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Perception of Risk of Vertically Acquired HIV Infection and Acceptability of Provider-Initiated Testing and Counseling Among Adolescents in Zimbabwe

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Almost 3 decades after the emergence of the HIV epidemic, underdiagnosis of HIV infection remains a significant issue globally, with more than 60% of adult HIV infections remaining undiagnosed in sub-Saharan Africa. Much attention has been given to facilitating HIV diagnosis in adults through provision of testing services in a variety of settings. The most notable change in recent years has been a shift from client-initiated to provider-initiated HIV testing and counseling (PITC) in adults, which has much lower costs per HIV-positive person tested than alternative strategies. International guidelines recommend routine PITC for all people seen in health facilities during generalized HIV epidemics as part of universal access to HIV testing and care. Routine implementation of PITC effectively increases uptake of HIV testing in a variety of health care settings.

In recent years, late presentation of vertically acquired HIV infection has become an increasingly important cause of adolescent mortality and serious morbidity in southern Africa. This trend reflects high regional HIV prevalence rates during the 1990s, lack of interventions to prevent mother-to-child transmission (MTCT) at that time, and the passage of enough time for HIV-infected infants who are long-term survivors to reach adolescence. It is now recognized that the probability of long-term survival following MTCT was greatly underestimated in the early days of the HIV epidemic. Although only about half of infected infants survive their first 2 years without antiretroviral treatment, about a quarter will live 10 years or more.

Infants born in southern Africa during the late 1990s were exposed to exceptionally high risks of acquiring HIV infection, with no effective prevention interventions in place and national antenatal surveys of pregnant women showing an HIV prevalence of 30% or higher in several countries, including Zimbabwe. Although infant diagnosis is well established, the need to consider HIV in acutely or chronically unwell older children has not been emphasized, leaving guardians and health providers alike potentially unaware of the high risk of HIV as the underlying cause of ill health in older children and adolescents in this region. Without this awareness, older children may not be offered HIV testing and guardians may feel unable to raise their suspicion of HIV with health providers, resulting in failure to diagnose underlying HIV despite frequent consultations. HIV testing of minors also requires consent from a legal guardian, a potential barrier that may be compounded by changing or informal guardianship due to parental death. Orphans may be further disadvantaged by poverty and suboptimal parenting.

Objectives. We investigated attitudes toward provider-initiated HIV testing and counseling (PITC) in the suburbs of Harare, Zimbabwe, where late presentation after mother-to-child HIV transmission (MTCT) is a major cause of adolescent mortality.

Methods. Adolescents (10–18 years) attending 2 primary clinics were offered PITC. Participants completed a questionnaire investigating acceptability of PITC, and in-depth interviews with 41 adolescents and 30 guardians explored understanding of long-term survival after MTCT.

Results. Of 506 participants, 16 were known to be HIV-positive; of the remaining 490, only 5 (1%) declined HIV testing. Infected adolescents and their guardians often anticipated a positive result and reported being advised by relatives (but not health workers) to be tested because of chronic illness, especially if parents or siblings had died or were HIV-infected. However, HIV-negative participants were not aware that long-term survival following MTCT could occur. All adolescents felt that HIV diagnosed at their age would be assumed to have been sexually acquired regardless of the true mode of transmission.

Conclusions. Including late diagnosis of MTCT in pretest counseling and health educational messages may facilitate PITC for older children and adolescents, especially for those who have not had their sexual debut. (Am J Public Health. 2011;101:2325–2332. doi:10.2105/AJPH.2011.300250)
METHODS

We invited consecutive patients aged 10 to 18 years attending primary care clinics for acute care over a 6-month period in 2009 in 2 high-density suburbs in southeast Harare, Zimbabwe to take part in the study. The primary care clinics in Mabvuku and Epworth had catchment populations of about 60,000 and 120,000 people, respectively. Primary care clinics were staffed by nurses and provided antenatal as well as acute care services.

We obtained written informed consent (in Shona or English) at a level appropriate for age from all participants and from the guardians of participants younger than 16 years. If there was disagreement between the guardian and adolescent about undergoing diagnostic HIV testing or participating in the study, both were counseled until consensus was reached. Patients attending for antenatal care, those too ill to take part in the study, and those younger than 16 years who were not accompanied by a guardian were excluded from study.

Study Procedures

We offered all participants an HIV test after group pretest counseling (opt-in approach). Those who declined diagnostic testing were offered individual pretest counseling and a second offer to be tested. The pretest discussion covered basic facts about HIV, including vertical and horizontal modes of transmission, the benefits of HIV testing, and a description of the testing process. HIV testing, which we performed according to national guidelines, used 2 rapid tests run in parallel: SD Bioline (Standard Diagnostics Inc, Suwon, South Korea) and Abbott Determine (Inverness Medical Innovations Inc, Johannesburg, South Africa). We resolved discordant HIV test results with an enzyme-linked immunosorbent assay (ELISA) (Vironostika Uniform II plus O, Biomerieux, Marcy l’Etoile, France). Posttest counseling, which was carried out individually, included HIV prevention and options for referral for onward care and support for those testing HIV positive.

All patients who tested HIV positive were referred for onward HIV care and support to adolescent HIV clinics at the 2 central hospitals in Harare. We invited HIV-infected participants to a group counseling session 3 months later to check whether they had registered for HIV care and to offer HIV testing to the participants’ relatives.

We asked participants and guardians (when available) to complete a confidential questionnaire with open-ended questions to elicit (1) reasons for consenting to or declining HIV testing, (2) any perceived advantages of HIV testing, and (3) components of the pretest counseling that may have influenced their decision whether or not to undergo HIV testing. The questionnaires were completed before HIV testing was performed.

We used in-depth interviews to explore participants’ acceptability of HIV testing, including their perception of risk of HIV infection and the benefits and disadvantages of HIV testing for adolescents. We did not interview those who already knew themselves to be HIV-infected before participation in the study. We designed the sample to include both recruitment clinics and participants who had declined as well as those who had accepted testing, and used deliberate oversampling of HIV-positive participants. We conducted 71 interviews: 30 with participants who tested HIV positive, 29 with guardians of participants who tested HIV positive, 7 with participants who tested HIV negative, 4 with participants who declined HIV testing, and 1 with a guardian who declined consent for her child to be tested. We conducted interviews in the participants’ homes 1 week after HIV testing had been offered. Participants were interviewed by an experienced researcher of the same sex as the interviewee and in the local language, Shona. The interviews lasted between 30 and 45 minutes and were recorded and transcribed verbatim.

Data Analysis

We translated questionnaires and interview transcripts into English for data processing and analysis. We subjected qualitative data to thematic analysis using grounded theory, whereby common themes were identified and topical codes developed and applied to transcripts. We entered and analyzed quantitative data with SPSS version 17.0 (SPSS Inc, Chicago, IL). We used a χ2 test or Fisher’s exact test as a test for association between categorical variables and a Student t test for normally distributed variables; P<.05 was considered statistically significant.

RESULTS

Of 538 adolescent clinic attendees, 506 were recruited, 12 were not accompanied by a guardian, 7 were too ill to be recruited, and 13 declined consent. The median age of participants was 14 years (interquartile range=11–16), and 51% were female (Table 1). Nearly half of all participants were orphaned and 23% were not currently attending school. The demographic characteristics of the adolescent interviewees were broadly similar to those of the whole study group (Table 1). The guardians interviewed were mothers (n=9), aunts (n=6), siblings (n=6), grandmothers (n=3), uncles (n=2), fathers (n=1), stepmothers (n=1), or nieces (n=1).

Acceptability of Provider-Initiated Testing and Counseling

Uptake of HIV testing among participants and their families. Of the 506 participants, 16 had previously tested HIV positive and 490 were offered PITC. Only 5 participants (1%) declined HIV testing, and 70 (14%) tested HIV positive (Figure 1). Of the 86 HIV-infected participants, 21 (24%) relocated from the area, 6 (1%) died, and 44 (51%) attended for the further counseling session. A further 56 family members of 28 HIV-infected participants underwent HIV testing; 7 of 16 siblings, 6 of 7 mothers, 3 of 3 fathers, 2 of 2 partners, and 6 of 28 other relatives tested positive for HIV (Figure 1).

As shown in Table 2, the 3 main reasons for accepting HIV testing related to the high perceived importance of knowing one’s HIV status, recurrent as well as chronic illness, and the ability to access treatment if diagnosed with HIV infection. HIV-positive adolescents were significantly more likely than were their HIV-negative counterparts to cite recurrent ill health as the main reason for testing, as were their guardians compared with guardians of HIV-negative participants (P<.005 and .001, respectively). Reasons for declining HIV testing. Of the 5 participants who declined HIV testing, 3 stated that they had not expected to be offered HIV testing and feared the test outcome. In the in-depth interviews, participants stated their reasons for not being tested. One participant declined to be tested in front of his father, and 1 participant wanted to be tested but was not allowed to by his mother. The fears expressed...
by these 5 participants were not being able to get married if HIV-positive, fear of being beaten at home, fear of dying, and fear of other people finding out.

As the mother of a 12-year-old boy who opted out explained,

I wasn’t ready for it. I only came to treat him for what was wrong that day. I wasn’t going to accept the results; I was scared to hear. No one can expect something that terrifies you. As a young boy he has never thought of anything that can go wrong. Knowing might not affect him but it will affect me as an adult.

A 17-year-old boy who opted out said,

I was afraid to get tested, not because of any bad thing which I was suspected to have done. I had some fear inside: how will my parents accept it, how am I going to cope with the situation? If only I was above 18 years I could stand for myself but now I am dependent on my parents; how will they accept it? My health would be affected because I would be thinking of that most of the time.

Benefits of and concerns about provider-initiated testing and counseling. Regardless of the participants’ HIV status or whether they accepted testing, there was unanimous agreement among adolescents that HIV testing was beneficial. Benefits included earlier access to HIV treatment, access to HIV prevention, motivation to stay HIV-negative, and the ability to plan lives around marriage and childbearing. Some participants were motivated to be tested after learning that vertically infected children could survive to adolescence.

Participants stated that more detailed post-test counseling was needed, including a focus on HIV prevention messages, and expressed concern about the availability of psychosocial support for those testing HIV-positive. The main concerns about HIV testing were adverse psychological reactions such as depression, worry about premature death and withdrawal from society, stigma, and complacency after a negative HIV test leading to risk-taking behaviors.

A 15-year-old HIV-negative girl said,

You can start thinking too much, which is not good, so you keep being sick and die early. Also, people you live with might say, “You and your disease, we can’t live together.”

Perception of HIV Infection Risk in Adolescence

Prior suspicion of HIV infection. Eight (28%) HIV-infected participants and 19 (66%) guardians of HIV-infected participants had strongly suspected HIV infection; the main reasons for their suspicions were a child’s recurrent ill health or poor growth and a death or known HIV infection in the child’s family. More than two thirds of guardians (n = 23) cited the deaths or known HIV infection of parents and siblings as a reason for having their child tested, with 8 guardians reporting 14 sibling deaths. Twelve guardians (41%) and 9 participants (31%) mentioned that family members or friends, but not health care workers, had also raised the possibility of HIV infection, for similar reasons.

An 18-year-old HIV-infected male said that “My father died of TB, my mother is HIV-positive and I have been diagnosed with TB.”

A 17-year-old HIV-infected male explained,

The way I was being affected by headaches with the whole of my body feeling weak, I suspected it could be HIV. I had noticed that my symptoms were the same as my sister and two brothers who have died.

The guardian of a 16-year-old HIV-infected boy stated that “He is really stunted in his growth and is forever sick with a runny stomach and severe acne and pimples.”

The guardian of another HIV-infected boy said,
My child was born with the virus. I could tell from his health as he was not fit and strong like other children of his age. By the age of 2 he was not crawling and he was supposed to be running. He was tested for HIV at the age of 2 and was positive but I didn’t believe it. I just ignored it. He has been living with the virus from that time without any treatment and he is now 17.

The mother of an 11-year-old HIV-infected boy related that Two of his siblings have died—a girl who was 21 months old and a boy of 11 months. I even relocated because of their deaths because I thought people were bewitching me. . . . My sister encouraged me to be tested and now I know they died because of this disease.

A third of HIV-infected participants interviewed had contemplated HIV testing in the past, and 17 guardians (65%) of HIV-infected participants had also considered getting their child tested. The main reasons mentioned by participants and their guardians for not having been tested previously were lack of awareness of testing services, lack of money for transport or clinic consultation fees, and having no one to accompany them.

An HIV-infected 17-year-old boy said, “I wanted to go on my own before I became seriously ill but I had no money for transport and to pay at the clinic.”

The guardian of a 12-year-old HIV-infected boy explained,

Yes, I thought about it but didn’t realize that children were being tested for AIDS. I thought only adults were tested. I didn’t know of any clinic that was offering the service and thought you could only go to a private doctor if your child was seriously ill.

Some HIV-infected participants had expected a negative result because they had not been sexually active and had not experienced ill health.

A 14-year-old HIV-infected boy said, “I had a very positive mind and thought that if I had the virus from birth I would have been dead long back so I was expecting a negative result. I was never sick from childhood, which would have made me suspect I could be positive.”

Community’s perception risk of HIV infection in adolescence. Although most HIV-infected adolescents and their guardians felt that the source of HIV infection was maternal transmission, fewer than half of those interviewed felt that others would believe that this was the case, as most people in their communities believed the only source of infection for adolescents was sexual transmission. Eleven guardians (38%) said that people did not expect a child infected by its mother to survive early childhood.

As a 16-year-old HIV-infected boy explained,

The general public lacks knowledge because they think that one can only be infected through sexual intercourse. They don’t think of these other means. They say since young ones have not experienced sexual matters, they can’t be affected.

Similar views were expressed by those who had tested HIV negative and those who had opted out of HIV testing. These participants stated that adolescents were not at risk for HIV infection unless they engaged in unprotected sex. Some participants remained skeptical that HIV-infected infants could live into their teens and remarked that it was generally assumed that an HIV-positive adolescent had contracted the virus sexually.
According to a 15-year-old HIV-negative boy,

It is very difficult for other members of the family to accept that one of the children is positive. They would just think I get it from a sexual partner even if I have not engaged in that. Very few will think of themselves as having infected their children. The knowledge about mother-to-child transmission is not widespread.

A 17-year-old HIV-negative girl said,

Some would chase away the child and say “Go and stay where you got the disease,” because many people still think one gets HIV through being mischievous.

A 17-year-old boy who opted out claimed that

The risk is very low for boys compared to ladies. The ladies become sexually active early. You find 4 ladies in love with one man. The risk for boys is only if you get a sugar mummy or have used a sharp instrument.

A 17-year-old girl who opted out thought that

People who are at risk are those who go to beer halls and pubs—prostitutes. They will be after boyfriends and sleep around with all sorts of people.

DISCUSSION

The main finding of this study was the high acceptance rate of PITC among adolescents attending acute care services in urban primary care clinics. There was strong endorsement from adolescents and their guardians that PITC was beneficial, regardless of the level of perceived risk of being HIV infected. Our pretest counseling explained that long-term survival with undiagnosed HIV could occur following MTCT in infancy; this information was not widely known, and may have made testing more acceptable by providing a reason other than sexual activity to consider testing. The substantial burden of undiagnosed HIV infection strongly supports routine implementation of HIV testing for older children and adolescents in countries such as Zimbabwe, where adult HIV prevalence has been high for more than a decade and where vertically acquired HIV infection is now a major cause of adolescent ill health.12,23 Additionally, many family members of HIV-infected adolescents underwent testing; nearly 50% of relatives who were tested were also HIV-infected. Hence, PITC in older children and adolescents may be an entry point for the whole family to access HIV testing and care.

The high prevalence of HIV infection among adolescent attendees of acute primary care facilities (17%) is consistent with recent estimates of HIV prevalence among children aged 10 to 15 years in Southern Africa, which are based on currently available evidence that about a quarter of HIV-infected infants will live 10 years or more even without treatment.14,15 If these estimates are correct, HIV prevalence among 10-year-old children living in Harare would have been about 3% at the time of this study and would be expected to be higher among health facility attendees than in the general population. As in a previous study of hospitalized adolescents in Harare, where HIV prevalence was 46%, our HIV-infected primary care participants had features suggesting that long-term survival following MTCT was the most likely source of HIV infection in the majority of cases.12,17 Of our 86 HIV-infected participants 6 died shortly after diagnosis, highlighting the importance of prompt HIV diagnosis and referral for care following primary care consultation.

Notably, nearly a quarter of our HIV-infected participants had relocated from the area within 3 months of their HIV diagnosis. Although it is speculative, these participants may have been sent to their rural home, where medical consultation fees are lower and anti-retroviral treatment is often easier to access than in Harare. This relocation of HIV-infected participants contributed to the suboptimal uptake of HIV testing among family members and highlights the need for interventions to facilitate linkage into care, ideally through family-based interventions, after HIV diagnosis in children.

A high proportion of our newly diagnosed HIV-infected adolescents and their guardians had anticipated a positive HIV test result. They cited years of ill health and poor growth, together with HIV infection in immediate family members or the death of a parent or...
sibling, for their suspicions. These adolescents were willing to be tested in order to access treatment, and they reported that relatives and friends had encouraged them to consider HIV testing. By contrast, uninfected and asymptomatic HIV-infected participants had generally perceived their personal risk of HIV infection as low; they believed that adolescents were not at risk for HIV infection unless they were sexually active.

Lack of awareness of voluntary counseling and testing services and the reluctance of health care providers to discuss risk behaviors and HIV testing create barriers to HIV testing. With respect to HIV infection in older children and adolescents, there has been a dearth of health information and education about long-term survival with maternally acquired HIV. Many years of misinformation has led to the popular belief that few HIV-infected infants would survive beyond the first few years of life. Lack of awareness that these infants could survive to adolescence has contributed to missed opportunities for PITC and family testing, as shown in Figure 2. Participants reported that friends and relatives—but not health care providers—had advised them to be tested, and adolescents and guardians reported they had contemplated HIV testing but had not known where to go.

This study raises the possibility that the lack of awareness of long-term survival from MTCT may deter adolescents from being tested for HIV. Adolescents with likely vertically acquired HIV expressed dismay at the prospect of community members assuming that their HIV was sexually acquired. Moreover, if HIV testing and counseling messages stress only sexual transmission in this age group, then this may deter vertically infected adolescents—who commonly have delayed puberty and report less sexual activity than their HIV-negative peers—from seeking or accepting HIV testing. Health care providers may also be left feeling reluctant to discuss HIV infection with sexually immature adolescents and their guardians unless they can explain a mode of transmission other than sex; otherwise, the question of sexual abuse arises.

The study had several limitations. Although we interviewed guardians whose consent was required for adolescents to undergo testing, the

Note. LTS = long-term survivor; MTCT = mother-to-child transmission; PITC = provider-initiated HIV testing and counseling.

role of other factors, such as the genders of a guardian and a participant and their precise relationship, needs further study as possible influences on the decision to test. We did not investigate health care workers’ perceptions and views of PITC, and we did not assess uptake of PITC among family members of HIV-negative participants. The questionnaires were given after the pretest discussion, and the information given may have influenced participants’ responses as well as the acceptability of HIV testing. The interviews were conducted some time after the HIV test, which may have introduced recall bias. Data on sexual risk behaviors were not collected, and we may have underestimated sexual abuse as a reason for being HIV-infected, as participants and their guardians may have been reluctant to divulge this. However, although we do not discount the high rates of sexual abuse reported from African countries, at the population level penetrative forced sex during childhood occurs at a much lower frequency than does exposure to HIV at birth and in infancy in this region, with the possible exception of South Africa. The thematic analysis performed may be subject to interpretivism (i.e., constructs created by the investigators) in that the views of the participants were constructed by the study investigators, and thus verbatim quotes have been provided to illustrate the main themes. Vertically infected HIV-positive adolescents face formidable barriers to accessing diagnosis, including incapacitating ill health, vulnerability following parental illness and death, the need to be accompanied by a guardian able to provide consent, and a lack of appropriate health information materials and messaging to encourage patients and health providers to consider long-term survival with maternally acquired infection as a cause of ill health in adolescence. The high prevalence of previously undiagnosed HIV infection among adolescents reported here supports routine PITC for older children attending primary care services in regions of Africa with a high prevalence of HIV. HIV testing is also a means of promoting HIV prevention in a group that will soon be at risk for acquiring and transmitting HIV in sexual relationships. Our results provide evidence that informing health workers and the general public about the potential for long-term survival following MTCT will encourage families with older children who may have been exposed to HIV as infants to have them tested at an early stage. Within primary health care services, adequate staff training, mechanisms to ensure confidentiality and referral for onward care for those who test positive for HIV, and development of interventions to reduce stigma and discrimination will be an essential accompaniment of PITC scale-up.

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Human Participant Protection
Ethical approval for the study was provided by the Medical Research Council of Zimbabwe, the London School of Hygiene and Tropical Medicine Ethics Committee, and the Biomedical Research and Training Institute Ethics Committee. Written informed consent was obtained from all participants and also from guardians of participants younger than 16 years.