

# Challenges in status disclosure and adherence to antiretroviral therapy in children living with HIV: An observational study

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## Abstract

**Background and Objectives:** The advent of highly active antiretroviral therapy has increased the longevity in children living with HIV (CLHIV), which has brought forth new concerns related to status disclosure and adherence to treatment. Information regarding this is limited in Punjab; hence, this study was done to find the relation of disclosure with sociodemographic factors and the problems faced in adhering to antiretroviral therapy (ART) in this region. **Materials and Methods:** An observational cross-sectional study was conducted on CLHIVs aged 18 months to 15 years visiting the ART center of a tertiary hospital from June to December 2021. Willing caregivers were approached with semistructured validated pretested questionnaire developed for the study. **Results:** Ninety-eight caregivers of CLHIV were interviewed and 25% were found to be aware of their serostatus. Children between 5 and 12 years comprised the largest group (57%) and this was also the statistically significant age group in whom the status was not disclosed. Disclosure was more in children having single parents. The low economic status, rural background, and low education status of the caregivers were inversely related to disclosure. Sixty-five percent of the caregivers believed that the appropriate age for status disclosure should be 14–18 years. Adherence was optimal in 85% CLHIVs and distance was the foremost challenge. **Conclusion:** The mean age for disclosure was found to be higher than the World Health Organization guidelines in this study; hence, there is a need to encourage caregivers for timely and systematic disclosure and motivate them for maintaining optimal adherence in CLHIV which is important for the success of ART program.

**Key words:** Adherence, caregiver, children living with HIV, disclosure

## Introduction

The epidemiology of pediatric acquired immunodeficiency syndrome (AIDS) has evolved significantly since 1983, when it was first described in children. The expanding availability of free highly active antiretroviral therapy (HAART) has significantly improved morbidity and mortality, leading to a longer lifespan in children. This, in turn, brings new challenges related to the disclosure of the disease status and maintaining optimal adherence to antiretroviral therapy (ART).

There are an estimated 81,428 children living with HIV (CLHIV <15 years) in India, which is 3.4% of the total people living with HIV (PLHIV). Punjab has about 65,078 PLHIV, which includes 1793 CLHIV. Access to HIV testing and counseling is available at 115 integrated counseling and testing centers in Punjab, with 19 ART centers catering to their needs.<sup>[1]</sup>

With deoxyribonucleic acid-polymerase chain reaction becoming available in the national program, more children are being diagnosed. While vertical transmission is the predominant route for the acquisition of HIV, less frequently, children may acquire infection by horizontal route.<sup>[2]</sup> Disclosure improves adherence and immunological outcomes in CLHIVs and ensures a smooth transition to adulthood.<sup>[3]</sup> Thus, it is a step in the process of adjustment by the child and caregivers to the illness.

In a developing country like ours, disclosure is difficult because the environment is stigmatizing.<sup>[4]</sup> This, along with child's emotional and maturational ability to cope with illness, poses the problem as to when, how, by whom, and under what conditions children should be

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informed about their own or their caregivers' HIV status. The recommendations focus on counseling for disclosure of HIV status to children who are 12 years of age or less so that young children would receive sufficient attention.<sup>[5]</sup> Besides age, other characteristics considered important for disclosure include gender, education level, whether the child asks questions, and their perceived ability to understand their diagnosis.<sup>[6]</sup>

Maintaining an optimal level of adherence (=95%) to ART is essential for successful viral suppression<sup>[7]</sup> and defiance of this can result in sub-therapeutic drug levels leading to drug resistance.<sup>[8]</sup> In children, barriers to adherence to ART operate at multiple levels. These can be child related like low palatability, large size, multiple drugs, or adverse effects. Caregiver factors and system-related factors for drug procurement are crucial for regular treatment because of the dependency of children on adults.

This study was undertaken on CLHIV's and their caregivers in an attempt to determine the challenges associated with disclosure and factors affecting adherence to ART, which may help to find gaps and suggest interventions to guide the health-care professionals (HCPs) and caregivers.

### Materials and Methods

An observational cross-sectional study was conducted on children, aged between 18 months and 15 years from June to December 2021 in the ART center of a tertiary care hospital in Punjab. The study was done after obtaining approval from the Institutional Ethical Committee and Punjab State AIDS Control Society.

A total of 200 children were enrolled during this period, which constituted the sampling frame for this study.

Using the formula  $[(DEFF \times Np(1 - p)) / ((d^2 / z^2) - a/2 \times (N - 1) + p \times (1 - p))]$  for finite population size with 95% confidence interval and 5% absolute margin of error,

Hypothesized % frequency of outcome factor in the study population (HIV adherence) is 87% +5%<sup>[9]</sup>

Confidence limit as % of 100 (absolute + %) (d):5%

Design effect = 1

Sample size came out to be 94 and with nonresponse rate of around 5%, the final sample size would be 98. The subjects were selected using a systematic random sampling technique and thus every second CLHIV with his primary caregiver was approached.

The purpose of the study was explained to all 100 children and their caregivers. Ninety-eight caregivers agreed and were recruited after taking written informed consent along with assent from children above 12 years of age. Participation was voluntary, and confidentiality was maintained. A semi-structured validated pretested questionnaire was used for the interview process. All the interviews were carried out by the same investigator to avoid inter-observer variability in a separate room, ensuring privacy for the interviewee, in the language as per caregivers' convenience, and the responses were recorded.

Information regarding sociodemographic profiles such as age, socioeconomic status, caretaker's education, caretakers' HIV status, duration of ART drug intake, and method of reminder used to take medicines at home was obtained. Furthermore, the problems faced by the caretakers in

seeking services from the ART center or at home in giving medicines to the child were assessed and compiled.

Since disclosure was the outcome variable for this study, caregivers were asked diligently about the status of disclosure, the age at which it was disclosed, the person who disclosed it, and reasons for nondisclosure. Depending on disclosure status, children >12 years of age were accordingly interviewed.

### Nomenclature used

The CLHIV status was considered disclosed if the child knows that he/she is suffering from some chronic illness with the name HIV and also had disease-specific information (e.g. how the virus works, how it is transmitted). The term partial disclosure was used for describing situations in which children were given some but not all information about their illness. They were informed of the need to take medicine to keep their virus or "illness" at bay or learn how their virus or "illness" can be transmitted without learning that their virus or "illness" is called HIV or AIDS. Nondisclosure was no mention of any virus or illness.<sup>[10]</sup>

Adherence was recorded by a pill-counting method and was classified as optimal (95%) and suboptimal (<95% adherence).

The data was analysed using SPSS software version 22 (SPSS Inc., Chicago, Ill., USA).

### Results

Characteristics of all the 98 CLHIVs and their relation with disclosure status were assessed statistically [Table 1]. Children between 5 years and 12 years comprised the largest group (57%) and this was also the statistically significant age group in whom the status was not disclosed. The duration of ART was more than 5 years in 61% ( $n = 60$ ). Eighty-nine percent ( $n = 88$ ) of CLHIVs were going to school and 10

**Table 1: Characteristics of children living with HIVs and their relationship with disclosure status**

Characteristics of CLHIV and their relation with disclosure				
Sociodemographic factors	CLHIV (n=98)	Disclosure status of CLHIV		P value with 95% CI ( $\chi^2$ /Fisher's exact test)
		Disclosed (full/partial)	Not disclosed	
Age (years)				
5-12	56	2	54	$\chi^2$ with Yates correction=34 P=0.0001
>12	36	22	14	
Duration of ART (years)				
<2	20	-	20	P=0.0004 Fisher's exact test
2-5	18	2	16	
>5	60	22	38	
Education status				
Going to school	88	23	65	P=0.48 Fisher's exact test
School dropout	10	1	9	
Parental status				
Both parents alive	46	6	40	$\chi^2=6.156$ P=0.046
Single parent alive	40	14	26	
Orphan	12	4	8	
HIV status of parents				
One or both parents positive	83	24	71	P=0.85 Fisher's exact test
Both parents negative	3	0	3	

CLHIV=Children living with HIV; CI=Confidence interval; ART=Anti-retroviral therapy

were school dropouts. Both of the above factors did not affect the disclosure status. Forty-six CLHIVs had both parents, while 40 had single parents and nondisclosure was statistically significant in children with both parents live. Of the 12 CLHIVs who had lost both parents, 9 were looked after by a grandparent, 2 by an extended relative and 1 was in an orphanage. Serostatus of parents did not have any impact on status disclosure in children.

The influence of the sociodemographic profile of the family on status disclosure to CLHIV was assessed [Table 2]. Rural background was seen in 70% ( $n = 69$ ) families and 69% ( $n = 68$ ) had low economic status. Caregivers of 49% ( $n = 48$ ) CLHIVs had no education beyond primary school. All the above three factors were found to be statistically significant in nondisclosure. More than 85% of caregivers had adequate knowledge regarding modes of transmission of HIV, dose, duration, and importance of adherence to ART; however, their impact on disclosure status was not significant.

Out of the 24 CLHIVs who knew about their status, 10 were only partially disclosed. All the caregivers believed that the child should know the diagnosis at an appropriate age, which 65% thought to be 14–18 years [Figure 1].

Sixty-one percent ( $n = 60$ ) of caregivers wanted to disclose the status to the child themselves, 17% wanted disclosure by HCP alone, while the rest wanted to do so in the presence of a doctor. Various reasons given for disclosure of status to the child are depicted in Figure 2.

Of those who had not disclosed the status, 71% (58/82) felt that the child was too young to understand. Other reasons given are shown in Figure 3.

Adherence was optimal in 85% ( $n = 84$ ) CLHIVs, but despite this, they faced many challenges in achieving this level of adherence. Distance of ART Centre was

the foremost challenge with 47% ( $n = 46$ ) complaining about ART Centre being far from their place while 31% faced financial restraints in their procurement. In child-related barriers associated with intake of medicine, dislike due to taste, and child vomiting, the drug was the foremost (27%) [Table 3].

Suboptimal adherence (<95%) was documented in 14 CLHIVs, of which 9 were found to have missed doses for 1 or 2 months only. 28.5% ( $n = 4/14$ ) of defaulters cited a lack of transportation. Forgetfulness in 21% ( $n = 3/14$ ) and change of caregiver were some other reasons [Figure 4].

## Discussion

The present study had a maximum number of children in the 5–12 years age group. Only 24.4% of CLHIVs were actually aware of their seropositive status. According to the systematic review by Vreeman *et al.*, the disclosure rate amongst children and adolescents ranged from 0% to 69.2% in resource-limited settings.<sup>[3]</sup> Another study carried

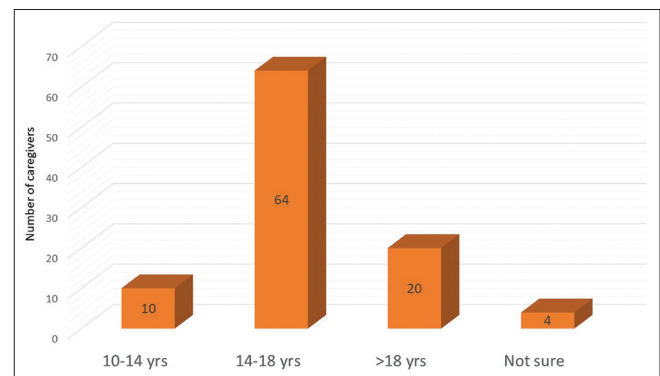


Figure 1: Appropriate age for disclosure according to caregivers

Table 2: Characteristics of families and their relation with disclosure

Sociodemographic factors	Care giver ( $n=98$ )	Disclosure status of CLHIV		$\chi^2$ /Fisher's exact test with P (95% CI)
		Disclosed (full/partial)	Not disclosed	
Resident				
Rural	69	10	59	$\chi^2=12.6$ $P=0.000385$
Urban	29	14	15	
Economic status				
Middle	30	12	18	$\chi^2=5.6$ $P=0.0171$
Lower	68	12	56	
Family type				
Joint	36	11	25	$\chi^2=1.132$ $P=0.288$
Nuclear	62	13	49	
Education status of primary caregiver				
Primary or less	48	7	41	$\chi^2=7.54$ $P=0.02$
Intermediate	38	12	26	
Secondary or above	12	6	6	
Level of knowledge regarding spread of HIV				
Adequate	86	23	63	P = 0.725 Fisher's exact test
Poor	12	2	10	
knowledge about dose and duration of ART				
Adequate	91	23	68	P=0.90 Fisher's exact test
Poor	7	1	6	
Knowledge about importance of adherence				
Adequate	89	22	67	P>0.999 Fisher's exact test
Poor	9	2	7	

CLHIV = Children living with HIV; CI = Confidence interval; ART = Antiretroviral therapy

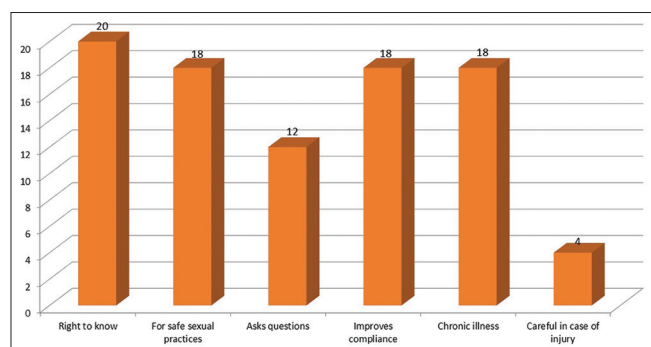


Figure 2: Reasons for disclosure

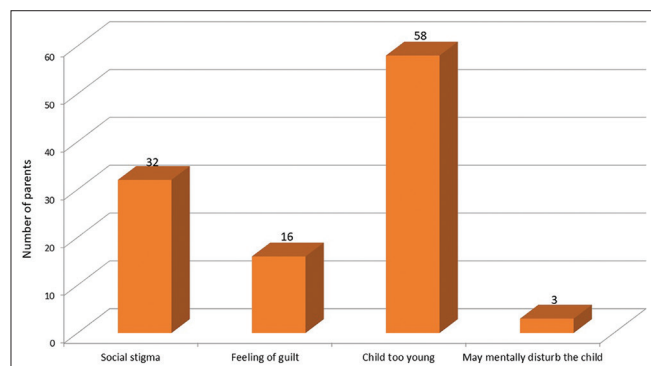


Figure 3: Reasons for nondisclosure

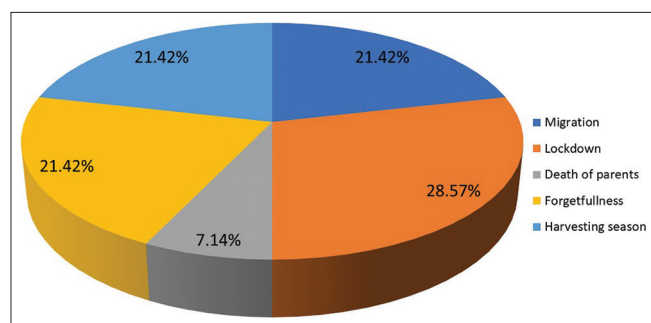


Figure 4: Reasons for suboptimal adherence

out in North India reported a disclosure rate of 33.33% in CLHIVs aged 6–16 years.<sup>[11]</sup> The predominance of younger age group (5 years–12 years) in the present study explains the lower disclosure rate.

With improved health due to ART, more CLHIVs, 89% in the present study, were going to school. In 76%, school authorities were aware of their status, which becomes important in case of child getting any injury or indulging in any unwanted behavior with other fellow students.

In the majority of CLHIVs, a primary caretaker was one or both parents, which is in concordance with studies by Mumburi *et al.*<sup>[12]</sup> In this study, the mother was the primary caregiver in 60% of cases. Verma *et al.*<sup>[13]</sup> observed the same in two-thirds (71%) of the children, whereas in a study by Ingle and Deshmukh<sup>[14]</sup> a slightly higher number of subjects had fathers as their caregivers. Nondisclosure was statistically significant in children having both parents. 58.3% (14/24) of the disclosed CLHIVs had single parents, majority being paternal orphans. Disclosure in such cases

**Table 3: Challenges faced by children living with HIVs in optimal adherence to anti-retroviral therapy regimen**

	Participants, n (%)
Child related	
Dislike for taste/vomit the med	26 (27)
Dependency on adults	24 (25)
Too many medicines	18 (19)
Friends don't take	2 (3)
Caregiver related	
Inability to take leave from work/financial	30 (31)
Tiredness of daily administration of drug	12 (13)
Change of caregiver	3 (4)
ART center related	
Distance	46 (47)
Lines too long	10 (11)
Drugs out of stock	2 (3)

ART=Antiretroviral therapy

may be from sources other than caregivers due to the loss of an earning male member,<sup>[11]</sup> which may lead to wrong and incomplete knowledge, resulting in negative implications. This also implies that systematic psychological counseling and social support should be given to AIDS orphans.<sup>[15]</sup>

The rural background was seen in 67.34% (66/98) children and 69.38% (68/98) belonged to low socioeconomic status, which is similar to another study conducted in Ahmedabad.<sup>[16]</sup> Nondisclosure was significantly high in the above two categories, which probably is due to the lack of awareness about the importance of disclosure in such groups but this was not consistent with a study from Central India.<sup>[14]</sup>

In the same study,<sup>[14]</sup> caregivers education and disclosure rate had inverse relation, but in this study, in contrast, the disclosure rate was significantly low in CLHIV's whose caregivers were educated only till the primary level. This may be due to increasing openness about HIV among the educated.

While the World Health Organization (WHO) recommends 12 years to be the upper age limit for disclosure, most caregivers (65%) wanted to disclose the status at a mean age of 16 (14–18 years), which is similar to a study by Arun *et al.*<sup>[17]</sup> but in some previous Indian studies, the mean age was lower ranging from 9.2 to 12 years.<sup>[11,18]</sup>

In concordance with the observations of another study of North India,<sup>[11]</sup> majority of the caregivers wanted to disclose the status to the children themselves, but despite the above sentiments, 29% of CLHIV's in this study came to know their status inadvertently as the children nowadays have access to social media.

The study identified many reasons for disclosure to CLHIVs as it is a chronic disease, sexually transmitted, needs lifelong treatment, and requires caution in case of injury/accident. Most of the caregivers felt the need for systematic disclosure to the child at an appropriate age i.e., before they become sexually active. Other reasons given were his right to know, improved compliance, the child asks questions, etc.

The main concerns which inhibited disclosure were the age of the child, social stigma, feelings of guilt, and that the child may get disturbed and would have a negative effect on his self-esteem. Similar concerns were observed in other studies.<sup>[19]</sup>



ART adherence is the most important determinant<sup>[20]</sup> and is the “Achilles heel” of ART treatment success,<sup>[21]</sup> but adherence to ART in young children poses unique and formidable challenges. Dependency on a caregiver and hesitancy in taking medications, especially in cases of nondisclosure are major difficulties. This study showed that 85% of the CLHIVs had more than 95% adherence to HAART, which could be attributed to good counseling by Health care workers (HCWs) to caregivers, clinical benefits apparent to the caregivers, who were mostly parents and taking medicines themselves, and availability of free treatment. Other studies undertaken in Africa and other parts of India also show adherence ranging between 73% and 97%.<sup>[9,22]</sup>

Many barriers were perceived by caregivers while taking treatment for their CLHIV, though a majority of them were not consistent. Distance of ART Centre was the foremost faced by 47% but in contrast, 2% were hesitant in collecting medicine near to their residence because of chances of meeting known people and hence fear of stigma. Although medicines are dispensed free of cost, 31% experienced financial constraints as they had to leave their day's work to collect medicines. Child-related difficulties mainly faced in taking the medicines were dislike for taste, vomit after medicine and too many medicines, but a majority of the caregivers felt that these occurred when the child was very young and decreased with an increase in the duration of HAART.

Since the study was conducted post-COVID-19, 28.5% (4/14) of those showing suboptimal adherence cited a lack of transportation during lockdown. 21.3% of defaulters complained of forgetfulness, which was also reported as a cause of nonadherence in other studies.<sup>[13,22,23]</sup> Extra counselling sessions about methods to remember, like marking on the calendar or alarm setting, were given to those who missed doses due together forgetfulness or change in caregiver in harvesting season.

## Conclusion

In this study, the most suitable age for disclosure as per the caregivers is 14–18 years, which is higher than WHO guidelines indicating regional mindset and it should be a systematic and guided event. Consistent counseling and motivation of caregivers for timely disclosure of status and adherence to ART are important for the improved quality of life of CLHIVs.

## Recommendations

Need to develop socioculturally acceptable regional guidelines to help caregivers and HCPs in disease disclosure at the appropriate age in a positive and systematic manner.

Extra counseling sessions about a method to remember like marking on calendar or alarm setting where required.

More Link ART cents can be opened up, which would save the time and cost to procure medicines and the choice of the caregiver should be sought.

## Limitations and strengths

The study is based on caregivers' responses, which can have both recall bias and provision of giving socially acceptable answers. The sample size was small, thus limiting the study of the relationship of disclosure and adherence to ART therapy. Despite these limitations, the current study is the first of its kind in Punjab, which

highlights challenges faced by caregivers in status disclosure and adherence to ART.

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## Conflicts of interest

There are no conflicts of interest.

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