

Why Must I take medicine?” Ugandan Children’s understanding of Antiretroviral Therapy

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Study Overview

Study Title: HIV+ children's perspectives and communication about their health and medicines

- ▶ Data presented in this paper is from the cross-sectional survey that sought to establish associations between HIV+ children's socio-demographic characteristics and family situations and their knowledge and communication about their health and medicines.
- ▶ A survey involving 394 HIV+children aged 8-17 years and their (393) caregivers was conducted in 9 H/U in Jinja District.
- ▶ Data was entered into Epi-info version 7.0 and exported to Stata version 10 and SPSS version 12 for analysis .

Background

- ▶ The number of HIV infected children on ART in Uganda rose from 17,000 in 2008/2009 to 26,699 in 2011(UAIS, 2011).
- ▶ ART and HIV counseling guidelines recommend that children infected with HIV/AIDS should be informed of their diagnosis and ART (WHO 2011, MOH ART Treatment Guidelines 2009, MOH National Policy on HIV Counseling and Testing 2005).
- ▶ Children however are often introduced to ART when they are still too young to appreciate the gravity of the diagnosis and
- ▶ The need to take medicines daily even when they are feeling well.



Guidelines: Who, how and when to disclose

Guidelines	Age of Disclosure	How to disclose	Who to disclose
WHO Guidelines on Disclosure Counseling for Children (2011)	<ul style="list-style-type: none"> - 6-12 (school-age children) - consider emotional maturity & cognitive ability of child 	<ul style="list-style-type: none"> -Disclosure is a process, - should be culturally sensitive 	<ul style="list-style-type: none"> - decision to be guided by the need a) to promote child's welfare b) minimize risk to quality of relationship between child and caregiver
Handbook on Pediatric AIDS in Africa (2011)	<ul style="list-style-type: none"> - Start as early as 5-7 years 	<ul style="list-style-type: none"> - gradually, in a culturally sensitive manner 	<ul style="list-style-type: none"> - with consent & participation of parents/caregivers
MOH ART Treatment Guidelines (2009)	<ul style="list-style-type: none"> - process should start at 7years - Children above 12 years can be counseled & tested on their own 	<ul style="list-style-type: none"> -Process based on child's age and understanding - Plan & introduce disclosure in sequential manner 	<ul style="list-style-type: none"> -Caregivers with support from H/Ws By H/W on request from child
MOH National Policy on HIV Counseling & Testing (2005)	<ul style="list-style-type: none"> -Children above 12 years -Children below 12 	<ul style="list-style-type: none"> -can be tested & disclosed to on their own. -provide on going counseling until child is 	<ul style="list-style-type: none"> -By H/W on request from child - Caregiver with support from H/W.

Background Cont'd

- ▶ Even with these guidelines, studies on pediatric disclosure reveal that communication remains problematic.
- ▶ Studies conducted in USA and Europe reveal that 25-45% of children in USA and 75-82% in Europe had not been informed of their HIV status (Vaz et al. , 2008, Heeren , 2011).
- ▶ In low and middle income countries, pediatric disclosure prevalence is as low as 20.4%(Pinzón-Iregui et al. 2012).
- ▶ Even in Uganda where there has been more openness and acceptance about HIV/AIDS, a study conducted in 2006 showed only 29% disclosure among children aged 5-17 years(Bikaako-Kajura et al.,2006).

Background Cont'd

- ▶ Communication about a potentially life threatening stigmatized and transmissible illness poses a serious psychosocial challenge to caregivers of HIV+ children (Blasini et al.2004; Instone, S.L, 2000; Wiener et al., 2007)
- ▶ In this study, we sought to establish associations between socio-demographic characteristics of HIV+ children and caregivers, and their knowledge and communication about ART.



Socio-Demographic Characteristics of HIV+ Children

Variable	Category	Frequency (N=394)	Percentage
Sex	Male	176	44.7
	Female	218	55.3
Age-group	8 - 10	135	34.3
	11-14	160	40.6
	15-17	99	25.1
Attending School	Yes	365	92.6
	No	29	7.4
Education level	Primary	308	84.4
	Secondary	57	15.6
Who do you live with	Biological parent	188	47.7
	Other	206	52.3
Orphan status	Single orphan	144	53.9
	Double orphan	123	46.1

Socio-Demographic Characteristics of HIV+ Children

- ▶ All children included in the survey were 8 years and above
- ▶ Nearly all (92.6%) were in school, majority (84.4%) being in primary school.
- ▶ More than two-thirds (67.7%) were orphans.
- ▶ Slightly less than half (46%) of these were double orphans.
- ▶ Slightly more than half (52.3%) were living with caregivers who were not their biological parents.



Socio-Demographic characteristics of Caregivers

Variable	Category	Frequency (N=393)	Percentage
Sex	Male	75	19.1
	Female	318	80.9
Ever been to school	Yes	308	78.4
	No	85	21.6
Highest level of Education	Primary	153	49.7
	Secondary +	155	50.3
Age group	≤ 30	89	22.6
	31- 40	142	36.1
	41-50	95	24.2
	51+	67	17.1
Marital status	Not married	208	52.9
	Married	185	47.1

Socio-Demographic characteristics of Caregivers

- ▶ The majority of caregivers (80.9%) were female.
- ▶ Less than a quarter (21.6%) had never been to school, half of them (50.3%) had secondary education and above.
- ▶ More than half (52.9%) were not married.
- ▶ The overall mean age was 40 years.

Caregivers were asked about their communication with the children based on the opportunities that presented themselves.

Caregivers' communication to the children regarding their medicines

Characteristic	Category	N=393	%
Explained to the child why s/he was taking him/her to clinic	No	241	61.3
	Yes	152	38.7
Explained to the child about medicines	No	80	20.4
	Yes	313	79.6
Does the child understand what the medicines are for?	No	105	26.7
	Yes	288	73.3
Has the child asked what the medicines are for?	No	251	63.9
	Yes	142	36.1
Has the child asked when s/he will stop taking medicines	No	266	67.7
	Yes	127	32.3
Explained to children that treatment was for	Yes	223	56.8%

HIV+ children's knowledge of ART

What were you told the medicines are for?	Frequency	%
T.B	32	8.1
Sickle cells	18	4.6
Malaria	29	7.4
HIV	200	50.8
Other	70	17.8
They didn't say anything	45	11.4
Total	394	100

Association between HIV+ children's demographic characteristics and knowledge of what the medicines are for

Variable	HIV	Other illnesses	Crude OR	(95%CI)	P-Value
Age group					
8-10	21	114			
11-14	92	68	0.14	0.07-0.25	< 0.001
15-17	84	15	0.03	0.01-0.07	< 0.001
Level of Education					
Primary	129	179	0.08	0.03-0.21	<0.001
Secondary	51	6			
No. of H/H members					
< 5 people	79	100	0.65	0.48 – 0.03	0.03
> 5 people	118	97			
Orphan status:					
Single orphan	70	74	0.46	0.27-0.77	<0.001
Double orphan	83	40			

Logistic Regression model for association between HIV+ children's demographic characteristics and knowledge of what the medicines are for

Variable	HIV	Other illnesses	AOR	(95%CI)	P-Value
Age group					
8-10	21	114			
>10	176	83	6.12	2.79-13.45	<0.001
Level of Education					
Primary	129	179	2.98	0.98-9.06	0.054
Secondary	51	6			
No. of H/H members					
< 5 people	79	100	1.50	0.82-2.75	0.186
> 5 people	118	97			
Orphan status					
Single orphan	70	74	1.16	0.56-2.38	0.685
Double orphan	83	40			

Findings

- ▶ Age of the child was associated with children's knowledge that they were taking medicines for HIV/AIDS.
- ▶ Based on the guidelines, all children in our study ideally should have known what the medicines that they were taking for were for.
- ▶ In reality, however only half (50.8%) of the children reported that the medicines they were taking were ARVs or medicines for HIV/AIDS.
- ▶ This is in sharp contrast to the reports given by caregivers, 79.6% reported they explained to the children why they were taking them to the clinic.
- ▶ 73.3% reported that the children understood what the medicines are for and
- ▶ 68.8% reported that they told the children they were taking medicines for HIV.

Discussion

- ▶ The fact that children younger than 10 years were less likely to know that they were taking medicines for HIV/AIDS than the older ones suggests that caregivers think that children < 10 years are too young to disclose to.
- ▶ The fact that 73.3% of the caregivers reported that the children knew that they were taking ARVs when in reality only half (50.8%) knew suggests that there is a communication gap between caregivers and their children.
- ▶ The fact that 61.3% of the caregivers did not explain to the children why they were taking them to the clinic suggests missed opportunities for communication about ARVs.

Discussion

- ▶ Reports by majority (63.9%) of caregivers that children did not ask what the medicines were for or when they would stop taking medicines (67.7%) suggests that communication between caregivers and children is minimal.
- ▶ When children were asked what they would like to know about their medicines, majority wanted to know what the medicines were for and when they would stop taking them.
- ▶ This is an indication that children would like to discuss their medicine if given opportunity.

Discussion cont'd

- ▶ Contrary to the assumptions made by the majority of caregivers that children understand what the medicines are for, in reality many of the children posed questions that indicated that they had not fully understood.
- ▶ This underscores the importance of ongoing communication about ARVs between caregivers and children.
- ▶ The fact that the caregivers were oblivious to the children's need for communication in this area suggests the need for caregivers to be supported in this area.

Implications for Policy

- ▶ Guidelines mandate caregivers to inform HIV-infected children their diagnosis by age 6 but this is not the case, indicating a communication challenge.
- ▶ Our findings suggest the need for interventions to help caregivers communicate messages regarding diagnosis tailored to the age and development of the child.
- ▶ Interventions should include children's perspectives on when and how information regarding their diagnosis should be communicated to them.

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