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Full Length Research Paper

HIV/AIDS stigmatization amongst the youths in Gulu, Northern Uganda: A major drawback in the fight against the spread of HIV/AIDS

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In Uganda, HIV/AIDS epidemic has been accompanied by epidemic of fear, ignorance, and denial leading to stigmatization and discrimination against people living with HIV/AIDS and their families. HIV/AIDS-related stigma and the resulting discriminatory acts create circumstances that fuel the spread of HIV. The fear of being identified with HIV prevents people from seeking to know their sero-status, changing unsafe behaviours and caring for the people living with HIV/AIDS. A cross-sectional study was conducted among the youths in Gulu district. Questionnaires were interviewer administered to 100 youth of ages 18 to 30 years. The level of knowledge, attitude and practices regarding HIV stigmatization was assessed. 51% did not know HIV stigmatization, 43% did not test for HIV/AIDS because of fear of stigma. 90% of the youths have practiced stigmatization and are still willing to continue doing it to others as a strategy for HIV prevention. There is sufficient knowledge (49%) about HIV stigmatization. However, there is a negative attitude towards it. 56% youths believe that stigmatization is the best way in reducing the spread of HIV/AIDs. There is a negative practice, (90%) practised stigmatization on suspected HIV/AIDs patients.

Keywords: HIV/AIDS stigmatization, youths, Gulu (Uganda)

INTRODUCTION

HIV/AIDS-related stigma and discrimination have been described as epidemic in its own right (Mann, 1987) and the single greatest obstacle to effective national response to HIV/AIDS. From the start of AIDS epidemic, stigma and discrimination have fuelled the transmission of HIV and have greatly increased the negative impact associated with the epidemic. HIV stigma and discrimination continue to be manifested in every country and region of the world, creating major barriers to further infection, alleviating impact and providing adequate care, support and treatment (UNAIDS 2005). HIV stigma has a profound effect on the epidemic's course. The report from WHO and UNAIDS (2008) cited fear of stigma and discrimination as the main reason why people are reluctant to be tested for HIV/AIDS, disclose status and to take antiretroviral drugs. These factors all contribute to the expansion of the epidemic as many people get reluctant to determine HIV status or to discuss or practice safe sex and this means that people are more likely to infect others, do not change behavior and thus a higher number of AIDS related deaths. The unwillingness to take HIV test means that people are diagnosed late, when the virus has progressed to AIDS, making the treatment less effective, increased spread and early death. Despite the relatively cheap institutional support for HIV/AIDS, patients in Uganda still shy away from HIV/AIDS counseling and testing services (HCT) (Mugisha Kemirembe et al, 2000). The concept and practise of stigma originated in the ancient Greece with the use of bodily marking to identify socially deviant or inferior members of the society (Varas Diaz et al, 2003). In the context of the HIV/AIDS epidemic, HIV related stigma is

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described as a process of devaluation of people either living with or associated with HIV/AIDS. Discrimination and stigmatization are the unfair and unjust treatment of an individual based on his or her real or perceived HIV status (UNAIDs, 2003).

HIV/AIDS and culture (HASC) has been identified and described all over the world in both national and ethnic subgroups with the most negative impact on a variety of issues ranging from HIV prevention and testing, access to treatment and care (Aggleton, 2000), identity, and disclosure of status. There is greater stigmatization of particular groups due to pre-existing prejudices against particular sexual lifestyle. Persons living with HIV/AIDS were able to evade much HASC through what Anderson (2007) calls “stigma avoidance strategies” the most important of these are limited disclosure, deception and engaging in casual and doomed relationships or in no relationships at all, secrecy is then the key part of living with HIV. Norman et al., (2006) found that most of the students they interviewed claimed that they would not stigmatize on an HIV- positive family member or a friend. This non-avoidance was associated with sympathy, HIV knowledge, education and awareness.

The impact of stigmatization on the fight against HIV/AIDS is enormous. Stigmatization has exacerbated the problems faced by children orphaned by AIDS. Orphans encounter hostility from their extended families and communities and may be rejected, denied access to schooling and health care and left to fend for themselves. The wide spread of stigmatization is held accountable for the relatively low uptake of prevention of mother to child transmission (PMTCT) programs in countries where treatment is free. In Botswana for example, despite the fact that antenatal services are available and free in every antenatal clinic in the country, only 26% of the pregnant women availed themselves the opportunity to protect their unborn children. Over half refused to take tests and nearly half of those who tested positive did not accept treatment.

Despite the relatively cheap institutional support for HIV/AIDS, patients in Uganda still shy away from the services (Mugisha Kemirembe et al., 2000). At HIV clinic, patients seeking HIV/AIDS care and treatment were closely observed with regard to their social and psychological behaviours and the nature of the complaints they presented with or their relatives’ complaints. It was noticed that stigma was a major problem to the patients and their caregivers. Majority of the patients presented in stage III of the disease progression, with multiple opportunistic infections and would always be forced to the clinics by the relatives. The patients who presented early were characterized with false identity, multiple registrations with different names to avoid being known. They would try to get out of the center as soon as possible, usually not completing all the necessary care procedures. Some families refuse to take their relatives to the clinic for fear of being identified with HIV/AIDS themselves. Some religious faiths in Uganda act as a deterrent to seeking HIV/AIDS care at all or early enough, therefore despite the massive education in Uganda, still some HIV/AIDS patients decline to go to the health care centers because of stigma (Mugisha Kemirembe et al., 2000).

Olley (2004) concluded that HIV/AIDS stigma is usually associated with high rates of psychiatric and emotional problems. He found out that these problems contribute to the people not sticking to their drug regiments. It can even speed up the progression of the disease and hasten the death of the patients.

The level of HIV/AIDS stigma is high in Uganda and particularly Northern Uganda and has highly and negatively impacted on the progress of the prevention because people fear to disclose their status (Kaleeba, 2008). Unfortunately the risk of transmission has been used by numerous employers to terminate or refuse employment to the victims. It has also been found that if people living with HIV/AIDS (PLHA) were open about their status at work, they may well experience stigmatization and discrimination by fellow employees. In some developing countries instances of compulsory pre-employment testing took place, some of these industries have used the information to deny employment to PLHA (Herek and Capitanio, 1993). The same associated with AIDS – a manifestation of stigma has been described by some writers as “internalized” stigma- may also prevent people living with HIV from seeking treatment, care and support and exercising other rights such as working, attending school, etc. Such shame can have a powerful psychological influence over how people with HIV see themselves and adjust to their status, making them vulnerable to blame, depression and self-imposed isolation (UNAIDS, 2005). The object of this study was therefore to explore in details the reasons why HIV/AIDs prevalence was slowly but progressively increasing in Northern Uganda (from 6% to 10%) over a period of 5 years especially among the youths. One of the hypothesis was that the high prevalence of HIV stigmatization among the youth was the factor behind this sudden increase. This was the reason why we undertook a descriptive study focusing on the knowledge, attitudes and practices of the youths on HIV/AIDS stigmatization in this region.

METHODOLOGY

Population and sample

We conducted in-depth interviews from June to September 2009 with the youths of Pece division, one of the sub-counties in Gulu Municipality of northern Uganda. This is a place which is just recovering from the 20 year-old civil war. Gulu is strategically located and endowed

with its transport terminals and pivoted role in the vast and profitable distribution of goods in the region. It shares borders with southern Sudan where brisk businesses have been taking place. It is the regional center for northern Uganda and draws a largely rural population, many people were displaced in to camps famously known as the internally displaced peoples camps (IDPS) for safety from the insurgency. According to the Revised Gulu District Development Plan 2009/2010, Gulu municipality has a population of 119,430 and composed of 4 sub-counties: Laroo, Bardege, Layibi and Pece.

Pece Sub-county was chosen as a study site purposively because of its high population density and youthly population. It is composed of 4 parishes and 16 villages with an overall population of 36,133. This sub-county was massively affected by this displacement of persons from the neighboring rural communities. A cross-sectional study conducted among the youths aged 18 to 30 years using a prepared questionnaire designed for data collection. A total sample of 100 respondents was selected, interviewed from different households, 10 villages and 4 parishes to complete the numbers for the study population. The study variables were controlled by interviewing only respondents who were residents of the area and of qualifying age.

Questionnaire administration

Questionnaires were administered by the interviewers at the respondents' residence to collect the data required. Informed verbal and written consent were obtained from the respondents before the interview and they had to freely agree to join the study and provide the required information. The questionnaire was pilot tested among the youths of Bardege division in Gulu, Uganda and was specially designed to collect the background demographic data and the detailed information on HIV stigmatization. After the test, it was improved to help the youth recall the stigmatization events and space added to consider other relevant information. The tested questionnaires were then administered to the respondents to obtain the accurate information needed. In order to avoid an unnecessary semantic misunderstanding, the questionnaire was written in simple English and translated into Luo, the main regional language by the investigators in conjunction with a trained interviewer and interpreter. The respondents were asked open-ended questions to describe their knowledge, attitude and practices on HIV/AIDS stigmatization and also made to restate their information before entry in to the questionnaire. The extra spaces were used as qualifying remarks which aided considerably in giving answers to specific questions and providing additional information which assisted the researchers in drawing up conclusions. The sampling technique was purposive for the division to parishes to the villages up to households. In the households the youths were consecutively sampled for the interviews based on the area of residence, consent and age. It should be noted here that in Uganda, a youth is defined as that person whose age ranges from 18 to 30 years and this is the reason why only that age group was considered. Ethical clearance and approval of the study was obtained from the research committee and the administration of Gulu Regional Referral Hospital. The data obtained were put in descriptive form and analyzed in percentages and fractions.

RESULTS

100 respondents were successfully recruited from the 115 eligible ones. The other 15 youths did not give their consent for the study mainly due to lack of time for the interviews. The respondents' mean age was 25 years with a modal age of 25-28 years. The male to female ratio was 1.1:1 (52:48).

Knowledge of the respondents to HIV stigmatization

Forty nine (49%) respondents had fair knowledge of HIV/AIDS stigmatization but the majority (51%) did not know exactly what HIV stigmatization was. According to those who knew, verbal abuse, denial of food and refusal to share utilities was HIV/AIDS stigmatization.

Sources of information about HIV stigmatization

Seventy four respondents (74%) obtained this information from radios, 15% from friends, 10% from youth clinics and 1% from others like television and health workers.

Knowledge of respondents about youth friendly clinics

Ninety seven respondents **(**97%) knew exactly the location of the youth friendly clinics whereas 3% did not know.

Respondents' attitudes towards HCT

Forty three respondents **(**43%) have not and were not willing to undertake HCT whereas 57% confirmed having tested for HIV/AIDS.

Respondent's feeling about disclosing their HIV status

Eighty two percent of those who tested would easily agree to disclose their HIV status to friends if found to be HIV negative whereas 18% would not agree to disclose

their HIV status if found positive mainly due to fear of stigmatization and discrimination by friends, relatives and associates.

DISCUSSION

Knowledge on HIV/AIDs stigmatization

The study revealed that the knowledge of the respondents were average with 49% of the respondents able to define correctly what HIV stigmatization was, and most information were received from FM radio stations, others from friends and youth friendly clinics in that order of frequency. Those who could define the stigma well (51%) only thought stigma occurred when a suspected HIV positive victim was abused verbally. Many authors including Gilmore and Somerville (1994) would not agree since stigma could be felt, perceived or enacted. The majority of the youths (51%) was able to define stigma and gave two or more examples of HIV related stigma. Most of them talked about isolating those suspected to be infected from social activities such playing football, communal eating and sharing the same beddings. The forms of stigma and discrimination around HIV/AIDS are diverse: they range from partner abandonment, accusations of infidelity and isolation to total rejection by family and friends. The surrounding community as well, might resort to physical violence, graffiti, name calling and destruction to property as acts of stigmatizing HIV positive person and his/her family (Wambayi, 2010). However, some of these extreme actions were not undertaken by these youth in the study (See Table 1 - 6).

Ninety respondents (90%) who admitted having practised stigmatization said they did so basing on some of the perceived defining characteristics that are usually associated with people suspected to be HIV positive like weight loss, red lips, body rashes and persistent cough among others. Some of the youths admitted that they stigmatized some people on the basis of their lifestyles which were deemed unfit for a particular society for example when one is suspected of being a prostitute, it is suspected that she would be infecting others. Ninety seven respondents (97%) knew at least one or two of the youth friendly clinics though only 59% were able to attend the clinics and obtain the required services of HIV Counseling and Testing (HCT) and 10.3% able to get HIV related stigma information from the clinics. HIV stigma causes undue stress to individuals living with HIV/AIDS and is an impediment to effective care and management of the disease. At the same time those who have just been diagnosed have internalized stigma that further distances them from accessing support services (Rachael et al., 2002). The causes of stigma in the HIV pandemic are rooted in fears associated with HIV/AIDS. Many people in the vulnerable population around the world are steeped in the surroundings characterized by an unnecessary fear of HIV/AIDS. Studies in African communities have shown how attributes such as stigma, suffering and shame are preventing the efforts to fight the disease (Chesney, 2010).

Attitude of respondents towards HIV stigmatization

Eighty two percent of the respondents who tested for HIV/AIDS were comfortable disclosing their HIV status and this occurred only in the event that their HIV status was negative while 18% who tested for HIV and were found positive would be uneasy to disclose their status for the fear of losing their friends and being talked about and stigmatized further. Stigma impedes the fight against HIV/AIDS. It causes reluctance to disclosure, thus promoting secrecy, finally arguably abetting transmission. It drives the epidemic underground. Health seeking is minimized and preventative measures left unused. No open discussions about HIV/AIDS take place when stigma prevails in a community. Pervasive stigma also prevents identification of AIDS orphans and promotes the oppression of women (Wambayi, 2010).

The myths associated with HIV/AIDS in many communities perpetuate the growth of stigma. Common beliefs, misconceptions and folk explanations further reinforce both disinformation and denial. Many youths feel that they are invincible and that nothing bad can happen to them, many more still believe that HIV does not cause AIDS. Many people live in denial, or fail to disclose their HIV status, in order to protect their families from social condemnation (Wambayi, 2010).

Of those who ever practised stigmatization, 73.3% have comfortably done them on people they knew, 13.3% on strangers and only 8.9% have done it on a close friend and 4.5% on their family members. When the youth were asked specifically if they would stigmatize one of their family members, 96% said they would never do such a thing on their family members while 4% said they would not have any problem stigmatizing their family members as long as it would help others avoid contracting the infection and if that process of stigmatization would discourage other members of the family from making the same mistake. This was because most of the respondents believe immorality was the main reason for the spread of HIV and these immoral acts such as prostitution should be discouraged. Many still associate HIV infection with instant death, even in communities with more acute endemic diseases such as malaria. Closely related to the fear of death is the denial in many communities of the existence of the disease. Often the cause of death due to AIDS is not disclosed at funerals or in the obituaries, obscuring the reality of the epidemic. Family members are ashamed to disclose the cause of death as AIDS. It is common to hear the relation of someone who died identify the cause of death as

Table 1. Distribution of people stigmatized by the youths for being HIV/AIDS positive

People stigmatized	No. ofrespondents	Percentage
1. Family member	4	4.5
2. Close Friend	8	8.9
3. Someone you know	66	73.3
4. Stranger	12	13.3
Total	90	100.0

Family members 4.5%, Close friends 8.9%, someone you know 73.3% and a stranger 13.3%.

Table 2. Distribution of respondents who thought HIV/AIDS stigmatization reduces its spread

s/no	Options	No. of Respondents	Percentage
1	Doesn't Reduce	44	44
2	Reduces spread	56	56
	Total	**100**	**100.0**

Fifty six respondents' (56%) reason for HIV/AIDS stigmatization was to help reduce the spread of HIV infection and only 44% believed it would not help reduce spread in the population.

Table 3. Respondent's views on HIV Stigmatization to family members

s/no	Options	No. of Respondents	Percentage
1	Would stigmatize family member	4	4
2	Would Never stigmatize	96	96
	Total	**100**	**100.0**

Ninety six respondents (96%) would never stigmatize their family members and would not love anyone from doing so whereas four respondents (4%) would stigmatize any HIV/AIDS family member in order that he/she would not spread the virus to other people.

Table 4. Distribution of respondents who Practiced HIV/AIDS stigmatization

s/no	Options	No. of Respondents	Percentage
1	Practiced Stigmatization	90	90
2	Did not stigmatize	10	10
	Total	**100**	**100.0**

Ninety respondents (90%) practiced HIV/AIDS stigmatization and only 10 % have never.

witchcraft or poisoning (Wambayi, 2010). In this study the majority of the respondents believed that stigmatization of those suspected of being HIV positive is one of the ways by which the spread of the pandemic could be controlled, it is their belief and thinking that when one is suspected of being HIV positive and is frequently "talked about" (stigmatized), he/she would be made known throughout the community and therefore those in the community would take extra care in choosing them as sexual partners. Forty three respondents (43%) have not and were not willing to undertake HCT and 57% of the respondents confirmed that they tested for HIV/AIDS.

Table 5. Distribution of respondents on the methods of HIV/AIDS stigmatization

s/no	Options	No. of Respondents	Percentage
1	Verbal abuse of victim	20	22.2
2	Point accusing finger at Victim	20	22.2
3	Avoidance of the victim	30	33.3
4	Denial of food	5	5.6
5	Refusal to share utilities	5	5.6
6	Others	10	11.1
	Total	90	100.0

The main method of HIV/AIDS stigmatization was by openly avoiding the person (33.3%), abuse of victim (22.2%), pointing accusing finger (22.2%), denial of food (5.6%), refusal to share utilities (5.6%) and others (11.1%).

Table 6. The evidence they consider to stigmatize a person

s/no	Options	No. of Respondents	Percentage
1	Weight Loss	9	10.0
2	Red Lips	8	8.9
3	Body rashes	7	7.8
4	Persistent cough	8	8.9
5	Loss of a spouse	15	16.7
6	Loss of a child & rumours	10	11.1
7	Seen HIV/AIDS test results	25	27.8
8	Taking Antiretroviral drugs	8	8.9
	Total	90	100.0

The evidence used were mainly, evidence of a positive test result (27.8%), loss of a spouse (16.7%), loss of a child and rumours (11.1%), weight loss (10%), red lips and taking ARVs each at 8.9% and body rashes (7.8%).

Successful structural and social marketing interventions that aim at reducing stigma will drastically reduce resistance against seeking voluntary counseling and testing among other services. Government as well as the community organizations, advocacy groups and religious groups need to work together for effective change. In particular governments need to re-examine laws that perpetuate stigma against HIV/AIDS. Such laws include those that require compulsory screening and testing especially for the “risk groups” notification of HIV/AIDS cases (Wambayi, 2010).

Practices to HIV/AIDS stigmatization

The study revealed that the majority of the respondents were practising HIV stigmatization with 90% of the respondents having practised stigmatization to suspected HIV positive patient though only 56% of those agreed that it was the best way of controlling the spread of HIV pandemic within their community. Several interventions have been attempted in the fight against stigma. Many begin with- and are based on academic research. Some studies addressed the issue of tolerance and coping mechanisms of people living with HIV/AIDS in the general population, for example, to seek means to increase such tolerance and ability to cope. Strategic interventions to educate all stakeholders should continue (Lissane, Kate, Lea, 2001).

The study also revealed that the majority (97%) of the youth knew the location of the youth friendly services. The youth friendly clinics are those youth centers created in most parts of Uganda to provide free information and treatment for the youth, being a vulnerable group especially on HIV/AIDS related issues, reproductive health and general health. Only 3% of the respondents were not aware or had no clue of such youth clinics. Of those who knew the clinics and services only 59% went to visit them and tested for HIV/AIDS. Note that only 10.3% of them got information about HIV-related stigma from these clinics. It therefore looks certain that at these clinics, inadequate information on HIV related stigma was being provided.

CONCLUSION

There is sufficient knowledge of the youth on HIV stigma-

tization. There is poor attitude of the youth towards HIV stigmatization with 56% of the youths believing that it is the best method in reducing the spread of HIV/AIDs. The practice on HIV stigmatization is still rampant with 90% of respondents having practiced stigmatization on those suspected to be HIV positive.

RECOMMENDATIONS

The ministries of Health and Education should introduce HIV related stigma issues in the syllabuses of the secondary and primary schools. Prevention and mitigation of HIV stigmatization should be made into policy, adopted and spread among the youths.

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