs to treat and care for the sick. It can be that the pragmatic way of solving their problems (Novell. B, 1999) force them to send PLWHA away. It is also possible that they do not know how the disease is spread and feared to become infected as well. It is not known how and why they blame and shame the PLWHA for bringing the disease to their community or how PLWHA stigmatise themselves.

There was not a clear understanding of the HIV-related stigma among PLWHA in the communities. If it is known, what exactly contributes to the increase of stigma it would be possible to adapt programs focused on particular parts of HIV-related stigma.

Insight in the dynamics of HIV-related stigma among the PLWHA in the community, gives insight in what support the community needs in order to reduce stigma and discrimination. Information on HIV-related stigma could be used to assess the impact of interventions from the HBC program.

4.2 Research questions

From the problem statement, the following research questions can be defined:

- What are factors contributing to HIV-related stigma among PLWHA in the communities of Jie County?
- Is there a relationship between HIV-related stigma and disclosure of the HIV status by PLWHA?
- Does the knowledge on HIV, the economic status, education, age or gender influences the level of HIV-related stigma?
- In which groups is less HIV-related stigma and why?
- What recommendations can be given to increase the well-being of PWLHA and stimulate social acceptance of PLWHA?

4.3 Research objective

With the above-mentioned research questions, the objective of this study is defined as:

> *To identify factors contributing to HIV-related stigma of PLWHA in the communities of the Karimojong in Jie County and to give recommendations for programmes that supports communities to increase well being of PLWHA..*

4.4. Target audience

The target audience are the organisations who carry out programmes on HIV and AIDS in the villages in Karamoja; Non Governmental Organisations (NGOs), Community Based Organisations (CBOs) or government programmes that focus on reducing the spread of HIV and sustaining PLWHA and their communities.

5. Method of research

5.1 Description of the research method

The study was based on quantitative research methods. A cross-sectional, comparative study design was used. The research was based on six weeks of fieldwork. It was the rainy season at that time, which delayed the study, because areas where unreachable and people were busy preparing the field.

Two suitable Research Assistants were recruited, a man and a woman. The female assistant interviewed the women and the male assistant interviewed the men. The Research Assistants were native Karimojong speakers, had a good understanding of English, and were good translators.

Interviews by research assistant

Native speakers translated the questionnaires (See Appendix 1, 2, and 3) and the guides in Karimojong. To verify that the meaning did not change substantially, a second translator translated the questions back into English as stipulated in the Participation Scale Users Manual.

The Research Assistants received training in the first week of the research. A training manual was developed for them. The topics covered in the training included HIV-related stigma, the purpose of the research, research instruments, data collection procedures and the planning for the research. Each Research Assistant did two interviews as exercise to have clear understanding of the meaning of the research.

The availability of PLWHA willing to contribute to the research was challenging. The number of people who was tested for HIV is very small in most areas. It was very difficult to include people who had signs of HIV, but had not had the HIV test. The person could be suffering from another disease. The experience was also that denial of having HIV was in some areas very high. The people who mobilized who were also HBC members helped us a lot to get PLWHA willing to contribute to the research. Especially in Kacheri, were there were no HBC programs, it was very difficult to find PLWHA.

Interviews by research assistant

To safeguard independency, the research was done with the least possible involvement of the Church of Uganda in Karamoja. Total independency was not possible, because their facilitation was needed and the PI would have been seen by the Karimojong as ‘one of them’, because of a previous working relationship.

The research team went all together to the village to carry out the interviews. The questionnaires were read and filled in by the research assistants. Per area, we asked somebody to mobilize people to get ready to come for the interviews. In Rengen and Kanawat, the people who did this were members of the HBC program. In Kacheri, we used a person who was known in the community and carries out trainings in the community.

The chosen villages are in the rural area of Jie District in Karamoja. Kotido is the main village in Jie. The most nearby village is Kanawat and the distance from Kotido and Kacheri is the longest.

At the end of the research, members of the HBC program meeting in Kotido were also interviewed. Only the people who spoke Karimojong were selected. The time to interview them was limited and therefore they were asked a limit number of questions. The Participation Scale was used and they were asked to indicate how their health condition was and how long they stayed in the HBC program.

5.2 Sampling methods

The communities were chosen in cooperation with the HBC program of the Church of Uganda, because they knew exactly where HBC activities were carried out, how and with whom we could work in the villages. The aim was to get the similar villages with and without HBC programs in order to get insight in the differences of existence of stigma. During the fieldwork, we were sitting in the central place of the village and we asked the mobilisers to ask women and men to come for the interview. They did convenient sampling and not random

5.3 Validity study

The Participation Scale measures participation among PLWHA and included in the questionnaire. Beside the PLWHA, interviews were also conducted with community members to collect normative data of healthy controls. For the other part of the questionnaire, PLWHA and community members were interviewed twice within 2 days to determine test-retest reliability of the questionnaires. Reliability study was done, but the analysis of the reliability data was outside the scope of this thesis.

5.4 Instruments

Question guides were developed which included the Participation Scale and the UNAIDS indicators to measure stigma related to HIV and AIDS.

There were two questionnaires developed: one for the group of PLWHA and one for the community members (See Appendix 1, 2, and 3)

5.4.1 Participation Scale

The Participation Scale is the outcome of an international research project started by the INF RELEASE project in Nepal. The Participation Scale Development Programme coordinated by The Leprosy Mission International developed an interview-based scale to allow quantification of participation (restrictions) experienced by people affected by leprosy, disability or other stigmatized conditions like HIV and AIDS (van Brakel et all, 2006). It is a tool that aims to measure social participation in order to assess needs, monitor progress, and evaluate the impact of rehabilitation. It is used to measure *participation*, which determines participation restrictions. The higher the score, the more restriction people are.

The Participation Scale covers eight out of nine major life domains defined in the International Classification of Functioning, Disability and Health (ICF) published by the WHO in 2001: learning and applying knowledge, communication, mobility, self-care, domestic life, interpersonal interactions, and major life areas, community social and civic life. Most questions ask the interviewee to compare him or herself with an actual or hypothetical 'peer'. Peers are people known to the interviewee who is similar to him or her in all aspects (socio-cultural, economic, and demographic) except from the health condition or disability. The interviewee is asked whether (s)he perceives their level of participation to be the same or less than that of their peer(s). If the interviewee indicated a potential problem, (s)he was asked how big a problem this is to them.

The Participation Scale allows assessment of restrictions due to the health condition or disability, not restrictions due to practices that are part of their culture. To eliminate these cultural influences, the questions ask the interviewee to compare their situation with that of his or her peers. (Participation Scale users manual, 2006)

At any point of time, certain members of society face participation restrictions in various domains of life, due disease, disability, deformity, age, gender of other stigmatizing conditions. For that reason, the questionnaire was administered also to people in the community without HIV, to determine the normal level of participation in the whole community. By comparing the participation in both groups, it is possible to conclude if PLWHA have more or less participation restriction than the community.

5.4.2 Questionnaire based on indicators

Besides the Participation Scale, a questionnaire was used with questions developed by ICRW in cooperation with USAID. (Nyblade et all, 2005) USAID had to measure the effectiveness of an expanded response to the HIV and AIDS epidemic and experienced the need to include indicators on Stigma. The USAID Stigma and Discrimination Indicator Working Group (S&DIWG) proposed a set of indicators for the USAID expanded response in May 2002. In the 2004, USAID started a project to examine, test, and validate selected stigma indicators. The project builds expressly on the findings of the ICRW and its partners' multi-country study on stigma and on the Horizons and Policy Project work on stigma. (Nyblade et all, 2005)

The questions developed by the S&DIWG, which were based on the stigma indicators, were used in the questionnaire. The questions measure four domains of stigma. The first is fear of casual transmission and refusal of casual contact with PLWHA. The second domain is moral- or value-driven stigma that refers to assumptions and judgments made. Three key dimensions are important to measure: shame, blame, and judgment. The domain Enacted stigma (or discrimination) includes stigmatising actions, such as gossip, social en physical isolation, and loss of business due to HIV status. The fourth domain is 'disclosure' and is often considered a proxy measure for stigma and discrimination. (Nyblade et all, 2005)

The questionnaire also contained questions on demographic characteristic such as, age, gender, level of education, economic status, source of income, and source of safe water. Besides this, the knowledge about HIV transmission and prevention was tested. Those questions were asked both to members of the community and to the PLWHA. Separate questions for the PLWHA focused on disclosure and experiences of support. Some were included that can give an indication for internalized stigma. PLWHA were asked how their life goals have changed and if they did something different because of HIV.

The questions to the community members only aimed at fear to contracting HIV, blame and shame, enacted stigma (or discrimination) and experienced disclosure of PLWHA.

5.5 Limitations, ethical considerations, ethical review and approval

Before each interview, people were verbally informed about the purpose of the research and about what would be done with the information obtained. Verbal consent was obtained and ticked on the questionnaire by the research assistant.

The names of the participants were numbered separately in an exercise book. Only the number corresponding to the participant's name appeared on the questionnaire. Only the number was further used in the research. It was not possible to identify information of a particular person.

Incentives were given to each village. The mobiliser from the village received a few shillings (5.000 Ugsh) at the end of the days of interviewing.

The focus of the research was to measure stigma among the PLWHA and among the people expect to have HIV. To ask people about their HIV status and their experienced stigma requires them to disclose their HIV status. It happened that people who were HIV+ or likely to be expected to have HIV feared to disclose their status and refused to contribute to the study. Those people probably experienced a high level of HIV-related stigma, but could not be included in the study. Therefore, we missed those very important people in this study. It was even problematic to interview people to be expected to have HIV. They might have had HIV, but they could also have suffered from other diseases.

Several questions e.g. on fear, blame and shame had several limitations. They were hypothetical and might suffer from socially acceptable answers or could be interpreted in different ways. In addition, they did not capture the underlying cause. Therefore, the results of the research would provide only a limited insight into stigma.

5.6 Data analyses

All answers were written on data forms and entered into an Excel spreadsheet. The data were analyzed using EPI info: a program for statistical analyses. Descriptive statistics were generated using means and frequencies. By the use of the multiple linear regression analyses, the combined effects of several factors contributing to a certain outcome variables were examined. Outcome variables were social participation, fear to contract HIV, fear to buy from PLWHA, blaming and shaming PLWHA, enacted stigma, and internalized stigma among PLWHA. In the tables where the multiple linear regression results are presented, also some variables are included that had a p-value above 0.05. Although these were not significant as independent factors, they still contributed to the model enough to be included.

6. Results

6.1 Description of the study population

In 2005, the first HBC activities started in Kotido Town and Kanawat and later in Rengen in 2006. At the time of the study, there were very few HBC activities in Kacheri. Activities of the HBC program were: training the community on HIV, meetings with PLWHA in Kotido, supplies such as soap, smearing oil, blankets, bed nets to PLWHA, training of PLWHA on health and income generating activities, provision of Anti Retrovirals (ARV's) and treatment of opportunistic infections in KDDO HC, supply of Septrin/Cotrimoxazol to all PLWHA and visiting PLWHA at home.

In total 277 people were interviewed in the villages Kacheri, Rengen and Kanawat: 45 PLWHA and 232 community members. Beside those also 76 PLWHA who lived in Kotido town were interviewed. Because of the restricted time, they were only asked on their health condition and participation.

The Participation Scale was also conducted with 232 community members to collect normative data of healthy controls. For the other part of the questionnaire based on the indicators, 11 PLWHA and 43 community members were interviewed twice within two days.

Over the three villages equally distributed, 45 PLWHA were reached equally distributed over the three villages. The average age of the population interviewed was between 34 and 41 and lives in grass-roofed hut with mud walls. The majority has is illiterate and gets income as peasant (See Table 2)

Table 2 Socio demographic characteristics of the study population

	PLWHA (n=45)			Community members (n = 232)			Members HBC program (n=76)		
Age	n	means	SD	n	means	SD	n	means	SD
female	31	37.9	8.3	107	39.4	11.0	47	33.0	8.0
male	14	43.4	9.0	124	40.9	16.4	29	35.4	8.7
Gender	n	%		n	%		n	%	
male	14	31.1		108	46.6		29	61.8	
female	31	68.9		124	53.4		47	38.2	
Villages									
Kacheri	13	28.9		123	53.0				
Kanawat	17	37.5		47	20.3				
Rengen	15	33.3		62	26.7				
Kotido Town							67	100.0	
Education									
< 2 years of education	35	77.8		208	90.0				
> 2 years of education	10	22.2		24	10.0				
Source of income									
none	4	8.9		43	18.3				
peasant	21	46.6		108	46.5				
employment	10	22.2		12	5.1				
busines	9	20.0		20	8.6				
keeping cows	1	2.2		29	12.5				
Housing									
grass roof and mud walls	34	75.6		221	95.3				
iron roof and cement walls	2	4.4		1	0.4				

6.2 Knowledge

Women more often gave correct answers than men did. People in Kanawat had more knowledge on HIV, than those in Rengen and Kacheri. Young people less than 20 years and especially people older than 60 more often gave incorrect answers to questions about transmission and prevention of HIV. The level of education or poverty of people had no influence on their level of knowledge. The people in the community who reported high levels of fear did have less correct knowledge about transmission. Besides that, the PLWHA who reported a high level of internalized stigma did have less correct knowledge about transmission of HIV. On average, PLWHA had a higher level of correct knowledge about transmission and prevention of HIV than people in the community. In contrast with women, men gave more often wrong answers than women did. (See Table 3)

Table 3 Profile of people that had knowledge on transmission and prevention of HIV

		Score on knowledge of ways of transmission (1-14) (n=276)		**Score on knowledge of prevention of HIV (1-11) (n=276)**	
Age	**n**	**means**	**SD**	**means**	**SD**
0-20	8	3.4*	5	3*	3.5
21-30	74	1.7*	3.1	1.3*	2..3
31-40	92	1.5*	2.7	1*	1.9
41-50	53	2.2*	4.2	1.9*	3.2
51-60	28	1.8*	2.6	1.1*	1.3
61-70	14	4.2*	4.1	2.6*	2.8
>71	7	10.1*	5.2	7.2*	4.7
Gender					
female	139	0.7*	2.7	0.5*	2.1
male	138	3.5*	3.9	2.6*	2.7
Village					
Kacheri	136	2.8*	4.2	2*	3.1
Kanawat	64	1.1*	2.1	0.8*	1.7
Rengen	77	1.4*	3.4	1.7*	2.3
Fear to contract HIV in the community					
no fear	52	1.5*	3.2	1.3*	2.6
1	10	1*	0.9	0.9*	1
2	4	1.8*	1.3	0.3*	0.5
3	57	0.8*	3.2	0.7*	2.5
4	5	0.6*	0.9	0.2*	0.4
5	103	3.8*	4.3	2.7*	3
Internalized stigma among PLWHA					
no internal stigma	11	1.4*	1.6	1.3*	1.3
1	11	0.1*	0.3	0.8*	1.3
2	18	0.4*	0.7	0.1*	0.2
3	2	2.5*	2.1	3.5*	0.7
4	1	7*	0	3*	0
5	1	2*	0	0*	0
6	1	7*	0	4*	0
Target group					
Community members	232	2.3*	3.8	1.7*	2.8
PLWHA	45	1.0*	1.7	0.8*	1.3

* the difference between row categories is statistically significant ($p<0.05$, Chi-squared test)

The knowledge concerning transmission of HIV by mosquito bites was poor between both people in de community and PLWHA. 42% of the people in the community and 24% of the PLWHA thought that HIV is transmitted by mosquitoes. Especially 72% of the men thought that HIV can be transmitted by mosquito bites. 29% of the community members, 16% of the PLWHA and 64% of the men thought that avoiding mosquito bites is a prevention method. The knowledge about mother to child transmission was poor. 29% of the people in the community, 13% of the PLWHA, and 39% of the men answered wrongly. More than 15% of the people in the community said that HIV is transmitted by kissing 19%, shaking hands 18%, sharing eating and drinking utensils 16%, sharing toilet area 20%, sweat 18% and saliva 18%. Around 30% of the men reported that

HIV can be transmitted by kissing, sharing eating and drinking utensils, sweat, and saliva. (See Table 4)

Table 4 Profile of the percentage columns indicates what percentage said 'Yes' to the question asked.

	Community members (n=232)		**PLWHA (n=45)**		**Gender**			
					female (n=139)		**male (n=138)**	
HIV can be transmitted by...	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
mother to child transmission	165	71.1	39	86.7	120	86.3	84	60.9
blood transfusion	201	86.6	44	97.8	134	96.4	111	80.4
sharing razors	208	89.7	43	95.6	132	95.0	119	86.2
unprotected sex	213	91.8	43	95.6	132	95.0	124	90.0
sharing needles	213	91.8	44	97.8	133	95.7	124	90.0
sex with multiple partners	215	92.7	44	97.8	134	96.4	125	90.6
sex with prostitutes	216	93.1	45	100	134	96.4	127	92.0
HIV can *NOT* be transmitted by...								
mosquito bites	135	58.2	34	75.6	130	93.5	39	28.3
sharing same toilet areas	186	80.2	42	93.3	133	95.7	95	68.8
kissing	187	80.6	42	93.3	131	94.2	98	71.0
sharing eat and drink utensils	190	81.9	41	91.1	133	95.7	98	71.0
sweat	191	82.3	41	91.1	133	95.7	99	71.7
saliva	191	82.3	41	91.1	134	96.4	98	71.0
shaking hands	196	84.5	41	91.1	133	95.7	106	76.8
HIV can be prevented by...								
abstain from sex	215	92.6	40	88.9	129	92.8	126	91.2
use condoms	215	92.6	43	95.6	132	95.0	126	91.2
be faithfull to one sex. Partner	215	92.6	44	97.8	133	95.7	126	91.2
limit nor of sex. partners	216	93.1	44	97.8	133	95.7	127	92.0
avoid sex with protitues	216	93.1	45	100	134	96.4	127	92.0
partners	216	93.1	43	95.6	133	95.7	126	91.2
avoid sharing razors	213	91.8	45	100	134	96.4	124	90.0
avoid sharing needles	214	92.2	45	100	134	96.4	125	90.6
HIV can *NOT* be prevented by...								
avoid injections	124	53.2	37	82.2	133	95.7	28	20.3
avoid kissing	166	71.4	38	84.4	132	95.0	72	51.8
avoid mosquito bites	148	71.4	33	84.4	131	94.2	50	35.8

6.3 Social participation

Participation of PLWHA in society was strongly associated with the health conditions they reported. Other factors with a statistically significant association were the village of residence, whether their HIV status was ever revealed without their consent and the knowledge about transmission of HIV. Participation was not associated with disclosure of HIV status initiated by people themselves or with internalized stigma. (See Table 5)

Table 5 Multiple linear regressions showing the combined effect of several factors on participation among PLWHA

Variable	Coefficient	F-test	P-Value
HIV status revealed without consent	5.000	6.1799	0.017563
health condition of PLWHA	-8.738	39.4246	0.000000
knowledge about prevention of HIV	-0.736	1.0002	0.323767
village (Kanawat/Kacheri)	-7.277	9.0126	0.004783
village (Rengen/Kacheri)	-9.125	13.6527	0.000708
CONSTANT	40.383	67.0253	0.000000

Correlation Coefficient: r^2	0.56

On average, PLWHA with higher level of participation restriction were more likely to live in Kacheri and have a poorer health condition. In comparison to the other villages and especially to the members of the HBC program in Kotido Town, PLWHA in Kacheri reported more participation restrictions. In addition, PLWHA who reported that someone else had revealed his or her HIV status without his or her consent had a higher level of participation restriction. Finally, the health condition of the PLWHA had consequences for the participation restriction. PLWHA with a poor or very poor health condition had more participation restrictions. (See Table 6)

Table 6 Profile of Participation among PLWHA

	Participation Restriction among PLWHA (n=121)			Normal Participation Restriction (n=232)		
Village	**n**	**means**	**SD**	**n**	**means**	**SD**
Kacheri	13	10.7	13.2	123	1.2	3.7
Kanawat	17	7.7	6.7	47	2.1	4.0
Rengen	15	6.8	5.3	62	2.0	5.6
HBC group Kotido town	76	5.7	7.1			
HIV status revealed without consent						
no	28	7.6	9.9			
yes	16	9.9	6.1			
Health condition of PLWHA						
very poor	9	12.7*	14.4			
poor	17	10.8*	8.5			
neither poor or good	49	6.1*	5.6			
good	37	4.5*	6.9			
very good	7	4.0*	6.0			

* The difference between row categories is statistically significant. (p<0.05, Chi-squared test)

46% of the PLWHA reported that they cannot work as hard as their peers do. 38% said that they do not have equal opportunities to find work. In addition, 20% said that they could not contribute to the household economically in similar way as their peers do. Even visiting public and common places was a problem for 24% of the PLWHA. 16% took less part in casual social activities than their peers. 22% reported that they had problems in taking care of themselves. The members of the HBC program in Kotido Town reported less often problems especially in taking care of themselves (1%), visiting common place (12%) and economic contribution to the household (15%), but 18% of them reported that they lost respect in the community. (See Table 7)

Table 7 Profile of Participation Restriction according to the individual items in the scale

	PLWHA in the villages (n=45)		Member of the HBC programe in Kotido Town (n=76)	
PLWHA reported to have problem	**n**	**%**	**n**	**%**
working as hard as their peers do	25	45.6	23	30.3
equal opportunity to find work	17	37.8	18	23.7
visiting all public/common places	11	24.4	9	11.8
opportunity to take care of yourself	10	22.2	1	1.3
economic contribution to the houshold	9	20.0	11	14.5
taking part in casual recreational/social activities	7	15.6	14	18.4
visiting other people in the communtiy	5	11.1	6	7.9
taking part in major festivals and rituals	5	11.1	2	2.6
respect in the community	4	9.1	14	18.4
help other people	4	8.9	5	6.6
socially active	4	8.9	5	6.6
doing of houshold work	4	8.9	5	6.5
moving around inside and outside the house	3	6.7	6	7.8
keeping eating utensils with the rest of the household	3	6.7	2	2.6
feeling confident in learning new things	2	4.4	4	5.2
visiting outside village/neighbourhood	1	4.4	6	7.9
comfortable meeting new people	1	2.2	5	6
counting of opinion in the family discussions	1	2.2	3	3.9

6.4 Fear

Fear of transmission was significantly associated with the village of residence, knowledge about transmission of HIV, and the level of blaming PLWHA to have HIV (See Table 8)

Table 8 Multiple linear regressions showing the combined effect of several factors on fear to contract HIV among the community

Variable	Coefficient	F-test	P-Value
blaming PLWHA	0.167	4.4670	0.036323
experiences of disclosure by PLWHA in the community	-0.531	1.2927	0.256786
knowledge about prevention of HIV	-0.213	3.4002	0.066527
knowledge about transmission of HIV	0.209	6.2367	0.013242
gender	0.386	1.974	0.161432
village (Kanawat/Kacheri)	-1.908	35.6024	0.00001
village (Rengen/Kacheri)	0.067	0.0551	0.814685
CONSTANT	2.026	13.7070	0.000270

Correlation Coefficient: r^2	0.25

In Kanawat village, people reported less fear than in Kacheri and Rengen village. People who had less knowledge about HIV had more fear to contract HIV. Compared to women, men scored higher on the overall fear score. People who blame the PLWHA of having HIV were also more fearful of contracting HIV. (See Table 9)

Table 9 Profile of people that feared to contract HIV

	Fear of contracting HIV by the community (0 - 5) (n=231)		
Gender	**n**	**means**	**SD**
female	108	2.7*	1.7
male	123	3.3*	2.2
Experiences of disclosure by PLWHA in the community			
no	214	3.2	2.0
yes	17	1.9	2.0
Blaming PLWHA (0-8)			
less blame (0-3)	11	1.8*	2
high blame (4-8)	219	3.2*	1.9
Knowledge about transmission of HIV (0-14)			
right answers	110	2.8*	1.8
one or more wrong answers	121	3.5*	2.1
Knowledge about prevention of HIV (0-11)			
right answers	116	2.5*	1.8
one or more wrong answers	115	3.7*	2
Village			
Kacheri	122	3.6*	1.7
Kanawat	47	1.5*	2
Rengen	62	3.5*	1.9

* The difference between row categories is statistically significant. (p<0.05, Chi-squared test)

In general, the scores of fear were high. Around 72 % of the people had fear of being exposed to saliva, to excreta, or to sweat from PLWHA. Half of the community was afraid of caring for PLWHA or of letting PLWHA care for their child. Especially men were afraid of caring for PLWHA or of letting PLWHA care for their child. The levels of fear were the highest in Kacheri. Only in Kanawat were moderate levels of fear, but still approximately 30% of the community reported fear. (See Table 10)

Table 10 Profile of fear to contract HIV according to the individual items

			Gender				Village					
	TOTAL (n= 232)		female (n=108)		male (n=123)		Kacheri (n=122)		Kanawat (n=47)		Rengen (n=62)	
Fear to contract HIV	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
being exposed to saliva of PLWHA	166	71.9	82	75.9	84	68.3	103	84.4	14	29.8	50	80.6
being exposed to excreta of PLWHA	169	73.2	83	76.9	86	69.9	104	85.2	15	31.9	50	80.6
being exposed to sweat of PLWHA	167	72.3	81	75.0	86	69.9	102	83.6	14	29.8	50	80.6
their child get care from PLWHA	109	47.2	23	21.3	86	69.9	64	52.5	13	27.7	32	51.6
caring for PLWHA	113	48.9	27	25.0	86	69.9	65	53.3	16	34	32	51.6

Whether or not the community was afraid to buy from PLWHA was significantly associated with gender, level of shaming PLWHA to have HIV, village they live in and the level of education. (See Table 11)

Table 11 Multiple linear regressions showing the combined effect of several factors on fear to buy from PLWHA

Variable	Coefficient	F-test	P-Value
experiences of disclosure by PLWHA in the community	-0.295	2.5704	0.110312
education	-0.138	7.8097	0.005656
gender	-0.552	22.9734	0.000003
shaming PLWHA	0.171	12.1832	0.000583
village (Kanawat/Kacheri)	-0.500	15.3323	0.000120
village (Rengen/Kacheri)	-0.028	0.0644	0.799893
community reports on enacted stigma towards PLWHA	0.042	1.9722	0.161622
CONSTANT	1.484	133.7845	0.000000

Correlation Coefficient: r^2	0.27

Although men were more afraid to contract HIV in general, women expressed more fear of buying products from PLWHA. People who had less than 2 years of education appeared more afraid of buying from PLWHA than people with more education. (See Table 12)

Table 12 Profile of people that feared to buy from PLWHA

	fear to buy from PLWHA (0-2) (n=231)		
Gender	**n**	**means**	**SD**
female	108	1.5*	0.7
male	123	1.1*	0.8
Education			
< 2 years of education	207	1.4*	0.7
> 2 years of education	23	0.5*	0.7
Shaming PLWHA (0-3)			
no shame	35	1.1*	0.9
more than one shame	195	1.3*	0.7
Village			
Kacheri	122	1.5*	0.7
Kanawat	47	0.7*	0.9
Rengen	62	1.3*	0.7
Experiences of disclosure by PLWHA in the community			
no	214	1.3*	0.8
yes	17	0.9*	0.9
Community reports on enacted stigma towards PLWHA (0-14)			
few experiences	218	1.3*	0.8
much experiences	13	1.2*	0.7

* The difference between row categories is statistically significant. (p<0.05, Chi-squared test)

Half of the population feared buying from PLWHA whether they had signs or not. If they were showing signs, the majority would not buy anymore from PLWHA, especially the women and the people from Kacheri and Rengen. Men and people in Kanawat feared also, but less severe. (See Table 13)

Table 13 Profile of people that feared to buy from PLWHA according the individual items

			Gender				Village					
	TOTAL (n= 231)		female (n=108)		male (n=123)		Kacheri (n=122)		Kanawat (n=47)		Rengen (n=62)	
Fear to buy PLWHA	n	%	n	%	n	%	n	%	n	%	n	%
looking strong and healthy	115	49.8	67	62.0	48	39.0	68	55.7	17	36.2	30	48.4
with signs of sickness	186	80.5	92	85.2	94	76.4	111	91	21	44.7	54	87.1

6.5 Blaming and shaming PLWHA

The level of blaming and of shaming PLWHA by the community is strongly associated with each other. In addition, gender, fear to buy from PLWHA and age were significantly associated with shaming PLWHA of having HIV. Shaming of PLWHA for having HIV was associated more strongly with gender and fear to buy from PLWHA than with the variable 'blame'. Knowledge on prevention or transmission of HIV, economic status, and disclose were not significantly associated with blame and shame (See Table 14 and Table 15)

Table 14 Multiple linear regressions showing the combined effect of several factors on blaming PLWHA by the community

Variable	Coefficient	F-test	P-Value
age	0.009	1.9781	0.161004
gender	0.325	2.3233	0.128890
village (Kanawat/Kacheri)	0.383	2.2186	0.137799
village (Rengen/Kacheri)	-0.397	3.7061	0.055509
education	-0.136	2.1281	0.146049
fear to contract HIV	0.061	1.5817	0.209861
shaming PLWHA	0.720	56.0805	0.000000
CONSTANT	4.720	180.6179	0.000000

Correlation Coefficient: r^2	0.38

Table 15 Multiple linear regressions showing the combined effect of several factors on shaming PLWHA by the community

Variable	Coefficient	F-test	P-Value
age	0.008	4.4634	0.035755
gender	0.956	65.7235	0.000000
village (Kanawat/Kacheri)	-0.185	1.4760	0.225705
village (Rengen/Kacheri)	-0.159	1.5831	0.209645
marital status	-0.214	2.4608	0.118158
fear to buy from PLWHA	0.236	9.9344	0.001848
blaming PLWHA	0.274	56.8285	0.000000
CONSTANT	-0.545	3.4595	0.064224

Correlation Coefficient: r^2	0.51

The levels of blaming and shaming were high, even in Kanawat. Compared to women, men blamed and shamed PLWHA more. People younger than 20 years and older than 60 years had higher scores on blame and shame. In Kacheri, the levels of shaming and blaming PLWHA were higher. (See Table 16)

Table 16 Profile of people that blamed and shamed PLWHA

		Blaming PLWHA (0-8) (n= 231)		Shaming PLWHA (0-3) (n=231)	
Gender	**n**	**means**	**SD**	**means**	**SD**
female	108	6.2*	1.6	1.6	1.2
male	123	7.4*	1.5	2.8	0.6
Village					
Kacheri	123	7.0*	1.4	2.4	1
Kanawat	47	6.9*	1.6	2.1	1.2
Rengen	61	6.4*	1.8	2.0	1.2
Age					
< 20	7	7.6*	1.1	2.9*	0.4
21-30	64	6.4*	1.9	1.9*	1.2
31-40	75	6.7*	1.6	2.1*	1.2
41-50	37	7.2*	1.3	2.3*	1
51-60	27	6.9*	1.7	2.4*	1
61-70	13	7.8*	0.6	2.9*	0.3
>71	7	7.6*	0.8	2.8*	0.4
Education					
< 2 years of education	207	6.8	1.6	2.2	1.1
> 2 years of education	23	6.7	2.0	2.3	1.1
Fear to buy from PLWHA (0-2)					
no fear to buy (0)	46	6.7	2.0	1.9*	1.3
fear to buy (1-2)	184	6.9	1.5	2.3*	1.1
Shaming PLWHA (0-3)					
less shame (0)	35	5.0*	2.0		
high shame (1-3)	196	7.2*	1.3		
Blaming PLWHA (0-8)					
less blame (0-3)	11			0.6*	0.8
high blame (4-8)	220			2.3*	1.1

* The difference between row categories is statistically significant. ($p<0.05$, Chi-squared test)

In general, the scores for blame and shame were high. Most people would be ashamed if they were infected (81%) and find that PLWHA should be ashamed of themselves (75%). Almost all see having HIV as a punishment for bad behaviour, spread by promiscuous men or promiscuous women or as punishment of the spirit world. Men and women scored high in most of the variables and even in all the villages. The score were only lower on blaming PLWHA for bringing the disease to the community among women (37%) and people in Kanawat (55%). Only 36% of the women said that PLWHA should be ashamed of themselves. (See Table 17)

Table 17 Profile of shaming and blaming PLWHA according to the individual items

	TOTAL		Gender				Village					
			female (n=108)		male (n=123)		Kacheri (n=123)		Kanawat (n=47)		Rengen (n=61)	
Shaming PLWHA	n	%	n	%	n	%	n	%	n	%	n	%
I would feel ashamed if I was infected with HIV	187	81.3	72	67.3	115	93.5	108	88.5	34	72.3	45	73.8
People with HIV/AIDS should be ashamed of themselves	173	74.9	62	57.4	111	90.2	100	81.3	31	66.0	42	68.9
I would be ashamed if someone in my family has HIV/AIDS	154	66.7	39	36.1	115	93.5	84	68.3	34	72.3	36	59.0
Blaming PLWHA												
HIV is a punishment for bad behavior	226	98.3	106	99.1	120	97.6	122	100	46	97.9	58	95.1
Promiscuous men are the one who spread HIV in our community	221	95.7	105	97.2	116	94.3	117	95.1	45	95.7	59	96.7
Promiscuous women are the one who spread HIV in our community	218	94.4	105	97.2	113	91.9	116	94.3	43	91.5	59	96.7
HIV is a punishment from the spirit world	211	91.3	104	96.3	107	87.0	113	91.9	44	93.6	54	88.5
It is the women prostitutes that spread HIV in our community	187	81.0	70	64.8	117	95.1	105	85.4	41	87.2	41	67.2
People with HIV/AIDS are promiscuous.	184	79.7	68	63.0	116	94.3	106	86.2	41	87.2	37	60.7
HIV is a punishment from God	175	75.8	72	66.7	103	83.7	93	75.6	40	85.1	42	68.9
People with HIV/AIDS are to blame for bringing the disease to the community	156	67.8	40	37.4	116	94.3	92	75.4	26	55.3	38	62.3

6.6 Enacted Stigma

Enacted stigma was associated significantly with gender, knowledge of transmission and prevention of HIV and AIDS, experiences of disclosure by PLWHA and the level of education (See Table 18)

Table 1 Multiple linear regressions showing the combined effect of several factors on enacted stigma reported by the community

Variable	Coefficient	F-test	P-Value
Age	-0.009	1.4576	0.228622
experience of disclosure by PLWHA in the community	1.467	13.3034	0.000331
fear to buy from PLWHA	0.158	1.2185	0.270880
education	0.292	7.7606	0.005810
knowledge about prevention of HIV	-0.365	13.7525	0.000265
knowledge about transmission of HIV	0.263	13.2600	0.000339
gender	1.022	14.3320	0.000198
shaming PLWHA	0.140	1.5518	0.214213
CONSTANT	-0.495	1.3899	0.239701

Correlation Coefficient: r^2	0.25

The reports on enacted stigma from community members were few in general. 23% of the people interviewed reported enacted stigma toward PLWHA or suspected to have HIV. People who reported enacted stigma had less knowledge about transmission and prevention and men reported more enacted stigma than women did. People with more than two years of education reported more enacted stigmatization. In most of the cases, they were witnesses of gossip (19%), or PLWHA who were treated differently at a social gathering (15%) or excluded from social gatherings (10%). (See Table 19)

Table 19 Profile of people who reported on enacted stigma according to the means and individual items

	Enacted Stigma TOTAL (n=232) (0-16)			People reporting on gossip about PLWHA (n=44)		People reporting on different treatment of PLWHA during gatherings (n=34)		People reporting on exclusion of PLWHA from gatherings (n=23)	
Gender	**n**	**means**	**SD**	**n**	**%**	**n**	**%**	**n**	**%**
female	108	0.1*	0.7	0	0.0	1	0.9	0	0.0
male	124	1.2*	2.2	44	26.6	33	26.6	23	18.5
Knowledge about transmission of HIV (0-14)									
correct answers (0)	110	0.1*	0.4	1	0.9	4	0.0	0	0.0
one of more mistakes (1-14)	122	5.2*	2.3	43	35.2	30	0.3	23	18.9
Knowledge about prevention of HIV (0-11)									
correct answers (0)	117	0.2*	1.2	2	1.7	4	3.4	0	0.0
one of more mistakes (1-11)	115	1.2*	2.1	42	36.5	30	26.1	23	20.0
Experience of disclosure by PLWHA in the community									
no	215	0.6*	1.4	41	19.1	4	14.4	22	10.2
yes	17	1.8*	4.2	3	17.6	30	17.6	1	5.9
Education									
< 2 years of education	208	0.5*	1.2	35	16.8	24	11.5	18	8.7
> 2 years of education	23	2.1*	3.6	8	34.8	9	39.1	4	17.4
Village									
Kacheri	123	0.8	1.6	28	22.8	19	15.4	21	17.1
Kanawat	47	1.1	2.8	5	10.6	8	17.0	1	2.1
Rengen	62	0.3	0.8	11	17.7	7	11.3	1	1.6

* The difference between row categories is statistically significant. ($p<0.05$, Chi-squared test)

6.7 Disclosure

Only 7% of the respondents knew someone who disclosed their HIV status to them. Disclosure happened more often to women, to people with higher economic status and people in Kanawat than to men or people living elsewhere.

More than half of the people who had experiences of disclosure of HIV+ status to them knew also someone living with HIV without symptoms (58%). (See Table 20)

Table 20 Profile of experiences of disclosure by PLWHA in the community

	TOTAL (n=232)	Experience of disclosure by PLWHA in the community (n=17)	
Gender	**n**	**n**	**%**
female	108	13	12.0
male	124	4	3.2
Knowing somebody with HIV without signs			
no	123	6	2.8
yes	19	11	57.9
Community reports on enacted stigma towards PLWHA			
no	178	14	7.9
yes	54	3	5.6
Economic status (0-10)			
Low economic status	180	8	4.4
high economic status	52	9	17.3
Village			
Kacheri	123	3	2.4
Kanawat	47	8	17.0
Rengen	62	6	9.7

People knew that somebody in the community is HIV+ because the person looks ill and has lost a lot of weight (60%) and from general rumours and gossip (33%). Especially men (50%) knew from gossip that somebody is HIV+. Only 8% of the people knew it from the PLWHA themselves. (See Table 21)

Table 21 Profile of individual ways of knowing if somebody in the in community is HIV+

			Gender			
	Total (n=232)		female (n=108)		male (n=123)	
	n	**%**	**n**	**%**	**n**	**%**
Ways of knowing somebody is HIV+ in the community						
when the person looks ill and has lost a lot of weight	140	60.3	66	61.1	74	60.2
from general rumors/gossip	76	32.8	14	31.1	62	50.4
from HIV+ person's friends neighbors	30	12.9	17	15.7	13	10.6
PLWHA discloses their status	18	7.8	13	12.0	5	4.1
from the health center/health worker where the person got tested	6	2.6	1	0.9	5	4.1
from HIV+ person's family	2	0.9	1	0.9	1	0.8

People in the community would advise somebody who is HIV+ but not showing signs and symptoms to disclose their HIV status to the community (76%). The risk of spreading HIV by PLWHA was the main reason for this advice 72%. 20% understood also that other PLWHA can encourage others to prevent the spread of HIV. Only few said that disclosure of HIV status by PLWHA can help in creating care and support from the community (7%) and reducing stigma (3%). The majority of the PLWHA advised others with HIV, but who did not yet show signs of symptoms

to disclose their HIV status to the community (71%). Two PLWHA would advise others to keep the HIV status to themselves and two advised to disclose only to family members.
The prevention of spreading HIV by PLWHA was the main reason why PLWHA advised others to disclose their HIV+ status. (See Table 22)

Table 22 Profile of advises by people to (dis)close HIV status

	PLWHA (n=45)		Community members (n=232)	
Advise to (dis)close HIV+ status	**n**	**%**	**n**	**%**
tell no body	2	4.5	5	2.2
tell only family	2	4.5	17	37.8
make available to the community	32	71.1	176	75.9
don't know	9	20.0	34	14.7
Reason to keep HIV+status secret				
personal problem	3	6.7	0	0.0
people act differently toward PLWHA	2	4.5	3	1.3
person would be neglected	1	2.2	4	1.7
no one would care for the person	0	0.0	1	0.4
Reason to disclose HIV+ status to the community				
to avoid spreading HIV by PLWHA	25	11.3	123	53.0
PLWHA can teach others to prevent spreading HIV	8	17.8	34	75.6
PLWHA can creat opportunity for care and support from the community	4	8.9	12	5.2
to reduce stigma against PLWHA	0	0.0	5	2.2

The women with HIV (90%) told others more often about their HIV+ status than men 57%. PLWHA who disclose their HIV status were mostly allocated in Rengen en Kanawat. PLWHA who are members of an HBC support group had always disclosed their status to others. (See Table 23)

Table 23 Profile of PLWHA that disclosed their HIV+ status

	TOTAL (n=45)	PLWHA that disclosed their HIV status (n=36)	
Gender	**n**	**n**	**%**
female	31	28	90.3
male	14	8	57.1
Period of time PLWHA have known their HIV+ status			
< 6 months	4	1	25.0
6-12 months	6	5	83.3
1-3 years	33	30	90.9
Village			
Kacheri	13	7	53.8
Kanawat	17	14	82.4
Rengen	15	15	100
Age			
< 20	0		
21-30	10	10	100
31-40	17	15	88.2
41-50	16	10	62.5
51-60	1	1	100
61-70	1	0	0.0
>71	0		
Economic status			
low economic status	26	21	80.8
high economic status	19	15	78.9
Member of HBC program			
no	26	17	65.4
yes	18	18	100
Health condition of PLWHA			
very poor	1	0	0.0
poor	5	4	80.0
neither poor or good	28	24	85.7
good	10	8	80.0
very good	1	0	0.0

Women and PLWHA who are married reported more times problems regarding releasing without their consent by other than others. PLWHA who knew their status more than 6 months have more times experienced that their status was revealed by others. 36% of the PLWHA experienced disclosure without their consent. (See Table 24) PLHWA said that the mother (13%), the health provider (9%), the partner (7%) or a brother (7%) were the actor in the disclosure. (See Table 25)

Table 24 Profile of type of people who revealed status of PLWHA without their consent

	PLWHA (n=45)	
	n	%
Person who revealed status without PLWHA consent		
mother	6	13.3
health provider	4	8.9
partner/husband	3	6.7
brother	3	6.7
total	16	35.6

Table 25 Profile of PLWHA whose status was revealed without their consent

	TOTAL (n=45)	Ever status revealed without their consent (n=16)	
Gender	n	n	%
female	31	16	36.4
male	14	0	0.0
Marital status			
with partner	30	6	20.7
no partner	15	10	66.7
Period of time PWLHA have known their HIV+ status			
< 6 months	4	0	0.0
6-12 months	6	3	42.9
1-3 years	33	13	40.6

6.8 Internalized stigma

Internalized stigma was significantly associated with the knowledge of transmission of HIV and gender (See Table 26).

Table 26 Multiple linear regressions showing the combined effect of several factors on internalized stigma among PLWHA

Variable	Coefficient	F-test	P-Value
age	-0.034	2.6566	0.112089
knowledge of transmission of HIV	0.376	12.1418	0.001345
gender	-0.889	4.2899	0.045775
village (Kanawat/Kacheri)	0.786	2.8853	0.098268
village (Rengen/Kacheri)	0.672	2.4137	0.129273
marital status	-0.405	1.0092	0.321981
knowledge about cure of AIDS	-1.096	3.5431	0.068127
knowledge that healthy person can have HIV	1.254	5.0906	0.030406
CONSTANT	2.440	6.0321	0.019155

Correlation Coefficient: r^2	0.49

Compared to men, women reported more internalized stigma. The people with correct knowledge about transmission of HIV more often experienced internalized stigma. PLWHA in Kacheri reported less internalized stigma than PLWHA in Kanawat and Rengen. The majority of the PLWHA have experiences of avoiding doing something, because of their HIV status. 56% said that their life goals and hopes have changed, because of the HIV+ status, while 67% said that they decided not to have a child anymore and 47% decided not to get married anymore. (See Table 27)

Table 27 Profile of internalized stigma of PLWHA according to the means and individual items

	Internalized stigma of PLWHA (0-7) (n=45)			Not to get married (n=21)		Not to get a child (n=30)		Change of life goals (n=25)	
Gender	**n**	**mean**	**SD**	**n**	**%**	**n**	**%**	**n**	**%**
female	31	1.6*	1.1	16	48.4	27	87.1	23	74.2
male	14	1.2*	1.7	5	35.7	3	21.4	2	14.3
Knowlegde about transmission of HIV (0-14)									
correct answers (0)	28	1.3*	0.7	13	46.4	22	78.6	18	64.3
one or more mistakes (1-14)	17	1.9*	1.9	8	47.1	8	47.1	7	41.2
Village									
Kacheri	13	1.0	1.4	3	23.1	5	38.5	4	30.8
Kanawat	17	1.9	1.6	9	52.9	12	70.6	12	70.6
Rengen	15	1.5	0.6	9	60	13	60	9	60.0

* The difference between row categories is statistically significant. ($p<0.05$, Chi-squared test)

7. Discussion

The study gives useful information on the dynamic process of HIV-related stigma in Karamoja. Stigma appears to be different among women and men, but also in villages were HBC programs are present. It is encouraging that PLWHA are willing to speak about HIV. It reduces the fear to contract HIV in the community, but it has no real effect on the judgment of the community towards PLWHA. The HBC program has positive impact on the living conditions of the PLWHA in Kotido Town. Compare with the PLWHA in the villages; PLWHA in Kotido Town had problems in keeping respect in the community. All this information provides insight in the particular area of HIV-related stigma and is instrumental for improving the HBC programs.

7.1 Gender

There was a prominent distinction between HIV-related stigma among women and men. Compared to women, men scored higher on fear, blame, and shame. They reported more enacted stigma among PLWHA in their community. Men did not experience much disclosure by PLWHA and men who had HIV did not disclose their HIV status easily. In contrast, women had more knowledge on transmission and prevention of HIV and, perhaps as a result, they had less fear. The fact that disclosure by PLWHA happened more frequently among women had an impact on the fear of contracting HIV. That does not mean that stigma among women did not exist. Although it was less than among men, women still had high levels of blame and shame towards PLWHA. It was a good sign that women witnessed less enacted stigma than men did, but internalized stigma among women with HIV was higher. Their status had been revealed more frequently without their consent, especially among women without partner or husband. It seemed that women without partner are more vulnerable to HIV-related stigma.

Women were more involved in the HBC program than men were. Possible reasons for this are that either men feared to come out receive support or they had enough support to avoid going for HBC support. It is even possible that the services offered did not address the needs of men. It can even imply that women had fewer problems with HIV-related stigma or had no other support than the HBC program and had nowhere else to go. The exact reason for it is not identified in this study but it is important for future research to investigate the difference in needs or challenges of women and men living with HIV.

Although fear among women in general was lower than among men, women scored higher in fear to buy from PLWHA. Whether PLWHA looked strong and healthy or had signs of sickness, women were more afraid to buy from PLWHA than men. The explanation could be that they had more knowledge on transmission and prevention and they knew that a healthy looking person could have HIV. The most reasonable explanation is that the task of going to the market and buying food in the cultural setting of the Karimojong belongs to the women and not the men. Therefore, the fear of buying food from PLWHA is likely to be stronger among the women, since men are not confronted with this dilemma.

Men who are HIV+ had a problem to be open to others about their HIV status. The exact reason for this was not clear, but it would be interesting to know the relationship between people maintaining their status and position among community and their disclosure of their HIV+ status. It might be possible that men do not disclose their status in order not to lose their position in the community.

The knowledge that HIV can be transmitted by sexual contact reached in most cases also the men. The majority knew that HIV is transmitted by sexual contact and can be prevented by limiting sexual partners and using condoms. The misunderstanding that HIV can be transmitted by shaking hands, sweat, saliva, sharing same toilet areas, and sharing eating and drinking utensils and mosquito bites is worrying. It is encouraging that men knew about the HIV transmission by sexual contact, but their involvement in the dynamics of HIV is broader. Men have an important role in making decisions in family and community life. The mentioned misunderstandings can have an important impact on the decision-making for the daily life activities of PLHWA and their relatives. If men continue to believe that HIV can be transmitted by daily contact and mosquitoes, exclusion of PLWHA and their relatives from the community can be the direct result. PLWHA can lose their respect in the community and quality of life will decrease.

7.2 PLWHA

PLWHA, who lived in Kotido Town, on average, had less restriction on participation, particularly concerning caring for themselves and earning income, compared to the PLWHA living in the village. This is a possible indication that the HBC program had a positive impact on the health and economic status of PLWHA in Kotido Town.

On the other hand, they reported a remarkably high level of losing respect in the community. Exploring the reason for this was outside the scope of this study, but it was known that several PLWHA lived in the villages before and went to Kotido Town because of their problems in the villages. Coming to Kotido was another way of trying to find support. The research was only done among Karimojong-speaking PLWHA in Kotido Town. Therefore, it is not likely that this loss of respect was related to tribal issues, but to their position in the community. PLWHA, in Kotido Town, lived in a separate and not integrated group in the community. It can be argued that the community in Kotido Town sees them as those who have problems and if they interfered with them, they also interfere with their problems and therefore they left them separate. Judgement and loss of respect for the separate group of PLWHA might be present. To clarify this, further study is needed to find out the challenges and way of living of PLWHA living in Kotido town.

PLWHA in the village indicated that they had a higher level of participation restrictions compared to people in Kotido Town. Participation restriction was significantly associated with the health condition of the person with HIV. In the detailed profile, PLWHA in the village reported more problems with caring for themselves than PLWHA in Kotido Town. The reason why maintaining their health was a challenge to them, was outside the scope of this study, but it might be related to poor access to health care facilities. The meetings of the HBC program were held in Kotido and people received their supplies. Because of distance, it is more difficult for PLWHA in the village to benefit from this. Supply of ARV was also problematic, because it was distributed in Kaabong Hospital or in Kotido Town. There is need to meet the needs of PLWHA in the villages to enable them to care for themselves and to keep a healthy status.

It was not confirmed in the study that fear, blame and shame in the community had influence on the participation of PLWHA. Still PLWHA reported on average more participation restrictions. Not surprisingly, the health condition of PLWHA had a significant impact on participation. PLWHA with a poor or very poor health condition reported significantly more participation restrictions than those with a good health condition. This emphasizes the need for ARV treatment and other interventions to improve access to health care and the health of PLWHA.

Women with HIV reported more internalized stigma than men did. Women decided more often neither to get married nor to get more children. Their perception of the future had changed. That means that HIV had a greater impact on the way women see the goals for their future compared to the future perspectives of HIV+ men.

In the stigma theories, it is stated that existence of stigma is related to the system of power. People who are marginalized are more likely to be stigmatised and to suffer from different stigmas. The study affirmed that women and especially women without a partner where more often confronted with people revealing their status without their consent. People, of whom others revealed their HIV status, reported more participation restrictions. This is an indication that they had less control over their own lives. Women, women without partner, and women without children are in this perspective more marginalized in the Karimojong context and have less social support. Women without children were not included in this study, but if women without partner already have a problem, women without children are likely not to be excluded from this. Therefore, there is a need to involve purposely women and especially women without partner and/or without children in the objectives of the HBC programs and address their special needs.

7.3 Village

There was a difference in HIV-related stigma in the three villages. As already said, in Kacheri only a few HBC activities were done for PLWHA. It is therefore not surprising that the highest levels of symptoms of HIV-related stigma were seen in Kacheri. In this village, the highest levels of fear, fear to buy from PLWHA, shaming and blaming PLWHA, and participation restrictions among PLWHA were reported. They made the largest number of errors in the questions about HIV transmission and prevention. There was no common experience of disclosure of HIV status in the community and as a result, most of the PLWHA did not disclose their HIV status. On the other hand, there were only few reports given on enacted stigma and PLWHA reported less internalized stigma. This is probably because HIV is not an observable fact in the community. People do not know who is HIV+, are not aware about the implications of the disease and do not know whom to fear or to judge.

The HBC program existed in Kanawat for two years and in Rengen for one year. This has a reflection on the differences of stigma in these villages. The majority of the PLWHA in Rengen and Kanawat had disclosed their HIV status. There were already some experiences in Rengen of disclosure in the village. Knowledge of HIV and the level of participation restriction among PLWHA was almost the same as in Kanawat. The level of fear to contract HIV in the village was still high as in Kacheri and the reports on enacted stigma were few. Kanawat had the highest level of internalized stigma among PLWHA and there were more reports about enacted stigma. The level of blaming and shaming PLWHA in each village was high, despite the HBC activities.

Compared to the villages of Rengen and Kacheri, people in Kanawat reported more often enacted stigma. It is possible that HIV was more visible in Kanawat because of the higher number of people who disclosed their status and because of the clearly organized group of PLWHA. Therefore, if enacted stigma occurred towards PLWHA, people in the community may have recognized this directly because of the HIV-status of the person. Although, it was expected HIV-related stigma in Kanawat to be lower because of the knowledge of HIV in the village and the presence of an organization of PLWHA, the underlying blaming and shaming still existed. The deeper root causes of stigma, like judgment towards PLWHA and internalized stigma among PLWHA were not effectively addressed.

7.4 Knowledge about transmission and prevention of HIV

In the study, it is observed that knowledge has partial influence on HIV-related stigma. Fear to contract HIV and reports given on enacted stigma were significantly associated with the level of knowledge of transmission and prevention of HIV, but had no influence on the level of blame and shame.

PLWHA who had less knowledge about transmission of HIV reported more internalized stigma. This is an indication that knowledge on HIV had an influence on the decision PLWHA make for themselves and their future. Therefore, it is important that PLWHA have appropriate knowledge on

HIV. They might be more able to make suitable decisions that build their self-esteem and respect in the community

The knowledge that HIV is transmitted by sex and blood was known, even among men and community members. They indicated that prevention of HIV is about avoiding sex, limiting the number of sex partners, and/or using a condom. It is clear that activities to increase the knowledge had achieved part of their objective. In this light, it is remarkable and worrying that the misunderstanding still existed that HIV is transmitted by mosquito bites and therefore that mosquito bites should be avoided. Even some PLWHA thought this way. That HIV can be transmitted from mother to child was not known among a large group of people, including women. The belief that HIV is transmitted by daily contact remained prevalent among groups of men and community members.

7.5 Fear, blame, and shame

There was a strong relationship between shaming and blaming PLWHA. People who said they blame less did also shame less. People who blamed less had on average less fear to contract HIV. There seems to be a relationship between fear, shame, and blame but the link is not very clear. Therefore, it is difficult to draw conclusions regarding this variable. People who had a high level of fear scored more mistakes in the knowledge scores. It was evidence that knowledge had an influence on reduction of fear to contract HIV. This was not the case with blaming and shaming PLWHA.

7.6 Enacted stigma

Reports on enacted stigma were almost all given by men, people with less correct knowledge of HIV, and people who experienced disclosure by PLWHA. It was difficult to give detailed information about people who are involved in enacted stigma. People who gave reports on enacted stigma are not necessarily the actors, though they were at least witnesses. There was no evidence that they agreed or disagreed with what happened, stimulated it, or were actors. Neither was there evidence that the level of fear, blame, or shame had an influence on the number of reports of enacted stigma.

7.7 Disclosure

It might be that people to whom PLWHA had disclosed their status had less fear to contract HIV and less fear to buy from PLWHA, but there were not significant associated to confirm this linkage at this point. Disclosure however had no influence on blaming or shaming of PLWHA. The assumption that disclosure by PLWHA has influence on the reduction of stigma is not confirmed.

Experiences of disclosure by PLWHA happened more often among people with higher economic status. That can be explained by the fact that the PLWHA, compared to the general population, had higher economic status and therefore more PLWHA belong to this group.

Community members advised PLWHA without signs of symptoms to disclose their status. The main reason was that they wanted to prevent spreading HIV. Only few said that it was needed to mobilise support for the PLWHA. It seemed that they wanted to know who HIV+ is in order to avoid this person because of the fear to contract HIV. Even PLWHA advised to disclose HIV status to avoid the spread of HIV in this way possibly with the same reason. This can be a possible indication that PLWHA have internalized stigma.

Although most PLWHA had disclosed their HIV+ status to others, the experiences in the community of disclosure by PLWHA were few. Community members knew that somebody is HIV+ because of the person losing a lot of weight and from general rumours and gossip. It seemed that PWLHA did not feel free just to tell and to speak out that they were HIV+. They might tell it some persons, but not in general. If somebody becomes sick and loses weight for any reason it might be possible that he or she becomes 'news' around. This is another sign of danger of the broader impact of HIV on populations. HIV may affect people in this way, even when he or she is not HIV+.

The health system and health staffs have a crucial position in HIV-related stigma of PLWHA. However, the expectation is that staff in the health system keeps all information concerning patients confidential, in two part of the study it was seen that confidentiality was a problem. PLWHA said that health workers had revealed their HIV+ status without their consent and some people even reported that they learned from a health worker that somebody was HIV+. Although the reports were few, the incidences can have a critical impact. It means that PLWHA could not trust the health worker to keep all what he or she told confidential. If this is the case, it becomes hard to seek advice and counselling. It can further discourage people of the community to come for an HIV test, since there is a possibility that the person might become 'news' around and will be excluded. It can disempower people and can make them vulnerable toward HIV and HIV-related stigma.

The information that people in Kanawat and women had more often experienced disclosure than people in Kacheri can be related to the fact that in Kanawat more people had been tested and can therefore disclose their HIV status.

The high levels of fear, blame and shame in Rengen did not prevent PLWHA to disclose their HIV status to others. It did not become clear in the study why the high levels did not prevent them to disclose their status. It could be the encouragement of the small group of PLWHA that lives in Rengen and are members of the HBC program that played an active role in this. It would be interesting what exactly the reason is for this.

7.8 Limitations of the study

The number of people interviewed was small and standard deviations were large most of the time. Therefore, it is difficult to draw firm conclusions out of this study. To confirm these preliminary findings, further study needs to be done.

The way of selection of the interviewees was convenient sampling and not random. This happened from the households. In addition, on this, the field study took place during the first time of rain and people were going to the field for preparing the land. The people who were at home were invited to come. The number of old and disabled people included in the study might be more than usual. Because of convenient sampling, it is possible that the group of people selected came from one side of the villages and not fully represents the whole village.

8. Conclusions and recommendations

HIV-related stigma has several components whose relations vary in different situations and periods. It turned out to exist at different levels among men and women in Kacheri, Kanawat, or Rengen and several factors were indentified that contributed to HIV-related stigma.

8.1 Factors contributing to HIV-related stigma among PLWHA

8.1.1 Access to health care, income earning, and keeping of respect

PLWHA in Kotido Town had fewer problems in caring for themselves and earning income compared to PLWHA in the village. However, they reported more problems with losing respect. In addition, participation restriction was significantly related to the health condition of PLWHA, especially in the villages. There is need to investigate if it is possible to increase access to health care and to promote income generation for PLWHA in the villages. This can have a positive impact on their health and consequently improve their economic status and will likely help them to keep or regain their position, and respect in the community. There is need to investigate the problem of lack of respect of PLWHA in Kotido Town. If the loss of respect were because of the separation from their family in the villages, this would indicate that keeping PLWHA in the village, by providing support activities in the village, would increase their quality of life. In that case, activities should specifically target HIV-related stigma in the villages.

8.1.2 Internalized stigma

There were several signs that PLWHA had more challenges in internalizing of stigma even when they were already involved for long time in the HBC activities in their village. Compared to men HIV-related stigma was lower among women, but women internalize stigma more often than men do. In Kacheri were few HBC activities were was less internalized stigma among PLWHA. It seemed that increasing awareness on HIV might also increase internalized stigma among PLWHA. For the same reason as community members, PLWHA advised that others should disclose their HIV status to avoid spreading HIV, and not to mobilise support from the community. Especially PLWHA with less knowledge about transmission of HIV had internalized stigma. It is important to empower PLWHA and build their self-esteem even with those who are already in the program for a longer period. There is a need to counsel them intentionally to promote a positive perspective.

8.1.3 Confidentiality of health staff

To get more people tested for HIV, to get more PLWHA to take up ARV treatment and to improve access to health care the challenge of potential lack of confidentiality among medical staff needs to be tackled. Health care systems can have all kinds of facilities, but especially in the case of HIV, which is highly affected by stigma, people need a system that can be completely trusted. Only one report of failure in confidentiality is devastating and is a threat to the empowerment of PLWHA and the prevention of the spread of HIV.

8.1.4 Women without partner

Women and especially women without a partner face problems with other people revealing their HIV status without their consent. This is an indication that women with HIV and especially women without partner have less control over their lives. The HBC program therefore needs to include purposely the marginalized women who are HIV+ to help them not to remain on the fringe, but to have a valuable integrated position in the community.

8.2 Relationship between HIV-related stigma and disclosure by PLWHA

A conclusion that disclosure of HIV by PLWHA has a clear relationship with the level of fear, blame, and shame in the community could not be made. Disclosure by PLWHA did not decrease the level of fear, shame, and blame. On the other hand, the high levels of fear, shame, and blame did not prevent PLWHA in Rengen to disclose their HIV status.

The community knew that somebody is HIV+ because the person looks ill and loses weight and from general gossip. People might be seen as HIV+ when they loss weight even when they are not HIV+. There is need to prevent that people become affected by HIV, even when they are not HIV+.

8.3 Influences on the level of HIV-related stigma

8.3.1 Knowledge

Appropriate knowledge on HIV decreased fear to contract HIV, but did not show a relation with the underling cause of stigma, as blame and shame. The facts about transmission and prevention by sexual contact were known, but there were still gaps. There is a need to aim at the suggestions that daily contact and mosquitoes transmit HIV. If this belief continues to exist, the fear to contract HIV will not disappear. An important group of women did not know that HIV is transmitted from mother to the child. To save little children from getting HIV, there is a need to teach more women about transmission of HIV from mother to child.

8.3.2 Economic status, education and age

The economic status of somebody does not appear in the study as an essential factor. There is no difference in HIV-related stigma among educated, illiterate, old, or young people

8.3.3 Gender

HIV-related stigma appeared to be different between men and women. Men scored the highest levels of fear, blame, shame, and enacted stigma. The experiences of disclosure of HIV status by PLWHA is less among men. From the results of the study, we can conclude that HIV-related stigma was stronger among men than among the women. Their involvement in HIV-related stigma is broader than their part in sexual behaviour. They have different tasks and a different position in the community than women and therefore other challenges. To address HIV-related stigma and prevent the spread of HIV, the approach of an HBC program should also be appropriate for the needs and challenges men face and needs to result in a higher and more appropriate involvement of men.

8.3.4 Blame, shame and fear

Increasing knowledge of HIV had an impact on the fear to contract HIV in the community, but had no influence on blaming and shaming PLWHA. To aim at the reduction of HIV-related stigma, activities should not only focus on knowledge of HIV, but also on the persisting values and beliefs of the community despite the gained knowledge. It is very difficult to eliminate gossip and to change labels and stereotyping directly in the people's beliefs. This will not happen overnight, but needs a persistent and comprehensive program. There is a need to make them aware that the HIV problem is not theirs, but concerns the whole community. It is even important to keep in mind that stigma especially happens to people who are already marginalized and powerless. Therefore, PLWHA need empowerment and a voice in the society to avoid this situation.

Executive Summary

Stigma is a dynamic process that varies in intensity and appearance. HIV worsens the stigmatisation of groups who are already marginalized. The process of stigma may result in discrimination, also called ‘enacted stigma’. Stigma may also result in internalized stigma. The person affected accepts that he or she is bad or a devaluated person. PLWHA face challenges in participation in various domains of life.

The study took place in Karamoja; the least is developed area of Uganda. The majority live under poverty line and is illiterate. The prevalence of HIV varied from 7.6% in 1994 to 5.9 in 2006.

The PLWHA in the central town Kotido told stories about stigmatisation. The exact reason was not known. The objective of this study was to identify factors contributing to HIV-related stigma of PLWHA in the communities in Jie County and to give recommendations for programs that aim at the well-being of PLWHA.

A questionnaire was developed in Karimojong to measures fear, blame, shame, enacted stigma, internalized stigma, participation of PLWHA and knowledge on HIV. The two native speaking Karimojong conducted the interviews. Mobilisers from the villages, Kacheri, Kanawat, and Rengen invited a convenience sample of people to come for the interviews in a central place in their village. 45 PLWHA in the villages, 232 community members and 76 PLWHA in Kotido town were interviewed. EPI Info was used for statistically analyses.

The following conclusions can be made. Women had more knowledge on HIV than men did. Although, the HIV-related stigma among women was less than among men, women with HIV faced more internalized stigma. In Kacheri, were few HBC activities took place, more HIV-related stigma was found compare to Rengen and Kanawat. Despite of the HBC activities, PLWHA in Kanawat had more problems with internalized stigma and reported more on enacted stigma. PLWHA in the villages reported more problems in maintaining their health and livelihood. In contrast, the PLWHA in the Kotido town were more confronted with loss of respect. Knowledge on HIV had influence on the level of fear to contract HIV not on the level of blame and shame.

The recommendations that follow from this study are:

It is recommended that the needs and challenges of men should be addressed appropriately. PLWHA in the village needs to improve quality of life by sustaining health and income. To decrease HIV-related stigma there is need to focus on blaming and shaming of PLWHA by the community. In order to avoid internalized stigma all PLWHA have a need to empower and to re-build their self-esteem.

Key words: HIV, Stigma, Karamoja

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After all, this thesis I dedicated to God. He will accomplish what He started once.

APPENDIX 1

Community Baseline Individual Questionnaire

INTRODUCTION

INFORMED CONSENT - read, agreed, signed, approved

SECTION 1: Respondent and Household Characteristics

no	Questions	Coding categories		Skip
104	In which village and parish do you live?	village parish	……….. ………..	
104a	How long do you stay in this place?	years	………	
104b	When you stay here less than 1 year, what was the reason that you moved to this place?	marriage Other (specified)………	1 95	
105	Have you ever attended school? If so, what is the highest level of school you attended	None Less than P2 Less than P5 Less than P7 Completed P7 Less than S4 Completed S4 less than S6 Completed S6 University	1 2 3 4 5 6 6a 6b 7 8	
106	Do you have a wife or husband?	Yes No	1 0	
106 AA	If no, are you divorced, widowed or never married?	Divorced Widowed Never Married	2 3 4	
106a	if yes, how many wives do you have?	only one two or three more than three	1 2 3	skip for women
106b	if yes, what position do you have	first wife second or third wife third of more	1 2 3	skip for men
107	What is your source of income?	none/depending on others keeping cows keeping sheep, goats keeping chicken selling beer shop keeping business	0 1 2 3 4 5 6	

		employment peasant builder/constructor	7 8 9	
107a	Does your household have the following items?	 1. blanket 2. saucepan 3. mattress 4. radio 5. bicycle 6. mobile 7. generator	no yes 0 1 0 1 0 1 0 1 0 1 0 1 0 1	
107b	Type of house roof	grass iron sheets Other (specified)………	1 2 95	
107c	Type of house walls	mud cement Other (specified)………	1 2 95	
108a	What is the main source of drinking water for members of your households?	piped into residence/yard public tap public well river/stream pond/lake bottled water water tanker or water seller	1 2 3 4 5 6 7	
108b	What is the distance to the source of water for members of your households?	less than 30 min. walking less than 60 min. walking more than 60 min walking	1 2 3	

SECTION 2 Knowledge of HIV

(INTRODUCTION :) Now, I would like to talk with you about HIV and AIDS

No	Questions	Coding categories		Skip
201	Is there a difference between HIV and AIDS?	No Yes Don't know	0 1 98	
202	In your opinion, if a mother is pregnant and has HIV, would the virus be passed on to the baby?	No Yes Sometimes/rarely Don't know Depends…………………..	0 1 2 98 90	
202a	When a woman is pregnant and has the virus, can the virus be transmitted to the baby?	 2. During delivery 3. During breastfeeding Other (specify)……………………	no yes 0 1 0 1 95	

203	Please tell me all the ways you know of that HIV can be transmitted		no yes	
		1. unprotected sex/sex without condom	0 1	
		2. sharing needles	0 1	
		3. blood transfusions	0 1	
		4. Mother-to-child transmission	0 1	
		5. sex with prostitutes	0 1	
		6. sex with multiple partners	0 1	
		7. Kissing	0 1	
		8. shaking hands	0 1	
		9. mosquito bites	0 1	
		10 sharing razors/blades	0 1	
		11. sharing food/drink/eat utensils	0 1	
		12. sharing same toilet area	0 1	
		13. sweat	0 1	
		14. saliva	0 1	
		15 don't know	98	
		16. other (specify)……………………	95	
204	How can people protect themselves from getting HIV?	1. abstain from sex	0 1	
		2. use condoms	0 1	
		3. be faithful to one uninfected partner	0 1	
		4. limit number of sexual partners	0 1	
		5. avoid sex with prostitutes	0 1	
		6. avoid sex with persons who have sex with many partners	0 1	
		7. avoid sharing razors/blades	0 1	
		8. avoid sharing needles	0 1	
		9. avoid injections	0 1	
		10. avoid kissing	0 1	
		11. avoid mosquito bites	0 1	
		don't know	98	
		other (specify)……………………………	95	
205	Can a healthy and strong looking person have HIV?	no	0	
		yes	1	
		don't know/not sure	98	
206	Is there a cure for AIDS?	no	0	go to 208
		yes	1	
		don't know/not sure	98	go to 208
207	if yes, what kind is it?	modern medicine	1	
		traditional medicine	2	
		faith healing/prayer	3	
		other (specify)……………………………	95	
208	Do you know of treatment that can prolong the life of PLWHA?	no	0	go to 209
		yes	1	

208a	if yes, what treatment	1. local herbs 2. treatment of opportunistic infections 3. faith healing/prayer 4. ARV 5. good nutrition other (specify)………………………………	0 1 0 1 0 1 0 1 0 1 95	
209	*please tell me if you are worried/have fear, or not worried about contracting HIV, in response to the following statements:*			
209.1	Being exposed to the saliva of a person with HIV or AIDS	have fear do not have fear	1 2	
209.2	Being exposed to the excreta of a person with HIV or AIDS	have fear do not have fear	1 2	
209.3	Being exposed to the sweat of person with HIV or AIDS	have fear do not have fear	1 2	
209.4	Your child could become infected with HIV if they get care from somebody who has HIV or AIDS	have fear do not have fear	1 2	
209.5	Caring for a person with HIV or AIDS	have fear do not have fear	1 2	
210	in a market of several food vendors, would you buy food from a person with HIV or AIDS looking healthy and strong?	no yes	0 1	
210a	and what about if they were showing signs/symptoms?	will still buy will not buy anymore	1 2	

SECTION 3 Shame and Blame

No	Questions	Coding categories		Skip
301	Do you agree/disagree with the following statements			
301.1	It is the women prostitutes that spread HIV in our community	agree disagree	1 2	
301.2	People with HIV/AIDS should be ashamed of themselves	agree disagree	1 2	
301.3	I would be ashamed if someone in my family has HIV/AIDS	agree disagree	1 2	
301.4	People with HIV/AIDS are promiscuous.	agree disagree	1 2	
301.5	Promiscuous men are the one who spread HIV in our community	agree disagree	1 2	
301.6	Promiscuous women are the one who spread HIV in our community	agree disagree	1 2	
301.7	HIV is a punishment from God	agree disagree	1 2	

301.8	HIV is a punishment from the spirit world	agree disagree	1 2	
301.9	I would feel ashamed if I was infected with HIV	agree disagree	1 2	
301.10	HIV is a punishment for bad behaviour	agree disagree	1 2	
301.11	People with HIV/AIDS are to blame for bringing the disease to the community	agree disagree	1 2	
302	How do you think most people in your community would answer the following questions:			
302.1	It is the women prostitutes that spread HIV in our community	agree disagree	1 2	
302.2	People with HIV/AIDS should be ashamed of themselves	agree disagree	1 2	
302.3	I would be ashamed if someone in my family has HIV/AIDS	agree disagree	1 2	
302.4	People with HIV/AIDS are promiscuous.	agree disagree	1 2	
302.5	Promiscuous men are the one who spread HIV in our community	agree disagree	1 2	
302.6	Promiscuous women are the one who spread HIV in our community	agree disagree	1 2	
302.7	HIV a punishment from God	agree disagree	1 2	
302.8	HIV is a punishment from the spirit world	agree disagree	1 2	
302.9	I would feel ashamed if I was infected with HIV	agree disagree	1 2	
302.10	HIV is a punishment for bad behaviour	agree disagree	1 2	
302.11	People with HIV/AIDS are to blame for bringing the disease to the community	agree disagree	1 2	

SECTION 4: Enacted Stigma Questions - Primary Stigma

No	Questions	Coding categories		Skip
401	Do people in your community toward people suspected of having HIV/AIDS or people with HIV/AIDS treat differently?	no yes Don't know	0 1 98	

402	Do you personally know someone who in the last 12 months has had the following happen to them because they were known to have, or suspected of having, HIV or AIDS?			
402.1	Excluded from a social gathering (wedding, funeral, party, community association group)	yes no how many people with HIV?............	1 0 no……	
402.2	Treated differently/ignored at a social gathering	yes no how many people with HIV?............	1 0 no……	
402.3	Abandoned by their spouse/partner	yes no how many people with HIV?............	1 0 no……	
402.4	Abandoned by their family/sent away to the village	yes no how many people with HIV?............	1 0 no……	
402.5	Isolated in household e.g., made to eat alone/made to use separate eating utensils/made to sleep alone in own room	yes no how many people with HIV?............	1 0 no……	
402.6	no longer visited, visited less by family and friends	yes no how many people with HIV?............	1 0 no……	
402.7	Visitors increased to 'check them out'	yes no how many people with HIV?............	1 0 no……	
402.8	Teased, insulted or sworn at	yes no how many people with HIV?............	1 0 no……	
402.9	Lost customers to buy their products/good or lost a job	yes no how many people with HIV?............	1 0 no……	
402.10	Lost housing or not been able to rent housing	yes no how many people with HIV?............	1 0 no……	
402.11	not allowed/denied religious rites/services (marriage, communion, burial, prayers/ not allowed to go to church	yes no how many people with HIV?............	1 0 no……	
402.12	Given poorer quality health services, for example: not given medicines, denied treatment, treated harsh)	yes no how many people with HIV?............	1 0 no……	
402.13	Had property (land, household goods, animals etc) taken away	yes no how many people with HIV?............	1 0 no……	
402.14	Lost respect/standing within the family and/or community	yes no how many people with HIV?............	1 0 no……	

402.15	Gossiped about	yes no how many people with HIV?............	1 0 no……	
402.16	Physically assaulted (i.e., hit, kicked punched)	yes no how many people with HIV?............	1 0 no……	

SECTION 5: Disclosure

No	Questions	Coding categories		Skip
C501	In what way do you know if somebody in your community has HIV?	the infected person discloses his/her status from general rumours/gossip from the HIV+ person's family from the HIV+ person's friends/neighbours from the health centre/health worker where the person got tested when the person looks ill and has lost a lot of weight other (specify) …………………………	1 2 3 4 5 6 95	
C502	Is there anyone who is currently living in this community that you know of who has HIV, but has not yet shown signs and symptoms of AIDS?	no yes	0 1	
506	imaging, somebody is coming to you. He/she is HIV+, but is not yet showing signs/symptoms of AIDS. What would you advise to him/her to do?	tell nobody tell only family make available to the community don't know	1 2 3 98	go to 506b go to 507
506a	If you recommend that people with HIV should keep their status secret, why?	personal problem people act differently toward a person with HIV person would be isolated/neglected/avoided no one would care for the person other (specify) …………………………	1 2 3 4 95	
506b	If you recommend that HIV+ status, be made available to the community, why?	To avoid spreading HIV by PLWHA PLWHA can encourage/teach others to prevent spreading HIV PLWHA can create opportunity for care and support from community To reduce discrimination/stigma against PLWHA other (specify)………………	1 2 3 4 95	

507	Are there people you personally know who have either disclosed their HIV+status directly to you or publicly?	yes no how many? …………	1 0 no….	

APPENDIX 2

STIGMA INDICATOR PLWHA QUESTIONAIRE

INTRODUCTION

INFORMED CONSENT - read, agreed, signed, approved

SECTION 1: Respondent and Household Characteristics

no	Questions	Coding categories		Skip
104	In which village and parish do you live?	village parish	……….. ………..	
104a	How long do you stay in this place?	years	……….	
104b	When you stay here less than 1 year, what was the reason that you moved to this place?	marriage Other (specified)………	1 95	
105	Have you ever attended school ? If so, what is the highest level of school you attended	None Less than P2 Less than P5 Less than P7 Completed P7 Less than S4 Completed S4 less than S6 Completed S6 University	1 2 3 4 5 6 6a 6b 7 8	
106	Do you have a wife or husband?	Yes No	1 0	
106 AA	If no, are you divorced, widowed or never married?	Divorced Widowed Never Married	2 3 4	
106a	if yes, how many wives do you have?	only one two or three more than three	1 2 3	skip for women
106b	if yes, what position do you have	first wife second or third wife third of more	1 2 3	skip for men
107	What is your source of income?	none/depending on others keeping cows keeping sheep, goats keeping chicken selling beer shop keeping business	0 1 2 3 4 5 6	

		employment	7	
		peasant	8	
		builder/constructor	9	
107a	Does your household have the following items?		no yes	
		1. blanket	0 1	
		2. saucepan	0 1	
		3. mattress	0 1	
		4. radio	0 1	
		5. bicycle	0 1	
		6. mobile	0 1	
		7. generator	0 1	
107b	Type of house roof	grass	1	
		iron sheets	2	
		Other (specified)………	95	
107c	Type of house walls	mud	1	
		cement	2	
		Other (specified)………	95	
108a	What is the main source of drinking water for members of your households?	piped into residence/yard	1	
		public tap	2	
		public well	3	
		river/stream	4	
		pond/lake	5	
		bottled water	6	
		water tanker or water seller	7	
108b	What is the distance to the source of water for members of your households?	less than 30 min. walking	1	
		less than 60 min. walking	2	
		more than 60 min walking	3	

SECTION 2 Knowledge of HIV

(INTRODUCTION:) Now, I would like to talk with you about HIV and AIDS

No	Questions	Coding categories		Skip
201	Is there a difference between HIV and AIDS?	No	0	
		Yes	1	
		Don't know	98	
202	In your opinion, if a mother has HIV, would the virus always be passed on to the baby?	No	0	
		Yes	1	
		Sometimes/rarely	2	
		Don't know	98	
		Depends…………………..	90	
202a	in your opinion, when can the virus that causes AIDS be transmitted from a mother to her baby?		no yes	
		2. During delivery	0 1	
		3. During breastfeeding	0 1	
		Other (specify)……………………	95	

203	Please tell me all the ways you know of that HIV can be transmitted		no yes	
		1. unprotected sex/sex without condom	0 1	
		2. Sharing needles	0 1	
		3. blood transfusions	0 1	
		4. Mother-to-child transmission	0 1	
		5. sex with prostitutes	0 1	
		6. sex with multiple partners	0 1	
		7. Kissing	0 1	
		8. shaking hands	0 1	
		9. mosquito bites	0 1	
		10 sharing razors/blades	0 1	
		11. sharing food/drink/eat utensils	0 1	
		12. sharing same toilet area	0 1	
		13. sweat	0 1	
		14. saliva	0 1	
		15 don't know	98	
		16. other (specify)………………………………	95	
204	How can people protect themselves from getting HIV?	1. abstain from sex	0 1	
		2. use condoms	0 1	
		3. be faithful to one uninfected partner	0 1	
		4. limit number of sexual partners	0 1	
		5. avoid sex with prostitutes	0 1	
		6. avoid sex with persons who have sex with many partners	0 1	
		7. avoid sharing razors/blades	0 1	
		8. avoid sharing needles	0 1	
		9. avoid injections	0 1	
		10. avoid kissing	0 1	
		11. avoid mosquito bites	0 1	
		don't know	98	
		other (specify)………………………………	95	
205	Can a healthy and strong looking person have HIV?	no	0	
		yes	1	
		don't know/not sure	98	
206	Is there a cure for AIDS?	no	0	go to 208
		yes	1	
		don't know/not sure	98	go to 208
207	if yes, what kind is it?	modern medicine	1	
		traditional medicine	2	
		faith healing/prayer	3	
		other (specify)………………………………	95	
208	Do you know of treatment that can prolong the life of PLWHA?	no	0	go to 209
		yes	1	

208a	if yes, what treatment	local herbs	0	1	
		treatment of opportunistic infections	0	1	
		faith healing/prayer	0	1	
		ARV	0	1	
		good nutrition	0	1	
		other (specify)……………………………	95		

SECTION 5: Disclosure

(INTRODUCTION:) Now, I would like to ask you some questions about your experience about disclosing your HIV status.

No	Questions	Coding categories		Skip
P501	How long have you known that you are HIV+?	less than 6 months	1	
		6 - 12 months	2	
		1-3 years	3	
		more than 3 years	4	
P502	Have you told anyone about your HIV+ status and when did you tell it	no	0	
		directly when I knew	1	
		after ……………….months	2	
503	Why have you not told anyone about your status?	They would tell someone else	1	
		I would be gossiped about/laughed at	2	
		It would become news around here	3	
		I would be physically isolated	4	
		I would lose respect	5	
		I would lose my income, house, livelihood	6	
		It would be difficult to get medical services	7	
		I'd be treated differently	8	
		I would be afraid of being stigmatized	9	
		private matter	10	
		don't know	98	
		other (specify)………………..	95	
505	Has your HIV status ever been revealed without your consent?	no	0	go to 506
		yes	1	
505a	Who revealed your status without your consent?	partner/husband	1	
		mother	2	
		father	3	
		sister	4	
		brother	5	
		health provider	6	
		religious leader	7	
		traditional leader	8	
		don't know	98	
		other (specify)………………	95	
506	Image, somebody is coming to you. He/she is HIV+, but is not yet showing signs/symptoms of AIDS. What would you advise	tell no one	1	
		tell only family	2	
		make available to the community	3	go to 506b

	to him/her to do?	don't know	98	go to 601
506a	If you recommend that HIV+ status, be kept private, why?	personal problem	1	
		people act differently toward a person with HIV	2	
		person would be isolated/neglected/avoided	3	
		no one would care for the person	4	
		other (specify)………………	95	
506b	If you recommend that HIV+ status, be made available to the community, why?	To avoid spreading HIV by PLWHA	1	
		PLWHA can encourage/teach others to prevent spreading HIV	2	
		PLWHA can create opportunity for care and support from community	3	
		To reduce discrimination/stigma against PLWHA	4	
		other (specify)………………	95	

SECTION 6: Experiences of support

No	Questions	Coding categories		Skip
601	How is your health in general?	very poor poor neither poor nor good good very good	1 2 3 4 5	
602	Have you ever had HIV/AIDS related signs/symptoms (e.g. skin rash, loss of weight, herpes) visible in your physical appearance?	no yes	0 1	
603	In the past 12 months, have you had any health concerns/worries that required medical attention?	no yes	0 1	go to 606
604	In the past 12 months, when you had health problems that required medical advice or treatment, who in your household took primary responsibility to facilitate your health care?	spouse child parent brother in law other relative no one other specify………	1 2 3 4 5 6 95	
605	In the past 12 months, where did you seek medical advice/treatment ?	Government health facility private health facility NGO health facility pharmacy/drug shop traditional practitioner other (specify)………………	1 2 3 4 5 95	

606	In the last 12 months, did you or your household receive support from any organisation to help you with **basic social, economic, and medical care** needs (e.g. food, medicines, medical advice, clothing, school fee)?	no yes	0 1	
606a	What organisation was this? …………………………………… …………………………………..	Government Religious based organisation other NGO local community CBO other (specify)………………	1 2 3 4 5 95	
608	Are you a member of any social support group of PLWHA?	no yes name of the group………………………………….	0 1	

SECTION 5: Internal Stigma

No	Questions	Coding categories		Skip
701	sometimes, having HIV changes what someone plans to do in his/her life. Would you please tell me if you have ever done any of the following because of your HIV status?			
701.1	avoided or withdrawn from applying for school further training, or scholarship?	no yes	0 1	
701.2	not applied for a job	no yes	0 1	
701.3	avoided or isolated yourself from your friends or family?	no yes	0 1	
701.4	decided not to go for social gatherings?	no yes	0 1	
701.5	avoided travel to another area of Uganda?	no yes	0 1	
701.6	decided not to get married or have a sexual partner?	no yes	0 1	
701.7	decided not to have (more) children	no yes	0 1	
701.8	Are there any other life goals or hopes you had that have changed because of you HIV+status? Please describe ………………………………………………………………………………………………… ………	no yes	0 1	

APPENDIX 3

PLWHA / COMMUNITY

NO NAME…………………………

VILLAGE / PARISH ………………………
GENDER: FEMALE / MALE
AGE…………….

NAME INTERVIEWER …………………

DATE AND DAY OF INTERVIEW: ……………………
NAME Lc 1 OF THE VILLAGE:……………………

Introduction:	* to get insight in level of stigma * prevent HIV transmission * how programs are doing
Beneficiaries:	* appreciation after interviewing
Method:	* there is no wrong answer * tell the truth from **YOURSELF**
Confidentiality:	* names separate from questionnaire * use number instead of real names

AGREE / DISAGREE

no	**Participation Scale** **Compare to you peers…**	Not specified, not answered	Yes	Sometimes	No	Irrelevant, I don't want to, don't have to	**NO problem**	**Small**	**Medium**	**Large**	**SCORE**
			0				**1**	**2**	**3**	**5**	
1	Do you have equal opportunity as your peers to find work?		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
2	Do you work as hard as your peers do? (same hours, type of work etc.)		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
3	Do you contribute to the household economically in a similar way to your peers?		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
4	Do you make visits (travel) outside your village / neighbourhood as much as your peers do? (except for treatment) e.g. Bazaars, nearby villages / neighbourhoods.		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
5	Do you help other people (e.g. neighbours, friends or relatives)?		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	

6	Do you take as much part in casual recreational/social activities as do your peers? (e.g. sports, chat, meetings)		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
7	Are you as socially active as your peers are? (e.g. in religious/community affairs)		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
8	Do you visit other people in the community as often as other people do?		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
9	Are you comfortable meeting new people?		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
10	Do you have the same respect in the community as your peers?		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
11	Do you move around inside, outside the house, and around the village/neighbourhood just as other people do?		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
12	In your village / neighbourhood, do you visit all the public places/common places? (including schools, shops, offices, market and tea/coffee shops)		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
13	Do you have opportunity to take care of yourself (appearance, nutrition, health etc.) as well as your peers?		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
14	In your home, do you do household work?		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
15	In family discussions, does your opinion count?		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
16	In your home, are the eating utensils you use kept with those used by the rest of the household?		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
17	Do you take part in major festivals and rituals as your peers do? (e.g. weddings, funerals, religious festivals)		0								

	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	
18	Do you feel confident to try to learn new things?		0								
	(*If sometimes, no or irrelevant)* how big a problem is it to you?						1	2	3	5	

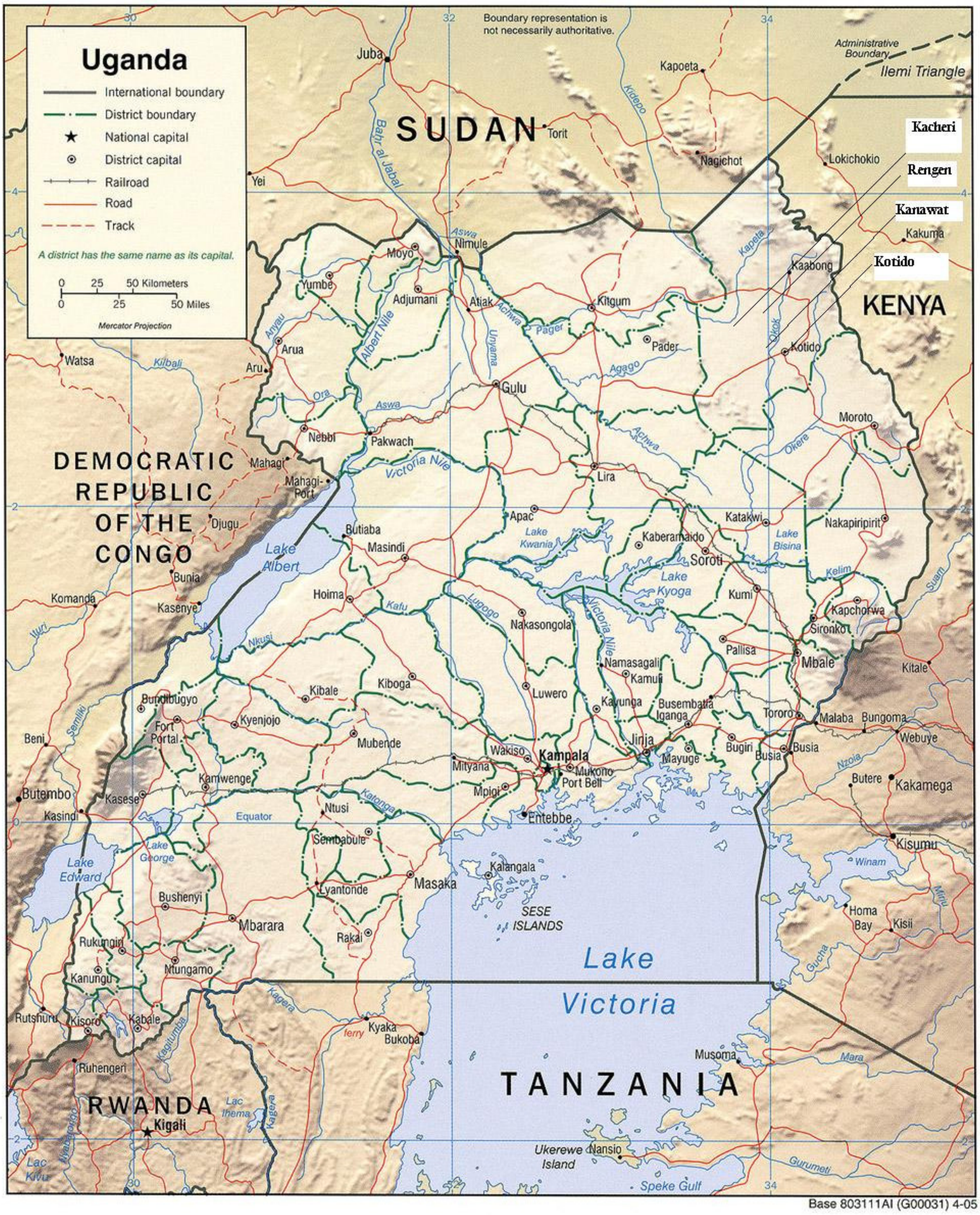
Comment:

TOTAL

Grades of participation restriction

No significant restriction	Mild restriction	Moderate restriction	Severe restriction	Extreme restriction
0 - 12	13 - 22	23 - 32	33 - 52	53 - 90

APPENDIX 4



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