

FACTORS ASSOCIATED WITH DISCLOSURE OF HIV STATUS AMONG HIV-POSITIVE CHILDREN IN RWANDA

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ABSTRACT

As the number of treatment-managed cases of pediatric Human Immunodeficiency Virus (HIV) increases, the issue of disclosure has become increasingly important. In this article, we evaluate factors associated with disclosure in Rwanda among HIV-positive children of 7 to 15 years. A 2008 survey in Rwanda was conducted to determine these factors. Participants in the study included 1,034 children on HAART and in the pre-HAART phase; among them 65% knew their HIV status, and 35% were unaware. The child's age was positively associated with awareness of HIV status. Children with illiterate parents were two times (aOR: 2.2, 95% CI: 1.4-3.6) more likely to be disclosed than children with high school educated parents. Children who engaged in dialogue with their parents or other family members were 15 times and four times, respectively, (aOR: 15.2, 95% CI: 9.4-24.7 and aOR: 4.1, 95% CI: 2.4-6.9) more likely to be disclosed than those who did not. Findings offer ways for Rwanda to improve its approach to disclosure issues, counseling and psychosocial support for HIV-positive children.

Keywords: pediatric HIV - disclosure - children - caregivers - Rwanda

RESUME

Le nombre de cas pédiatrique de virus de l'immunodéficience humaine (VIH) gérés avec traitement augmente dans le monde, et la question de la divulgation est devenue de plus en plus importante. Dans cet article, nous évaluons les facteurs associés à la divulgation au Rwanda parmi les enfants séropositifs de 7 à 15 ans. Une enquête de 2008 au Rwanda a été menée afin de déterminer ces facteurs. Les participants à l'étude portent sur 1.034 enfants sous HAART et dans la phase de pré-HAART, parmi lesquels 65% connaissaient leur statut VIH, et 35% ne savaient pas. L'âge de l'enfant a été positivement associé à la prise de conscience de leur statut sérologique. Les enfants dont les parents sont analphabètes étaient deux fois (aOR: 2,2; IC 95%: 1,4-3,6) plus susceptibles d'être divulgués que les enfants dont les parents sont diplômés du secondaire. Les enfants qui se sont engagés dans le dialogue avec leurs parents ou d'autres membres de la famille étaient 15 fois et quatre fois, respectivement (aOR: 15,2; IC 95%: 9,4-24,7 et aOR: 4,1; IC 95%: 2,4-6,9) plus susceptibles d'être divulgués à ceux qui n'ont pas. Les résultats offrent des moyens pour le Rwanda pour améliorer son approche des questions de divulgation, de conseil et de soutien psychosocial pour les enfants séropositifs.

Mots-clés: VIH pédiatrique - la divulgation - enfants - soignants - Rwanda

INTRODUCTION

Of the estimated 33 million of people living with Human Immunodeficiency Virus (HIV) worldwide, two million are children under 15 years old [1]. Sub-Saharan Africa bears the highest burden of HIV accounting for 67% of total number of people living with HIV worldwide; and 91% of all new infections among children [1]. HIV-positive infants who are "slow progressors" have a median life expectancy of 14-16 years without the availability of Highly Active Antiretroviral Therapy (HAART) [2, 3]. Yet life expectancy of HIV-positive children has improved

in recent years with the availability of HAART, inevitably augmenting the number of HIV-positive adolescents [4]. As the number of treatment-managed cases of pediatric HIV infection increases, disclosure to infected children has become increasingly important.

One of the biggest psychosocial challenges that health care providers and parents face is disclosure of status to perinatally infected HIV-positive children [5]. Disclosure has the potential to affect a child's psychosocial wellbeing, in addition to his or her physical health. According to a recent systematic review on disclosure of pediatric HIV infection, the debate on the psychosocial outcomes of disclosure versus non-disclosure is ongoing [5]. Yet in the context of all chronic illnesses, Wiener et al (2008) note that the disclosure of health conditions to children with

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chronic diseases does provide psychosocial benefits to the child and the family. From a clinical standpoint, there is general agreement in the literature on the benefits to the patient and their families when the child is disclosed his or her status.

Although there is limited research on these topics, various studies have been conducted on the associations between disclosure, family life, and psychosocial and clinical outcomes. A study conducted among HIV-positive children in Romania found significant associations between non-disclosure and disease progression defined as either death or CD4 decline [6]. Another study demonstrated that HIV disclosure did not seem to have any negative impact on quality of life among children [7]. Further research found that children who knew their HIV status not only scored higher on total and internal scales of the Child Behavior Checklist, but also had significantly lower scores on depression anxiety measures than those who did not know their HIV status [5].

The association between HIV disclosure and adherence, however, is inconclusive [5]. A study in Belgium concerning children 0-18 years of age found that some caregivers reported a higher level of adherence when children were aware of their status [8]. In Uganda, a study was conducted with 42 participants who were caregivers of 42 HIV-positive children aged 5-17 (median 12 years) [9]. Among those 42 children, 29% were fully disclosed, 38% were partially disclosed, and 29% were not disclosed their HIV status. Results demonstrated that when children were non-disclosed and caregivers were the only ones to know a child's HIV status, the child was three times less likely to adhere to HAART. Among children in the Ugandan study who were aware of their status, the majority never missed a HAART dose [9]. However, other literature has reported a lower level of adherence after disclosure [10, 11]. For example, Mellins et al 2004 report borderline significance of a positive association between non-adherence and HIV disclosure ($P<0.07$) in univariate analysis of children ages 3-13 years in two urban pediatric HIV programs [11].

In Rwanda, the population suffers from a generalized HIV epidemic with a prevalence of approximately 3%. 174,000 people currently live with HIV in Rwanda, and 22,000 of these are children [12]. In terms of a response to the HIV epidemic, Rwanda established a national program in 1986. In 2003, the 3 by 5 Initiative was jointly launched by the World Health Organization (WHO) and the Joint United Nations Program on HIV/AIDS (UNAIDS) to facilitate the delivery of HAART globally [13]. This same year, Rwanda started its HAART program and by 2009, HAART coverage was estimated at 77% [12]. Rwanda achieved the highest coverage of any low-income country in 2007 for HAART [13]. At the end of 2008, 63,149 patients including 5,635 children were receiving HAART through 217 health facilities across the country [14].

At the time of our study, there were no guidelines on HIV disclosure among children in Rwanda. In order for Rwanda to advance its national approach to mitigating individual, and medical and social implications of pediatric HIV, we studied disclosure patterns and associated factors among HIV-positive children aged 7-15 years enrolled in the national HIV care and treatment in Rwanda.

METHODS

This study is based on data collected in a larger, cross-sectional study aimed to evaluate the environment of care for children infected and affected by HIV/AIDS in Rwanda. The evaluation analyzed socioeconomic, demographic and clinical data; and the obstacles contributing to the lack of HIV care and treatment for children in Rwanda across societal, community, school and family contexts. Mixed methodologies were employed, though data analyzed in the present article concern a subset of results from quantitative surveys within the larger study. For the purpose of clarity, the methodology described in this article only concerns those methods employed to gather data for the smaller subset of the larger study. Details concerning the larger study's methodology can be provided on request to the corresponding author.

Study participants and selection processes

Selection of study sites

A stratified, two-stage sampling method was used to select HIV-positive children on HAART. The primary units were health facilities in Rwanda and the secondary units were children. The sites were selected by the statistical method of probability proportional to size (PPS). Sites considered for this study included those that were providing ARVs to 15 or more pediatric patients as of 30 June 2007. A total of 68 sites fit this criterion. Of the 68, 30 were selected by systematic PPS.

Criteria for participant selection

Participants in the smaller subset of the study included children; and additional clinical data were gathered from each child's medical records. Children were considered if they were between ages 7 and 15 years, if they were HIV-positive, and if they were attending school. Children were not considered if they were not within the age range specified (7 to 15 years), if they had not been infected with HIV, and/or if they were not attending school. Within this eligibility criteria, three groups of children were selected: (1) HIV-positive children on HAART who were unaware of their status; (2) HIV-positive children on HAART who were already aware of their status; (3) HIV-positive children who were in the pre-HAART phase who were either aware or unaware of their status.

Selection of HIV-positive children on HAART who were unaware of their status.

Given the dearth of research on the proportion of children disclosed in a representative national program sample, the proportion equal to 50% was considered. Assuming 5% precision, 95% confidence interval (CI), and using the Cochran's formula for small population and a 25% non-response rate, a sample size of 718 children between 7 and 15 years was needed. In sites with fewer than 50 children registered, 50% of the children were selected; in sites with 50 to 100 children, 37% of children were selected; and in sites with over 100 children registered, 13% were selected.

Selection of HIV-positive children on HAART who were already aware of their status.

A non-random sample was also selected, comprised of 144 HIV-positive children between 7 to 15 years old who were already aware of their HIV status. The following criteria were taken into account during the selection: gender, orphanhood, and location of health facility (urban-Kigali, semi-urban, and semi-rural).

Selection of HIV-positive children in the pre-HAART phase who were either aware or unaware of their status

Since a sampling frame for this population was not available, it was impossible to calculate the sample size in advance. The enumerators made a list of children in the pre-HAART phase in each of the 30 sites selected at the first level. The lists were sent to the National Institute of Statistics of Rwanda (NISR) to calculate the sample size. A total of 382 HIV-positive children in the pre-HAART phase aged 7 to 15 years were included in the study.

Study aims

The purpose of this study was to determine factors associated with disclosure of HIV status among HIV-positive children from 7 to 15 years old. HIV disclosure was defined as whether or not a child knew his or her serologic status; this information was given by the children after consent was obtained. Factors associated with disclosure included child's gender, education level, age, residence, orphan status, HAART status, dialogue with parents and family members, and drug counseling; and parents' education level and occupation.

Data collection

Multiple techniques were used to collect data from participants. All demographic and quantitative data was collected using a questionnaire; and a medical chart review was done to determine which children were on HAART or pre-HAART.

To ensure standard procedures during survey administration, each enumerator had a survey guide. This survey guide specified all procedures for interview

preparation, including informed consent for the child and parent or caregiver. Supervisors reviewed all completed surveys, in addition to ascertaining omissions and giving feedback to enumerators to enhance data quality.

Data management and analysis

Data entry personnel were trained on survey administration to understand the logic and sequence of questions in order to minimize non-sampling errors. Additionally, double data entry was done using Epi Info 3.2 to minimize errors. STATA/SE 10.0 was used for data analysis; and Pearson chi square test was used to evaluate the difference in HIV disclosure by potential predictors. A logistic regression model was used to determine factors associated with HIV disclosure. Categorical independent variables were coded as dummy variables in the regression model. Stepwise selection with a probability of 0.05 for a variable to enter the model and a probability of 0.10 to be removed from the model were used. Those following variables were analyzed in bivariate analysis: child's gender, child's age, child's and parents'/caregivers' education levels, residence, orphanhood, occupation of caregivers/parents, child's HAART status, dialogue with parents and dialogue with family members about HIV/AIDS, drug counseling. All variables statistically significant at 95% in bivariate analysis were included in the model. The final model included the following variables: child's age, parent's education, dialogue with parents, dialogue with family members and drug counseling.

Ethical considerations

Appropriate measures were taken to ensure survey participant protection, understood voluntariness of participation, and anonymity of participants. Participation in the study was contingent on informed and written consent given by the pair of child and parent or child and caregiver was prior to other questions asked. A description of the purpose and design of the study was explained clearly to both child and his or her parent or caregiver, in such a way that both children and adults could understand the protocol fully. In addition, formal review and approval of the protocol were obtained from the Rwandan National Ethics Committee. Full precautions were taken to ensure that no child participants who were unaware of their status were unintentionally disclosed during the process of the survey administration.

RESULTS

Description of participants

Of the 718 HIV-positive children on HAART selected, 652 (91%) responded to the questionnaire. In addition, 382 HIV-positive children in the pre-HAART phase participated in the study. A total of 1,034 HIV-positive children were included in the study. Five hundred sixty-three (55%) of the children interviewed were female. Fifty-nine percent of all participants were between 10 and 15 years old and 41% were between 7 and 9 years old. The majority (90%) of children had a primary school education and only 6% were illiterate. Almost a quarter of the children had illiterate parents. Fifty-six percent of the children lived in urban areas. Twenty-eight percent of the children were double orphan and 36% had only one parent alive. Forty-three percent of the caregivers or parents were unemployed. Six hundred fifty-two (62%) of the children interviewed were already on HAART at the time of the survey [Table 1]. Five hundred and eighty-seven (90%) children on HAART were in primary school. Out of the 587 children on HAART in primary school, 158 (27%) were over 12 years old and 429 (73%) were under 12 years old. A total of 341 (89%) children in the pre-HAART phase were in primary school at the time of the survey. Out of the 341 children in pre-HAART phase and in primary school, 71 (21%) were over 12 years old and 270 (79%) were under 12 years old.

Table I: Background characteristics of the study sample

	Characteristics	N	%
Gender	Male	471	45.5
	Female	563	54.5
Age	7-9 years	421	40.7
	10-15 years	613	59.3
Education of child	Illiterate	58	5.6
	Primary	928	89.7
	Secondary and above	20	1.9
	Not mentioned	28	2.7
Education of parents	Illiterate	223	21.6
	Primary	543	52.5
	Secondary and above	161	15.6
	Not mentioned	107	10.3
Residence	Urban	578	55.9
	Rural	456	44.1
Orphanhood	Both parents alive	362	35.0
	One parent dead	372	36.0
	Both parents dead	288	27.8
	Not mentioned	12	1.2
Occupation of care giver/parent	Unemployed	416	40.2
	Farmer	157	15.2
	Civil servant	70	6.8
	Private business	63	6.1
	Other	253	24.5
	Not mentioned	75	7.2
HAART status	Children on Pre -HAART	382	36.9
	Children on HAART	652	63.1

Factors associated with HIV disclosure

Out of the 1,034 children included in the survey, 676 (65%) were aware of their HIV status. The methodology sought participants on HAART who were both disclosed and undisclosed; 445 (68%) out of 652 HIV-positive children on HAART were disclosed, 32% were undisclosed. The methodology sought HIV-positive children in the pre-HAART phase but inclusion criteria for these participants was not based on disclosure status in pre-HAART phase; 231 HIV-positive children out of 382 (60%) in the pre-HAART phase were aware of their HIV status. Among the children aware of their HIV status, 246 (36%) were informed by their health care provider and 244 (36%) by their mothers. Only 44 (7%) were informed by their father, 46 (7%) by their brother and sisters and 49 (7%) by other family members [Table 2].

In bivariate analysis, among all participants, a child's age was associated with HIV status disclosure. The oldest children (10-15 years) were more likely to know their HIV status compared to the youngest (7-9 years) (81% versus 41%, $p=0.000$). However, no significant association was found between HIV disclosure and either sex or education of the child. Parents'/caregivers' education levels were inversely associated with HIV disclosure. Seventy-eight percent of children whose parents/caregivers were illiterate knew their HIV status. Among children of parents/caregivers who had a primary school education, 65% knew their status; and among those whose parents/caregivers had a high school education, 60% knew their status ($p\text{-value}=0.000$). Children living in rural areas were more likely to be informed of their status than those living in urban areas. Orphanhood was positively associated with HIV disclosure. Seventy-eight percent of the double orphans were aware of their HIV status, compared to 71% of children with one parent alive, and 52% of those whose both parents were alive. Dialogue with parents or family members was positively associated with HIV status disclosure among children. Drug counseling was positively associated with HIV disclosure [Table 3].

In multivariate analysis, the following criteria were associated with HIV disclosure: the age of the child; whether or not the child engaged in dialogue with their parents or other family members; and whether or not the child received drug counseling. As seen in bivariate analysis, children who were 10-15 years old at the time of the survey were nearly four times (aOR: 3.9 ; 95% CI: 2.6-5.7) more likely to know their HIV status compared to the 7-9 year old children. A further concordance with bivariate analysis was parents' level of education, which proved to be inversely associated with HIV disclosure among children. A child whose parents were illiterate was twice (aOR: 2.2; 95% CI 1.4-3.6) more likely to be aware of his HIV status than a child whose parents had a high school

education level. Children who engaged in dialogue with their parents or other family members were respectively 15 times and 4 times (aOR: 15.2, 95% CI: 9.4-24.7 and aOR: 4.1, 95% CI: 2.4-6.9) more likely to know their HIV status compared to those who did not engage in dialogue with their parents or other family members [Table 3].

Table II: Disclosure of Status and Responses

	Status Disclosure	%
Status Disclosed By	Health Care Provider Family Members	46% 54%
Response to HIV Status Disclosure	Felt emotionally hurt; or emotional suffering Accepted news of status Withstood distressed feeling Surprised Cried No reaction	35% 22% 24% 7.1% 11% 21%

Table III: Association between HIV disclosure and selected characteristics of children and caregivers/parents

Characteristics	No		Yes		Univariate Analysis P value	Multivariate analysis (Logistic regression)	
	N	%	N	%		Odds ratio	95% CI
Gender							
Male	187	33	376	67	0.298		
Female	171	36	300	64			
Age					0.000		
7-9 years	242	57	179	43			
10-15 years	116	19	497	81		3.9	2.6-5.7
Education of child					0.201		
Illiterate	26	45	32	55			
Primary	318	34	610	66			
Secondary and above	4	20	16	80			
Education of parents					0.000		
Illiterate	50	22	173	78			
Primary	189	35	354	65			
Secondary and above	63	40	96	60			
Residence					0.001		
Urban	225	39	353	61			
Rural	133	29	323	71			
Orphanhood					0.000		
Both parents alive	175	48	187	52			
One parent dead	109	29	263	71			
Both parents dead	69	24	219	76			
Occupation of caregivers/parents					0.002		
Unemployed	115	28	301	72			
Farmer	67	43	90	57			
Civil servant	30	43	40	57			
Private business	25	40	38	60			
Other	96	38	157	62			
HAART status					0.011		
Pre HAART	151	40	231	60			
HAART	207	32	445	68			
Dialogue with parents					0.000		
No	329	64	184	36			
Yes	29	6	492	94			
Dialogue with family members					0.000		
No	332	52	312	48			
Yes	26	7	364	93			
					15.2	9.4-24.7	
					4.1	2.4-6.9	
							Reference

Children's Responses to HIV disclosure

Thirty-five percent of the children reported feeling emotionally hurt and suffered when they learned their HIV status. Eleven percent of the children cried and 7% reported to have been surprised. Twenty-two percent accepted their HIV status while 24% withstood (i.e. tolerated) the distress they felt. Twenty-one percent of children reported they had no reaction. Sixty five percent of the children reported to have overcome the fears they had immediately after their status was disclosed to them [Table 2].

DISCUSSION

At the time of the survey, 65% of the HIV-positive children between 7 and 15 years old knew their HIV status. Although the methodology selected children on HAART who were both disclosed and undisclosed, among the group of children in the pre-HAART phase, disclosure and non-disclosure was not inclusion criteria and the prevalence of disclosure was still 60%. Such a high percentage is relevant given that the study was conducted at a time when no national guidelines or protocols on HIV disclosure to children were available in Rwanda. The prevalence of HIV disclosure among children in Rwanda was also high in comparison to the rate of disclosure in other HIV endemic nations. In a study conducted in Zambia, only 37.8% of HIV-positive adolescents aged 11-15 years knew their HIV status [15], compared to 81% of children 10-15 years old who knew their status in our study. In a study carried out in Thailand, 30.1% of HIV-positive children aged 6 years and older were aware of their HIV status [16]. Another study – conducted in India – found that only 7 out of 50 children (14%) were aware of their HIV as reported by their guardians/parents [17].

Our study suggests that HIV disclosure prevalence was higher among older children. This pattern is seen in several studies in other countries [18, 19]. In addition, the children of illiterate parents were most likely to be aware of their HIV status compared to those of more educated parents. Such an association could possibly be explained by reliance on health worker management of care by illiterate parents; or by a geographic bias of rural versus urban possibly linked to education attainment of parents/caregivers.

The majority of children reported not feeling emotionally hurt after disclosure and the majority of those who were hurt reported to have overcome the fears shortly thereafter. This result is consistent with findings from the aforementioned study showing that HIV disclosure among children does not have a negative impact on quality of life [7]. In a study of 40 children informed of their HIV diagnosis, (70%) had feelings of normalcy 6 months post-disclosure in addition to positive psychosocial adjustment [20]. Other studies that examined the psychological impact

of disclosure found little or no difference in psychological functioning between disclosed and non-disclosed children [5, 7, 18].

A study conducted in Botswana found that most parents only disclose their HIV status when it cannot be hidden anymore; however, children are often aware of their positive HIV status before they are told [21]. In Brazil, a study [22] found that mothers of HIV-positive children displayed phobic, controlling and overprotective behavior towards their children, thereby preventing them from participating in their treatment. Many parents have good intentions when deciding not to disclose HIV status to their children, as they do not want to cause emotional or psychological harm. However, the result of our study shows that, if initially upset, most children were able overcome these feelings. This should be an additional reason to encourage parents and health care providers to practice earlier disclosure of HIV status to infected children.

Article 12 of the Convention on the Rights of the Child - an international treaty promulgated in 1989 [23] - states that a child who is capable of expressing his or her views has the right to state them freely in matters concerning the child. Moreover, those listening to the child expressing his or her views must take those views into account. This right to participation in decisions is especially important when ensuring the human rights of children living with HIV. Yet, by not allowing a child to know his or her status, parents are denying the child's right to participate in decisions regarding his or her health, care and treatment. Moreover, parents and caregivers may potentially damage their relationship with their children by causing parental distrust, as has been proved in other research [24]. A study conducted in the United States of America found that children who were kept from knowing their HIV status for 2 to 8 years expressed severe emotional distress, social isolation and negative self-image; parents reported to have been unaware of their children's concerns [25].

In an age-appropriate manner, children's opinions regarding their health care should always be sought and respected. Families and society at large should be encouraged to value children's input and viewpoints and understand that devaluing children's voices is contrary their human rights. In order to allow children's participation in decision-making about their health and health care, Rwanda must promote HIV status disclosure to HIV-positive children, and must promote productive dialogue between children and their parents and other family members.

A limitation of this study is that HIV disclosure was treated as a dichotomous variable. HIV disclosure is a process and some children may have been partially disclosed – a concept that was not captured in the study.

CONCLUSION

The majority of HIV-positive children on HAART and those in the pre-HAART phase in the present study were aware of their HIV status (68% and 60% respectively) and had been informed by their family members. Parents and caregivers play an important role in the factors associated with disclosure, and it is crucial to reinforce counseling given to parents or caregivers and promote family counseling. Parents and caregivers should be encouraged and supported to disclose HIV status to their children in an appropriate manner. This study established that many children were hurt and felt a sense of suffering when they learned of their HIV-positive status. This fact reiterates the need to offer enhanced counseling and psycho-social support to HIV-positive children and their parents. After conducting the survey in Rwanda in 2008, the Treatment and Research AIDS Center (TRAC) Plus developed and started implementing guidelines for disclosure of HIV infection status among children and adolescent in Rwanda. Health care providers should continue to work closely with caregivers - especially with caregivers who have a higher level of education - to improve disclosure. This will improve the rights of children infected by HIV and allow children to express their views and participate in decisions concerning their own health.

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