

Caregivers' knowledge and attitudes towards HIV testing in chronically ill Malawian children.

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Abstract

Objectives

To determine background knowledge of HIV/AIDS among the caregivers of chronically ill Malawian children.

To assess the attitude of caregivers to HIV testing of these children.

Design

Interviews were conducted using a structured questionnaire conducted in the local language, Chichewa.

Setting

Paediatric Department of Queen Elizabeth Central Hospital, Blantyre, Malawi.

Participants

Caregivers of inpatient and outpatient children who were being investigated for suspected TB.

Results

One hundred and five surveys were completed. The level of knowledge of transmission and management of HIV infection was good. Important distinctions were made between HIV and TB, re transmission and management. 83% of respondents felt that it was good for parents to know their child's HIV status. 98% said that it was good for doctors to know a child's status.

The main benefits of an HIV test were understood to be:

- being able to help the child.
- a better understanding of the child's problems.

75% felt that all children admitted to hospital should be tested.

There were several misconceptions about the hospital's policies and practices:

- 27% indicated their belief that all children admitted to hospital are tested.
- 29% believed that they did not have the right to refuse testing for their child.

Conclusions

Staff should feel able to discuss with caregivers the HIV testing of chronically ill children, since the majority of caregivers have a good background knowledge and are open to the idea of testing. Staff also need to be vigilant to clarify misconceptions, including those about the hospital's testing policies.

Introduction

It is estimated that over 90% of the 570,000 children throughout the world who became infected with human immunodeficiency

virus (HIV) in 1999 are from sub-Saharan Africa.¹ The vast majority are infected by vertical transmission. Malawi is one of the worst affected countries in the region. Seroprevalence rates in pregnant women are highest in urban centres such as Blantyre, and around 8% of children born at Queen Elizabeth Central Hospital (QECH) become HIV-infected.² Consequently, a substantial proportion of childhood illness and mortality is HIV-related, especially in children with chronic disease.³ HIV testing of hospitalized patients is not a routine procedure in Malawi for a number of reasons, including inadequate resources for counselling and laboratory analysis, and limited treatment options. Health care workers prefer to limit testing in children to the small proportion of patients in whom the test result will directly affect management decisions.

Specific diagnosis of lymphoid interstitial pneumonitis, for example, can lead to effective treatment and avoid an unnecessary course of anti-TB therapy.³ This can create a difficult dilemma. While having potential benefits, the finding of a positive HIV result in a child has major implications for the entire family, for whom specific management options are very limited. Additionally, there is a concern that awareness of a positive result may have disastrous social consequences for the mother.⁴

There are no published data about background knowledge of childhood HIV infection in the community or about the attitudes of parents or guardians to HIV testing of their children.

We conducted a survey of caregivers' attitudes to HIV testing in children who had presented with a chronic illness that had a high likelihood of being HIV-related.

Material and Methods

The study site was the Department of Paediatrics, College of Medicine and Queen Elizabeth Central Hospital (QECH), Blantyre. QECH provides primary and secondary care for residents of Blantyre District (population approximately 1 million) and is the tertiary referral centre for the Southern Malawi region. There are around 100,000 paediatric outpatient visits and 12,000 paediatric admissions per annum. HIV seroprevalence among all sick children admitted to the paediatric wards at QECH is approximately 20% but is more than 60% in children presenting with suspected tuberculosis (TB).³

Study subjects were the parents or guardians of children with chronic symptoms consecutively admitted to the paediatric TB ward or assessed in the outpatient TB contact clinic. All surveys were completed using a structured questionnaire conducted in Chichewa, the regional language of Southern Malawi. The questionnaire was in two sections. The first section assessed knowledge of transmission, presentation and management of HIV/AIDS. For comparative purposes, knowledge of similar aspects of TB was also assessed. The second section assessed attitudes towards HIV testing in children and perception of current hospital practices. The question as to why or why not HIV testing was considered acceptable was open-ended. A ward nurse and a medical student

(WM) acted as translators to English. Verbal consent to participate was obtained before proceeding with the survey.

Results

105 surveys were completed during July/August, 1998, of which 36 were conducted in the inpatient ward and 69 in the outpatient clinic. The majority of the respondents were parents (69 mothers alone, 7 fathers alone, 2 both parents) and the remainder of caregivers included grandmothers (11), aunts (10) and older siblings (2). The age range of the children was 0-14 years of age with a median of 3 years. Background knowledge of transmission and management of HIV and TB in children and adults is shown in Table 1.

Overall, attitudes towards testing were positive with 98% responding that they would agree to HIV testing and 83% feeling that it was good for parents to know their child's HIV status (Table 2). Of the caregivers who thought that it was not good for parents to know their child's status, the most frequent response (16 of 18 caregivers) was that parents would feel despair, fear or disappointment if they knew that their child had HIV infection. Almost all (98%) felt that it was good for the health workers to know a child's status for the reasons listed in Table 2, the commonest reason being that they could help the child.

In response to questioning on hospital testing practices, 75% of respondents felt that all children admitted to hospital should be tested for HIV and 59% felt that doctors should obtain parental consent before testing. It was a belief of 27% that all children admitted to hospital are routinely tested and 29% felt that they did not have the right to refuse HIV testing for their child.

Discussion

This is the first published study that documents knowledge and attitudes of caregivers to HIV testing of African children. This is surprising as sub-Saharan Africa is the region in which the bulk of global childhood HIV infection occurs and research studies that include HIV testing of African children are common. These studies usually report high levels of acceptance of HIV testing with consent and counselling. However, there is a theoretical concern that compliance to testing might be high in this context because there is a real or perceived benefit to the child from being a study subject in a well-resourced project.⁵ There may even be a fear that refusal to consent may jeopardize further management. Our study found a high level of acceptance by parents and guardians to the principle of HIV testing in Malawian children in the context of usual clinical practice.

The findings of this study have practical relevance as was conducted in a typical setting in which health careworkers might normally approach caregivers for consent. An earlier study by our group of attitudes of parents towards HIV testing in Malawian children questioned parents of healthy children in a theoretical context.⁶ It found that the knowledge of HIV

disease and transmission was high and that the majority of mothers were open to HIV testing. Others have shown, however, that there may be substantial differences between stated intention to consent and actual practice.⁷ The information that we obtained of background knowledge suggests that some parents of chronically ill children may already suspect that their child is HIV-infected and might be less agreeable to testing partly because of implications for themselves. This was not found to be the case when we compared our findings to those of the earlier study.

In this study we found a good level of background knowledge of aspects of HIV transmission, presentation and management. This is also consistent with findings from the earlier survey of 318 caregivers, the majority of whom were mothers.⁶ In that study, all respondents knew that HIV infection was sexually transmitted and that there is no cure, and 94% thought it possible for an infected mother to infect her unborn child. Questions of TB epidemiology were asked in the present study for comparison because TB is the other important infectious disease in the region that usually presents with chronic illness. TB is commonly associated with and often confused with HIV infection. Important and correct distinctions between TB and HIV were made by most respondents. Further, the majority knew that HIV/AIDS is incurable whereas TB is potentially curable. Some of this information, particularly relating to transmission of HIV or TB, is readily available in Malawi via radio programmes or posters found in hospitals and health centres.

Major differences found in the present study, in comparison to the earlier study,⁶ were that twice as many caregivers of chronically ill children believed that a HIV test would help themselves and health workers to care for the child, and that a much greater proportion would agree to an HIV test without parental consent. The perceived benefits and actual modes of care were not specific and yet the respondents were nearly unanimous in their opinion that it was good for health workers to know a child's status. A smaller proportion felt that it was good for parents to know, and many admitted to the pain, fear and disappointment that they would have to face if their child was diagnosed. We believe that this reflects an overriding hope that a diagnosis of HIV infection will result in clinical improvement in their child but that some parents would prefer this to happen without having to face up to all the negative implications of a positive result.

Staff must be vigilant to clarify misconceptions about the hospital's HIV testing policies. Over one-quarter of respondents indicated their belief that all children admitted to hospital are tested and nearly one-third felt that they did not have the right to refuse testing for their child. Neither of these statements is true at QECH. Similar misconceptions were noted but not quantified in the earlier survey (personal communication, K Phiri). One explanation may be that all children admitted to the paediatric wards at QECH routinely have a finger-prick blood sample taken for malaria diagnosis

and measurement of haematocrit, and that this practice has been misinterpreted by the community as routine HIV testing. There are difficulties with interpretation of the results of this study.

When asking caregivers to state reasons why they approved HIV testing, we did so using an open-ended approach. We felt that such an approach might provide responses that more accurately reflected beliefs than asking them to respond to a fixed range of answers. However, some of the responses listed in Table 1 were difficult to interpret. For example, a common response to the question 'why it is good for parents to know a child's HIV/AIDS status?' was 'it is important to know the diagnosis'. The Malawian translators were not able to clarify what the caregiver really meant by this response. Further, most of the respondents were female and yet most Malawian households are headed by a male who makes most of the important decisions. It is possible that fathers may not be as open to the issue of HIV testing.

Table 1: Comparisons of attitudes towards HIV testing of children between caregivers of healthy children⁵ and caregivers of children with chronic respiratory disease.

Proportion of caregivers with response

<i>Attitude to HIV testing</i>	<i>For healthy children⁵ n=318</i>	<i>For chronically ill children n=105</i>
Would agree to HIV testing with consent	98.7%	98.1%
without consent	88%	57.1%
	10.7%	41%
Of benefit for parent /guardian	270(84.9%)	87(83%)
Reasons:		
Understand the problem	54.1%	51.7%
Help the child	18.9%	37.9%
Know whether parents are infected	11.6%	12.6%
Prevent spread	4.4%	11.5%
Think about future children	2.5%	0%
Spare money and time	1.9%	3.4%
Know if child will live long	0%	3.4%
Of benefit for health worker	300(94.3%)	103(98%)
Reasons:		
Help the child	25.8%	53.4%
Make a diagnosis	25.8%	11.7%
Advise the parents	23.5%	18.4%
Spare medicine and time	2.5%	7.8%
Their duty	10.4%	0%
Know numbers of HIV patients	2.5%	4.9%
Careful to prevent spread	1.9%	2.9%

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