AIDS CARE (2002), VOL. 14, NO. 5, pp. 699–706

Taylor&Francis
healthsciences

HIV counselling and testing in rural Uganda: communities' attitudes and perceptions towards an HIV counselling and testing programme

W. KIPP,[1] G. KABAGAMBE[2] & J. KONDE-LULE[3]

[1]*Department of Public Health Sciences, Faculty of Medicine and Dentistry, University of Alberta, Canada,* [2]*District Director, Kabarole District, Uganda &* [3]*Makerere Medical School, Institute of Public Health, Kampala, Uganda*

Abstract *Study results on the assessment of a community-wide HIV counselling and testing programme are presented. The aim of this qualitative study was to elucidate whether HIV counselling and testing (HIV CT) was acceptable to a rural community and whether they expressed a need for it. From a total of 2,267 persons of Kigoyera Parish, western Uganda, who were HIV tested and counselled, 171 persons participated in 17 focus group discussions. Most participants expressed a strong need for HIV counselling and testing services. The counsellors were seen as competent and confidential. Community health workers were favoured as the preferred provider of HIV CT services. However, participants stressed that they should not come from the same community. Most participants felt that a HIV CT programme available only once is not enough and did not induce a change in sexual behaviour, e.g. increased condom use. They requested counselling services that are continuously offered. The study results also showed that there is a demand for HIV counselling services without being HIV tested.*

Introduction

The role of HIV counselling and testing (HIV CT) in a resource constraint developing country setting has been viewed as controversial. This is partly due to the mixed results of HIV CT in changing sexual behaviour towards safe sex practices and its high costs involved. Another factor is the lack of sufficient knowledge on how HIV CT services work in developing countries. Most information on HIV CT services is collected in developed countries. In a study of homosexual men it was found that voluntary HIV CT services induced a change from high risk to lower risk behaviour (Godfried, 1988). Knowledge of HIV serostatus was found to be an additional motivation for behavioural change to low risk practice (Des Jarlais *et al.*, 1988; Godfried, 1988). But other authors raise questions about the management, costs and effectiveness of voluntary HIV CT services, even in most sophisticated programmes, e.g. the USA (Centers for Disease Control, 1994). A meta-analysis of 35

Address for correspondence: Walter Kipp, Department of Public Health Sciences, 13–103 Clinical Sciences Building, University of Alberta, Edmonton, Alberta, Canada T6G 2G3. Tel: 780 492 8643; Fax: 780 492 0364; E-mail: walter.kipp@ualberta.ca

ISSN 0954-0121 print/ISSN 1360-0451 online/02/050699-08 © Taylor & Francis Ltd
DOI: 10.1080/0954012021000005524

studies from developed countries showed mixed results—some studies revealed some evidence that HIV CT services motivated to reduce high-risk behaviour, while others did not (Wolitsky *et al.*, 1997). In developing countries the role of HIV CT services in a comprehensive HIV/AIDS control programme is even more questionable (Alwano-Edyegu, 1996). Campbell *et al.* (1997) raise serious concerns about HIV testing in developing countries, in regard to the costs for testing and the mixed results of behavioural change for those knowing their serostatus and receiving HIV CT services. Some authors even noted a higher risk for the spread of HIV by those who have learned that they are HIV-positive (Otten *et al.*, 1993).

As facilities for HIV testing are expanding and HIV testing becomes more widely available in developing countries, possible adverse consequences for persons with a positive HIV serostatus are a concern. Also, in countries where human rights are not respected HIV testing is more likely to lead to breaches of confidentiality, discrimination, quarantine and violence (Tomasevski, 1992). For example, a study in Kenya reported increased violence and loss of security for pregnant women who shared information about their positive HIV serostatus with their spouses (Temmermann *et al.*, 1995). Although most women in this study did not share their HIV results with their partners, out of the 19 women who did inform their partners, 11 were replaced with another wife, seven were beaten and one committed suicide. Other studies showed similar adverse effects of HIV CT where HIV-infected persons informed their sexual partners of their serostatus which resulted in blame, physical violence, abandonment and destruction of marriages or personal relationships (Gostin, 1990; Landesman *et al.*, 1990). Protection from discrimination is of particular concern, because those at greatest risk of being HIV infected belong to groups already stigmatized by society, e.g. commercial sex workers and homosexuals. Persons with HIV infection have experienced loss of employment, housing and health insurance and have, on occasion, been refused treatment by health care workers. In contrast with the doubtful benefits of HIV CT services, the social risks to the tested individual are real.

There is literature on technical aspects of HIV CT services in terms of procedures for HIV testing, quality control of HIV testing, cost for a HIV test, cost-effectiveness of HIV CT services, etc. Most of the literature concerns statements of professional views on HIV CT services. Other studies have been carried out in selected populations (e.g. clients of an urban counselling centre). Few studies have examined rural communities' views on HIV counselling and testing or have not elucidated their perceptions, demands and needs for those services. However, this information is required in order to plan HIV CT services for all populations properly and make them acceptable to clients. Design, implementation and evaluation of HIV CT services in developing countries should contain such a component in order to be able to appraise the attitude of health care clients and the public at large towards HIV counselling and testing. Some information on the clients' perceptions of HIV counselling and testing is collected from pregnant women. There is a need for information on how the general population views HIV counselling and testing services and clients' expectations and satisfaction with regard to HIV counselling and testing services (Beardsell *et al.*, 1996). More information on the community and clients' needs in relation to HIV CT services may also clarify the role of HIV CT services within a comprehensive HIV/AIDS control programme. This may provide new arguments for or against the establishment of widely offered HIV CT services.

Study background

We conducted a qualitative study in a rural area of western Uganda, where a majority of the population participated in an HIV CT programme. The aim of this study was to elucidate

views of a rural community on a large scale HIV CT programme and to examine whether this programme was needed and accepted by the community. The HIV testing programme had already been carried out during an earlier study in Kigoyera, a rural parish in western Uganda. This earlier study was part of an ongoing onchocerciasis and HIV surveillance research programme in Kabarole district. The study included the assessment of the HIV serostatus and of the incidence of HIV infection of Kigoyera residents. The purpose of the HIV testing was to recruit study participants with a known HIV serostatus. Out of the total of 3,049 census-registered inhabitants over the age of 15 years in Kigoyera, 2,267 (74%) had participated in the HIV counselling and testing programme (Fischer *et al.*, 1995). The counselling programme consisted of pre-and post-test counselling. One counselling session lasted approximately 30 minutes. Content of the pretest counselling was chosen according to the *Manual of the Ugandan Support Organization for AIDS Patients* (TASO). Clients were informed about the personal implications of the HIV test, about safe sex practices, about other sexually transmitted diseases and about the importance of condom use. Condoms were made available during the pre- and post-test counselling sessions. Prevailing misconceptions about condom use were also explained and correct information given. In the post-test counselling session, a personal risk reduction plan was developed by the counsellor and the client, based on the individual needs of the client. Persons who were found to be HIV infected were referred for further counselling and support to a support group of individuals with HIV/AIDS in the district capital. Ongoing counselling services were not available in Kigoyera Parish during this time. The four counsellors who offered these services were trained by TASO in a four-week course and had to pass an examination at the end of it. All counsellors had substantial working experience in HIV counselling prior to the study. The study presented here was conducted in 1993, one year after the HIV CT programme was executed within the earlier study. The time lag between HIV testing and our response study was approximately one year. Kigoyera is a rural parish within the north-east region of Kabarole district. The educational level of its population is lower than the average in the district.

Methodology

Focus group discussions (FDGs) were conducted in four of the 13 villages in Kigoyera. The selection of these villages was by simple random sampling. From each selected village, six focus groups were assembled roughly based on age categories with the help of village leaders. Only those who had participated in the HIV counselling and testing programme were recruited in the groups. Each group consisted of 8–12 participants assembled with the assistance of the village leaders. A prepared topic guide was used to focus the discussions on the selected objectives. Focus groups were held in the vernacular language and were tape-recorded. All results were translated into English for analysis. Controversial issues were discussed at length in order to arrive at a group consensus. However, dissenting views were not disregarded in the analysis. Male groups were moderated by male interviewers and female groups by female interviewers. One of the two interviewers moderated the discussions while the other one noted any issues to be discussed later or any expressions (facial or otherwise) that were exhibited by the discussants.

The topics for the FDGs were related to areas such as knowledge and awareness of HIV/AIDS, knowledge of HIV transmission, need for HIV testing and counselling and selection and quality of HIV/AIDS counsellors and their confidentiality. Special attention was given to discussions about adolescents and sexual health. Condom use in the community was discussed at length. Reactions and perceptions to the HIV CT programme were discussed

with topics such as reasons for taking an HIV test, reasons why some people did not come back for test results, confidentiality of counsellors, client satisfaction with counsellors, changes in sexual practice after the HIV CT programme, etc.

The research tool was pre-tested in the two neighbouring villages of Kigoyera Parish. We transcribed qualitative data from the tapes into notes. These notes were compiled separately for each focus group according to the list of themes. Inclusion criteria for the study were: 15 years of age or older, being a resident in Kigoyera for at least one year, and having participated in the earlier study described above. The research protocol was approved by both the Ugandan National Council for Research and Technology and by the Ugandan Ministry of Health.

Results

Results were available from 17 FDGs for analysis. The groups were composed as follows: (1) married women above 35 years of age (three groups), (2) married women below 35 years of age (two groups), (3) married men above 35 years of age (four groups), (4) married men below 35 years of age (three groups), (5) unmarried boys (three groups), and (6) unmarried girls (two groups). There were a total of 171 participants.

All the groups confirmed that premarital sexual relations are widely practised and that it also involves married persons having sex with unmarried boys and girls. Dancing places and wedding festivities were associated with pre-marital sex. The reason for pre-marital sexual contacts was given as a consequence of poor economic status. Young girls use sex as a means of achieving what they would otherwise not be able to afford. Some groups linked pre-marital sex to the failure of the parents to pay the dowry price. The youths are then unable to marry and therefore engage in pre-marital sexual relationships. Others were of the view that the parents are not role models to their children. All groups said that extra-marital sexual relationships are widespread. Men were more likely to attribute extra-marital sexual affairs to the consumption of 'waragi' a local brewed liquor.

All the groups had heard of condoms and the people had a local name for them ('obupira'). Most of the participants said that they did not know how to use them. A majority of the discussants felt that condom use was minimal in the area and that the HIV counselling and testing programme did not cause any changes in sexual behaviour and did not increase condom use. Reasons given for low condom use were: condoms are not culturally accepted, most people do not like them, condom use has 'side effects'. Also, HIV testing/counselling sessions were seen by the participants primarily as an opportunity to know their HIV serostatus and not so much as an educative opportunity that could impact behaviour change. (Behaviour change workshops, which had been conducted in the district, were seen as the primary resource for providing information.)

Younger persons had a more positive attitude towards condom use and they believed that condoms protect against HIV/AIDS. Misconceptions of condom use were prevalent in most groups. Others were that condoms can easily break and they reduce the enjoyment of sex. Some of the female participants knew about female condoms and asked for them to be made available to allow women to control condom use themselves. There was a widespread belief, expressed by many, that HIV-positive women could not become pregnant.

Most discussants expressed a need for HIV CT services in the community. Pre-marital HIV testing and counselling was mentioned most often, but also needs for other individuals were recognized. Pregnant women were hardly mentioned as a special group in need of HIV counselling and testing. It was mentioned in some groups that people are not receiving HIV counselling and testing because the nearest HIV testing center is 65 km away. Most partici-

pants said that it should be the right of everybody to have a convenient opportunity to be tested. The younger age groups stressed pre-marital HIV testing more. When asked why, no clear answers were given.

No specific population groups were singled out in the way that they needed HIV counselling and testing more than others. All participants agreed that HIV counselling and testing was useful and needed service in the community. Reasons given as to why HIV CT is useful were: better knowledge about HIV/AIDS, better understanding of HIV/AIDS in the community, less stigmatization of persons with HIV/AIDS. Concerns about HIV counselling and testing were also raised. Some discussants were worried that those persons found to be HIV infected would go on a 'rampage' and therefore further spread HIV/AIDS. A few participants believed that HIV-infected persons are given intentionally negative results by the counsellors so as to avoid bad consequences such as committing suicide or deliberately spreading HIV/AIDS. Some participants mentioned the need for HIV counselling without necessarily taking a HIV test.

All groups stressed that HIV counselling and testing should be provided by counsellors with the required skills, including passing an examination. Most groups were of the opinion that counsellors should be non-residents of the area. Non-residents were considered more credible and would offer greater confidentiality than residents. The issue of parents counselling their children was not supported, as most older participants thought that adolescents do not listen to their parents. One group suggested that counsellors should be HIV-positive persons in order to give more authentic information to them. Regarding venue, most participants felt that counseling and testing should take place at a neutral site where confidentiality can be assured, e.g. having private rooms. A community centre was considered to be suitable. Churches, homes, trading centers and schools were only suggested by a few. Most participants said that the preferred providers of counselling services were community health workers, followed by religious leaders, village leaders, teachers and others.

Many participants expressed satisfaction with the way HIV counselling and testing services were provided. The high quality of HIV CT services was seen by them as one reason why participation in this programme was so high. However, it became clear that most discussants wanted continued provision of HIV CT services, rather than a programme which is only available once. It was mentioned that HIV CT services should be available at least on two to three occasions per month. During the discussions it became evident that inhabitants from neighbouring areas who were not eligible, tried desperately to get enrolled in the earlier study in order to have an opportunity for HIV counselling and testing. Most participants believed that HIV test results should be given by the counsellor to the client confidentially. A few people felt that the public should be informed of the HIV test results in order to warn people that they should not engage in sexual contact. In some groups it was suggested as a compromise that the community should only be informed about the magnitude of the HIV problem in the area, i.e. how many persons are HIV infected in one particular community and no names should be given to anybody except the client by the counsellors. Most participants thought that the counsellors did not reveal any information about HIV status to others and kept the personal information they received during the counselling sessions confidential.

Most people thought that those who were participating in the HIV counselling and testing programme were genuinely interested in the HIV test results and returned to post-test counselling sessions. The following constraints for those who did not come back for the post-test counselling sessions were mentioned: did not know the time when the post-test counselling took place, feared a positive test result, was away during time post-test counselling was given, had no time.

Many participants felt that one HIV testing and counselling session was not enough to change sexual behaviour towards safe sex methods and did not meet their needs. They stated that they did not believe that a change in sexual behaviour had taken place in the previous year. This was also clearly related to condom use in the area: it was apparent from all discussions that condom use was considered very low and that participants thought that there had been no increase in condom use after HIV counselling and testing was received.

Discussion

We examined the response of rural communities in an area in western Uganda to a large-scale voluntary HIV CT programme. Out of a total of 3,049 persons over the age of 15 years in the parish, 2,267 had participated in an HIV CT programme that consisted of an HIV test and one session of pre-and post-test counselling. The sample in our study consisted of 171 persons who took part in the 17 focus group discussions in randomly selected villages. As the four villages were well distributed in the parish and all the tribes were represented, we feel confident that the results of the FDGs are representative of Kigoyera Parish.

In Kigoyera Parish the acceptance of HIV CT services was high, as shown by the participation of 74% of the population over the age of 15 years in this programme. The client satisfaction rate with the HIV testing and counselling programme was also high, with most of the participants reporting that they were satisfied with the way testing and counselling was offered. Most participants expressed the need for HIV testing at the village level, as opposed to travelling 65 km to the district capital for HIV testing. They considered HIV counselling and testing to be a valuable and essential component of their health care delivery. This is similar to findings from a study in several developing countries in sub-Saharan Africa (Abidjan, Kenya, Tanzania, Malawi, Zambia and Zimbabwe), where HIV testing and counselling was found to be highly acceptable to pregnant women (Cartoux *et al.*, 1998). The same authors found in Ivory Coast and in Burkina Faso that HIV counselling and testing was not well accepted by pregnant women (Cartoux *et al.*, 1998).

Our study clearly shows that there is a high demand for HIV CT services in communities. Furthermore, people from neighbouring areas were reported to have desperately tried to enroll in the HIV counselling and testing services, without success. The demand for continuous HIV CT services shows that these services are not only considered an opportunity for HIV testing, but also as a reliable source of information on sexual matters, even though behaviour change was minimal. Thus, HIV testing and HIV counselling could be 'delinked'. By separating these two services, each would be more appropriately accessed by those who want to receive counselling but who do not want to be HIV tested. We have some indications from informal talks during the study that people believed that if they went for HIV counselling they had to take the HIV test. The option of receiving HIV counselling without HIV testing was new to them. If delinked, determining where these services would be located, especially the HIV testing services, would need to consider the trade-offs between accessibility and affordability. The strong demand for HIV testing close to the participants' homes cannot be overlooked. Also in accordance with the principles of primary health care, it is important to locate HIV testing services closer to the people. Since testing services are more costly to provide than counselling services, making HIV testing services more accessible at the periphery will require solid planning, e.g. people could be required to pay for HIV tests, as user fees are part of the health-financing system of the district where people are already accustomed to paying for services. However, deterrents to using services must be avoided.

Another important finding from the Kigoyera experience is that HIV counsellors were seen to respect individual's confidentiality and did not release HIV-related information

to others. No case was reported where participation in the HIV CT programme had adverse social effects on an individual participant. However, study participants clearly indicated that due to the sensitivity of the issues involved, HIV counsellors should not reside in the area where they work. This suggested approach is contrary to the usual practice, where community-based counsellors are selected by the community and are living and working within the same community. We suggest that an alternative way to enhance client confidentiality would be to more strictly enforce staff responsibilities in dealing with client confidentiality. This could include: (1) introduction of processes where all staff with access to client information sign a confidentiality form and take an oath of confidentiality when they start the job, (2) development of staff policies which provide clear guidelines on confidentiality of client information, (3) initiation of disciplinary measures for staff who have breached client confidentiality, i.e. warnings, loss of employment, etc., and (4) initiation of supervision responsibilities to enforce client confidentiality during regular supervision visits which already occur.

The dangerous belief that HIV-infected women cannot become pregnant was widespread in most groups of both men and women. The finding in another study in this area that out of seven HIV-infected female participants, five became pregnant within one year after learning that they were HIV-positive is of concern and shows that there is possibly a large gap of knowledge in many communities about issues surrounding maternity and HIV infection (Kipp *et al.*, 2001). This would indicate an urgent need to emphasize this issue in the counselling sessions, as well as to provide more public education.

Conclusions

We conclude that there is a high need and demand for HIV CT services, as expressed by most study participants. This needs to be acknowledged and to be considered despite the fact that the effectiveness of widely offered HIV counselling and testing services (as measured by sexual behaviour change) are not proven and may be questionable. The decision-making process regarding if and what kind of HIV CT services are required has to be made a local one, balancing professional judgements (about the effectiveness and costs of HIV CT services and the level of HIV infection in the area) with the community's demands and perceived needs. For Kabarole district we believe that a one-time community-wide HIV CT service is not warranted. An alternative might be to develop a service model that provides counselling services without HIV testing and at the same time increases access to HIV testing in peripheral areas. We advocate the establishment of small counselling centres attached to all district health facilities (i.e. community level), where services are continuously available from trained community volunteers who are regularly supervised by professionals and where client confidentiality is vigorously enforced. HIV testing could be more decentralized if made available at the county or sub-county level, depending on the financial resources provided.

Acknowledgement

We would like to thank the Ministry of Health in Uganda for its support in this work and permission for publication. We are indebted to members of the Kabarole District Health Management Team, who gave advice during the conduct of the study and who provided valuable information for the study team. We thank Jean Kipp for critical comments on the first draft of the manuscript. Steven Moses gave valuable comments during the design and implementation of the study. The study was supported by the Federal Republic of Germany through the project PN 87.2591.3 (Basic Health Services, western Uganda).

References

ALWANO-EDYEGU, M., GUMISIZIRA, E., CAMPBELL, C., MOORE, M., MARUM, E., KALIBALA, S., KALEEBA, N. & MCFARLAND, D. (1996). The negative argument—HIV counselling and testing: resolved that government and public resources for HIV prevention in the developing world should not be directed toward the provision of HIV counselling and testing services. Plenary Debate at the Eleventh International Conference on AIDS, Vancouver, British Columbia.

BEARDSELL, S. & COYLE, A. (1996). A review of research on the nature and quality of HIV testing services: a proposal for process-based studies. *Social Science and Medicine*, *42*, 733–743.

CAMPBELL, C., MARUM, M., ALWANO-EDYEGU, M., DILLON, B., MOORE, M. & GUMISIZIRA, E. (1997). The role of HIV counselling and testing in developing countries. *AIDS Education & Prevention*, *9*(Suppl. 3), 92–104.

CARTOUX, M., MEDA, N., VAN DE PERRE, P., NEWELL, M., DE VINCENZI, I. & DABIS, F. (1998). Acceptability of voluntary HIV counselling and testing (VCT) by pregnant women in developing countries: an international survey. Ghent International Working Group on Mother-to-Child Transmission of HIV. *AIDS*, *12*, 2489–2493.

CENTERS FOR DISEASE CONTROL (1994). External review of CDC's HIV prevention strategies by the CDC Advisory Committee on the Prevention of HIV infection. Atlanta: CDC.

DES JARLAIS, D. & FRIEDMANN, S. (1988). The psychology of preventing AIDS among intravenous drug abusers: a social learning conceptualization. *American Journal of Psychology*, *43*, 865–870.

FISCHER, P., KIPP, W., KABWA, P. & BUETTNER, D. (1995). Onchocerciasis and Human Immunodeficiency Virus in western Uganda: prevalences and treatment with ivermectin. *American Journal of Tropical Medicine & Hygiene*, *53*, 171–178.

GODFRIED, J., VAN GRIESEN, M. & ERNEST, M. (1988). Impact of HIV antibody testing on changes of sexual behavior among homosexual men in the Netherlands. *American Journal of Public Health*, *78*,1575–1577.

GOSTIN, L. (1990). The AIDS litigation project: a national review of courts and human rights commission decision. Part two. Discrimination. *Journal of the American Medical Association*, *263*, 2086–2093.

KIPP, W., KABAGAMBE, G. & KONDE-LULE, J. (2001). Low impact of a community-wide HIV counselling and testing program on sexual behavior in rural Uganda. *AIDS Education & Prevention*, *13*(3), 297–307.

LANDESMAN, S. & DEHOVITZ, J.A. (1990). HIV diagnostic testing: ethical, legal, and clinical considerations. *Sexually Transmitted Diseases*, *81*, 975–983.

OTTEN, M., ZAIDI, A., WROTEN, J., WITTE, J. & PETERMAN, T. (1993). Changes in sexually transmitted diseases rates after HIV testing and posttest counselling. *American Journal of Public Health*, *83*, 529–533.

TEMMERMANN, M., NDINYA-ACHOLA, J., AMBANI, J. & PIOT, P. (1994). The right to know HIV test results. *Lancet*, *345*, 969–970.

TOMASEVSKI, K. (1992). AIDS and human rights. In: J. MANN, D. TARANTOLLA & T. LETTER (Eds), A global report on AIDS in the world (pp. 537–573). Cambridge, MA: Harvard University Press.

WOLITZKY, R., MACGOWAN, R., HIGGINS, D. & JORGENSEN, M. (1997). The effect of HIV counselling and testing on risk-related practices and help seeking behavior. *AIDS Education & Prevention*, *9*(Suppl. B), 52–67.