

BMJ Open Perinatally acquired HIV-positive status disclosure and associated factors in Dire Dawa and Harar, Eastern Ethiopia: a health facility-based cross-sectional study

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ABSTRACT

Objectives The aim of this study was to assess the level and factors associated with caregivers' disclosure of perinatally HIV-infected (PHIV+) children's seropositive status.

Design We conducted a cross-sectional study in five public health facilities providing HIV treatment and care in Dire Dawa and Harar, Eastern Ethiopia. The data were collected from 310 caregivers through face-to-face interviews and record reviews. Data analyses were done using STATA V.14.2 and statistical significance was declared at p value <0.05.

Results The study revealed that the level of PHIV+ diagnosis disclosure was 49.4% (95% CI 43.8 to 54.9). Mean age at disclosure was 11.2 years. Disclosure level was higher among children who frequently asked about their health status (aOR (adjusted OR) 2.04, 95% CI 1.04 to 4.03) and when caregivers knew other people who had a disclosure experience (aOR 2.49, 95% CI 1.17 to 5.32). Disclosure level was less among children of 12 years or below (aOR 0.04, 95% CI 0.02 to 0.09) and among caregivers practising deception about the children's HIV positive status (aOR 0.38, 95% CI 0.19 to 0.74).

Conclusion Only half of the caregivers disclosed their child's PHIV+ diagnosis. To facilitate disclosure, caregivers should be counselled about the appropriate age of disclosure and related misconceptions that hinder it. It is also apparent that caregivers need to be guided as to how to address children's frequent questions about their health status. These interventions can be made in a one-on-one approach or through patient group counselling when they come to get healthcare services.

INTRODUCTION

Globally, at the end of 2016, an estimated 2.1 million adolescents aged 10–19 years were HIV infected, and 1.7 million were in sub-Saharan Africa.¹ Only a few decades ago, due to lack of treatment options, diagnosis with HIV for children was like a death sentence.² Perinatal HIV infection (PHIV+) has dramatically decreased with the advent of highly effective antiretroviral treatment (ART). However, it

Strengths and limitations of this study

- The study presents the level of perinatal HIV infection (PHIV+) diagnosis disclosure and associated factors in resource-limited settings where such aspects have been overlooked in HIV care and treatment.
- All caregivers in public health facilities providing HIV/AIDS care and treatment services in the study settings were included, increasing the generalisability of our findings.
- As we measured disclosure based on the caregiver's report, the study may have suffered from a social desirability bias.
- Health facility-related factors that might affect the study outcome were not assessed and need to be addressed in the future.

was reported that only three in five HIV-positive pregnant and breastfeeding women received ART in 2014, leading to continued perinatal HIV transmission.³ Effective treatment means that children with PHIV+ who are living anywhere in the world can now safely pass through adolescence and enter into adulthood.² The continued burden of new PHIV+ and the transition of the HIV infection from a rapidly fatal to a chronic condition has brought challenges in the treatment and care of these groups of children.^{2,4}

The increasing survival of children with PHIV+ into adolescence and adulthood has brought significant adherence challenges to the long-term treatment, as well as developmental issues including, among many, peer relationships, puberty and sexuality.^{5,6} On the other hand, another important challenge, as more of these children reach adolescence and adulthood, is disclosure of their HIV status.^{7,8} HIV diagnosis disclosure entails communication about a potentially life-threatening, stigmatised and transmissible illness.

Consequently, caregivers fear that such communication may create distress for children and reveal a family secret related to HIV infection.⁹ PHIV+ diagnosis disclosure is further complicated by lack of skill on the caregiver's side to undertake disclosure. Furthermore, poor access to training and lack of clear guidelines for healthcare workers on PHIV+ diagnosis disclosure might have played a role in delaying disclosure.¹⁰ Delay in disclosure has implications both for the clinical outcome as well as transmission of the infection, as children enter the pubertal stage and start romantic relationships and ultimately sexual intercourse.^{10–13}

In resource-limited settings, only a few children with PHIV+ know their HIV-positive status^{14 15} despite several studies reporting the benefits of disclosure both to the caregiver and the child. Benefits of disclosure reported in previous research include improved adherence, providing answers to children's questions, fulfilling the child's right to know and the child being able to protect him/herself or others.^{16 17} Research also suggests that HIV-infected children who know their status may be better able to seek social support and have improved coping skills.^{18 19}

Previous studies have reported factors related to caregivers' disclosure of PHIV+. However, the findings come from context-specific qualitative studies or from quantitative studies with small sample sizes making generalisation difficult.²⁰ The child-related factors of disclosure in previous studies include age, level of maturity/awareness, level of education, duration since HIV diagnosis and initiation of ART.^{14 15 17 21} Similarly, caregiver-related factors include fear of the negative effects of disclosure and feeling worried about disclosure or unprepared to disclose.^{14 17 22}

Despite several studies conducted elsewhere, there is a dearth of information on the magnitude of PHIV+ diagnosis disclosure and associated factors specifically in eastern Ethiopia. Previous studies conducted on PHIV+ diagnosis disclosure in Ethiopia considered children below the age of 15 years or were conducted using a small sample size.^{14 23–25} In our study, all children had started ART, which was reported as one of the factors associated with disclosure.¹⁷ Therefore, we aimed to assess the proportion of PHIV+ diagnosis disclosure and its correlates among caregivers who had PHIV+ children between the ages of 6 and 18 years.

MATERIALS AND METHODS

Study setting and design

A cross-sectional study was conducted from 1 February to 30 April 2016 in five public health facilities in Eastern Ethiopia: four hospitals (two in Harar and two in Dire Dawa) and one health centre in Dire Dawa. The adult HIV prevalence in Dire Dawa City Administration Council was 4.0% (4.3% for women, 3.7% for men) and it was 2.8% (3.8% for women, 1.7% for men) in Harari Regional State.²⁶ According to a projection estimate for the year 2016, there were 456 HIV-positive children between the

ages of 0 and 14 years in the urban areas of Harar and 1029 in Dire Dawa.²⁷

Participants

Primary caregivers who had PHIV+ children between the ages of 6 and 18 years were included. A caregiver who had more than one PHIV+ child in the specified age range reported information only about one randomly selected child to avoid problems with the estimation of the level of disclosure. In this study, a primary caregiver is defined as a person who is responsible for all needs of the child, takes care of the child and lives with the child. All children for whom information was collected had started on ART.

Sample size

Four public hospitals (two in Harar and two in Dire Dawa) and one health centre located in an urban area with at least 10 eligible caregivers were included. All eligible caregivers in these facilities were included. Accordingly, a total of 325 caregivers were identified and 310 provided information: 210 from Dire Dawa and 100 from Harar.

Data collection

Data were collected through face-to-face interviews with primary caregivers using a structured questionnaire and a checklist from the children's and caregivers' medical record card in the ART units of the respective health facilities. Data collectors were nurses who had been working in the ART units of the respective health facilities for at least 3 years. They received a 1-day orientation on the objectives of the study, on data collection techniques and on ways to avoid interviewer bias during data collection. Onsite supervisors both in Dire Dawa and Harar study sites checked the proper administration of the data collection and checked the completeness and consistency of the questionnaires.

Measurement and definitions

Caregiver-related and child-related sociodemographic and HIV-positive status data were collected during the caregiver interviews. Furthermore, the primary caregiver's HIV diagnosis test results (if applicable) and the child's HIV diagnosis and ART status were confirmed from the medical record card using the patient's unique ART number. The sociodemographic data collected included age, sex and educational status of the caregiver and the child, caregiver's religion, ethnicity, relation to the child and the child's biological parent survival.

We assessed children's HIV-positive status disclosure and other disclosure variables using items shown in [table 1](#).

In this study, deception was defined as a caregiver's intentional false answer to a child's question regarding his/her health status or intentionally attributing a child's health problem to other unrelated health-related conditions. Disclosure was said to happen when a caregiver told his/her child that the child has HIV/AIDS by naming the disease.

Table 1 Disclosure-related caregiver questionnaire items administered in the perinatal HIV infection diagnosis disclosure study, East Ethiopia, 2016

Items 1–7 were administered to ALL caregivers

1.	Does the child ever ask questions about his/her health status?
2.	Do you ever intentionally give the child wrong information in response to questions about his/her health status?
3.	Does the child know that the name of his/her illness is HIV?
4.	At what age do you perceive that a perinatally acquired HIV-positive child should know that he/she has HIV?
5.	Do you know someone (eg, a caregiver like you) who has disclosed perinatally acquired HIV status?
6.	What do you think about the importance of a third person's presence to assist disclosure?
7.	Whom do you prefer to seek help from for HIV status disclosure?

Items 8–9 were administered ONLY to disclosed caregivers (answered 'YES' to item 3)

8.	Duration since the child has known that he/she has HIV (in months)
9.	Child age at disclosure (in years)

Statistical analysis

The data were entered in to EpiData V.3.1 and cleaning and analysis were done using STATA V.14.2. The outcome variable was disclosure dichotomised into disclosed (Yes=1) and not disclosed (No=0). A multivariable binary logistic regression model was applied to identify independent factors. Multicollinearity was tested using the variance inflation factor (VIF) and 'children's educational status' was dropped from the final model as it had a VIF as high as 6.37. The Hosmer-Lemeshow goodness-of-fit test was used to assess model adequacy. Statistical significance was declared at p value <0.05 .

Ethical issues

Ethical approval was obtained. Written informed consent was obtained from each eligible caregiver before the data collection. No personal identifiers were collected, and data confidentiality were strictly maintained.

Patient and public involvement

Growing literature on PHIV+ disclosure indicates challenges in providing disclosure-related services in resource-limited settings. The authors had closely observed these in one of the hospitals in the study settings and hence designed the conduct of this study. Research assistants working in ART units recruited study participants. To communicate the findings, a summary of key results will be translated into local languages and will be communicated to health facilities in the study settings.

Table 2 Sociodemographic characteristics of caregivers and their perinatally HIV-infected children, East Ethiopia, 2016

Variables	Response category	n=310 (%)
Caregivers' characteristics		
HIV serostatus	Positive	229 (73.9)
	Negative	76 (24.5)
	Don't know	5 (1.6)
Age in years, median (IQR)	38 (15)	
Sex	Male	56 (18.1)
	Female	254 (81.9)
Educational status	No formal education	85 (27.4)
	Primary education	111 (35.8)
	Secondary and above	114 (36.8)
Religion	Christian	226 (72.9)
	Muslim	84 (27.1)
Ethnicity	Amhara	172 (55.5)
	Oromo	88 (28.5)
	Other*	50 (16.2)
Relation to the child	Biological caregiver	209 (67.4)
	Non-biological caregiver	101 (32.6)
Children's characteristics		
Age, mean (SD)	12.07 (± 3.06)	
Sex	Male	146 (47.1)
	Female	164 (52.9)
Educational status	Not school going	8 (2.6)
	Primary, below grade 5	144 (46.5)
	Primary, grade 5 to 8	126 (40.6)
	Secondary and above	32 (10.3)
Parent/s alive	Both parents alive	145 (46.8)
	Only mother alive	75 (24.2)
	Only father alive	51 (16.5)
	Both parents not alive	39 (12.6)

*Guraghe, Somali, Tigray and Harari.

RESULTS

Sociodemographic characteristics

Of the 325 eligible caregivers, 15 caregivers did not keep their appointments during the study period, making the response rate 95.4% (310/325). Most of the caregivers, 81.9% (254/310), were women, and 67.4% (209/310) were biological parents. Seventy four per cent (229/310) of the caregivers were HIV positive and their median age was 38 years. More than half of the PHIV+ children were girls: 52.9% (164/310). The mean age of children was 12 years and 12.6% (39/310) had lost both biological parents (table 2).

Table 3 Level of perinatal HIV infection diagnosis disclosure by caregiver and child sociodemographic characteristics, East Ethiopia, 2016

Variables	Response category	Disclosure		Pearson's χ^2 (df)	P values
		Yes=153, n (%)	No=157, n (%)		
Caregiver's characteristics					
Age in years	<30	19 (12.4)	29 (18.5)	3.5(2)	0.171
	30 to 44	84 (54.9)	89 (56.7)		
	≥ 45	50 (32.7)	39 (24.8)		
Sex	Male	27 (17.7)	29 (18.5)	0.04(1)	0.85
	Female	126 (82.4)	128 (81.5)		
Educational status	No formal education	38 (24.8)	47 (29.9)	1.13(2)	0.569
	Primary education	58 (37.9)	53 (33.8)		
	Secondary and above	57 (37.3)	57 (36.3)		
Religion	Christian	127 (83.0)	99 (63.1)	15.6(1)	<0.001
	Muslim	26 (17.0)	58 (36.9)		
Ethnicity	Amhara	91 (59.5)	81 (51.6)	2.2(2)	0.33
	Oromo	41 (26.8)	47 (29.9)		
	Other*	21 (13.7)	29 (18.5)		
Relation to child	Biological caregiver	104 (68.0)	105 (66.9)	0.04(1)	0.837
	Non-biological caregiver	49 (32.0)	52 (33.1)		
Child's characteristics					
Sex	Male	65 (42.5)	81 (51.6)	2.58(1)	0.108
	Female	88 (57.5)	76 (48.4)		
Age in years	6 to 9	8 (5.2)	69 (44.0)	114.6(2)	<0.001
	10 to 12	28 (18.3)	60 (38.2)		
	13 to 18	117 (76.5)	28 (17.8)		
Educational status	Did not start education	3 (2.0)	31 (19.8)	72.0(2)	<0.001
	Below grade 5	36 (23.5)	82 (52.2)		
	Grade 5 and above	114 (74.5)	44 (28.0)		
Parent/s alive	Both parents alive	58 (37.9)	87 (55.4)	10.5(3)	0.015
	Only mother alive	41 (26.8)	34 (21.7)		
	Only father alive	29 (19.9)	22 (14.0)		
	Both parents not alive	25 (16.3)	14 (8.9)		

*Guraghe, Somali, Tigray and Harari.

df, degree of freedom; significant at p value <0.05.

PHIV+ diagnosis disclosure

Overall, 49.4% (95% CI 43.8 to 54.9) of the caregivers had disclosed PHIV+ diagnosis. The level of disclosure increased as child age increased. For example, of the total children who were reported to know their HIV-positive status, 76.5% were 13 years and above. In contrast, children below the age of 10 years constituted only 5.2%. Furthermore, other caregiver and child characteristics which had some association with disclosure included a caregiver being Christian, both parents were alive and the child being grade 5 or above (table 3).

For school-age children (6–12 years), more boys than girls knew their HIV-positive diagnosis. Conversely, for adolescents of age 13 and above, more girls than boys knew their HIV-positive diagnosis (figure 1). The median

duration since a child had his/her PHIV+ diagnosis disclosed was 24 months and the mean age at disclosure was 11.2 (SD=±2.4) years.

Caregivers reported that they needed assistance in the process of PHIV+ diagnosis disclosure. Of the total caregivers, 56% (173/310) reported that they needed assistance. Among these, 65.9% (114/173) said they needed it from a healthcare worker, 17.9% (31/173) from a family member, 11.6% (20/173) from their partner, 3.5% (6/173) from an HIV-positive person and 1.2% (2/173) from other sources.

Factors associated with PHIV+ diagnosis disclosure

The variables with p value <0.2 in the bivariate binary logistic regression were entered into the final model.

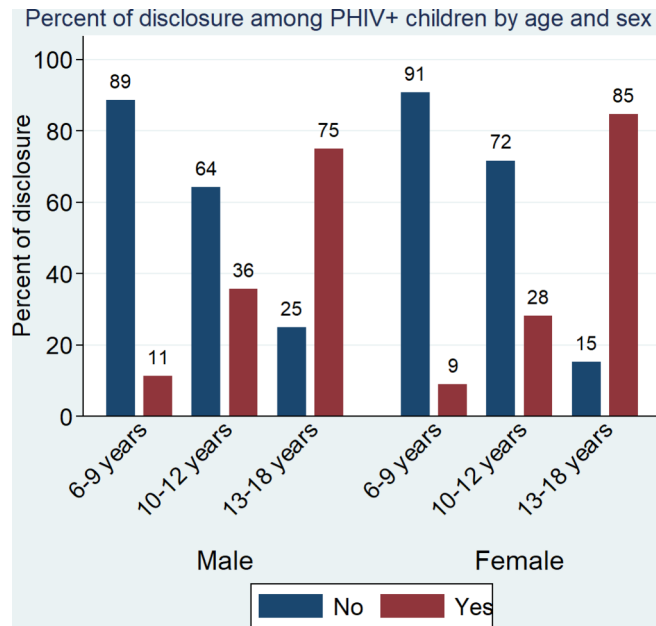


Figure 1 Level of perinatal HIV infection (PHIV+) diagnosis disclosure to children in Dire Dawa and Harar, Eastern Ethiopia, 2016. Disclosure was said to happen when a caregiver reported that the child knows the name of his/her illness is HIV/AIDS.

Factors that favour PHIV+ diagnosis disclosure in the final model were the caregiver's knowledge of a person who had disclosure experience (aOR 2.49, 95% CI 1.17 to 5.32) and the child's inquiry about his/her health condition (aOR 2.04, 95% CI 1.04 to 4.03). A caregiver was less likely to make disclosure if the age of the child was 12 years or less (aOR 0.04, 95% CI 0.02 to 0.09), if the caregiver practised deception about the child's HIV-positive status (aOR 0.38, 95% CI 0.19 to 0.74) and if the caregiver preferred an older child age for disclosure (10–12 years, aOR 0.30, 95% CI 0.11 to 0.84; or ≥ 13 years, aOR 0.06, 95% CI 0.02 to 0.18) (table 4).

DISCUSSION

This study revealed that half of the caregivers reported full disclosure. Factors positively associated with disclosure included the child's inquiry about their health status and the caregiver's knowledge of other people with a disclosure experience. On the other hand, the caregiver's deception about the child's illness, preference of older child age for disclosure and the child being younger age hindered disclosure.

The level of disclosure identified in our study was higher compared with previous studies in Ethiopia (17.4% to 39.5%),^{14 23 24} East Africa (26% to 43.1%),^{15 28 29} West Africa (21% to 29%),^{21 30} South Africa 39.6%³¹ and a review of 22 primary studies in low/middle-income countries (1.7% to 41%)%.³² The higher level of disclosure in our study may be attributed to the higher mean age of children. Furthermore, in our study, all children about whom information on disclosure was provided by caregivers had

started ART, a factor already reported to be positively associated with disclosure.¹⁵ However, the level of disclosure in this study is low compared with a 70% level of disclosure to children aged 9 to 16 years in four medical centres in New York city³³ that might be related to the difference in study settings and other related factors.

In our study, children have their own HIV status disclosed when they become old enough to understand the implications of having HIV. Similar findings were reported from Ethiopia and other settings.^{14 15 23 24 33 34} Delaying disclosure until the child is too old is against the WHO's recommendation to disclose PHIV+ diagnosis to school-age children,³⁵ and does not follow the national guidelines recommendation that children aged 10 years and above should receive full disclosure.³⁶ Such delay in disclosure poses a risk of an inadvertent disclosure or psychological harm for the child.¹⁰ Furthermore, it has the negative implications of losing the mental health benefits of disclosure, gaining cooperation of the child with medication adherence and improving the caregiver–child relationship.^{12 37} More urgently, a delay in disclosure has a public health risk of transmitting the HIV infection, including drug-resistant HIV strains, as undisclosed adolescents do not have a chance to prevent transmission through safe sexual behaviours and through self-disclosure to partners.^{13 38 39} Therefore, rather than waiting until a child is considered old enough for disclosure, consistent support for caregivers should be facilitated to prepare children for full disclosure.^{10 38}

Deception about a child's HIV-positive status among caregivers was common in our study settings and had negatively influenced disclosure. Similar findings have been reported elsewhere.^{14 24 28} A review article by Britto *et al* in low/middle-income countries reported deception as high as 49.5% where caregivers provided a non-HIV-related reason for explaining illness and healthcare visits.³² Deception is used by caregivers as a coping mechanism for their lack of self-efficacy to manage disclosure and fear of negative outcomes.^{24 37 39 40} Deception reveals that caregivers should be assisted on how to communicate truthfully, pass on disease-related information and understand the implications of deception on future full disclosure, child behaviour and medical care.^{10 37}

This study replicated the findings of other studies that caregivers demand a third person for assistance in the disclosure process^{24 29 32 37} which opens an opportunity for trained individuals to engage in and guide families through the disclosure process. Therefore, to produce a better disclosure outcome, trained healthcare workers are required to collaborate with caregivers as disclosure needs to be individualised to the child's context as discussed elsewhere.²⁹ Furthermore, there is a need for context-specific guidelines on disclosure which will undoubtedly affect the scope of support that healthcare workers can provide to caregivers.¹⁰

The finding that children's inquiry about their own health status triggered disclosure was consistent with other studies.^{24 34} As reported, caregivers deflect

Table 4 Factors associated with caregiver's disclosure of PHIV+, East Ethiopia, 2016

Variables	cOR (95% CI)	P value	aOR (95% CI)	P value
Caregiver's age in years				
<30	0.51 (0.25 to 1.04)	0.065	0.92 (0.33 to 2.58)	0.871
30–44	0.74 (0.44 to 1.23)	0.243	1.56 (0.67 to 3.64)	0.307
≥45	1	Ref.	1	Ref.
Religion				
Christian	2.86 (1.68 to 4.87)	<0.001	1.75 (0.85 to 3.61)	0.130
Muslim	1	Ref.	1	Ref.
Biological parent survival				
Both parents alive	0.37 (0.18 to 0.78)	0.008	0.74 (0.26 to 2.13)	0.578
Only mother alive	0.68 (0.30 to 1.50)	0.334	1.84 (0.56 to 6.06)	0.317
Only father alive	0.74 (0.31 to 1.74)	0.488	1.42 (0.42 to 4.77)	0.572
Both parents not alive	1	Ref.	1	Ref.
Child age in years				
≤12	0.07 (0.04 to 0.12)	<0.001	0.04 (0.02 to 0.09)	<0.001
>12	1	Ref.	1	Ref.
Child asked questions about their health status				
Yes	1.48 (0.95 to 2.31)	0.087	2.04 (1.04 to 4.03)	0.039
No	1	Ref.	1	Ref.
Deception				
Yes	0.42 (0.26 to 0.66)	<0.001	0.38 (0.19 to 0.74)	0.005
No	1	Ref.	1	Ref.
Caregiver's perceived appropriate age for disclosure				
<10	1	Ref.	1	Ref.
10–12	0.31 (0.14 to 0.68)	0.003	0.30 (0.11 to 0.84)	0.021
≥13	0.16 (0.07 to 0.36)	<0.001	0.06 (0.02 to 0.18)	<0.001
Child sex				
Male	1	Ref.	1	Ref.
Female	1.44 (0.92 to 2.26)	0.109	1.13 (0.60 to 2.15)	0.705
Caregiver knew someone who did a disclosure				
Yes	2.58 (1.48 to 4.52)	0.001	2.49 (1.17 to 5.32)	0.019
No	1	Ref.	1	Ref.
Caregiver's ethnicity				
Amhara	1.55 (0.82 to 2.93)	0.176	na	–
Oromo	1.20 (0.60 to 2.43)	0.602		
Other*	1	Ref.		
Caregiver's educational status				
No formal education	0.81 (0.46 to 1.42)	0.460	na	–
Primary education	1.09 (0.65 to 1.85)	0.735		
Secondary and above	1	Ref.		
Caregiver's relation to the child				
Biological parent	1.05 (0.65 to 1.69)	0.837	na	–
Non-biological caregiver	1	Ref.		
Child educational status†				
None	1	Ref.		–
Below grade 5	4.54 (1.30 to 15.81)	0.018	na	
Grade 5 and above	26.77 (7.79 to 92.06)	<0.001		

Significant at p value <0.05.

*Guraghe, Somali, Tigray, Harari.

†Child educational status was dropped from the final model due to multicollinearity issue.

aOR, adjusted OR, cOR, crude OR; na, not applicable (variables with p value ≥0.2 did not enter in the multivariable logistic regression); PHIV+, perinatal HIV infection.

illness-related information rather than provide answers to children's questions.^{14 24 28} This, however, denies the right of children to know about their health status.³⁷ Providing children with age-appropriate and consistent information means preparing them for self-care and cooperation with medication adherence.^{8 37 41} Conversely, denying the appropriate information in response to children's question may have an impact on the child-caregiver relationship and affect the children's quality of life as they seek to understand the truth about their health status.^{9 10 33 37}

Consistent with the finding reported by Marhefka *et al*,⁴² the caregiver's knowledge of people with PHIV+ diagnosis disclosure was positively associated with disclosure. This finding showed the importance of sharing experiences among caregivers with regard to disclosure difficulties that caregivers might face. Therefore, encouraging social ties among caregivers with PHIV+ child/children may be helpful for caregivers to gain confidence and learn context-specific skills of disclosure.

The strength of this study is that it was conducted in multiple centres that provide HIV care and treatment services in the region using a relatively larger sample size making the findings more generalisable. However, this study is not without limitations which need to be reported. The outcome was assessed by the caregiver's report who might have reported positive values to assume a desirable behaviour. However, due to the relatively small number of caregivers who had children with PHIV+ per facility surveyed, healthcare workers in the ART units knew them well and we do not expect that social desirability bias would be a significant problem. As the outcome and exposure variables were assessed at the same time, the reported associations may not show temporality. Finally, the study did not assess healthcare-related factors which might have affected caregiver's disclosure and tendency to seek counselling for disclosure, which need to be considered in future studies.

CONCLUSION

The study revealed that only half of the caregivers disclosed their child's HIV diagnosis. We recommend that caregivers should be well counselled about the recommended time and approach to facilitate timely disclosure. Caregivers should also be equipped with the appropriate knowledge and skills to address their children's questions. Healthcare workers in HIV/AIDS care and treatment units need to be specifically trained so that they can guide caregivers in the disclosure process. Furthermore, interventions involving experience sharing among caregivers on disclosure issues would be helpful, and this can be implemented in a one-on-one approach or through patient group counselling. Finally, further study is required on the challenges of disclosure from the healthcare services' perspective to establish a comprehensive package to address this issue.

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