

# **“WHY MUST I TAKE MEDICINE?” UGANDAN CHILDREN’S UNDERSTANDING OF ANTIRETROVIRAL THERAPY (ART)**

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# 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).
- HIV+ children's understanding of ART is dependent on ongoing communication with them about their health and medicines.
- ART and HIV counseling guidelines recommend that caregivers inform HIV+ children about their diagnosis and ART by the time they are 6 years (WHO 2011, MOH ART Treatment Guidelines 2009).
- Yet studies on pediatric disclosure reveal that communication on HIV diagnosis and ART between caregivers and infected children remains problematic (Heeren, 2011; Bikaako-Kajura et al.,2006).
- This study sought to determine the associations between HIV+ children's socio-demographic characteristics, caregiver communication and knowledge of ART.

# Methods

- Data presented in this paper is from a cross-sectional survey of 394 HIV+ children aged 8-17 years and their (393) caregivers conducted in 9 Health facilities in Jinja District, Eastern Uganda, from Sept-November 2011.
- Data was entered into Epi-info version 7.0 and exported to Stata version 10 and SPSS version 12 for analysis .

## Socio-Demographic Characteristics of HIV+ Children

Variable	Category	Frequency (N=394)	Percentage
<b>Sex</b>	Male	176	44.7
	Female	218	55.3
<b>Age-group</b>	8-10	135	34.3
	11-14	160	40.6
	15-17	99	25.1
<b>Attending School</b>	Yes	365	92.6
	No	29	7.4
<b>Education level</b>	Primary	308	84.4
	Secondary	57	15.6
<b>Caregiver</b>	Biological parent	188	47.7
	Other	206	52.3
<b>Orphan status -267</b>	Single orphan	144	53.9
	Double orphan	123	46.1 <sup>4</sup>

# Socio-Demographic Characteristics of Caregivers

Variable	Category	Frequency (393)	Percentage
<b>Sex</b>	Male	75	19.1
	Female	318	80.9
<b>Ever been to school</b>	Yes	308	78.4
	No	85	21.6
<b>Highest level of education</b>	Primary	153	49.7
	Secondary+	155	50.3
<b>Age group</b>	≤ 30	89	22.6
	31-40	142	36.1
	41-50	95	24.1
	51+	67	17.1
<b>Marital status</b>	Not married	208	52.9
	Married	185	47.1

# Communication by caregivers with HIV+ children regarding medicines

Characteristic	Category	N=393	%
Explained to the child why s/he was taking him/her to the clinic	No	241	61.3
	Yes	152	38.7
Explained to the child about the 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 medicine?	No	266	67.7
	Yes	127	32.3

# Children's understanding of what the medicines were for

What were you told the medicines are for?	Frequency	Percentage
T.B	32	8.1
Sickle cell	18	4.6
Malaria	29	7.4
HIV/AIDS	<b>200</b>	<b>50.8</b>
Other (flu, coughs, skin rashes, syphilis, headache, worms, measles)	70	17.8
Wasn't told anything	45	11.3
	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
<b>Age group (years)</b>				
8-10	21	114		
11-14	92	68	2.5 (4.0-14.3)	<b>0.000</b>
15-17	84	15	33.3 (14.3-100.0)	<b>0.000</b>
<b>Level of Education</b>				
Primary	129	179	12.5 (4.8-33.3)	<b>0.000</b>
Secondary	51	6		
<b>Orphan status</b>				
Single orphan	70	74	2.2(1.3-3.7)	<b>0.000</b>
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
<b>Age group (years)</b>				
8-10	21	114	6.1 (2.8-13.5)	<b>0.000</b>
>10	176	83		
<b>Level of Education</b>				
Primary	129	179	3.0 (1.0-9.1)	<b>0.054</b>
Secondary	51	6		
<b>Orphan status</b>				
Single orphan	70	74	1.2(0.6-2.4)	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.
- Only half (50.8%) reported that the medicines they were taking were for HIV/AIDS.
- This is in sharp contrast to the reports given by the caregivers where:
  - 79.6% reported that they had explained to the children what the daily medicines were for,
  - 73.3% reported that the children knew what the medicines were for.
- While the majority (64%) of caregivers reported that children did not ask what the medicines were for or when they would stop taking medicines (68%), these were the very questions posed by (40%) of the children when asked by the researchers *what would you like to know about your medicines?*

# Discussion

- Based on the guidelines, all children in this study should ideally have known what the medicines that they took daily were for (WHO 2011, MOH ART Treatment Guidelines 2009).
- The finding 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 there are communication challenges on the part of caregivers.
- It is possible that caregivers think that children < 10 years are too young to be disclosed to or they just find the subject difficult to communicate about (Menon et al., 2007, Wiener et al., 2007)
- The discrepancy between the 73.3% of the caregivers who reported that they had told the children what the medicines were for and the 50.8% of children who actually knew what the medicines were for shows that a communication gap exists between caregivers and HIV+ children.

# Discussion

- This communication gap is further exemplified by the 61.3% of caregivers who reported that they did not explain to the children why they were taking them to the clinic, the 64% who reported that children had never asked them what the medicines were for or when they would stop taking medicines (68%).
- Children's posing of questions to the researchers suggests that this is information that they would like to know about the medicine they are taking and underscores the need for ongoing communication with children about HIV and ARVs.
- There seemed to be missed opportunities for communication between caregivers and children about HIV and ART e.g. when taking the children to the clinic or when giving them medicines.

# Implications for Policy

- Guidelines recommend that caregivers should ideally be the ones to disclose HIV status to children. This assumes that the caregiver and child have a close interpersonal relationship, which is not always the case. Less than half (47%) of the children in this study were living with a biological parent.
- Our findings suggest the need for interventions that prepare and support caregivers for this task. Where caregivers have difficulty assuming the task, H/Ws in some cases may assume the responsibility of explaining to the child.
- Furthermore these guidelines recommend that disclosure happens by age 6 but this is not always the case as our findings show. Guidelines should stipulate on content and suggest how information can be packaged for the different age groups.
- Children's perspectives on what information should be communicated to them is also important to keep in mind.

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