HIV-related practices and ethics — survey of opinions in a paediatric department

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Summary

Seventy-five doctors working in an academic paediatric department each completed an anonymous self-administered questionnaire. Questions were posed relating to the need for consent before human immunodeficiency virus (HIV) testing and the informing of sexual partners of HIV-infected mothers. Only 9% of the doctors thought that the sexual partner of an HIV-infected mother should never be informed if the mother refused to do so. Sixty-one per cent of the doctors thought that pre-test consent was never necessary when screening hospital admissions. This opinion conflicts with the view of the South African Medical and Dental Council that pre-test consent is mandatory.

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The ethical issues arising from human immunodeficiency virus (HIV) infection and the acquired immunodeficiency syndrome (AIDS) have been written about and discussed probably more often and with more vigour than any other medical issue of our times. Official bodies are often called upon to formulate guidelines for the management of HIV-infected individuals. Because members of these bodies have often not had direct personal experience in treating HIV-infected persons, such guidelines are based on general ethical principles — they are seldom based on the opinions of doctors in the 'firing-line'.

A survey was undertaken to document the opinions of doctors working in an academic paediatric department regarding ethical aspects related to HIV-infected mothers and their children. The two aspects concentrated on were informed consent for HIV testing and informing sexual partners of HIV-infected mothers. Differences in opinion between senior and junior doctors and between doctors working at different hospitals (which have differing prevalences of HIV infection) were also analysed.

Subjects and methods

Doctors working at 3 teaching hospitals of the University of the Witwatersrand were asked to complete an anonymous self-administered questionnaire. The participating hospitals were Baragwanath Hospital (BH), which serves greater Soweto; Johannesburg Hospital (JH), which serves greater Johannesburg; and Coronation Hospital (CH), which serves the surrounding predominantly coloured areas.

The following questions were asked:

1. How many times have you been involved in the diagnosis and/or management of an HIV-infected child?

2. Do you think informed consent should be obtained from the parent(s) of the following groups of children before testing: (*i*) screening hospital admissions; (*ii*) children with suspicious clinical findings; and (*iii*) high-risk children (e.g. haemophiliacs)? Respondents were offered one of the following responses: always; sometimes; never; or undecided.

3. Do you think the sexual partner of an infected mother should be informed of her condition if she refuses to do so?

4. Do you think the ethical considerations related to HIV are different from those in other life-threatening illnesses?

5. For non-anonymous screening of hospital admissions, which of the following is the minimum pre-test information required? (more than one option allowed): (*i*) no information required; (*ii*) notice on the wall in the admission room; (*iii*) detailed booklet; (*iv*) limited description of illness by doctor or counsellor; (*v*) full details and its implications explained by doctor or counsellor; and (*vi*) screening should only be done anonymously without the subjects being informed.

Respondents were invited to give comments to justify their answers.

Results

A total of 75 questionnaires were returned out of 90 administered (83%). Of the respondents, 26 were consultants, 29 registrars/medical officers and 20 senior house officers (SHOs). Forty-two worked at BH, 9 at CH, and 24 at JH.

The comparisons between doctors of different seniority and those working at different hospitals in relation to their exposure to HIV-infected children are shown in Table I. It is evident from the table that the exposure of consultants, registrars and SHOs to infected children was similar but that doctors at BH were more likely to have seen at least 5 children with HIV infection compared with doctors at the other two hospitals.

The responses to the question on the need for informed consent before HIV testing are shown in Table II. Most of the doctors (81%) did not indicate a difference in approach to the three groups of children and gave the same answers to the three parts of the question. The majority of doctors (61 - 68%) thought that informed consent was not necessary before testing in each of the groups of children, whereas only 16 - 19% thought consent was always necessary. For statistical analysis, because of small numbers, the response 'never' was compared with the other three responses collectively. There were no differences of opinion between doctors of different seniority (not shown) but there were some differences between the doctors at different hospitals. Doctors at CH and JH thought that consent was never necessary more often than doctors at BH. This opinion prevailed for all three groups of children but was most evident for testing of high-risk children (88% of doctors at JH and CH v. 45% of doctors at BH).

A number of opinions justifying the necessity for pre-test consent were expressed. The most frequently given were related to the medicolegal implications of not informing parents and the feeling that counselling should be started before the test result was known. One response was that pre-test counselling was a good opportunity to educate the general population about HIV infection. Only 3 doctors noted that it was the parents' right to know what procedures or investigations were being performed on their child. Some doctors thought that the parents should be informed about the test but that consent

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TABLE I. EXPERIENCE WITH HIV-INFECTED CHILDREN — COMPARISON BY PROFESSIONAL STATUS AND HOSPITAL

No. of cases diagnosed	Consultants ($N = 26$)	Registrars ($N = 29$)	SHOs ($N = 20$)	BH ($N = 42$)	CH/JH ($N = 33$)
0	2	2	6	6	4
1-5	17	22	12	23	28
> 5	7	5	2	13*	1

* For BH v. CH/JH, $P < 0{,}01$; χ^2 test with Yates' correction.
No differences between consultants, registrars/medical officers and senior house officers.
For statistical analysis values for '0' and '1-5' cases (lines 1 and 2) were combined.

TABLE II. OPINIONS ON WHETHER PRE-TEST INFORMED CONSENT IS NECESSARY IN 3 GROUPS* OF CHILDREN

	Group 1			Group 2			Group 3		
Response	BH	CH/JH	Total	BH	CH/JH	Total	BH	CH/JH	Total
Always	11	2	13	11	1	12	14	0	14
Sometimes	3	3	6	6	1	7	5	3	8
Never	20	26	46	22	29	51	19	29	48
Undecided	8	2	10	3	2	5	4	1	5

For statistical analysis the response 'never' was compared to the other 3 responses combined.
$P < 0{,}01$ for each group.
*Group 1 — all admissions; group 2 — suspicious clinical findings; and group 3 — high-risk (for details see text).

was not necessary. The opinion was also expressed that under ideal circumstances consent should be obtained but that, in practice, this was often not feasible. The most common reason given for not requiring pre-test consent was in order not to miss HIV-infected patients who would pose a risk to medical staff.

Tables III and IV show the responses to questions 3 and 4. Overall, 71% of the doctors thought that sexual partners should always be informed. Most of the doctors who answered 'never' or were undecided worked at BH. Thirty-six per cent of doctors thought that ethical issues were different in HIV infection compared with other life-threatening illnesses. The reasons most frequently given to justify the opinion of differing ethics were that HIV is communicable and a threat to others and that the stigma associated with AIDS is unlike that associated with other diseases. There was a trend with increasing professional seniority to think that ethics differed but this was not statistically significant. Similarly, opinions at each of the hospitals were not significantly different.

Table V indicates opinions with regard to pre-test information (question 5). Once again, opinions of doctors of different status were very similar (not shown) as were those of doctors at the different hospitals. However, opinions were divided over this question and the most frequently identified minimum for communicating information to parents was a notice on the wall (31%). Only 15% of doctors thought that full disclosure about HIV infection was a necessary minimum.

Although not enquired about in this questionnaire, a number of doctors suggested that HIV infection should be notifiable.

TABLE III. WHETHER THE SEXUAL PARTNER OF AN INFECTED MOTHER SHOULD BE INFORMED IF SHE REFUSES TO DO SO

	BH ($N = 42$)		CH/JH ($N = 33$)		Total ($N = 75$)	
Response	No	%	No	%	No	%
Always	26	62	27	82	53	71
Sometimes	1	2	1	3	2	3
Never	6	14	1	3	7	9
Undecided	9	21	4	12	13	17

TABLE IV. PROPORTION WHO THINK THE ETHICS OF HIV INFECTION DIFFER FROM OTHER LIFE-THREATENING ILLNESSES

Status	No.	%
Consultants	12/26	46
Registrars	10/29	34
SHOs	5/20	25
Doctors at BH	17/42	40
Doctors at CH/JH	10/33	30
Total	27/75	36

No significant differences.

TABLE V. OPINIONS AT DIFFERENT HOSPITALS REGARDING MINIMUM PRE-TEST INFORMATION

	BH ($N = 42$)	CH/JH ($N = 33$)	Total ($N = 75$)	
			No.	%
None	4	5	9	12
Notice on wall	14	9	23	31
Booklet	6	7	13	16
Limited information	10	5	15	20
Full details	9	2	11	15
Anonymous only	4	8	12	16

No significant differences.

Discussion

The ethical and legal views of authoritative persons and bodies on HIV-related issues have been widely published[1-6] and recently the South African Medical and Dental Council (SAMDC) published similar guidelines on HIV testing and the management of HIV-infected individuals[7] (abridged in [8]). The interpretation and implications of these guidelines have been debated.[9-12] Although the SAMDC guidelines were published before this study was conducted, it is thought that these had not been widely read by the doctors participating in this study. It can therefore be assumed that the opinions put forth were largely uninfluenced by the SAMDC guidelines. Furthermore, ethical issues related to HIV infection had generally not been broached in our department before this study was conducted.

The results of this survey provide an opportunity to compare the opinions of doctors working in an academic paediatric department with the guidelines of the SAMDC as well as assessing the influence on ethical views of exposure to HIV-infected patients and professional seniority. An increasing number of HIV-infected children is being seen at Baragwanath Hospital[13] whereas only sporadic cases are seen at the other 2 hospitals in this study. Thus, varying opinions at the different hospitals may be related to exposure to HIV-infected individuals. The differences of opinion seen at the 3 hospitals were not observed between doctors of different seniority.

The SAMDC believes that the ethical approach to HIV infection should not differ from that of other life-threatening illnesses. However, some doctors (36% in this study) believe that ethical considerations are indeed different in that most other life-threatening illnesses are not contagious and that the stigma of HIV infection is unlike that associated with other illnesses.

The SAMDC has stated that doctors should ensure that sexual partners are informed, preferably with the consent of the infected person. Where consent is not forthcoming, the doctor is urged, nevertheless, to inform the partner. In this study only a few doctors were unconditionally against informing sexual partners and breach of patient confidentiality was the reason most often given for this view. The often quoted argument that informing partners may drive the illness underground[14] was not offered by any of the doctors in this study. A similar opinion was expressed by doctors in Western Australia where only 10,5% of doctors questioned thought that the partner should not be informed.[15]

With regard to the method of communicating information to parents when large scale screening of children being admitted to hospital is to be performed, the doctors were divided in opinion. Each of the options offered received support with the most popular method being a notice on the wall of the admission room. Anonymous testing, the method preferred by many researchers, was not favoured by most of the respondents.

Legal experts and ethicists commonly express the view that consent is necessary before HIV testing — and this is also the view taken by the SAMDC. There is, however, another point of view which holds that because the physical act of taking blood for testing is without risk, there is no need to inform the patient of the specific test being performed. Thus, all that is required is the patient's consent for the procedure of taking blood.[16] As Strauss[16] states, in South Africa, this latter view is of academic interest only because the SAMDC 'guideline' that informed consent before HIV testing 'is mandatory'[7] is almost certainly legally binding.[9,11,12] The results of this survey indicate a serious difference between the opinions of clinicians in our department and official guidelines. Most doctors were of the opinion that consent is generally not necessary and thus an HIV test was commonly perceived as similar to other tests for which consent is not specifically obtained.

The most commonly given reason for not requiring consent was the wish to identify infected persons who pose a risk to medical personnel. This reasoning can easily be faulted. Firstly, obtaining consent should not, at present, minimise the chances of obtaining a HIV-test result. It is the SAMDC's opinion and the author's experience that the vast majority of parents/patients will give consent for testing, although this may change with increasing public awareness. Indeed, the SAMDC has stated that where a person persistently refuses to be tested and where this may interfere with further management or investigation the doctor may 'terminate the therapeutic relationship'.

Secondly, the attempt to identify infected persons in order to minimise the risk to medical personnel may not be effective. This is because most investigative and curative procedures are carried out soon after the admission to hospital of a patient and before the results of an HIV test are available. In addition, the precautions medical personnel take with known HIV-infected patients should be taken with all patients in order to safeguard themselves in cases where the HIV status of a patient is unknown or is false-negative (e.g. during the 'window period').

Doctors at BH compared with the other hospitals were more often of the opinion that consent for HIV testing is always necessary but this was still a minority view. Similarly, the view that ethical issues related to HIV infection differ from those related to other illnesses was also held more commonly at BH although, once again, this was a minority view. From these findings it can be speculated that increased exposure to HIV infection has resulted in an increasing realisation of the complexity of HIV-related ethics and the problems that may arise when consent for testing is not obtained. Despite this realisation by some doctors, most still felt that they should be allowed to test without consent, even in the absence of clinical suspicion. A similar result was found in the Western Australian study[15] mentioned above, where 74,3% of doctors thought it was not always necessary to get pre-test informed consent.

In the SAMDC guidelines the exact extent to which a parent/patient should be informed before testing is not stipulated. Obviously, this depends on the parent/patient's level of knowledge and sophistication. There are also time constraints on medical personnel working in busy admission wards and long explanations are not always feasible. Indeed, only 15% of doctors thought that detailed personal explanations were required when screening hospital admissions. It appears, at present, that the amount of information to be imparted before testing is up to the individual doctor. It remains incumbent on individual departments to guide their front-line staff in this regard.

There is a need, certainly in our department, to educate doctors on the present legal requirement for pre-test consent and to encourage universal safety precautions when dealing with body fluids, thereby minimising the risk of exposure to unidentified infected patients. This study has been useful in highlighting issues that need to be addressed in our department and will, it is hoped, provide some food for thought for other departments. It should also be interesting for official bodies to note in which areas clinicians are at variance with their guidelines. The continued prescription to doctors by official bodies may lead to frustration and resentment where these guidelines conflict with the majority opinion of doctors.

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