



## COMMUNICATING WITH THE PEOPLE ABOUT HIV INFECTION RISK AS A BASIS FOR PLANNING INTERVENTIONS: LESSONS FROM THE KAGERA REGION OF TANZANIA

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**Abstract**—In order to deepen the understanding of risk factors associated with HIV infection in the Kagera region of Tanzania and to investigate the potentials of communicating with the people in planning for interventions, two studies were performed in the districts of Bukoba Urban, Bukoba Rural and Muleba in 1989. The HIV prevalence of these areas ranged between 4.5% and 24.2% according to the prevalence study performed earlier in 1987. The studies involved the community in ward meetings on the one hand, and previously studied individuals on the other hand. The studies aimed both at conveying to the people the results of a previously performed study and at collecting new data using a combination of quantitative and qualitative methods in order to better understand the associated risk factors, perceived or real, and what suggestions the community could offer for reducing HIV transmission in the region. From the initial study, awareness about AIDS was found to be universal. Change of sexual partners and infection with syphilis were found to be the major risk factors for HIV-1 infection. From the ward meetings people suggested a variety of solutions for interventions which we have categorized as either “hard” or “soft”. The “hard” solutions involved suggestions such as isolation, imprisonment, castration and killing of AIDS victims, while the “soft” solutions involved sympathetic handling of the sick and educating the people about the modes of transmission and how best to prevent infection. There was a greater tendency for the low HIV prevalence rural communities to suggest the “hard” solutions than the high HIV prevalence urban ones which tended to suggest the “soft” solutions. However, with the changing dynamics of HIV infection in the region towards higher HIV prevalence in rural areas, it is likely that the “soft” solutions will gain acceptance and become adopted for interventions throughout the region. The information obtained from these studies has provided lessons that can be used for rational counselling as well as for guiding the implementation of IEC activities geared at interventions. It is also suggested that there should be further research into new strategies or their combinations which could be crucial in prevention such as those of community participation, empowerment of women and solidarity in AIDS intervention work. © 1997 Elsevier Science Ltd

**Key words**—risk factors, HIV infection, feedback study, perceived risk, community participation, Tanzania

### INTRODUCTION

In many parts of Africa, HIV has been spreading in the general population mainly through heterosexual contacts (Quinn *et al.*, 1986; Piot *et al.*, 1988). In Tanzania, cases of AIDS were reported for the first time in 1983, from the Kagera region (Ministry of Health, 1992) which is one of the 20 mainland regions located in the north western corner of the country, west of Lake Victoria. The region is also bordered by the Mwanza region of Tanzania to the east, by Uganda to the north and Rwanda and Burundi to the west. To the south, the region is bordered by the Kigoma and Shinyanga regions of Tanzania. Kagera occupies an area of 29,000 out of the approximately 884,000 square kilometres that make up Tanzania, and has about 800 villages.

The region is composed of six districts, namely Bukoba Urban, Bukoba Rural, Muleba, Karagwe, Biharamulo and Ngara. These districts, like all districts in Tanzania, are further subdivided into divisions and the divisions into wards. Except for Bukoba town, each ward is in turn subdivided into villages and each village into 10-household units which are the smallest administrative units in the country. In the Bukoba Urban district there are no villages but wards are the smallest geographical subdivisions followed by 10-household units. The Kagera population consists of four major ethnic and two major religious groupings. The ethnic groupings are the *Haya* tribe which is predominantly found in the Bukoba Urban, Bukoba Rural and Muleba districts, the *Nyambo* of Karagwe district, the *Subi* of Biharamulo district and the *Hangaza* of Ngara district. Although most of these ethnic groupings are of Bantu stock they are cultu-

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rally diverse. The major religions are Christianity and Islam.

In 1987, a population-based study was carried out in Kagera where the aim was to determine the magnitude and risk factors for HIV-1 infection as well as to generate a study base for future studies on the dynamics of HIV-1 infection. In this study sample, the prevalence of HIV-1 infection among adults aged 15–54 years in the region was found to be 9.6% overall, with a higher prevalence in the urban area of Bukoba (24.2%) than in the three rural areas of the region (10.0% for the Bukoba Rural and Muleba districts, 4.5% for the Karagwe district, and 0.4% for the Ngara and Biharamulo districts) (Killewo *et al.*, 1990).

The same study showed that the age-specific HIV-1 seroprevalence was highest in the age group 25–34 years. The age-standardized sex-specific prevalence was found to be higher among females than males in the urban area while it was the same in the rural areas. Preliminary analysis of these cross-sectional data showed that sexual experience and change of sexual partners among adults were associated with an increased risk of HIV-1 seropositivity. Travelling outside the region but within the country was also found to be associated with increased risk of HIV-1 infection but only in the rural population. These findings confirmed those of case reports and studies performed by other investigators on heterosexual transmission of HIV infection in Africa (Gwede and McDermott, 1992; Miotti *et al.*, 1992).

In order to deepen our understanding of the risk factors associated with HIV-1 infection in the region and to investigate the potentials of communicating with the people of Kagera when planning for interventions, two other studies were designed and carried out. These included a case-referent study at the individual level and community meetings at ward level. The two studies were conducted simultaneously in connection with the feedback of results from a previously performed HIV-1 prevalence study. The aim was to combine methodologies in communicating with the people and in identifying risk factors for HIV infection in the community. The studies were performed under the hypothesis that effective communication with the people about what they feel to be their greatest need can stimulate their involvement and interest in planning community-specific effective and sustainable interventions.

Studies on the risk of HIV-1 infection performed in a variety of settings and in different African countries including Uganda (Migliori *et al.*, 1992; Serwadda *et al.*, 1992), Tanzania (Ter Meulen *et al.*, 1992; Kapiga *et al.*, 1994), Zaire (Laga *et al.*, 1993), Malawi (Dallabetta *et al.*, 1993), Zimbabwe (Bassett *et al.*, 1992), Ghana (Neequaye *et al.*, 1991), Rwanda (Allen *et al.*, 1991), Somalia (Ahmed *et al.*, 1991) and others (Houweling and Coutinho, 1991)

have found sexual activity to be the most important risk factor. Studies performed in different research settings have articulated the value of combining qualitative with quantitative methodologies in providing a richer and deeper understanding of the area under investigation than would otherwise be possible (Jick, 1979; Bryman, 1984; Stange and Zyzanski, 1989; Steckler *et al.*, 1991; Corner, 1991; Shtarkshall *et al.*, 1993; Adrien *et al.*, 1993). Likewise, many community-based studies have addressed the issue of community participation and the use of community leaders and traditional healers in mobilizing communities in surveys and interventions (Longoria *et al.*, 1991; Seeley *et al.*, 1992; Abdool Karim, 1993). Various studies have been performed in Uganda, Rwanda, Kenya, Zaire and South Africa to determine people's level of knowledge as well as their attitudes and perceptions regarding AIDS and HIV infection and the influence of such knowledge on taking action for prevention (MacDonald and Smith, 1990; Mathews *et al.*, 1990; McKinnon *et al.*, 1990; Prohaska *et al.*, 1990; Bertrand *et al.*, 1991; Friedland *et al.*, 1991; Strunin, 1991; Lindan *et al.*, 1991; Govender *et al.*, 1992; Muller *et al.*, 1992; Rogstad *et al.*, 1993). However, few studies have assessed the usefulness of returning and communicating research results to the studied communities and subsequently involving them in helping to solve the study problem.

This paper describes the methodology and presents results from two studies which were performed as part of a population-based study in Kagera. One of the studies provided for returning research results to the studied community while the other aimed at collecting new data using a combination of quantitative and qualitative methods involving interviews with individuals and discussions with informants, respectively, in order to better understand the associated risk factors, perceived or real, and what suggestions the community could offer for reducing HIV transmission in the region. The paper also argues that this combination of communicating research results and discussions with informants about the measures to be taken to solve a particular community problem might provide a useful point of departure for community participation in suggesting, designing, and implementing community-specific interventions.

#### MATERIALS AND METHODS

These studies were performed in the districts of Bukoba Urban, Bukoba Rural and Muleba in 1989. These areas had a prevalence of HIV infection ranging between 4.5% and 24.2% according to the prevalence study performed earlier (Killewo *et al.*, 1990). It was necessary to conduct these studies in the high and medium HIV-1 prevalence areas of Kagera to obtain a sufficient number of cases for the case-referent study. With the exception of the

urban district where there are no villages, the districts are composed of divisions and wards and within each ward there are villages in which the households are organized in 10-household cells, each under the jurisdiction of a 10-cell leader. In the prevalence study performed in 1987/1988, a multistage cluster sampling technique was used to select the study population.

In total, 17 wards were involved in the studies and each of them was regarded as a community for the purpose of this study. Of these wards, 15 were from Bukoba Rural and Muleba districts and two were from Bukoba Urban district. In each ward the studies were performed first at the individual level followed by the community level. For the purpose of these studies the field assistants were trained in counselling and interview techniques as well as in the basics of HIV infection and transmission.

At the individual level all those involved in the initial prevalence study sample in these districts were revisited. They were identified through a list, complete with addresses, that had been prepared during the prevalence study for purposes of follow-up. All individuals who were positive for HIV-1 infection during the prevalence study were taken to be the cases and the HIV-1 negative population the referents. However, since the number of cases was small, and the aim was to obtain as many as four times the number of referents as the cases, all the HIV-1 positives and the HIV-1 negatives in the selected areas were interviewed.

Interviews were performed using a structured questionnaire, prepared and translated into Kiswahili to address prevalent as well as antecedent risk behaviour. The interviews also addressed socio-demographic characteristics as well as knowledge of, and attitude towards AIDS and HIV infection and their prevention. During the interview, explicit enquiries were made to determine the subject's willingness to participate in future research work of a similar nature. However, to avoid interviewer bias and stigmatisation that might result from knowledge of the serological status of individuals, the interviewers were not given the results of HIV serology. After the interviews each individual was personally given the results of the syphilis-testing performed as part of the prevalence study and those who had positive syphilis serology were treated. This visit also involved counselling on syphilis as well as health education on HIV transmission and prevention.

At the community level, one meeting was organized in each ward involving community leaders and other self-selected or interested adult members in the community. The aims of the meetings were to discuss the problem of AIDS and HIV infection in the community, risk factors for HIV infection, the results of the prevalence study for that community and perceived measures to curb the epidemic. These meetings were organized by five field assist-

ants in consultation with the ward community leaders.

Guidelines for the meetings were prepared consisting of a set of themes which had been formulated for the community and which would later form the basis for assessment of how much they knew about AIDS and HIV infection and how much misconception existed in the community regarding important aspects related to control. During each meeting one of the field assistants used the guidelines to ask questions which would stimulate discussion around the theme. This was a focus group technique for data collection. There were seven themes all together and at the end of each theme the facilitator would clarify any misconceptions and answer questions posed by participants in the meeting. Another field assistant was responsible for taking notes from the discussions by recording the consensus on each theme. These notes were subsequently transcribed and used for this analysis. Thus, the meetings formed a dialogue of communication (Laver, 1993) between the study team and the community on topics related to health education for the prevention of HIV transmission. An implicit aim of the feedback component was also to enlist the co-operation of the people in future research and/or interventions aimed at HIV/AIDS in the region.

The methodological structure of the two studies is illustrated in Fig. 1. The figure shows that communication was done at two levels. At the community level on the one hand, research results were communicated in general and clarification of misconceptions as well as provision of health education on HIV/AIDS were made when discussing the problem. The figure also indicates that planning intervention strategies involves utilization of information obtained from NGOs currently performing intervention work in Kagera. At the individual level on the other hand, syphilis results were communicated individually with counselling, and treatment provided where necessary.

In the analysis of the data collected at the two levels, both qualitative and quantitative methods were used. The two methods were designed to capture both the qualitative picture of how the meeting participants, representing the norm systems of the wards perceive risks and evaluate the AIDS/HIV infection situation, and the quantitative one of estimation of risks and etiological patterns respectively. There is also a link between the two data collection methods at different levels in the sense that the self-selected representatives of villagers participating in the meetings functioned as opinion leaders or even as "gatekeepers" (Rogers and Kincaid, 1981), i.e. villagers who are dominant in defining the norm systems and therefore also dominant in "translating" information passing between the "objective" world and the inhabitants' subjective perceptions, attitudes and behaviour.

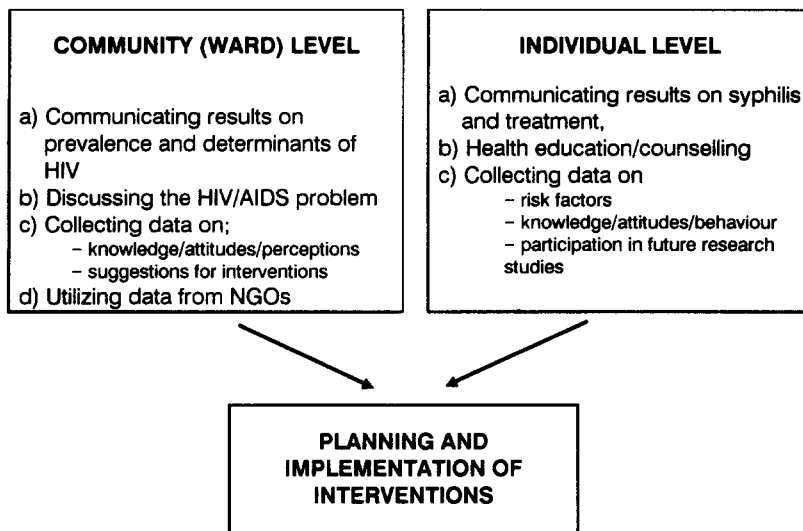


Fig. 1. Methodological structure of the studies.

The risk factor analysis involved calculations of odds ratios and their 95% confidence intervals for each risk factor using logistic regression techniques. The analysis included all those who participated fully in the study at the individual level and who had serological results available from the prevalence study. All those included in the prevalence study but who had migrated, died or were not found to be interviewed during this study were regarded as non-respondents. Those who were interviewed during this study but had missing serological results from the prevalence study were also excluded from the risk factor analysis. The transcribed material from the ward meetings was thematically analysed by comparing the resolutions, the consensus of what was known and the perceptions in the different wards.

## RESULTS

### *Individual level data*

A total of 682 adults were identified as responding members of the previous prevalence study population who had results of serological testing. Of these, 110 subjects had a positive serology for HIV-1 infection while 182 had positive serology for syphilis infection. There was no significant difference between the cases, the referents and those with

missing serological results in their response rates to the current study indicating that selection bias was minimal (Table 1).

For analysis, the risk factors were divided into four categories: socio-demographic, behavioural, knowledge perception, and socio-economic factors. Table 2 shows the association between HIV-1 seropositivity and factors representing these categories.

Table 2 shows that those adults who had changed sexual partners, or had had more than two sexual partners in the preceding eight years, or had positive syphilis serology, or had received past injections, or had perceived inadequate knowledge about AIDS, or lived in the urban area or had a disrupted or multiple marriage situation were significantly associated with the risk of HIV infection. This association was obtained after controlling for factors such as age, sex, area of residence and sexual exposure by the use of a multiple logistic regression technique. Table 2 also shows that those afraid of contracting AIDS appeared to be protected from the risk of HIV infection as indicated by  $OR = 0.5$  (0.3, 0.9)

Table 3 shows a comparison among the sexes, areas of residence, age groups and case-referent categories of the proportions with various perceptions and attitudes. The table shows that there was a higher proportion of males than females and cases

Table 1. Response pattern of the study population by serological status in the prevalence study

Response status during the case-referent study	Serological status in prevalence study						Total number
	HIV positive (cases)		HIV negative (referents)		Missing serological status		
	No.	(%)	No.	(%)	No.	(%)	
Responded	110	(61)	572	(63)	125	(60)	807
Reported to have migrated	30	(17)	121	(13)	32	(15)	183
Not found at home	27	(15)	130	(22)	47	(22)	204
Reported dead	11	(6)	5	(1)	5	(2)	21
Refused to participate	2	(1)	6	(1)	1	(1)	9
<b>Total</b>	<b>180</b>	<b>(100)</b>	<b>834</b>	<b>(100)</b>	<b>210</b>	<b>(100)</b>	<b>1224</b>

Table 2. Association between HIV-1 seropositivity and risk factor categories

Risk factor categories	% exposed to factor in study population	Bi-variate odds ratio	95% confidence limits	Multi-variate odds ratio	95% confidence limits
<b>Socio-demographic factors</b>					
Urban residence	51.0	3.4	2.1, 5.3	2.9	1.8, 4.6
Female sex	62.2	1.5	1.0, 2.4	1.5	1.0, 2.4
Age group 15-24 years	32.1	1.0		1.0	
Age group 25-34 years	35.9	2.2	1.3, 3.5	1.5	0.9, 2.5
Age group 35-44 years	20.4	1.1	0.6, 2.0	0.8	0.4, 1.5
Age group 45-54 years	11.6	0.4	0.2, 1.1	0.4	0.1, 1.2
<b>Behavioural factors</b>					
Change of sexual partner	70.4	2.6	1.4, 4.9	2.8	1.4, 5.3
More than two sexual partners	70.4	3.6	2.0, 6.7	3.5	1.8, 6.6
Syphilis seropositivity (TPHA)	24.3	3.1	2.0, 4.8	3.4	2.1, 5.4
Past injections	85.2	5.4	2.0, 14.8	3.4	1.2, 9.6
Blood transfusion	4.8	2.0	0.9, 4.5	1.7	0.7, 4.1
Past scarrification	39.9	1.6	1.0, 2.4	1.4	0.9, 2.1
Malaria infection	4.5	1.3	0.5, 3.2	1.5	0.6, 3.9
<b>Knowledge/attitudes/perception</b>					
Readiness to care for AIDS patients	94.7	1.2	0.5, 3.2	0.8	0.3, 2.4
Perceived risk of getting AIDS	64.8	1.8	1.1, 2.9	1.3	0.8, 2.1
Inadequacy of knowledge about AIDS	18.8	1.6	1.0, 2.6	1.9	1.1, 3.1
Fear of contracting AIDS	89.0	0.6	0.3, 1.1	0.5	0.3, 0.9
Willingness to participate in future studies	98.8	1.4	0.2, 11.0	1.6	0.2, 13.6
<b>Socio-economic factors</b>					
General and bar business <sup>a</sup>	18.2	2.5	1.6, 4.0	1.6	1.0, 2.6
Travel outside region	45.6	1.7	1.1, 2.5	0.9	0.6, 1.5
Disrupted/multiple marriage <sup>a</sup>	34.2	2.2	1.5, 3.3	2.0	1.3, 3.2

<sup>a</sup>Combined categories had similar levels of risk.

than referents who thought the knowledge they had received about AIDS was inadequate. However, there was no significant difference in the proportion who thought that their knowledge was inadequate between the areas or among the age groups. It also shows that a higher proportion of referents than cases and rural than urban residents thought AIDS could be prevented, while there was no significant difference in the proportion of those who thought AIDS could be prevented among the age groups and the sexes.

Regarding people's perceived risk of contracting AIDS, there was a significantly higher proportion of urban residents than rural ones, and cases than referents, who thought they could contract AIDS. However, there were no significant differences either between the sexes or among the age groups regarding this aspect. Table 3 also shows that attitude

towards caring for AIDS patients was somewhat more positive among women than men but there was no significant difference between cases and referents, areas of residence or the age groups in this regard.

To determine how knowledge about AIDS was being transmitted in the community during the early stages of the epidemic, an analysis was made to find out when this knowledge was actually acquired by the different age and sex subgroups in the community. Figure 2 shows a comparison of cumulative percent awareness with time among four age and sex categories (females aged 25-34, males aged 25-34, females aged 35 years or more and males aged 35 years or more). The figure indicates that even though all were aware about AIDS at the time of the study in 1989, the median cumulative knowledge (50%) among the older males (aged 35

Table 3. Percent with AIDS knowledge, perceptions, attitude and other feelings at the time of the study

Factor	% who thought they had inadequate knowledge of AIDS	% who thought AIDS could be prevented	% who thought they could get AIDS	% prepared to take care of AIDS patients
<b>Residence</b>				
Urban	19.0	92.0	71.8	95.0
Rural	18.6	96.1 <sup>a</sup>	57.8 <sup>a</sup>	94.0
<b>Sex</b>				
Male	23.3	94.6	60.5	90.0
Female	16.0 <sup>a</sup>	93.6	67.7	97.0 <sup>a</sup>
<b>HIV status</b>				
Positive	25.5	89.1	75.5	95.0
Negative	17.5 <sup>a</sup>	94.9 <sup>a</sup>	62.9 <sup>a</sup>	95.0
<b>Age group</b>				
15-24	20.1	94.5	63.5	93.0
25-34	15.9	93.1	70.2	96.0
35-44	18.7	93.5	64.0	93.0
45-54	24.1	96.2	54.4	97.0

<sup>a</sup>Difference in proportion is significant at the 5% level.

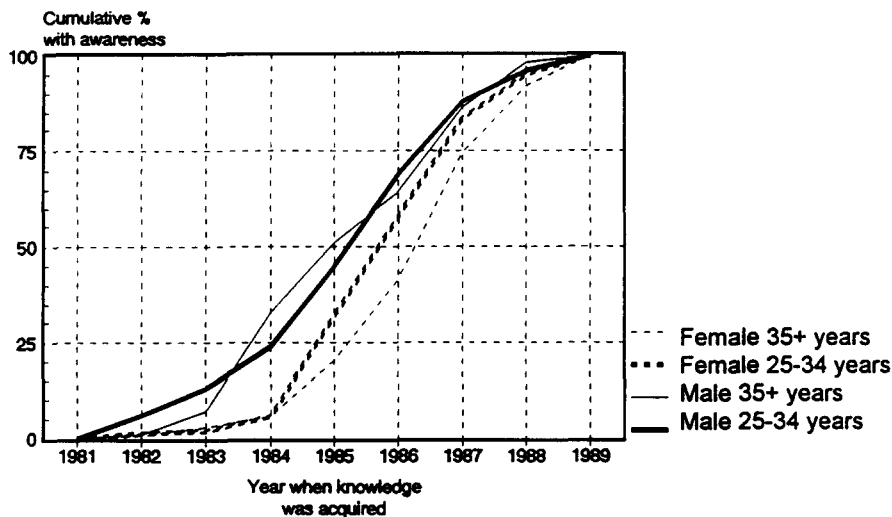


Fig. 2. Time when knowledge about AIDS was first acquired in Kagera. A comparison of four age and sex groups.

years or more) had been achieved about one year earlier than the same percentile among their female counterparts (aged 35 years or more). The order of awareness appears to have begun with the older males, followed by young males and young females and finally the older females as the last in the line.

#### *Community (ward) level data*

The themes discussed in the ward meetings followed the same rational order as the research process itself and they focused on the following questions: What is AIDS? How is it transmitted? Why has it come to us? What can we do about it? In these meetings people were eager to discuss these issues since they had been told what proportion of the people in their area was already infected with the HIV.

As was the case with the individual level data, the informants in the meetings were uniformly aware of the main characteristics of the disease; that people die of it and that it attacks the reproductive age groups—especially the women. There was anxiety over its consequences for the sick, the orphans and the widows or widowers who needed care. They expressed fear on the part of the sick of going to hospital as they perceived that they might be isolated or killed. The informants also feared that the sick might spread the disease deliberately out of anger.

In the ward meetings the mode of spread of infection in the community was largely known to be sexual. This answer was given and agreed upon in all the ward meetings during the discussions. Other modes mentioned were: blood transfusion, sick mother to her child, injections, kissing, instruments used for circumcision or for removing jiggers, re-use of condoms, breast milk from sick mothers, tooth-brushes, pipes/straws used in drinking locally brewed liquor, sharing meals, clothes and razor

blades with sick persons, water, air, mosquitoes, divine punishment, etc. Social and cultural mechanisms blamed for facilitating the spread were the norm of having many sexual partners in most areas and the night parties held during wedding ceremonies.

A predominant opinion in the ward meetings was that there was no known cure for AIDS. Some stated that there were hopes of a cure from traditional healers but for many this was only a myth. The Americans were "known" to be developing drugs for treating AIDS but these had not reached Kagera.

In most ward meetings, some key elements in prevention were stated as being faithful and trustworthy in marriage, using condoms properly, abstaining from sex, avoiding risky environments, testing for the disease before marriage, praying to God, etc. However, there were doubts regarding the role of the condom in prevention. Informants in some of the wards stated that people had even conducted local experiments and found that a condom on an erect penis could allow the "hotness" of pepper to penetrate if it came into contact. From this observation they concluded that the virus too could penetrate and therefore condoms might not be protective against the virus.

Some informants in the meetings thought nothing could be done to solve the problem of HIV/AIDS infection at community level until the government issued some working guidelines. Others stated that their community had formed committees to discuss this problem but expressed concern over their being inactive. It was also stated that some churches were preaching about it and that some wards had prohibited night parties in order to control and monitor the young while others had attempted to engage their young people in gainful activities to keep them busy. Other wards were reported to monitor the

movements of strangers to the area to stop them from "importing" AIDS into the area.

Regarding what the communities themselves could do to solve the problem, informants in the rural ward meetings on the one hand, more strongly than their urban counterparts included the following suggestions: prohibiting all night functions and parties as well as prostitution of all forms; screening all suspects and sending them to their home places to die; controlling the sales of local brews and banning their sale at certain places; screening for infection of all young people intending to marry etc. In the urban ward meetings on the other hand, the informants more strongly suggested voluntary testing of people and screening for HIV infection of all young people intending to marry.

To assist the community in solving the problem, the informants in the rural ward meetings more commonly suggested that the government should identify infected people and send them to a special prison or isolate patients in hospitals until they died or kill them by injection. It was also suggested that men and women with the virus should be castrated or have their genitalia closed, respectively, to prevent them from further sexual activities. However, the rural informants also suggested that the government should help to care for the orphans and provide them with material assistance. In addition, the informants in the urban ward meetings more strongly suggested that the government should issue certificates to uninfected people, provide educational materials, distribute condoms for protection, teach more about AIDS prevention in schools, hospitals and other public places and help to provide better care for the sick in hospitals.

#### DISCUSSION

The case-referent study on the individual level has shown that sexual behaviour, past injections, and syphilis seropositivity were associated with HIV infection. Those characteristics which were categorised as pertaining to individual behaviour were the most important in the association, both in the bi-variate and in the multi-variate analyses. Previous studies addressing behavioural characteristics as risk factors have revealed similar patterns of associations (Hrды, 1987; Berkley *et al.*, 1989; Cameron *et al.*, 1989; Wasser *et al.*, 1989; Mhalu, 1990; Nsubuga *et al.*, 1990; Martin *et al.*, 1992; Chetwynd *et al.*, 1993). The findings also show that urban residence, perceived inadequacy of knowledge and disrupted or multiple marriage were associated with HIV-1 infection. This is probably because urban residence and disrupted/multiple marriage were also associated with higher levels of sexual networking, i.e. sexual patterns of behaviour characterized by relatively frequent changes of sexual partners. Finally, perceived inadequacy of knowledge and risk of getting AIDS were also associated

with HIV-1 infection. The information collected about these factors is of great value in the planning of interventions.

The observation that 100% of the study population had heard about AIDS is not surprising because AIDS prevention education in the community was already widespread at the time of the study. However, their perception about the adequacy of the knowledge they had received about AIDS differed between cases and referents and between males and females. These studies have demonstrated that in general there are many similarities in knowledge, perceptions and values regarding AIDS in the wards of Kagera. Most people perceived themselves as having enough knowledge about AIDS to take preventive action at the individual level while a few felt their knowledge was inadequate. Although there were differences in the perceived adequacy of knowledge among the sexes and the case-referent categories, such differences may decrease as more intervention work percolates into the communities. Knowledge about transmission was also found to be universal, ranging from scientifically correct information to complete misconceptions such as transmission of HIV being by air or water. However, many studies have shown that while general knowledge or awareness about a health problem may increase, there is often little change in behaviour towards solution of the problem due to lack of motivation for internalizing such knowledge to achieve the desired goal (Bwayo *et al.*, 1991; Kapiga *et al.*, 1991; Lindan *et al.*, 1991; Govender *et al.*, 1992; McGrath *et al.*, 1993). Interventions must therefore be performed with these limitations in mind.

In our series of studies it was observed that large proportions of the people thought they were at risk of contracting AIDS with higher proportions among cases than referents and among urban than rural people. This observation is in contrast to that of a study in which it was shown that the level of knowledge about AIDS in the study population was high and yet only a small proportion of the participants felt they were at risk of getting AIDS (Agoki *et al.*, 1991). This contrast may be due to the fact that the study being referred to was conducted in an STD clinic atmosphere in which people may not be as free to admit being at risk as when they are at home. Thus, risk perception is best assessed under circumstances not related to provision of service.

AIDS transmission was perceived as being sexually related at both community and individual levels even though there were some misconceptions. A study in Kenya found that misconceptions regarding HIV transmission were present even in the educated group (Rogstad *et al.*, 1993). A study in Uganda using focus group methodology found that sexual transmission was always mentioned first in all the groups (Konde Lule *et al.*, 1993). This is a clear indication that sexual behaviour is a well

known risk factor for HIV infection and therefore, in the absence of effective vaccines, the only challenge in contemporary interventions to reduce HIV transmission is to make sexual behaviour safer.

In the early stages of the epidemic it appears that knowledge reached the Kagera community first among the adult males followed by the young males and the young females, and eventually the adult female. This order of access to information involving adult males as the first ones in the line seems to be culturally embedded in Kagera and probably in many other societies in Tanzania. If the order persists, it will certainly have serious implications in the control of the epidemic. A previous study in Kagera showed the incidence of HIV infection as well as that of syphilis to be high among young females (Killewo *et al.*, 1994) reflecting their disadvantaged position in the society in receiving relevant information for self-protection. The observed disparity in information acquisition is probably owing to a tendency for older males to monopolize the information for their own good, taking advantage of the females' ignorance to gain sexual favours. In this cultural setting, these young females are also virtually powerless in influencing community action for the control of HIV infection.

Our studies indicate that sources of knowledge were diverse, ranging from the news media (radio and newspapers) to friends and relatives and to authorities such as community and religious leaders as well as health staff. It appears therefore that news media, including posters prepared by the National AIDS Control programme as well as by various NGOs, were the most important sources of information for the people suggesting that these should be reinforced during intervention work. Findings from other studies indicate similar patterns of communication in AIDS control work although they may differ in detail regarding the ways messages are conveyed (Bosompra, 1989).

The lack of a cure for AIDS concerned many people, but the hopes and consolations, being spread by local as well as international therapists regarding possible treatments, may frustrate control efforts by the community. Discouraging people from false hopes about the availability of treatment is already one of the target attitudes in health education aimed at encouraging people to take advantage of the currently available methods of prevention and control.

The last two themes in the ward meetings were of a normative character. There were two main types of answers or solutions suggested for the HIV/AIDS problem. The first type argues for harsh or "hard" solutions such as closure of night clubs, isolation of the sick, mercy killing of the sick, castration of the infected to render them sexually inactive and screening of people by force. The second type argues for lenient or "soft" solutions which trusted in attempts to influence knowledge

and attitude by IEC means in the hope that the people will take heed and change their high risk behaviour. They recommended voluntary testing as a source of knowledge and as a basis for rational choice among individuals to protect themselves and others. A second variant of the soft solution related to the urgent need for assistance in caring for orphans resulting from AIDS deaths and provision of material assistance for them. In most wards this was seen as a priority problem of the community now and in the future. Distribution of condoms and disposable syringes and needles for use in hospitals was deemed as an important measure by the community for the protection of the uninfected.

The difference between the wards in the data presented was found to be small as almost the same pattern of answering was observed. However, when it came to questions about how to handle the situation collectively, there was a tendency from the rural ward meetings to suggest the hard solutions. This observation may suggest that the process of getting people to understand and accept the disease was more developed in the urban wards where the HIV prevalence was high. The community suggestions reflected the people's perceived risk of getting the disease. Thus, the perceived and actual risks were both high in the urban areas and therefore labelling or stigmatization under such circumstances is not beneficial. Hence infection cannot be regarded as a deviance in high prevalence areas since it becomes probable that anyone could be implicated and suffer from the undesirable effects of the hard solutions. The suggestions from the ward meetings therefore represent a meaningful assessment of the actual risk in the communities as expressed in terms of perceived risk (Snyder and Rouse, 1992; van der Velde *et al.*, 1994). However, owing to the changing dynamics of infection in the region towards higher rural prevalence the tendency to suggest hard solutions can be expected to decrease with increasing prevalence in the rural wards when deviance will no longer be the norm.

An issue frequently mentioned in the ward meetings was HIV testing. While there were suggestions of coercion, especially in testing people intending to get married there were also suggestions for voluntary testing with provision of test results. For the individual, the test result may increase the risk of stigmatization although awareness of being infected or otherwise can lead to greater care. However, there is no firm assurance of this positive step without further studies on stigmatization and the rigorous testing of the effectiveness of voluntary HIV testing in reducing transmission. On a collective level an increased openness may result in conflicts between infected and uninfected. It must be realized that what seems rational on a scientific level may not necessarily be good for either individuals or communities.



Community participation, empowerment of women and solidarity in interventions have been emphasized in current research (Robertson and Minkler, 1994). During the ward meetings it was stated that some wards had formed committees to discuss the problem and that churches and other community-based groups were teaching people about the moral aspects of prevention. Some communities were also said to be protecting their youth in various ways. However, the meetings also expressed concern over the effectiveness of such directions towards prevention and were therefore more willing to wait for government or health care directives or guidelines. This probably indicates that people trust the so-called medico-moral discourse and its ways of handling problems more than the alternative discourse of community participation (Seidel, 1993). Further studies are needed to elucidate the reasons for this impediment since the use of community-based groups in conducting or promoting intervention measures is known to be a viable means of achieving sustainable interventions (Kelly and St Lawrence, 1990).

The combination of methods in our studies has increased understanding of the HIV/AIDS problem in Kagera in a variety of ways. We have learned that knowledge was universal both at community and individual level and that many of the observations regarding knowledge, attitudes and perceptions at the community level were also confirmed at the individual level. Issues such as decisions on mandatory or voluntary HIV testing for communities, community suggestions for intervention (hard and soft solutions) and community participation which are difficult to obtain from individual level interviews were obtained from the community meetings through informants. Estimates of actual risk that cannot easily be gathered from the community were obtained through the quantitative methodology. Thus, the combination of methods and disciplines has been valuable in the dialogue between the project and the community in obtaining more complete answers than otherwise. The ward meetings have been characterized by moments of give and take during which the researchers and the community have learned from one another. Consequently, the knowledge gained under these circumstances is expected to provide useful and practical guidance to rational counselling and implementation of IEC activities geared at interventions for a serious problem such as AIDS and HIV infection in communities.

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