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FOCUS GROUP INTERVIEWS ABOUT AIDS IN RAKAI DISTRICT OF UGANDA

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Abstract—Focus group interviews about AIDS were held in Rakai district, Uganda during early 1990 with groups from various sections of the community. It was found that the knowledge of AIDS symptoms and its transmission were widespread. Attitudes regarding many aspects of sexual behavior, AIDS patients, condoms, injections, hospital treatment, sexually transmitted diseases and an AIDS cure were investigated. We found that most people no longer fear casual contact with AIDS patients but they blame spouses of people with AIDS for spreading the infection. Condoms are generally not trusted. Many people feel that condoms cannot prevent transmission of the AIDS virus and some fear that they may get torn and cause complications in women. Most people now do not like injections for treatment and when necessary, prefer disposable needles and syringes. Hospital treatment for AIDS patients is not trusted very much, and many people believe that AIDS patients are intentionally killed off by doctors. Sexual behavior was extensively discussed and it was found that there is generally a reduced level of multiple sexual partners. The reduction is more marked in rural areas but the urban areas are still having higher levels of multiple sexual partners.

Key words—AIDS, knowledge, behaviors, attitudes, focus groups, Africa

INTRODUCTION

In 1982 Rakai District became the first district in Uganda to record AIDS cases [1]. Since then the area has seen increasing numbers of AIDS patients and has had a higher mortality rate from AIDS than any other district in Uganda except Kampala [2]. It is a largely rural mixed agricultural district consisting of some 380,000 people. It has three large trading centers (towns) each having about 5000 people (Lyantonde, Kalisizo and Kyotera) and 25 small trading centers scattered throughout the district. A small trading center may have 10–50 shops and a population ranging between 300 and 1000 people. A sero-survey recently completed in the district shows that the infection has spread to all the corners of the district and sero-prevalence rates among adults range from an average of 12% among adults (age 13 years and above) in the rural areas to an average of 33% in the trading centers. All persons 13 years old and above were categorised as 'adults' because some persons are sexually active at this age in the community under study. The weighted district average sero-prevalence is 13% [3]. There is, however, a big village to village variation in HIV seroprevalence with some rural villages registering sero-prevalences of about 1% [3].

The dominant ethnic group in Rakai district is the Baganda, comprising about 70% of the population in the district. Other major groups include Banyankole, Bakiga and Rwandese. Previous studies on the Baganda have indicated that among the Baganda matters concerning sex have always been kept a guarded secret [4]. There is traditionally a desire for large families, and male sexual potency and female fertility are attributes that are generally held in high esteem [5].

The Rakai Project is a health education and KAP-sero-epidemiology project in Rakai district whose overall objective is to study the dynamics of HIV infection in the district and the effect of health education. A service component providing counselling and community based health care by community health workers is also part of the project.

Annual surveys of sero-prevalence and of knowledge attitudes and practices (KAP) are administered to a randomly selected general population cohort. In addition, focus group discussions have been used because they approach sensitive subject matters by a different, often more fruitful method than standardized questionnaires. They provide validation of interview based data, and they offered rapid, lower cost approaches to behavior evaluation. The focus group interviews were therefore targeted to provide more detailed explanations or confirm findings of the interview survey. They also generate new areas of investigation and questions that may be included in subsequent questionnaires and activities. Focus group data, however, is difficult to quantify and because of this the sample survey has continued to be used for quantitative assessment of specific issues. Also generalising the findings of focus groups to the parent population is usually more difficult to justify than for a sample survey.

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METHODOLOGY

Ten persons were trained in the conduct of focus groups interviews so that they could stimulate comprehensive group discussions about AIDS with the area residents. Interviews with male groups were moderated by men and women facilitated female groups. Focus groups contained 8–12 participants and each had 2 facilitators. Sites for holding the interviews were selected and visited in advance of the exercise. They were well scattered in the district and included both trading centers and rural areas. On the appointed days community leaders were asked to invite participants in various categories as indicated below. All discussions were fully tape recorded. In all instances the group facilitators summarized the tapes and made additional relevant notes soon after the end of each group discussion. Reports from all the focus groups were compiled into one report using the qualitative method.

Categories of groups included married men or women, manual workers, barmaids, youths, community leaders, police, business persons and traditional healers. The barmaids are young women working in public bars, restaurants and lodges who, in the past, have been known to have multiple sexual partners in return for financial or other compensation. Generally they do not view themselves, nor are they viewed by their 'friends' or clients as prostitutes. This is largely because they are often acquainted sometimes repeatedly over time rather than being simply hired. The traditional healers are herbalists who are practicing and organized through an association which is active throughout the district.

RESULTS

Knowledge of AIDS transmission and symptoms

A total of 35 focus group discussions were held in the district, 19 of them in trading centers, which we classified as urban areas, and 16 in rural areas. There were 18 interviews with male groups, 15 with female groups, and 2 were special groups in which both sexes were represented. After compiling transcripts from all the group discussions it was found that the methods of transmission for HIV infection were well known in all the groups. Sexual transmission was always mentioned first and common statements included the following. "AIDS is caused by moving about", or "The disease is caused by having many sex partners", and "Promiscuity is the cause". Blood transfusions and unsterilized instruments and injections, while well known, were mentioned as secondary causes of less importance. There were hardly any misconceptions expressed concerning the means of HIV transmission, but in rural areas a few people stated that witchcraft is a method for the spread of AIDS. Common symptoms including gross wasting, prolonged diarrhoea, prolonged cough, skin changes and oral thrush were well known in all groups. Many participants reported having seen many AIDS patients.

Knowledge and attitudes about preventive measures

Measures for controlling the spread of the AIDS virus were extensively discussed. Reducing the number of sexual partners was a common theme in all groups. Representative statements about prevention which came from both sexes included "stick to one sexual partner", "avoid prostitutes", and "keep to oneself". There was, however, less unanimous agreement regarding other preventive measures such as condoms and this was the same for both sexes.

Sexual behavior

Sexual behavior in the community was a widely and openly discussed topic in all groups. While most groups from the rural areas felt that promiscuity had declined in their areas, the urban groups on the other hand were unanimous in asserting that if there was any decline in sexual activity it was minimal. Some urban groups, especially those of married men and community leaders felt that the level of multiple sexual partner change was probably as high or even higher than before the AIDS era.

Urban groups felt that their neighbors have become more discreet than in the past but are still having as many sexual partners as they used to. Any claims to diminished sexual activity may be just a statement of newly acceptable norms and may not be reflective of actual behavior changes. Relevant statements which were made in many of the groups included the following: "People only appear to have changed during the day, but at night there is a lot of sexual activity", and "People only get scared when someone has just died of AIDS, but soon afterwards they resume high levels of sexual activity". There were, however, some statements which supported the idea that a change has taken place such as: "these days men go with their wives at social gatherings", "at social gatherings in the evenings in the past there was a lot of sex activity but these days people sit properly in their seats", and "these days wives are very happy with their husbands; in the past husbands used to return home late in the night, but these days they go home early and they have meals together". These statements were common in both male and female groups.

Many urban groups felt that there has not been any change in some groups, especially among barmaids and among the youth who were identified as more sexually active than others: but the barmaids and the youth groups on their part felt that they had modified their behaviours. Also, new habits may be evolving in response to the epidemic indicated by statements like: "Many mature men now prefer young girls because they think they are safer". Adolescent students frequently made the allegations that infected men use money to attract young girls for sex and that some infected men go to the extent of raping the girls.

There was agreement in the student discussions that sexual activity in the community was going on at the same rate as in the past and that the AIDS scare has not had a big impact on the levels of sex activity or promiscuity. Many male students strongly felt that girls engage in sexual activity for money with adults and that many girls subsequently get infected and then pass on the infection to their young boy friends. Economic considerations appear to play a major role in determining behaviors among barmaids. Some barmaids when discussing the subject of stopping commercial sex indicate their dilemma by such statements as: "How shall we live then?" or "How will I pay for food and for my room?"

In rural areas a marked sexual behavior change was reported. In all rural groups there was a strong consensus that promiscuity had sharply declined or even disappeared from the rural communities. There were some rural female groups where men were said to be having clandestine sexual relations with females from towns or other villages. The male groups similarly indicated that if any promiscuity was occurring, then the females were doing it with outsiders.

There was a general consensus that widows and widowers of AIDS patients migrate from areas where they are known to areas where they are not known and continue with sexual activity. Some groups felt that many widows and widowers spread the disease intentionally. "Widows are very smart and many look more beautiful than us", "Some widows are very young and they get re-married quickly", "Some widows do not believe that their husbands died of AIDS". Male groups did not appear to blame widows or widowers to the same extent that females did.

There were some groups which tried to explain the high levels of sex activity which was reported amongst infected persons. Some manual workers in the urban areas argued that frequent sexual activity especially for males may reduce the virus load in the body since the AIDS germs tend to be concentrated in the sex fluids. This trend of thinking, however, was limited to a few urban groups.

Condoms

Most of the focus group participants had heard about condoms and many had seen them but hardly anyone trusted or used them. There is a wide-spread fear that they are not effective barriers. "They may contain small holes through which the disease may pass", was a statement made by several groups. One car washer in a manual workers' urban group said, "You can never trust these manufactured things, even a brand new car lets in moisture and after locking it up properly overnight, in the morning the inner side of the windows will have droplets of water." There was an expressed fear by many participants that when close body contact occurs, sweat would transmit the infection. A statement heard several times especially in male urban groups went as follows: "the condom covers only one part of the body, what about the other parts and what about the sweat?" There was a frequently expressed fear that a condom may get stuck in the female and lead to serious illness. This was more frequently and strongly argued in female than in male groups. The belief that condoms may reduce sexual pleasure was heard in many of the discussions, but a few urban groups recommended that condom use should be promoted and that proper usage should be taught to the public. Among groups other than those of barmaids, there was an added fear that condoms may increase promiscuity. Relevant statements were "Condoms will ruin society", and "Condoms will make the youth less careful and AIDS will spread even more than now". These arguments were particularly common among the rural groups. The issue of how condoms should be disposed of was also discussed by several groups and it was recognized as a difficult problem. Many people thought that pit latrines would serve this purpose well.

The barmaids in the urban areas had a more positive attitude regarding condoms and some appeared to favor them, but they do not use them because according to them their clients do not like them. Frequent statements made in most focus groups of barmaids went as follows: "The men do not like them and they cannot accept them", and "If you ask someone to use a condom he will think that you are very loose or that you are a prostitute and he will go away." In rural areas condoms were less welcome than in urban areas. Many married women said that they did not know what condoms were and those who knew about them did not like the idea of promoting them in the community at all. The married men in the rural areas also said that they do not use condoms although there was less sentiment against them than from the females. Many groups saw no need for using condoms and recurring statements in many rural groups went as follows: "if you are happily married then what is the condom for?"; "they are not effective anyway and they can tear during intercourse"; "condoms are only used by a few young people".

Attitudes towards AIDS patients

In all the focus group discussions there was a striking positive attitude towards people with AIDS. There is no noticeable stigma or fear of contact with persons with AIDS. Virtually everyone in all the groups expressed the feeling of sympathy for the people with AIDS. One manual worker said "If someone I know gets AIDS I may buy him a present or something to eat or give him some cash as a way of saying farewell". Such sentiments were especially pronounced in urban focus groups. Blaming persons with AIDS for having acquired AIDS was not raised in any discussion group. A few less compassionate remarks came from adolescent students who insisted that since preventive measures are well known, people with AIDS should take full responsibility for having acquired the disease.

Attitudes about treatment for AIDS

Regarding the availability of a cure for AIDS, everyone is now aware that there is currently no cure for AIDS. A common statement made in almost all groups went as follows: "If there was a cure, then all these rich men would not have died." This attitude was quite widespread in all the groups.

Hospital treatment

There was a widespread belief in all the groups that AIDS patients are given some tablets in the health units which just shorten their lives or which kill them off prematurely. This has led many AIDS patients to stay at home rather than seek health care. Some common statements went as follows: "AIDS patients live longer at home than in the hospitals", and "the doctors give AIDS patients tablets knowing that by the time they finish up the tablets, they will have died".

Attitudes on medical injections

It is quite evident that people are no longer demanding treatment by injection when they go to hospitals. If they must have an injection then they prefer that disposable syringes and needles are used rather than the re-usable ones. Many people do not trust the sterilization process in the health units. Immunization was felt to be safe and most people in all the groups felt that immunization attendances have not been affected by the fear of AIDS. Private clinics use disposable needles almost exclusively. Many of the people who do not like re-usable needles and syringes believe that the AIDS virus cannot be killed by boiling. "Even when you boil it for 24 hours it won't die", one urban manual worker said. Although there have been some reports from Kampala, the capital city of Uganda, that the fear of injections with needles sterilized in hospitals has led many people to keep their own needles and syringes, this was not found to be the case in our focus groups in Rakai district.

Attitudes about HIV screening

Many people feel that HIV screening serves no good purpose and some have the view that it is detrimental. Common statements went as follows: "The test may give false results". "Positive results increase worry and may lead to suicide". "If people are told that they are infected they will spread the disease maliciously". One urban manual worker said, "If I discover that I have AIDS I will go out on a rampage to spread it and I will tell my wife to do the same."

Pre-marital screening was discussed a lot and it was generally supported. The support was strongest in rural areas especially among females. HIV screening for survey purposes was not opposed but almost everybody felt that results should not be given out to the screened persons. Many people were willing to participate in screening surveys which are for research because they have the belief that research may help to discover a cure for AIDS. There were a few eccentric statements which did not get support from many participants such as "infected persons should be removed from the public and imprisoned" or "infected people should be castrated so that they do not spread the disease". There was a general consensus in most of the groups that health education to modify behavior is more important than screening.

Sexually transmitted diseases

All groups expressed the view that sexually transmitted diseases (STDs) had markedly declined or even disappeared. One common statement went as follows: "This new virus has overpowered all other sexual diseases". Some barmaids, however, felt that the other sexual illnesses are still present but are less common. Some manual workers from urban groups felt that STDs have become rare because drugs are easily available from shops or clinics and people get quick therapy (self medication). Many rural persons felt that STDs have declined because people are not having multiple sexual partners any longer.

Traditional healers

The focus group discussion with traditional healers revealed that they had good knowledge about AIDS regarding transmission, common symptoms, the absence of a cure and preventive measures. None of them claimed to have a cure for AIDS and they were all very willing to collaborate with other health workers to fight AIDS. The traditional healers who participated in the focus group discussion were members of a district-wide association and their views may be quite different from the views of other healers who are not members of this association.

DISCUSSION

The focus group participants comprise small numbers of people who are not randomly selected and are therefore not a representative sample of the population. Any generalizations of the findings to the entire population should therefore be done with caution. However, since many of the ideas were repeatedly expressed in many focus groups which were widely scattered throughout the district and comprising different types of persons, we were inclined to believe that the same ideas are widespread in the community. Whereas the focus group discussions confirmed the earlier survey finding that the knowledge about AIDS symptoms and HIV transmission was quite good within the district, many unexpected beliefs and attitudes were unearthed during the discussions. These include the widespread fear that AIDS patients are probably killed off prematurely when they go to hospital, the general mistrust of condoms, and the concern that HIV infected persons may be intentionally spreading the infection.

It was also established that the practice of having multiple sexual partners was still common especially in trading centers. Employment outlets and opportunities for commercial sex workers may lead to a marked change in sex behavior. All these are issues that need to be seriously addressed by an aggressive health education and counselling program. The role of religion being one of the factors to influence any one's decision regarding condom use was not spontaneously mentioned in the focus groups. This aspect will be further investigated especially since the dominant religion in this district is the catholic church which disapproves of condoms.

We found the diminished interest in serological results to be a new development. Although during the survey carried out a year before the focus group discussions about 85% of all the persons screened indicated that they would be interested in knowing their results [6], during the focus group discussions there was almost no one interested in knowing their HIV serological results. It appears, from the focus groups, that most people prefer the comfort of ignorance to the uncertain probability of the pain of knowing that they are infected even when mixed with the potential pleasure of knowing that they are not infected. Further perspective on this issue comes from the records of the project's counselling service. About 10% of the surveyed adults have requested for their HIV results. To date there has not been any of the feared bad experiences such as suicide or sexual rampage [7]. Thus the expectations of the focus group participants on this issue were not met. The low rate of demand for HIV results, however, is more in agreement with the focus groups findings than with the survey findings.

The biggest success of this series of focus group discussions was that the reasons behind many of the various attitudes, beliefs and practices were explored and it is our view that the future direction of health education will be greatly influenced by these findings. The level of compassion expressed towards AIDS patients was striking. It is difficult to assess how much of this was genuine and how much was just politeness while speaking in a group atmosphere, but the trend was quite similar in all the groups. Some beliefs are potentially very dangerous and will need to be made special targets of any health education effort. These include the belief that AIDS patients are actively killed off by doctors, the negative views about condoms, and the belief among a small fraction of the population that sexual activity could be of benefit to an infected person. The high levels of sexual partner change in trading centers need to be seriously addressed as a matter of urgency. The decline in the popularity of, and demand for, medical injections can be regarded to be a postive development since injections have been associated with HIV infection in some studies [8, 9], and they have been over used in the past. The effect of the AIDS scare on childhood immunisation practices is an area that needs further investigation especially since the immunisation programme in Uganda uses re-usable needles and syringes.

Quality of the collected data

We were positively impressed by the quality and quantity of data that we collected through the focus group methodology. The speed at which data was collected and compiled contrasted very sharply with the questionnaire survey. This technique promises to be very practical especially for research in the rural areas of the developing countries. We have the view that the group discussions which do not pin down a single person to relate their secret lives to another person are more likely to give a better picture of reality especially regarding sexual behavior. This methodology also overcomes some of the ethical problems associated with confidentiality. Such problems are known to be a recurrent issue in medical practice and social research [10]. The focus groups provided us with the evidence to question the validity of some findings from an earlier survey with a standard questionnaire in the same area. The uncertain reliability of answers on sexual behavior is a problem that has been mentioned by other researchers [11], and it has been postulated that people from Africa may be more secretive than many others about sexual matters [4]. Although social pressures in a group atmopshere may lead participants to say only what is socially acceptable, the focus groups should play a significant complementary role to the sample surveys.

Traditional healers

Herbalists still play a big role in the health care systems of rural communities in developing countries. They need to be encouraged to disseminate correct knowledge about AIDS because they are highly regarded and trusted in many cultures [12]. Given the prevailing shortage of health workers, traditional healers may boost the strength of the health services in developing countries. It has previously been stated that traditional practitioners constitute the most abundant health resource in the community [13]. A lot of support, however, will be needed from both the modern health workers and from the political leaders if the traditional healers are to be properly utilized. It is likely to be a slow process since the medical establishment is known to be slow to adapt. It is known, for example, that even after several decades of trying, training programs for traditional birth attendants(TBAs) have not been particularly successful [14]. This is in spite of the fact that the World Health Organization has strongly advocated cooperation and mutual respect between traditional and modern practitioners [15, 16]. Mutual respect and recognition are important conditions for any collaboration. Some countries such as Norway and Botswana have attempted to promote contacts between traditional and modern practitioners through

dialogue groups [17], and may provide useful lessons for others.

In conclusion, while a lot of information about AIDS has filtered down to the Rakai district communities the focus groups revealed that there are many beliefs, attitudes and practices that still need to be tackled in well planned intensive health education programmes. This is particularly so since behavior changes must be regarded as an integral part of health education. Programs for social advancement especially for females in the urban areas may have a significant impact on commercial sex and may drastically influence the trend of the epidemic.

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