

Medical Ethics

Confidentiality, partner notification and HIV infection: Issues related to community health programmes

S. ABRAHAM, J. PRASAD, A. JOSEPH, K. S. JACOB

INTRODUCTION

The ethical issues relating to confidentiality and partner notification, within the context of human immunodeficiency virus (HIV) infection, are complex. The right of the individual to confidentiality can be in conflict with the right of the partner to be protected from the risk of infection.

We briefly describe a few clinical situations faced by the public health staff of the Department of Community Health, Christian Medical College, Vellore, Tamil Nadu, India and discuss the ethical issues related to confidentiality and partner notification. It documents problems relevant to India and to comprehensive community health programmes which have close links with the community.

THE CHAD PROGRAMME

The Community Health and Development (CHAD) programme is run by the Department of Community Health. The Department has worked in Kaniyambadi block for over 40 years. It serves a population of about 100 000. This programme, in conjunction with other governmental agencies, is responsible for health care. The programme has four major components: health care, animal husbandry and agriculture, adult and non-formal education and community development.

The frontline of CHAD's health care structure is the part-time community health worker (PTCHW). The PTCHW is supported by the community health team (comprising a doctor, nurse, community extension worker and health aide), which visits every village once in two weeks. Cases requiring greater medical input are referred to the base hospital. Morbidity and mortality data, birth and death statistics are reported to the base hospital. The computerized health information system maintained at CHAD, which includes census data, is updated every month based on the information provided.

The programme has set up two community-based organizations for socio-economic development of the region, namely:

1. Self Help Association for Rural Education and Employment (SHARE)
2. Community Development Society (CODES)

The CHAD programme started SHARE in 1989 as an organization to employ local women in different economic schemes (such as handicrafts, tailoring, weaving, poultry farming) and to educate the population through women's groups, youth

groups, and adult and non-formal education programmes. The association also runs *balwadis* (creches). Since the inception of CHAD, the local population has been a part of the decision-making process in the association. The association was handed over to the local population after the initial few years and is now functioning as an independent society. The CODES project is also a community-based organization started by the CHAD programme. It is involved in various economic activities for the benefit of the local population. It runs different projects including a steel fabrication unit, an automobile repair workshop, a transport service and livestock development. The majority of the members of this society are from the local population and control the decision-making process.

As the CHAD programme has close links with the community who are part of many decision-making processes, it is accountable and has to be responsive to the needs of the community. The issues faced by the programme in relation to HIV infection have to be seen in this context.

CLINICAL SITUATIONS

The following vignettes are examples of clinical situations faced by the programme:

Case 1

Ms A, a 30-year-old married housewife was admitted to the base hospital with a diagnosis of AIDS. Her husband, Mr B, was also tested and found to be positive for HIV infection. She died within a few weeks. Mr B, a soldier in the Army, married his wife's sister (Ms C) after a period of six months. Ms C was also from the local area. Although the staff of the Department of Community Health knew the diagnosis they did not interfere, as it would compromise Mr B's confidentiality. Two years later, Ms C came to the CHAD hospital with a letter from a military hospital stating that her husband, Mr B was diagnosed to be in the terminal stage of AIDS. Ms C also tested positive for HIV.

Case 2

Ms E, a 21-year-old primigravida, came to the base hospital in labour. She had an emergency caesarean section for foetal distress and developed a severe puerperal infection. She tested positive for HIV infection. A week prior to her delivery, her husband (Mr F) had died of a chronic diarrhoea and debilitating illness. He had visited the base hospital before his marriage to Ms E, for a chronic diarrhoeal illness and had tested positive for HIV infection at that time. Mr F and his parents were counselled about the illness and its implications. However, Mr F stopped visiting the hospital and got married, as his parents felt that marriage may cure his illness.

Christian Medical College, Vellore 632002, Tamil Nadu, India

S. ABRAHAM, J. PRASAD, A. JOSEPH

Department of Community Health

K. S. JACOB Department of Psychiatry

Correspondence to S. ABRAHAM sulo@chrd.cmc.ernet.in

Case 3

Ms K was referred to the high-risk antenatal clinic during her second pregnancy, as her first child had mental retardation and features suggestive of congenital syphilis. Ms K and her husband, Mr L, tested positive for syphilis and HIV infection. They were treated for syphilis and counselled regarding HIV infection. Ms K delivered an apparently normal child. However, the child developed severe septicaemia and died two weeks after birth. Ms K was asked by her husband to leave his home and sent back to her parental home. She mentioned that her husband, a long distance truck driver, was planning to marry a second time and provided the address of the bride. She wanted the hospital staff to help her prevent the marriage, as she knew the implications of the disease.

Case 4

Ms P had a tubectomy at the base hospital after a normal delivery at home. The neonate developed a swelling of the knee joint and tested positive for syphilis. Ms P and her husband (Mr Q) were tested for HIV infection and found to be positive. Mr Q admitted that he had another sexual partner, Ms R, a married woman. Ms R also tested positive for HIV infection. Her husband, Mr S, was not aware of his wife's extramarital relationship. However, Ms R refused to mention her HIV status to her husband, continued to have sexual relations with both the partners and refused to use condoms. All the four individuals were from the local area and were known to the staff of the Department of Community Health. The hospital staff found it difficult to take up the issue with Mr S, as it would violate the confidentiality agreement with Ms R.

Case 5

Mr X, a 22-year-old bachelor, was admitted to the hospital with septicaemia. He was tested for HIV and found to be positive. He was engaged to be married. Mr X and his parents were counselled about the nature of the illness and advised to postpone his marriage. Despite detailed discussion on the issues, the family was not keen to change its plans. The public health staff knew the prospective bride, who lived within the area and spoke to her parents and advised them to enquire about the nature of Mr X's illness before proceeding with her marriage. The family approached Mr X and enquired about his illness. They subsequently broke the engagement.

The public health staff have a responsibility not only to those with HIV infection but also to all residents of the block which they serve. Within this context, the patient's right to confidentiality is in conflict with the partner's right to protection from the risk of infection.

CONFIDENTIALITY

Confidentiality relating to HIV infection continues to be a primary concern of individuals with the disease, as well as to programmes and institutions that provide them with services.^{1,2} Many programmes have some form of confidentiality policy. The reason for such a policy, specifically relating to HIV, is the concern about the potential consequences of unwarranted disclosure—discrimination. Discrimination against people with certain medical conditions, impairment and disability is not a new phenomenon, but HIV infection has generated a significant amount of misinformation, fear and prejudice—the foundations of discrimination. Efforts to maintain confidentiality in order to

prevent discrimination have formed the cornerstone of the public health strategy to control the spread of the disease.

Respecting a person's right to privacy—the right to decide who receives personal information and how it may be used—requires that those privileged to have access to such information maintain its confidentiality. Confidentiality, rooted in the right to privacy, is a matter of personal autonomy. Since most public health strategies for dealing with HIV infection are based on individuals coming forward voluntarily for testing, counselling and treatment, failure to maintain confidentiality could threaten the continued cooperation of persons with HIV infection. Many public health and other authorities have argued that protection of the public's health was not compromised by the protection of confidentiality. On the contrary, the protection of confidentiality was a precondition for achieving public health goals.

PARTNER NOTIFICATION

The seriousness of the threat to the health of unsuspecting third parties resulted in the debate on informing people at risk,^{3,4} also called 'partner notification'. Two different approaches to informing third parties have been debated: (i) tracing of contacts, and (ii) duty to warn.

Tracing of contacts

The first approach involved the tracing of contacts and emerged from the sexually transmitted disease (STD) programmes.³ The approach was based on (i) the voluntary cooperation of the patient in providing the names of contacts, (ii) never disclosing the identity of the index patient (although these could be deduced in some cases), and (iii) the protection of absolute confidentiality through the entire process of notification. The patient maintained ultimate control over the process, retaining the ability to provide or withhold names of contacts. The fear of discrimination, especially against homosexual men in whom HIV infection first appeared in the USA, led to the opposition of this approach. The fact that no therapy was offered (at the onset of the epidemic) for HIV infection made it radically different from the role of contact tracing in other STDs. The proponents of contact tracing argued that attempting to change high-risk behaviour was reason enough to pursue contact tracing. Its opponents claimed that it was an intrusion of privacy without any compensatory benefits.

Some states in the USA legalized partner notification—making a voluntary act mandatory.^{3,5} However, the record of programmes which have emphasized contact tracing is very variable, with many showing poor results in tracing contacts. Nonetheless, the current emphasis is still on patient rather than provider notification. With the advent of treatment for HIV infection, the debate in the West related to contact tracing has shifted from privacy to efficacy of the available treatment.

Duty to warn

The second approach involved the moral 'duty to warn'.³ This approach came out of the clinical setting where the physician knew the identity of the person deemed to be at risk. It argued for disclosure to endangered persons without consent of the patient. It could also involve revealing the patient's identity.

The Tarasoff ruling in the USA in 1974⁶ formed the basis of partner notification. In this case, Prosenjit Poddar, a student and a voluntary outpatient at a mental health clinic at the University of California, told his therapist about his intention

to kill a girl readily identifiable as Tatiana Tarasoff. Realizing the seriousness of his intention, the therapist concluded that Poddar should be detained for observation. The therapist also notified the campus police. Concerned about the breach of confidentiality, the therapist's supervisor vetoed the recommendation and ordered that all records relating to Poddar's treatment be destroyed. At the same time, the police temporarily detained Poddar and released him on his assurance that he would 'stay away from the girl'. Poddar stopped going to the clinic after he learned from the police about his therapist's recommendation to detain him. Two months later, he carried out his previously announced threat to kill Tatiana. The girl's parents then brought a suit of negligence against the university. The ruling challenged the professional discretion of physicians when faced with patients who might endanger third parties. The court held that the physician/therapist could be held liable for failing to take adequate steps to protect a known intended victim of his/her patient, who in this case had threatened to murder his former girlfriend. With Tarasoff, a matter of professional discretion became a legal obligation. The basis of the decision was the ethical judgment that although confidentiality was crucial for individual patient autonomy, the protection of third parties vulnerable to potential serious harm must be given priority.

The Tarasoff doctrine formed the context within which ethical issues related to the breach of confidentiality were judged.³ The argument that the objective of medical confidentiality is perverted, if it is used to facilitate the intentional transmission of disease, gained acceptance. It was deemed ethically permissible for the physician to notify the person whom the physician believed was endangered. Many States in the USA legislated that physicians are legally obliged to notify subjects who are at risk of infecting third parties. However, civil liberty groups opposed such disclosure by physicians, without proper guidelines on which to base their decision. The result of the compromise between the opposing points of view was the policy of the 'privilege to disclose'. For clinicians, it offered the freedom to make complex ethical judgments without legal obligation. Further refinements to this policy included the criteria for disclosure. The criteria suggested were:³ (i) the physician reasonably believes that notification is medically appropriate and that there is a significant risk of infection; (ii) the patient has been counselled regarding the need to notify partners; (iii) the physician has reason to believe that the patient will not notify his/her partners; and (iv) the patient has been informed of the physician's intent to notify partners and has been given the opportunity to express a preference as to whether the partners should be notified by the physician directly or by a public health officer. Patient confidentiality continues to be a central issue, even in those subjects in whom the 'duty to warn' tradition has been invoked.

Persons unknowingly placed at risk, from an ethical perspective of a clinical relationship, have a moral right to information in order to protect them, seek testing and commence treatment, if necessary. Neither the principle of confidentiality nor the value attached to professional autonomy is absolute. Early identification of HIV infection in asymptomatic individuals has become increasingly beneficial with the availability of antiviral therapy and prophylactic antimicrobial agents.

The issues related to partner notification have been examined in detail.⁷ The effectiveness of partner notification can be summarized as: (i) many, if not most, HIV-infected individuals

will cooperate in notifying at least some of their sexual partners of exposure to HIV; (ii) sexual partners are generally receptive to being notified and will seek HIV testing; (iii) patient referral is probably not as effective as provider referral in reaching sexual partners; (iv) sexual partners are often unaware of or misunderstand their HIV risks; and (v) sexual partners frequently have high rates of HIV infection. However, the record of programmes is variable, with many programmes showing poor results at tracing contacts and notifying partners.⁸⁻¹⁰

ISSUES SPECIFIC TO INDIA AND THE DEVELOPING WORLD

Poverty and illiteracy in the developing world complicate issues related to HIV infection. The case for partner notification becomes more important with the infection shifting to populations with low awareness and limited capacity to act. The poor, uneducated and unemployed require special consideration, and partner notification may be especially important among these groups.

The limitation of resources in developing countries makes partner notification difficult. The labour-intensive nature of contact tracing makes it an expensive option and raises many questions related to policy. What proportion of the efforts at prevention should be devoted towards contact tracing? Should the limited resources be focused on educational and other efforts at limiting the spread of infection? However, regional variations prevent the formulation of a universal strategy.

Lack of antiviral and other therapy available to individuals with HIV infection in the developing world does not allow for treatment of subjects with infection. The tracing of contacts will benefit partners who are not infected. Partners who are infected and asymptomatic will not be able to use the various treatment options due to the high cost of therapy.

The National AIDS Control Organization's guidelines for HIV counselling suggest that there may be situations where partner notification is permissible. However, it does not discuss the issues nor does it offer specific criteria for disclosure.¹¹

The Supreme Court of India has ruled on the issue of the right to confidentiality of subjects with HIV infection and the breach of confidentiality in order to protect the health of third parties.¹² The opinion of the court was that the right to privacy and confidentiality is not absolute. This right may be lawfully restricted in situations where third parties are at risk. The judgment went on to state that persons with HIV infection, who knowingly expose others to health risk, are guilty of an offence and punishable under the law. The court ruling maintained that HIV-infected subjects did not have the right to marry.

Non-governmental organizations (NGOs) and human rights activists have pointed out that the law should look at the larger issues arising from it.¹³ They have argued that the right to marry is constitutive of one's right to life and that this right cannot be qualified on the basis of the health status of the person. Consequently, the denial of the right to marry to those who may be HIV positive is morally unsustainable. The Supreme Court ruling questions the legal status of marriages where informed, free and willing consent of partners forms the basis of union with HIV-positive persons. These issues have been raised in a Public Interest Litigation now before the Court.

ISSUES RELATED TO COMMUNITY HEALTH PROGRAMMES

Clinicians often do not have knowledge of the patient's back-

ground and family relationships. To obtain names of contacts, they need the voluntary cooperation of the patient. However, the situation in comprehensive community health programmes, which are closely linked to small population groups with a detailed knowledge of the local people, is very different. The public health staff of such programmes are aware of the subject's usual contacts (e.g. spouse). Such programmes are not only accountable to those with HIV infection but also to those partners who may not have been infected. Withholding information, which has a direct bearing on the health of the partner, is ethically indefensible. Maintaining confidentiality may be useful in obtaining the continued cooperation of people with HIV infection. However, the absence of partner notification within such programmes can antagonize the general population. Such programmes will have to tread a fine line in order to keep the interests of those with the infection and their partners in mind.

The CHAD programme diagnosed and managed 43 subjects with HIV infection since the onset of the epidemic. The initial response of the programme was to maintain absolute confidentiality about a person's HIV status. The focus was on a community education programme in order to increase the awareness of HIV/AIDS among the population, its mode of transmission and the methods of protection. With the increase in the number of persons with HIV infection in the area, there was a realization that the ethical issues were complex. The failure to warn persons at risk, known to the public health staff of the programme, was also ethically indefensible. It was also felt that not warning unsuspecting third parties would jeopardize the relationship the programme has with the general population.

The CHAD programme has since adopted the following guidelines for partner notification:

1. The physician reasonably believes that notification is medically appropriate and that there is a significant risk of infection.
2. The patient has been counselled regarding the need to notify partners.
3. The physician has reason to believe that the patient will not notify the partner(s).
4. The patient has been informed of the physician's intent to notify partner(s).
5. Partner notification will not involve disclosure of the identity of the index patient (although these may be deduced in some cases).

The programme has been notifying partners at risk for contracting the infection. Care is taken to minimize the risk of discrimination of people with HIV infection. The CHAD programme runs a regular AIDS awareness programme and covers all the villages in the Block once a year. Education is imparted using traditional forms of folk drama and ballads, which are part of village life (e.g. *Kathakalatchepam*). AIDS awareness is also part of the health education package at the village antenatal clinics, which the programme runs in all villages every month. Subjects with HIV and AIDS are not refused treatment because of their infection, either at the village clinics or at the base hospital. In fact, subjects with the infection who have medical and social problems have a fast-track access to the medical and counselling staff of the programme. The health aide, responsible for the village where the subject resides, visits all HIV-infected subjects in her jurisdiction and their families at home every month. She provides education and psychological

support for subjects and their families. When the emotional distress is significant and conflicts arise within families (usually related to lack of or misinformation about the spread of infection), senior counsellors or senior doctors visit the subjects at home to sort out issues, educate and provide emotional support. Those with persistent and clinically significant distress are referred to and seen by the staff of the Family Counselling Centre which is run by the CODES project of the programme. The CHAD programme also has a mental health initiative. Subjects with clinical depression are evaluated by a psychiatrist and prescribed appropriate antidepressant medication.

To date, all subjects with HIV infection/AIDS in the Block have continued to live with their families at home with no serious problems having arisen either within the family or local community. The frequent follow up of subjects with HIV infection by the programme staff and the policy of confidentiality (where the information on the subject's HIV status is shared only with a limited number of staff on a need-to-know basis) has helped in preventing social isolation and discrimination of subjects and their families. The initial experience with the policy and procedures related to confidentiality and partner notification suggests that the programme has been able to tread the fine line regarding the interest of persons with HIV and their partners. The issue of marriage among HIV-positive adults or marriage after consent when one partner is infected has not yet arisen in the local community.

CONCLUSION

As increasing numbers of HIV-infected persons come under the care of clinicians and community programmes, the question of breach of confidentiality in warning unsuspecting partners will be faced repeatedly in medical practice. Research and clinical experience suggests that many individuals who know that they are infected fail to inform their sexual partners of the fact. Clinicians will be increasingly called upon to notify partners. Policy-makers will have to decide whether this process of notification should be discretionary, as it is under the present circumstances, or be made mandatory. The moral claim of persons who have been placed at risk entails the correlative moral duty of clinicians to ensure that unsuspecting partners are informed. Comprehensive community health programmes will have to develop policies for confidentiality and partner notification related to HIV infection.

ACKNOWLEDGEMENTS

The authors would like to acknowledge the work done by the staff of the CHAD programme: community workers, health aides, community nurses, social workers, counsellors, laboratory staff and doctors. They would also like to thank the subjects with HIV for their cooperation.

REFERENCES

- 1 Rennett S. *AIDS/HIV and confidentiality: Model policy and procedures*. Washington: American Bar Association, 1991.
- 2 World Health Organization. *Prevention of sexual transmission of Human Immunodeficiency Virus. WHO AIDS series No. 6*. Geneva: World Health Organization, 1990.
- 3 Bayer R, Toomey KE. HIV prevention and the two faces of partner notification. *Am J Public Health* 1992;**82**:1158-64.
- 4 Fenton KA, Chippindale S, Cowan FM. Partner notification techniques. *Dermatol Clin* 1998;**16**:669-72.
- 5 Osmond DH, Bindman AB, Vranizan K, Lehman JS, Hecht FM, Keane D, et al. Name-based surveillance and public health interventions for persons with HIV infection. Multistate Evaluation of Surveillance for HIV Study Group. *Ann Intern Med* 1999;**131**:775-9.
- 6 Gutheil TG. Legal issues in psychiatry. In: Kaplan HI, Sadock BJ (eds).

- Comprehensive textbook of psychiatry*. Baltimore:Williams & Wilkins, 1996: 2747-66.
- 7 West GR, Stark KA. Partner notification for HIV prevention: A critical reexamination. *AIDS Educ Prev* 1997;**9** (3 Suppl):68-78.
 - 8 Dye TD, Knox KL, Novick LF. Tracking sexual contacts of HIV patients: A study of physician practices. *J Public Health Manag Pract* 1999;**5**:19-22.
 - 9 Seubert DE, Thompson IM, Gonik B. Partner notification of sexually transmitted disease in an obstetric and gynecologic setting. *Obstet Gynecol* 1999;**94**: 399-402.
 - 10 Niccolai LM, Dorst D, Myers L, Kissinger PJ. Disclosure of HIV status to sexual partners:Predictors and temporal patterns. *Sex Transm Dis* 1999;**26**:281-5.
 - 11 National AIDS Control Organization. *HIV/AIDS/STD counselling training manual*. New Delhi:Ministry of Health and Family Welfare, 1994.
 - 12 AIR 1999 Supreme Court 495. S. Saghir Ahmed and B. N. Kripal, JJ. Civil Appeal No. 4641 of 1998, D/-21.9.1998.
 - 13 Anonymous. Rights of AIDS patients. *The Hindu* 5 Jan 2000.

Attention Subscribers

The subscriptions for *The National Medical Journal of India* are being serviced from the following address:

The Subscription Department
The National Medical Journal of India
 All India Institute of Medical Sciences
 Ansari Nagar, New Delhi 110029

The subscription rates of the journal are as follows:

	One year	Two years	Three years
Indian	Rs 500	Rs 900	Rs 1300
Overseas	\$80	\$140	\$200

Personal subscriptions paid from personal funds are available at 50% discounted rates.

Please send all renewals and new subscriptions along with the payment to the above address. Cheques/Demand Draft should be made payable to **The National Medical Journal of India**. Please add Rs 20 for outstation cheques.

If you wish to receive the Journal by registered post, please add Rs 60 per annum to the total payment and make the request at the time of subscribing.