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Disclosure, consent, opportunity costs, and inaccurate risk assessment deter pediatric HIV testing: a mixed-methods study

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Abstract

Background—Prompt child HIV testing and treatment is critical; however, children are often not diagnosed until symptomatic. Understanding factors that influence pediatric HIV testing can inform strategies to increase testing.

Methods—A mixed-methods study was conducted at a tertiary hospital in Nairobi, Kenya. Three focus group discussions with health care workers (HCW) and 18 in-depth interviews with HIV-infected adults with children of unknown status were analyzed using thematic analysis. A structured questionnaire was administered to 116 HIV-infected caregivers of children of unknown status to triangulate qualitative findings.

Results—Analysis revealed 3 key periods of the pediatric HIV testing process: decision to test, test visit, and post-test. Key issues included: *decision to test*: inaccurate HIV risk perception for children, challenges with paternal consent, lack of caregiver HIV status disclosure to partners/older children; *test experience*: poor understanding of child consent/assent and disclosure guidelines, perceived costs of testing and care, school schedules, HCW discomfort with pediatric HIV testing; *post-test*: pessimism regarding HIV-infected children's prognosis, caregiver concerns about own emotional health if child is positive, and challenges communicating about HIV with children. Concerns about all three periods influenced child testing decisions. Additionally, three

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challenges were unique to pediatric HIV: inaccurate HIV risk perception for children; disclosure, consent, and permission; and costs and scheduling.

Conclusions—Pediatric HIV testing barriers are distinct from adult barriers. Uptake of pediatric HIV testing may be enhanced by interventions to address misconceptions, disclosure services, psychosocial support addressing concerns unique to pediatric testing, child-focused HCW training, and alternative clinic hours.

Keywords

pediatric HIV testing; barriers and facilitators; disclosure; risk assessment; challenges

INTRODUCTION

Untreated pediatric HIV has an aggressive course with high mortality [1-6]. While systems to diagnose infant HIV are improving, many older children remain undiagnosed [7]. Systems to routinely test older children, such as provider-initiated testing and counseling (PITC), often preferentially test symptomatic children, attenuating treatment benefits [8]. To achieve the UNAIDS 90-90-90 targets [9], progress is needed in expanding HIV testing for older children.

One strategy to close pediatric HIV testing gaps is testing children of HIV-infected adults in care; this index case testing (ICT) approach yields a higher likelihood of diagnosing pediatric HIV infection than in the general population [10, 11] and may identify asymptomatic children [10, 12-15]. Additionally, ICT engages adults familiar with the benefits of HIV care who may be amenable to testing their children.

We previously found that systematic ICT increased pediatric HIV testing four-fold; however, most (86%) adults did not complete child testing [12]. We conducted a nested study to determine key barriers to pediatric ICT.

METHODS

Study design

This was a cross-sectional mixed-methods study. The parent study CATCH (Counseling and Testing for Children at Home) included systematized offer of pediatric HIV testing at home or in clinic. Questionnaires and semi-structured in-depth interviews (IDI) were administered to caregivers with children of unknown HIV status prior to testing, and focus group discussions (FGD) with pediatric health care workers (HCW); data collection was concurrent with the parent study.

Ethics statement

University of Washington Institutional Review Board and Kenyatta National Hospital (KNH)/University of Nairobi Ethics and Research Committee approved the study. Written informed consent was obtained in IDIs and surveys; oral informed consent was provided for FGDs.

Recruitment and enrollment

HIV-infected caregivers were eligible if they had at least one child 12 years old (“older children”) of unknown HIV status and were attending Voluntary Counseling and Testing Clinic (VCT), PMTCT Clinic, and Comprehensive HIV Care Centre (CCC) sites at KNH from 2013-2014 [12]. Sequential caregivers were screened by clinic staff and referred. Eligible caregivers were invited to complete questionnaires and/or IDIs. All but one caregiver who completed the questionnaire stated intent to test their children at enrollment, although a third did not complete testing in the parent study [12]; it was not possible to determine which caregivers who completed IDIs tested children.

A variety of HCW cadres were purposively recruited for FGDs from the aforementioned clinics at KNH.

Qualitative data collection and analysis

Interview guides explored social, emotional, cultural, structural, and organizational barriers to child HIV testing, with questions drawn from our conceptual framework, an adapted *Andersen’s Behavioral Model for Health Services Utilization* [16] (Supplementary figure [SF] 1). Interviews were conducted in English or Kiswahili by a professional interviewer. Audio recordings were translated, transcribed and imported into Atlas.ti version 7 (ATLAS.ti Scientific Software Development, GmbH, Berlin, Germany). Data analysis began with two primary coders (ADW, OF) independently coding three transcripts using “start codes” informed by our conceptual model [17]. This process yielded additional codes which were incorporated into a more comprehensive codebook. Primary coders used this revised codebook to independently code a second set of 3 transcripts. Application of the codebook was reviewed jointly and differences resolved through discussion. Finally, each acted as primary and secondary coder for the remaining 12 transcripts. All coding was reviewed by GO for consistency and meaning. Content analysis proceeded using the constant comparison approach [18]; resulting major themes were discussed by the larger team until consensus on interpretation was reached.

Quantitative questionnaire data collection

A questionnaire collected sociodemographic characteristics; HIV testing history; and barriers and facilitators. Questions were developed *a priori* from Andersen’s framework; prompted questions asked participants whether they experienced each barrier, while open-ended questions allowed participants to list barriers spontaneously. Quantitative survey data were used to triangulate the qualitative data; analyses were conducted separately and compared.

RESULTS

Participant characteristics

Eighteen IDIs with caregivers and 3 FGDs (7-11 HCWs each) were completed; 116 caregivers completed the survey. Caregivers completing IDIs and surveys were demographically similar (Supplementary Table 1). While efforts were made to enroll caregivers reluctant to test children, none agreed to complete IDIs.

QUALITATIVE RESULTS

Themes from the qualitative data supported the modified Andersen's model to describe pediatric HIV testing (SF1). Themes highlighted time-period-specific concerns and revealed issues unique to pediatric HIV testing.

Decision-making, testing, and post-test coping

Caregiver and HCW concerns addressed stages of the HIV testing experience: *decision to test*, *testing visit*, and *post-test period*. Concerns about all three periods influenced decisions about whether to test a child (Table 1A). Notably, post-test period concerns influenced decision to test. Concerns differed between HCW and caregivers (Figure 1).

Challenges unique to pediatric HIV testing

Unique challenges to testing asymptomatic children for HIV emerged: I) inaccurate risk perception, II) issues with disclosure and consent, III) costs and scheduling.

I. Inaccurate risk perception: Caregiver and HCW lack of urgency around testing older children—Caregivers did not feel urgency to test asymptomatic older children. Children's symptoms were a common prompt for testing, for caregivers and HCWs. One caregiver described difficulty overcoming inertia in the absence of illness:

... there is no way you can stay [at] home and the child is not sick and you say, let me take my baby to be tested for HIV...

- Caregiver

However, other caregivers assumed that older HIV-exposed children were inevitably infected, expressing fear and reluctance to test. Caregivers noted that focusing on the potential of an infected child during the testing discussion could deter caregivers from testing.

II. Complex decision-making dynamics underlie reluctance to test—Unlike adult HIV testing—which is autonomous and private—pediatric HIV testing, disclosure, permission, and consent may involve multiple caregivers and must address the increasing autonomy and curiosity of the older child.

Caregivers discussed partnership dynamics extensively in the context of the *decision to test*, and in the *post-test period*. Some felt partners needed to be involved in deciding, while others felt it best to decide independently. Decision-making was influenced by fear of disclosure. Caregivers described their own and their partners' denial of their HIV status, and perceived or confirmed discordant relationships, as barriers to pediatric testing. Female caregivers sometimes explained that disclosing to one's partner was necessary to rationalize testing the child; women who were not ready to disclose their status to their partners felt unable to bring children for testing for fear of conflict, violence or withholding of financial support.

... it will be difficult because how are you going to tell him... If we have not talked about our status how are we going to talk about the status of the child?

- Caregiver

HCW felt challenged managing *decision-making* related to obtaining appropriate consent from caregivers. HCW found themselves caught between children's needs and the caregivers' resistance.

According to practice sometimes you face challenges when the parents don't want to give consent and you can see that the child needs the test and get treatment... that is where now the policy is not coming in...

- HCW

HCW felt that as children became older, they ask questions regarding testing. Most caregivers felt their children were too young to know the reason for testing and feared children would disclose their test results to others. They also felt that if a child knew he/she was HIV-infected, it would force the caregiver to disclose their own HIV status to the child. HCWs often did not feel equipped to handle family disclosure and thought twice about even performing the test.

...in your mind you are like if the tests turns out [HIV] positive, how do I start disclosing to this child? So it's kind of a dilemma... and kind of fear, do I want to do it or not?

- HCW

III. Perceived and real costs, and school schedules prevent caregivers from testing children—Caregivers repeatedly cited concerns about costs relevant to the *test experience* and the *post-test* periods. Costs included transportation, childcare, perceived costs of tests and treatment, and lost income from missed work. Many caregivers echoed one participant's claim of "when I get money, I will go", suggesting that caregivers delay testing due to lack of capital and competing financial priorities.

Just that, "I don't have money to go there"...and "I don't have time." Like maybe she is hustling for the meal for that day, so she is like..."if I go there, I will waste time, what are my children going eat in the evening?"

- Caregiver

HCWs described challenges with scheduling testing due to school and work, noting that services were not available after hours and when children were out of school (often boarding schools). Caregivers struggled with limited opportunities for testing. While home-based testing with late and weekend visits could overcome some scheduling barriers, HCWs noted that finding homes could be challenging and unsafe, and that residences often changed without notice.

Quantitative results

Among 116 caregivers completing questionnaires, the frequency of barriers identified in both prompted and unprompted questions supported the qualitative findings (Table 1B). While most themes in quantitative data were present in qualitative data, some themes were mentioned in only one data source (SF 1).

DISCUSSION

This mixed-methods study with HCWs and caregivers revealed a range of factors that affect uptake of pediatric HIV testing and revealed new opportunities for programmatic interventions. The primary challenges unique to pediatric testing included: inaccurate perception of child's HIV risk; challenges with disclosure, permission, and consent; and logistics of testing.

Consistent with previous studies, reasons for not testing children included the perception that older, healthy-seeming children were not at risk for HIV [11, 19], and not feeling ready to disclose one's own status to children or partners [11, 20, 21]. Barriers to testing included HCW perceptions of lack of clear guidelines and unfamiliarity with pediatric HIV testing and disclosure policies [20, 22-24] and HCWs' negative attitudes [11, 24]. At clinics, long wait times and costs were logistical barriers [21, 24]. A major concern was fear of positive results and the child's death [20]. Caregivers were hesitant to test because they wanted to protect themselves from blame, guilt, abandonment, and inadvertent disclosure [11, 20, 24, 25] and to protect children from stigma, discrimination, and emotional suffering [11, 19, 20, 25].

Caregivers highlighted challenges with clinic scheduling, citing boarding school and limited clinic hours, as barriers. This barrier could be addressed by expanded clinic hours or visits during school holidays.

Interventions to address gaps in pediatric HIV knowledge—true probability of infection and life-saving benefits of ART—and to address fatalistic attitudes are needed to assuage caregivers' fears, but few exist [26]. Notably, although HIV prevalence was relatively high in children tested in the parent study (7.4% [12]), caregivers can accurately be told that the chance that their child is negative greatly outweighs the chance that their child is infected. Caregivers and HCWs called for more hopeful language in counseling sessions about the probability of a negative child and the potential for children with HIV to live long healthy lives [27].

Interventions to facilitate family disclosure should address caregiver and HCW concerns. Family testing models may be effective but are resource-intensive [14]; lower-cost adaptations may be feasible. Task shifting pediatric testing discussions to peer mentors—other adults who have tested their children—may be effective [28]. Disclosure remains delayed in many settings [29-32] and family disclosure interventions may complement pediatric testing scale-up [27, 33-37].

Financial incentives may address economic barriers and facilitate testing. Financial incentives have increased uptake of adult [38-40] and adolescent testing [41], and are underway for children [42]. Testing on weekends and school holidays may overcome scheduling challenges unique to school children.

Our study had strengths; it systematically evaluated barriers hypothesized *a priori* within a conceptual framework, triangulated qualitative and quantitative data, and involved HCWs and caregivers. Our study was limited in that caregivers reluctant to test children were

underrepresented. However, a third of caregivers who stated intention to test did not ultimately complete testing.

CONCLUSION

The study revealed unique barriers to pediatric HIV testing including issues with disclosure, consent, and permission; and concerns about costs and scheduling. HCW training and caregiver and community education may improve pediatric HIV testing.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1. Barriers and facilitators to pediatric HIV testing from qualitative interviews and focus groups

Table 1A

Illustrative quotes about barriers and facilitators

DECISION TO TEST	
Information gaps in risk perception for older, asymptomatic children	To make that move is not easy... People know that HIV is real, but they try to assume, so people always wait, until it knocks, until they become sick, it's when they know it's real. - Caregiver
	...some people [don't] know HIV affect[s] children, they only know HIV affect[s] big people. - Caregiver
	You know in the community, not many people take HIV as being real, so not many people take their children to be tested or get tested themselves. - Caregiver
Complex partnership dynamics – Disclosure & permission	He usually tells me “I am alright, I know myself”... He never said he will not go for the test, he just said “I will go”, sometimes he usually tells me “I don't have time”, sometimes he usually tells me “I am ok, I know my status”. - Caregiver
	... you know I wouldn't have [told the child's status to the father] because he never knew, so if [I] start telling him that she [is] negative, he will ask “Why was she even tested?” Then he will just come with a click in his mind that this is it... - Caregiver
Blame language from HCWs biases parents away from testing	...the way you speak to a patient, it can be a big challenge which can block the services, sometimes you can use a very rough language when you are asking somebody “have you ever been tested for HIV” and... you are asking while others are hearing, that has already blocked... - HCW
Supportive, respectful HCW attitude motivates testing	... we stayed there for 2 hours of which he told me that he cares about me and about my health... In fact he smiled and told me, “You have the reason to live, medication, you will live, now your mind is settled, get settled, relax, feel loved, I will support you in way, anything you need, anything, because of this child”... He just gave me those positive hopes and already I have kept them to myself, if it is positive (HIV), I know how to handle it, if it is negative, I know how to handle it, you know. - Caregiver
TEST VISIT	
Disclosure challenging during test session – Inadvertent disclosure of parental status	I am putting myself in the shoes of this child... if the child asks, “where did I get this disease from?”... how can you say, “you got it from your mother”? - HCW
Perceived costs of services	Some people fear the cost, because they feel it's costly... For the people who are very needy, maybe the transport cost, maybe they think they will charge you when you go for the tests, things like that... those are the things that people feel. - Caregiver
Staffing not conducive to child testing – Project-based HIV funding means no continuity of services	I want to say it's a national challenge, because to me in this country it's like HIV is looked at a project. That is why you hear it's a project, there is a counselor project, so when the project off, the services cut and the facility remains like there is no support, what do you do about it. - HCW
POST-TEST	
Fear child death, disclosure, emotional distress, stigma	We tested him when he was 13 years old and I believe if we had tested him earlier on this boy could not have gone as far as he was with his severe infection, I am sorry he didn't make it because after...as he is saying, he asked “me, I don't know women. Where did I get the infection from?” and because I had mentioned mother to child he turned to the mother “does it mean you are HIV positive and you have never told me?”... We referred that boy for further management because now he was handled by [a] psychologist. After three months when I met the mother, she told me that he refused to eat, he became depressed and he died. - HCW
	There was time I brought the child, when the child was 5 years, but when I was told to come back and collect the result I did not come back, I was like asking myself “suppose the child is positive, what will I do, how will I tell the child, suppose they start giving her the drugs, what will I tell this child that these drugs are for this condition,” I said no, to hell, the child will know of her status later in life. - Caregiver
Feeling of parent blame, guilt, disclosure, stigma, abandonment	Yes, I was a bit scared to get to know... Because I wouldn't want to pass this thing to an innocent child. - Caregiver
	... you don't want disturbance of mind...They don't want to know [their child's HIV status], it's better you stay like that... It's not a good idea, it's a bad idea, but that is what they say there. - Caregiver
	There are some who are chased away from home, they chase them away, and they don't want to see them... Maybe they are the curse in the family. - Caregiver
Supportive messages of hope for child's life are encouraging	What made me happy was when he told me that the child will improve and is going to be ok, he even told there are so many children who are HIV positive, some of them are even in high school, so that gave me courage. - Caregiver
Communication with children about HIV status and care is challenging	I think sometimes it's usually a bit difficult on the part of the healthcare provider because when you test this child and it turns out to be positive and now the child now kind of asks those kinds of questions... and at

	some point the child now becomes rebellious towards the parent. Now you feel like you are the cause... it becomes a bit difficult ... - Caregiver
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Table 1B

Prevalence of barriers and facilitators among caregivers

	Overall	
	N	n (%)
“Why has the child not been tested for HIV?” (unprompted)		
Child is not sick	116	66 (60)
Do not think child is HIV positive	116	55 (47)
Afraid to know child’s status or fear positive	116	26 (22)
Disclosure or stigma concerns (Caregiver, partner, or child)	116	17 (15)
Never offered HIV testing for child	116	7 (6)
Partner or family concerns about testing child	116	7 (6)
Cost of transport, missing work, or childcare is prohibitive	116	5 (4)
Do not know where to get child tested or that children can be tested	116	5 (4)
Logistical issues (child lives far or caregiver has no time)	116	5 (4)
Concerned about... (prompted)		
Cost of transport	116	79 (68)
Missing work	116	65 (57)
Finding someone to care for other children at home	116	24 (21)
Cost of testing	116	7 (6)
Cost of HIV care if child is positive	116	70 (60)
Asking partner’s permission to test the child	84	23 (27)
Trust in clinical staff (prompted)		
Staff have adequate training to test child	114	109 (96)
Staff would treat caregiver differently if child tested positive	114	5 (4)
Staff would disclose caregiver status to others	112	2 (2)
Emotional and social concerns (prompted)		
Concerned about being able to offer adequate care and nutrition to child if positive	112	90 (78)
Concerned child will find out HIV his/her status (inadvertent disclosure)	115	74 (64)
Concerned child will experience stigma at school if HIV positive	116	72 (62)
Concerned child will experience stigma in the community if HIV positive	114	69 (61)
Concerned partner could be angry if child is HIV positive	79	13 (16)
Concerned partner could be violent if child is HIV positive	78	5 (6)
Someone may discover caregiver HIV status if child is tested	113	51 (45)
Positive support (prompted)		
Reports positive support about HIV status from partner	80	56 (70)
Reports positive support about HIV status from family	114	46 (40)
Reports positive support about HIV status from friends	116	26 (22)
Reports positive support about HIV status from support group or counselor	115	92 (81)

Notes. Unprompted = Number of participants noting these barriers in their response to the open ended question. Prompted = Number of participants answering "yes" to specific questions regarding Concerns, Trust in clinical staff, Emotional and Social concerns, and Positive support.

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