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HIV-1 DIAGNOSIS DISCLOSURE TO INFECTED CHILDREN ON ANTIRETROVIRAL THERAPY IN KENYA: PREVALENCE, CORRELATES AND CAREGIVERS' PERSPECTIVES

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**HIV-1 DIAGNOSIS DISCLOSURE TO INFECTED CHILDREN ON ANTIRETROVIRAL THERAPY IN KENYA: PREVALENCE, CORRELATES AND CAREGIVERS' PERSPECTIVES**

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**ABSTRACT**

**Background:** HIV-1 status disclosure to children is key to comprehensive paediatric HIV care. Increased access to antiretroviral drugs (ART) has led to survival of infected children posing a new challenge to parents on whether, when or how to disclose.

**Objective:** To understand the prevalence, correlates and caregivers' perspectives on disclosure to HIV-1 infected children on ART.

**Methodology:** A mixed methods study with a cross-sectional design for the quantitative aspect of the study was done. The target population was caregivers to HIV-1 infected children aged 6 to 14 years receiving HIV care at Mbagathi Hospital, Kenya. Data was collected using questionnaires and interview guides. Chi-square and logistic regression were used to determine predictors of disclosure while thematic analysis was done for qualitative data.

**Results:** Disclosure prevalence was 36% (n=254). Age 10-14 compared to 6-9 years (aOR=10.97; 95% CI=5.7-21.2; p<0.0001), longer duration on HIV care (aOR=1.91; 95% CI=1.02-1.97; p<0.0001) for >5 years compared to <1 year, which was similar to 1-5 years duration (aOR=1.03; 95% CI=0.36-1.97; p=0.233) and perceived importance of disclosure (aOR=2.58; 95% CI=1.36-4.90; p=0.004) were significantly associated with disclosure. Fear of stigma and discrimination was associated with low disclosure (OR=0.931; 95% CI=0.44-151; p<0.0001). Caregiver's perceptions of importance of disclosure and influence of socio-cultural factors influenced disclosure.

**Conclusion:** Disclosure prevalence was low despite high caregivers' perception of disclosure as important. Age of child, child's duration on care, caregivers'

**perceptions importance of disclosure and socio-cultural factors were associated with increased disclosure.**

## INTRODUCTION

The World Health Organization (WHO) recommends all school-going age children be informed of their HIV positive status incrementally (1). Despite this recommendation, majority of HIV infected children worldwide do not know their status. Increased access to ART has led to increased survival of infected children, posing a new challenge to parents on whether to disclose to them (2). Studies done in several countries showed that rates of HIV status disclosure to children aged between 6 to 14 years are low. Reasons cited by the caregivers included inability of the children to understand, fear that the children might disclose to others, fear of psychological disturbance of the children and fear of blaming the parents (3,4). In western Kenya, it has been reported that rates of disclosure in children are low, with only 11.1% of children knowing their status (4).

Disclosure to infected children has many benefits. Children who do not know they are infected may be unlikely to take medication regularly. Disclosure to children helps them overcome the anger of being HIV positive improving adherence (4,5) With disclosure, adherence is optimal since children are involved in their appointments (4). It helps in overall psychosocial development of the child, improving treatment outcome (6). Disclosure is associated with safer sex behaviors in adolescents (7). With non-disclosure and early sexual debut, transmission of already resistant virus may occur, leading to increased HIV-related illnesses and deaths (4,8).

In the Kenyan context, caregivers are in dilemma on whether to disclose or not. During clinical encounters, caregivers have reported disclosure related challenges including convincing their children to take ART, especially when their siblings are not infected. Disclosure is influenced by many factors from a caregivers' perspective (3). We thus set out to understand the prevalence, correlates and caregivers' perspectives on disclosure to HIV-1 infected children on ART.

## METHODS

*Study design and setting:* We conducted a cross-sectional study of caregiver-child dyads receiving HIV-1 treatment services at Mbagathi Hospital. It is one of the largest public health facilities in Nairobi County, Kenya. It provided HIV treatment services to an estimated 384 HIV-1 infected children at the time of the study. Caregivers of 254 HIV infected children aged from 6 to 14 years receiving HIV-1 care and treatment services were enrolled.

*Data collection and procedures:* Data on socioeconomic, cultural factors and caregivers' perceptions of HIV-1 diagnosis disclosure was collected by research assistants through questionnaires.

We held three in-depth interviews; one with caregivers who had disclosed, another with caregivers who had not disclosed and the third with a nurse counsellor to gain more insight on factors influencing disclosure from the health care worker perspective. The in-depth interviews were facilitated by a social scientist and assisted by the principal investigator.

Discussions were recorded and later transcribed.

*Data analysis:* Descriptive statistics were used to describe the study population. Frequencies (percentages) and medians (IQR) were used to present categorical and continuous data respectively. Bivariate analysis was done using Chi-square tests to determine association between independent variables and disclosure. Univariable and multivariable logistic regression models were used to identify factors associated with disclosure and control for confounding variables. Crude and adjusted odd ratios (OR), 95% CIs and p-values were reported. Quantitative data was analysed using Stata version 16 (9).

For qualitative data, recorded in-depth interviews were transcribed and closely examined to identify common themes. Each emerging theme was coded, reviewed and defined.

Ethical considerations

The protocol was approved by Kenyatta University Ethical Review committee (KU/R/COMM/51/750). Permit was obtained from the National Commission for Science, Technology and Innovation (NACOSTI/P/16/18171/13816) and Mbagathi hospital management. All participants signed an informed consent prior to participating in the study.

## RESULTS

A total of 254 caregivers of HIV-1 infected children participated. Most were aged 36-45 years (46.1%), followed by 26-35 years (35.8%), >45 years (11.8%), 18-25 years (5.1%) and 0.4% for 26-35 years and 36-45 years each. Among the caregivers, 46.9% were married, 55.1% had secondary education and 67.3% were biological parents to the infected children. 67.2% of the caregivers were HIV-1 infected. The children's median age was 12 years (IQR 10 – 13) and half (50.4%) were female.

**Table 1**

*Socioeconomic characteristics of the caregiver-child dyads, Mbagathi Hospital*

Variable		N (%)
Gender of Child	Male	126(49.6%)
	Female	128(50.4%)
Age of child (years) Mean =10.5; SD =3.0	6-9	54(21.3%)
	10-14	200(78.7%)
Age of Caregiver (years) Mean=37; SD=7.4	18-25	13(5.1%)
	26-35	92 (36.2%)
	36-45	119(46.6%)
	>45	30(11.8%)
Marital Status	Married	119 (46.9%)
	Divorced/ Separated	40 (15.7%)
	Single	56 (22.1%)
	Widowed	39 (15.4%)
Religion	Christian	245(96.5%)
	Muslim	9 (3.5%)
Education level	Primary	34(13.4%)
	Secondary	140 (55.1%)

	College/University	80 (31.5%)
Employment status	Employed	129 (51%)
	Self employed	104(41%)
	Unemployed	21(8%)
Relation to child	Parent	171(67.3%)
	Sibling	15(5.9%)
	Relative	68(26.8%)
Caregiver HIV Status	Negative	83 (32.8%)
	Positive	171(67.2%)

**Disclosure:** Of 254 caregivers, 36% had disclosed HIV-1 status to their children. Majority (78%) reported to have disclosed with the help of a healthcare worker. Caregivers felt pushed to disclose HIV-1 status to the children mainly because of constant enquiry by the children on why they were taking drugs and children's poor adherence to ART.

One 33-year-old female expert patient, mother to 11-year-old infected child remarked that:

*"My child was asking me why he is taking drugs. Sometimes he would take drugs well, other times he would refuse to take. This pushed me to disclose to him"*

Another 46-year-old HIV positive female caregiver, mother to 13-year-old child said that:

*"She was not taking her drugs well. She was telling me to give her siblings drugs as well. This made me to consider disclosure seriously"*

Misconceptions about HIV-1 that result in stigma and discrimination had an influence on non-disclosure. The most cited misconceptions were that being infected was seen as a result of promiscuity (67%), or as God's punishment (17%) or that the family is bewitched (16%). Of the 163 (64%) caregivers who had not

disclosed, 61% cited these misconceptions as influencing their nondisclosure.

**Correlates of Disclosure:** Characteristics of caregivers and children who reported disclosure of child's HIV-1 status were similar to those who did not with respect to sex of the child, caregiver relationship to the child, religion, caregiver HIV -1 infection status, marital status, caregiver education level and employment status as shown on Table 2.

Disclosure to older children aged 10-14yrs was higher than that of younger children aged 6-9 years ( $p<0.001$ ). Similarly, disclosure to children was higher among older caregivers than younger caregivers ( $p<0.001$ ). Children whose duration on HIV care was more than 5 years had a higher disclosure rate than those with a shorter duration in HIV care ( $p<0.001$ ). Caregivers' perception of importance of disclosure as very important was associated with a higher disclosure prevalence among their children compared to the other categories ( $p=0.003$ ). Caregivers who felt that fear of stigma and discrimination inhibited disclosure of HIV-1 to children had lower disclosure prevalence among their children ( $p=0.007$ ), as shown in Table 2.

**Table 2**  
*Correlates of disclosure among caregiver-child dyads, Mbagathi hospital*

Variable	Disclosure		X <sup>2</sup>	df	p-value
	No	Yes			
Sex of child			0.0505	1	0.822
Female	83(65%)	45(35%)			
Male	80(63%)	46(37%)			
Age of child			38.3	1	<0.0001
6-9yrs	54(100%)	0(0%)			
10-14yrs	109(56%)	91(44%)			
Age of caregiver			20.9093	3	<0.0001
18-25yrs	9(69%)	4(31%)			
26-35yrs	74(80%)	18(20%)			
36-45yrs	68(57%)	51(43%)			
>45yrs	12(40%)	18(60%)			
Relationship to child			3.317	2	0.19
Relative	44(65%)	24(35%)			
Sibling	8(53%)	7(47%)			
Parent	111(65%)	60(35%)			
Religion:-			0.3014	1	0.583
Christian	158((64%)	87(46%)			
Muslim	5(56%)	4(44%)			
Caregiver HIV status			3.432	1	0.402
HIV Negative	50(60%)	33(40%)			
HIV Positive	113(66%)	57(34%)			
Marital status			3.5992	3	0.308
Married	83(70%)	36(30%)			
Divorced/separated	22(55%)	18(45%)			
Single	35(63%)	21(37%)			
Widowed	23(59%)	16(41%)			
Caregiver education level			1.4024	2	0.496
Primary	19(56%)	15(44%)			
Secondary	90(64%)	50(36%)			
Tertiary	54(68%)	26(32%)			
Duration in HIV care (years)			25.0555	2	<0.0001
<1yr	15(94%)	1(6%)			
1-5yrs	39(91%)	4(9%)			
>5yrs	109(56%)	86(44%)			
Caregiver employment Status			5.3473	3	0.069
Employed	85(66%)	43(34%)			
Self employed	67(65%)	36(35%)			
Unemployed	11(48%)	12(52%)			
Partner HIV status			0.1745	1	0.676
HIV Negative	21(70%)	9(30%)			
HIV Positive	46(66%)	24(44%)			
Perceived importance of disclosure			8.713	1	0.003

No	55(79%)	15(21%)			
Yes	108(59%)	76(41%)			
Fear of stigma and discrimination			2.3137	1	0.007
No	51(55%)	42(45%)			
Yes	132(82%)	29(18%)			

At multivariable level, children aged 10-14 years were 10.97 times more likely to know their status compared to children aged 6-9 years (aOR=10.97; 95% CI=5.7-21.2;  $p < 0.0001$ ). Longer duration on care increased the chances of a child knowing his/her status. Disclosure prevalence was similar among children who had been on care for 1-5 years compared to those who were on care for less than a year (aOR=1.03; 95% CI=0.36-1.97;  $p=0.233$ ). However, those who were on care for >5 years were 1.91 times more likely to be disclosed to compared to those who were on care for less

than a year (aOR=1.91; 95% CI=1.02-1.97;  $p < 0.0001$ ). Caregivers who perceived disclosure as very important were 2.58 times more likely to disclose compared to caregivers who had a different opinion on importance of disclosure (aOR=2.58; 95% CI= 1.36-4.90;  $p=0.004$ ). Caregivers who had concerns on stigma and discrimination associated with disclosure were 0.931 times less likely to disclose compared to those who had a different opinion (aOR=0.931; 95% CI=0.44-1.51;  $p < 0.0001$ ), as shown in Table 3.

**Table 3**

*Regression analysis of socio demographic and economic determinants of HIV-1 sero status disclosure to infected children accessing care at Mbagathi Hospital*

Variable	Adjusted Odds Ratio	95% Confidence Interval	p-value
Age of child (years)			
6-9*	-	-	-
10-14	10.97	5.7-21.2	<0.0001
Age of caregiver			
18-25 yrs.*	-	-	-
26-35 yrs.	0.55	0.15-1.98	0.358
36-45 yrs.	1.69	0.49-5.79	0.405
>45 yrs.	3.38	0.84-13.49	0.085
Duration of care (years)			
< 1yr*	-	-	-
1-5 yrs.	1.03	0.36- 1.67	0.233
>5 yrs.	1.91	1.02-1.97	<0.0001
Perceived importance of disclosure			
No*	-	-	-
Yes	2.58	1.36-4.90	0.004
Influence of socio-cultural factors on disclosure			
No*	-	-	-
Yes	0.931	0.44 – 1.51	<0.0001

\*Reference category

**Caregivers' Perceptions on Disclosure of HIV-1 status to infected children:** On importance of disclosing to children, 184 (72%) caregivers rated it as "very important", 61 (24%) as "important", 6 (2.3%) had a neutral opinion and 3 (1.2%) rated it as "not important". Among those who rated disclosure as important or very important, it was because it helped reduce chances of accidental disclosure (38.3%) and helped in the psychosocial development of the child (0.3%). Among the caregivers who had disclosed to their children, 72.5% said that their children improved adherence to treatment after knowing their HIV status.

The caregivers cited stigma and discrimination as inhibitors of disclosure. These forms included isolation from family and friends; being negatively talked about; rejection by spouse or family; or being seen as promiscuous. The caregivers felt that socio-culturally driven misconceptions around HIV led to stigma and discrimination.

A 39-year-old HIV positive female, mother to 9-year-old child noted that:

*"Parents do not want to disclose because they will be termed as promiscuous by their children... HIV is viewed as witchcraft"*

This was reinforced by a 42-year-old female psychological counsellor at the hospital who remarked:

*"If the culture views HIV infection as promiscuity, caregivers fear because they don't want to be labelled as promiscuous, thus reluctant to disclose...The child will view me the way the community views me."*

## DISCUSSION

The findings showed low prevalence of disclosure to HIV-1 infected children (36%),

which was comparable to other findings in Ethiopia (33.3%), Nigeria (29%), Western Kenya (11.1%), Thailand (21%) and Uganda (31%) (3,4,10). However, some higher disclosure rates have been reported in other studies carried out in Uganda (56%), Rwanda (64%) and Indonesia (43.2%) (2,11,12). The low disclosure rates have been attributed to several reasons, including caregivers believing children are too young to understand, disclosure said to have negative emotional consequences for the child and caregivers saying that disclosure would stress the child (7). Others include fear of stigma and discrimination, fear that the child may disclose to others (3) and caregivers fearing blame from the children(13).

In this study, the main reasons for non-disclosure were the view that the children were too young, fear of negative health consequences to the child and that the children would disclose to other people.

Of the caregivers who had disclosed, the majority reported to have disclosed with the help of a health worker, while a low proportion reported that the caregiver disclosed without external help. This concurs with a study in India where majority of children who had been disclosed to had been informed by a health care workers (14). This differed with a study done in Ethiopia where a high proportion of the children were disclosed to by their caregivers. It has been argued that if disclosure was left to health care workers, it would be done at the right age and the children would get the right information. However, children would often like to hear it from the parent (5).

Disclosure has many benefits. It helps in psychosocial development of the child and improving treatment outcomes(6,15). Young people who have been appropriately informed

of their illness early exhibit better coping skills (7). Self-reported psychological distress has also been shown to be less among HIV positive children who know their status (8). With disclosure, adherence is optimal since children are involved in their treatment appointments (4,8). With non-disclosure and early sexual debut, transmission of already resistant virus strains may occur, leading to increased HIV-related illnesses and deaths which is a setback to HIV management (4,8)

In this study, majority of the caregivers believed it was very important to disclose to their children. However, this did not translate into the disclosure, since more than half had not disclosed. This concurs with a study done in Uganda, which showed that caregivers reported disclosure to be important but disclosure was low, at 23.% (16). This indicates that knowing the importance of disclosure to children is not enough to influence disclosure. Other factors like socio-cultural misconceptions, child being too young to understand and caregivers finding it difficult to explain to the child how the child got infected have had stronger influence on disclosure in this study.

We found that age of child influenced disclosure, with most caregivers more likely to delay disclosure until children were 10 years and above. This concurs with studies in several countries which indicated that it was more common for older children to know their status than younger ones (2,3). This is likely due to increasing maturity and responsibility for self-care that required knowledge of their HIV status (2). Most of the caregivers consider children younger than 10 years as incapable of understanding their illness (3,6,17).

Disclosure is more likely with increasing duration on care. Caregivers of children who have been on care for over 5 years were more likely to disclose compared to those of children

on care for less than 5 years. This concurs other studies which showed that children with less than 5 years since HIV diagnosis were less likely to know their status compared to those diagnosed 5 or more years earlier (18). This is likely so as children who have been on care for a longer period have more contact with health workers whereby, they may get information informally from the hospital environment. In addition, children tend to repeatedly question why they are always taking pills, prompting caregivers to disclose their HIV status (18).

We did not find any significant associations of disclosure with caregiver age, caregiver marital status, caregiver employment status, caregiver relationship to child and caregiver HIV status.

Influence of socio-culturally driven misconceptions resulting to stigma and discrimination was associated with non-disclosure of HIV status to infected children. Caregivers who thought they would be discriminated after people know their status of their children were less likely to disclose. This concurs with other studies that showed HIV was still seen as a sickness inflicted by the supernatural as a result of sins committed, thus influenced disclosure greatly (15,19). In this study, caregivers gave various reasons on how they thought culture would influence disclosure. These included HIV being seen as witchcraft and the HIV infected being seen as promiscuous. This may explain why caregivers who reported socio-culturally driven misconceptions resulting to stigma and discrimination were less likely to disclose to their infected children.

Addressing these socio-culturally driven misconceptions at the community can help promote disclosure to infected children.

The strength of this study is that sample used was as representative as possible, thus the findings can be generalizable in similar



settings. The study utilized a mixed method approach which obtained qualitative data providing better understanding of correlates and caregivers' perspectives of HIV-1 disclosure in Kenya. However, it had one weakness; it did not interview children. It relied on caregiver's report on whether one has disclosed to his/her child or not. Caregivers could have reported what the researcher 'wanted to hear'.

There was a possibility of social desirability bias whereby caregivers could have altered the way they responded to the question of disclosure. This was however minimised by counterchecking reported child's HIV status with disclosure follow up checklist on the child's records.

Multivariable logistic regression modelling was used to identify factors associated with disclosure and control for confounding variables. This has been added to the data analysis section.

## CONCLUSION

The prevalence of HIV-1 disclosure among infected children aged 6 to 14 years was very low though majority of the caregivers perceived disclosure as very important. Older child's age, longer duration on care and caregivers' perceptions of importance of disclosure were significantly associated with disclosure. Socio-culturally driven misconceptions about HIV that lead to fear of stigma and discrimination influenced disclosure adversely. There is need to empower caregivers and health workers to disclose and implement strategies to address HIV misconceptions. Further research is recommended on understanding the magnitude of HIV-related stigma and discrimination and the strategies of mitigating the same in Kenya.

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