

Confidentiality, partner notification and HIV infection

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The ethical issues relating to confidentiality and partner notification, within the context of Human Immunodeficiency Virus (HIV) infection, are complex. The individual's right to confidentiality can be in conflict with the partner's right to be protected from medical risk. This paper describes some situations faced by the staff of the Department of Community Health, Christian Medical College, Vellore. It discusses ethical issues related to confidentiality and partner notification, and documents problems relevant to India and to comprehensive community health programmes with close links to the community.

The CHAD programme

The primary health care programmes of CMC, Vellore, serve three administrative blocks in Vellore district, Tamil Nadu and the population of Vellore town. The Community Health and Development (CHAD) Programme serves one of these blocks, Kaniyambadi, reaching a population of 106,010, a significant proportion of which is from the lower socio-economic strata. The programme, run by the department of community health (which has worked in Kaniyambadi Block for over 40 years) is responsible for health care in the area in conjunction with governmental agencies.

The front line of CHAD's health care structure is the part-time community health worker supported by a community health team which visits every village fortnightly. Cases requiring greater medical input are referred to the base hospital. CHAD has close links with the community, and it must be responsive to the community's needs. The issues faced by the programme in relation to HIV infection have to be seen in this context.

Clinical situations

Ms. A, a 30-year-old housewife, was admitted to the hospital with a diagnosis of AIDS. Her husband, Mr. B, was also tested and found to be positive for HIV. She died within a few weeks. Six months later, Mr. B married his wife's sister, Ms. C, also from the area. Although the community health staff 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 another hospital stating that her husband, Mr. B, was diagnosed to be in the terminal stage of AIDS. She also tested positive for HIV.

Ms. K was referred to the high-risk antenatal clinic as her first child had mental retardation with 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 the 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. Later she mentioned that her husband was planning to marry a second time and provided the bride's address. She wanted the hospital staff to help her prevent the marriage, as she knew the implications of the disease.

Ms. P had a tubectomy at the hospital after a normal home delivery. 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 were 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. Her husband, Mr. S, was not aware of his wife's extra-marital relationship. However, Ms. R refused to mention her HIV status to her husband, continued to have sexual relationships with both partners and refused to use condoms. All four were from the area and known to the community health staff. The hospital staff found it difficult to take up the issue with Mr. S, as it would violate the confidentiality agreement with Ms R.

Mr. X, a 22-year-old male, was admitted to the hospital with septicaemia, tested and found positive for HIV. He was engaged to be married.. He and his parents were counselled about the nature of the illness and advised to postpone his marriage. Despite detailed discussion the family was not keen to change their plans. The public health staff knew the girl and advised her parents to inquire about the nature of Mr. X's illness before proceeding with her marriage. The family approached Mr. X, asked about his illness and went on to break the engagement.

Public health staff have a responsibility not only to those with HIV but also to all residents of the area they serve. In this context, the patient's right to confidentiality (when they refuse to discuss the HIV status with their partners) is in conflict with rights of their partners to protection from medical risk.

Confidentiality

Confidentiality as it relates to HIV 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 a confidentiality policy specifically relating to HIV, because of the potential consequences of unwarranted disclosure. HIV infection has generated significant misinformation, fear and prejudice, the foundations of discrimination. Efforts to maintain confidentiality to prevent discrimination have formed the cornerstone of 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 with 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 are based on individuals coming forward voluntarily for testing, counselling and treatment, failure to maintain

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confidentiality could threaten the continued cooperation of people with HIV. Many public health authorities have argued that the 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), called 'partner notification'. Two approaches to informing third parties have been debated: contact tracing and the duty to warn.

Contact tracing

The contact tracing approach emerged from sexually transmitted disease programmes (3). Based on the patient's voluntary cooperation in providing the names of contacts, this never involved the disclosure of the identity of the index patient (although these could be deduced in some cases) and entailed protecting the absolute confidentiality of the entire notification process. The patient maintained ultimate control over the process, and could provide or withhold names of contacts. The fear of discrimination led to opposition to this approach for HIV. The fact that no therapy was being 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 behavior was reason enough to pursue contact tracing. Its opponents claimed that it was an intrusion of privacy without any compensatory benefits.

The record of programmes using contact tracing is variable. However, the current emphasis is still on notification by the patient rather than the provider. With the advent of treatment for HIV, the debate in the West on contact tracing has shifted from privacy to efficacy of 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 the revelation of the patient's identity.

The *Tarasoff* ruling in the US in 1974 (6) formed the basis of partner notification. The ruling challenged the professional discretion of physicians 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 the disease gained acceptance. It was deemed ethically permissible for physicians to notify people whom they believed were endangered. Many US states legislated that physicians were legally obliged to notify subjects at risk of infecting third parties. However, civil liberty groups opposed such disclosure by physicians without guidelines on which to base the decision. 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 the legal obligation. The criteria suggested for disclosure 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 the patient will not notify 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 themselves, 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.

Issues related to partner notification have been examined in detail (7). The effectiveness of partner notification can be summarised as: (i) many, if not most, HIV-infected individuals will cooperate in notifying at least some of their sex partners of exposure to HIV; (ii) sex 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 sex partners; (iv) sex partners are often unaware of or misunderstand their HIV risks; and (v) sex partners frequently have high rates of HIV infection. However, many programmes have poor results at tracing contacts and notifying partners (8-10).

Issues in the developing world

Poverty and illiteracy 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, the uneducated, and the unemployed require special consideration and partner notification may be especially important in these groups.

Resource limitations in developing countries makes partner notification difficult. The labour-intensive nature of contact tracing makes it a expensive option. This raises

many policy questions. What proportion of the efforts at prevention should be devoted to contact tracing? Should limited resources be focused on educational and other efforts at limiting the spread of infection? 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 people with infection. Contact tracing will benefit uninfected partners, but the high cost of therapy is beyond most infected and asymptomatic partners.

The National AIDS Control Organisation's guidelines for HIV counselling suggest that there may be situations permitting partner notification, but they neither discuss the issues nor offer specific criteria for disclosure (11).

The Supreme Court of India has ruled on 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 court's opinion was that the right to privacy and confidentiality is not absolute; it may be lawfully restricted when 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 offense punishable under law. The Court ruling maintained that HIV infected subjects did not have a right to marry.

Non-governmental organisations and human rights activists have pointed out that the law should look at the larger issues (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 with HIV positive persons even when based on the informed, free and willing consent of partners. These issues have been raised in a Public Interest Litigation now before the Court.

Issues for community health programmes

Clinicians often do not know the patient's background and family relationships. They need the patient's cooperation to obtain names of contacts. The situation is different in comprehensive community health programmes closely linked to small population groups with a detailed knowledge of the local people. The public health staff are aware of the subject's usual contacts (e.g. spouse). They are not only accountable to those with HIV infection but also to those partners who may not have the virus. Holding back 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 antagonise 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.

CHAD has diagnosed and managed 43 subjects with HIV infection since the onset of the epidemic. Its initial response was to maintain absolute confidentiality about a person's

HIV status. The focus was on a community education programme to increase the awareness of HIV/AIDS, its mode of transmission and the methods of protection. With the increase in the number of persons with HIV in the area there was a realisation 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 jeopardise the programme's relationship with the general population.

CHAD has since adopted the following guidelines for partner notification: (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 partners; (iv) the patient has been informed of the physician's intent to notify partners, and (v) partner notification will not involve the 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 contacting the virus. Care is taken to minimise the risk of discrimination of people with HIV infection. CHAD runs a regular AIDS awareness programme for all the villages in the Block. AIDS awareness is also part of the health education package at the monthly village antenatal clinics. People with HIV and AIDS are not refused treatment because of their infection either at the village clinics or at the base hospital. In fact people with the infection who have medical and social problems have a fast track access to medical and counselling staff. The health aide responsible for the patient's village visits all HIV infected people in her jurisdiction and their families at home every month. She provides education and psychological support for patients and their families. On occasion senior counsellors or senior doctors visit the patient's home to sort out issues, educate and provide emotional support. Those with persistent and clinically significant distress are seen by the staff of a family counselling centre. The programme also has a mental health initiative.

To date all subjects with HIV infection/AIDS in the Block have continued to live with their families at home. No serious problems have arisen either within the family or with the local community. Frequent follow-up of people with HIV infection by the programme staff, together with the policy of confidentiality (information on a person's HIV status is shared with a limited number of staff on a need to know basis), has helped prevent social isolation and discrimination of patients and their families. Our initial experiences suggest that the programme has been able to tread the fine line between the interests of persons with HIV and those of 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 persons with HIV infection come

under the care of clinicians and community programmes, the questions of breaching confidentiality to warn unsuspecting partners will be faced repeatedly in medical practice. Research and clinical experience suggest 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 currently, 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.

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The kidney trade

When a woman working with a private construction company in the northern region lost both her kidneys, her considerate employer put up an advertisement in newspapers appealing to voluntary kidney donors. The response was tremendous. Donors demanded a consideration ranging from Rs 40,000 to Rs 10 lakh. Agents called up to fix the deal on a commission of 20 to 25 per cent. There were, of course, some noble souls from Tarn Taran and Ludhiana offering a kidney free of cost. But it all shows the extent of illegal kidney business thriving in Punjab for quite some time now. Although reports of the racket have been coming off and on from various places, Ludhiana has particularly taken the lead in this business. Hard-pressed migrant labourers, particularly those from Nepal, have been lured by offers of large sums of money, or threatened into dubious deals, or deprived of their vital organs without their knowledge and consent on the pretext of a medical examination. The gang active at Ludhiana, according to newspaper reports, used to bring on an average of 25 persons from Delhi every month for kidney transplantation and the victims included minors too. Most of the operations have taken place in Ludhiana's Dayanand Medical College and Hospital (DMC). What is shocking is the suspected involvement of doctors, although the DMC authorities have ruled out any connivance of their faculty. In Bathinda the police recently booked four doctors, including a couple, of a private hospital for extracting a woman patient's kidney without her knowledge, when she came for the treatment of a tumour in the spleen. Reports of doctors' involvement need to be thoroughly investigated by the medical fraternity itself and the black sheep should be brought to justice. The Medical Council of India representatives themselves should take up such cases, whenever reported, to salvage the prestige of the profession. Police inaction, involvement or delay is nothing surprising but the scandal is too serious to be left to the policemen only.

... If illegal operations continue, it is because of doctor-agent-police connivance which needs to be identified and smashed.

...The organ trade is not confined to Punjab. India, along with China, has emerged as a booming market for human organs.

Editorial in the Tribune, October 18, 2001. Sent by Mr Satya Pal Dang.

Conferences

March 10-13, 2002: A cross-cultural dialogue on ethical challenges in health care. Co-sponsored by the United Arab Emirates Ministry of Health, the World Health Organization, the Islamic Organization for Medical Sciences, the International Association of Bioethics, the Emirates Medical Association, and the Gulf Center for Excellence in Ethics. For further details, contact Dr Basil A Badir, conference co-ordinator, Ministry of Health, PO Box 26094, Abu Dhabi, UAE. Email: moh_basilb@hotmail.com and ethics_conf@moh.gov.ae. Website: www.uae.gov.ae/moh/start.htm