

**Are They Disclosed?: Situation of HIV Status Disclosure among Adolescents in Four Townships of Myanmar**

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Disclosing HIV status to vertically HIV infected adolescents is crucial for preventing further transmission of HIV, maintaining drug adherence, and preventing possible unsafe reproductive behavior. Little is known about the situation of HIV status disclosure among these adolescents. A cross-sectional, exploratory mixed method design was conducted in 2015 with the objective of identifying disclosure related information among HIV infected adolescents. Total of 66 adolescents were interviewed by using a structured questionnaire. Focus group discussions (FGD) and in-depth interviews (IDIs) were conducted with the guardians, providers and focal persons. Age of the adolescents ranged from 10-16 years (12.5±2.0). About 44% of adolescents were double orphans and 82% were currently attending school. Nearly 82% knew their HIV status in which over 42% were disclosed by health staffs. During FGDs, about half of the guardians stated that they have not disclosed HIV status to their children properly. They just let them know that they had an illness which needed daily medication for their survival. Less than half of the children were discussed about HIV with their guardians including transmission of HIV (16.7%), HIV virus (40.9%) and treatment (19.7%). Regarding reproductive health (RH), only few adolescents received information about sexually transmitted diseases (18.5%), puberty changes (7.7%), pregnancy (6.2%) and reproductive organs (4.6%). Most guardians revealed that they rarely discussed about RH with their children although they know that it is important for their future reproductive life. Proper and comprehensive disclosure counselling is needed for vertically HIV infected adolescents.

*Key words:* Adolescents, HIV, Status disclosure, Counselling, Myanmar

**INTRODUCTION**

Globally, an estimated number of people currently living with HIV are about 35.3 million. Additionally, there were 1.6 million deaths of HIV around the world in 2012. One of the adverse health consequences of HIV on children is mother-to-child transmission of the virus.<sup>1</sup> Specifically, 1,000 new cases of HIV were detected every day in the children under 15 years of age predominantly due to vertical transmission.<sup>2</sup> In low- and middle-income countries, about 260,000 new infections among children occurred in 2012.<sup>3</sup> According to the estimation of UNAIDS in 2012, there were 2.1 million adolescents aged between 10 to 19 years

living with HIV all over the world.<sup>1</sup> According to the WHO guideline, all people living with HIV should be on ART regardless of clinical stage and CD4 count.<sup>4</sup>

Along with the increasing coverage of ART, children with vertically acquired HIV infection are surviving and reaching adolescence.<sup>1</sup> Physical, mental, psychological and social changes occurring among adolescents (10-19 years) that lead to physical and sexual maturity. These situations make many opportunities for development, but at the same time, also pose risks to their health.<sup>5</sup>

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Besides usual developmental changes, adolescents living with HIV are experiencing the social, economic, mental and developmental consequences of life-long HIV.<sup>6</sup> Among these consequences, issues around disclosure are challenging for both children and their guardians.<sup>6-8</sup> Adolescents living with HIV in Asia Pacific region learn about their HIV status for the first time at different ages and from a range of sources. Disclosure should start as early as possible since it can empower children to take care of their health. However, negative psychological effects would be resulted if they learned their HIV positive status during middle adolescence.<sup>6</sup>

In Myanmar, National AIDS Program (NAP) estimated that adult HIV prevalence is 0.59% in 2014.<sup>9</sup> According to the results of sentinel surveillance in 2011, percent of pregnant women who are HIV infected was 0.9%. Moreover, percent of infants born to HIV infected mothers who are infected was 13%.<sup>10</sup> Disclosing HIV status to vertically HIV infected adolescents is crucial for preventing further transmission of HIV, maintaining drug adherence, and preventing possible unsafe reproductive behavior. However, little is known about the situation of HIV status disclosure among these adolescents in Myanmar. Therefore, the aim of the study was to assess HIV-disclosure status amongst adolescents living with HIV in Myanmar.

## MATERIALS AND METHODS

### *Study design and setting*

A cross-sectional, exploratory mixed method study was conducted at four townships of Myanmar in 2015. These four townships were situated in central part of Myanmar and all had similar socio-demographic background.

### *Study population*

Adolescents aged between 10 to 16 years who were vertically HIV infected from their parents were included in the study. Vertical

transmission was confirmed since all these children got HIV diagnosis since they were very young. Confirmation about the transmission of HIV was also done with their parents/guardians. Sample size was calculated based on the assumption of proportion of adolescents who have received comprehensive HIV status disclosure as 20% ( $p=0.2$ ), precision of 0.1 ( $d=0.1$ ) and at 95% confidence level ( $z=1.96$ ) resulting in a sample size of 61, by using the formula " $n=z^2 pq/d^2$ ".

### *Data collection*

A structured- questionnaire was drafted after reviewing the literature and it was pre-tested in a non-study township in Yangon. A pre-tested and modified structured questionnaire and guidelines for focus group discussions (FGDs) were used by trained interviewers and moderators, respectively. Adolescents were recruited through a network of people living with HIV (PLHIV) after coordination meeting at each township.

Firstly, a list of eligible adolescents was prepared with the help of adult PLHIV which was followed by random sampling. Fifteen to 17 vertically HIV infected adolescents were recruited from each township to get the required sample size. Face-to-face interviews were carried out with the adolescents by trained interviewers and four FGDs were done with their guardians by the investigators. Guardians consisted of fathers, mothers, grandparents, aunts/uncles and elder siblings. Six in-depth interview (IDIs) were conducted with service providers and focal persons from PLHIV network.

### *Variables*

Variables were age, sex, parental status (both parents alive/ paternal orphan/ maternal orphan/ double orphan), schooling (never attended school/ out of school/ in school), disclosure of HIV (disclosed/ not disclosed), age at knowing HIV status, receiving HIV information (yes/ no/ don't know), communication between parents and

adolescents about HIV transmission, virus and treatment (yes/ no), communication between parents and adolescents about RH information such as STI, puberty, pregnancy and reproductive organs (yes/ no).

#### Data management and analysis

Data entry and analysis were done by EpiData version 3.1 and SPSS version 16.0 after checking and coding the questionnaire. Range and consistency checks were done. Descriptive statistics were shown by mean/ median as appropriate for continuous variables and frequency distribution for categorical variables. Transcripts were prepared for each FGD session which was followed by manual coding and thematic analysis. Finally, quantitative and qualitative information were triangulated.

#### Ethical consideration

Informed consent was taken from the guardians and informed assent was taken from the adolescents after thorough explanation about the study. Confidentiality and anonymity were ensured. Privacy was strictly ensured in such a way that all the interviews were taken place at the private place as agree by the interviewees. All the ethical guideline required for conducting the research with the children were strictly followed. The proposal was approved by the Ethics Review Committee of Department of Medical Research.

## RESULTS

#### Background characteristics

Total of 66 adolescents were included in the study. As shown in Table 1, proportion of male exceeded female and their age ranged from 10-16 years with the mean age of  $12.5 \pm 2.0$ . About 44% of adolescents were double orphans (both parents passed away) whereas nearly one-fourth (24.2%) had both parents alive. Nearly 82% were currently attending school and 20.4 % were at the level of grade 4. Over 16% of the children were dropped out from the school and out of

school duration ranged from 1-7 years (mean:  $3.3 \pm 2.4$ ).

Table 1. Background characteristics of the adolescents infected with HIV from four selected townships, 2015 (n=66)

Characteristics	Number	Percent
<b>Sex</b>		
Male	37	56.1
Female	29	43.9
<b>Age</b>		
Range	10-16	
Mean±SD	12.48±2.04	
<b>Parental condition</b>		
Both parents alive	16	24.2
Paternal orphan	15	22.7
Maternal orphan	6	9.1
Double orphan (both parents passed away)	29	43.9
<b>Schooling</b>		
Never attended school	1	1.5
Out of school	11	16.7
In school	54	81.8

Table 2. Information related to HIV status disclosure among adolescents

Characteristics	Number	Percent
<b>Disclose about HIV (n=66)</b>		
Disclosed	54	81.8
Not disclosed	12	18.2
<b>Age at knowing HIV status (n=54)</b>		
Range	5-16	
Mean±SD	10.15±2.77	
<b>Received HIV (n=54)</b>		
Yes	44	81.5
No	8	14.8
Don't know	2	3.7
<b>Person disclosed (n=54)</b>		
Either parent	19	35.2
Family member	8	14.8
Health staff	24	44.4
Others (Neighbours, Friends)	3	5.6
<b>Reaction on knowing HIV status* (n=54)</b>		
Shocking	4	7.4
Crying	4	7.4
No expression	48	88.9
<b>Parent/guardian communicate adolescent about HIV (n=66)</b>		
Yes	37	56.1
No	29	43.9

\*Multiple response

Of all adolescents, 81.8% (54/66) knew their HIV status in which over 44.4% (24/54) of the children were disclosed by health staffs. Their mean age at the time of knowing HIV status was  $10.2 \pm 2.8$  years. About two-third of them reported that they had ever received counselling whereas 33% had not received any type of counselling. Nearly 90% of adolescents did not express their emotional responses when they were disclosed (Table 2).

Status of disclosure, counselling and communication with guardians among adolescents according to their parental condition was mentioned in Table 3. Disclosure status and receiving HIV counselling were not statistically different among children with both parents alive and single/ double orphans. Significantly higher proportion of adolescents having both parents received communication about HIV in comparing to orphans (81.2% vs. 66.7% vs. 34.5%,  $p < 0.01$ ).

Table 3. Status of disclosure, counselling and communication with guardians among adolescents according to their parental condition

Characteristic	Parental condition		
	Both parents alive n(%)	Paternal/ Maternal orphan n(%)	Double orphan n(%)
<i>Disclose about HIV (n=66)</i>			
Disclosed	15(93.8)	15(71.4)	24(82.8)
Not disclosed	1(6.2)	6(28.6)	5(17.2)
<i>Receive HIV (n=54)</i>			
Yes	2(13.3)	12(80.0)	21(87.5)
No	2(13.3)	3(20.0)	3(12.5)
Don't know	-	-	-
<i>Parent/guardian communicate adolescent about HIV (n=66)</i>			
Yes	13(81.2)	14(66.7)	10(34.5)
No	3(18.8)	7(33.3)	19(65.5)

Table 4. Responses of the participants during FGD

Responses during FGD	
Opinion on disclosure by grandparent	"... She doesn't understand why she has to take medicine every day. We don't try to explain her. Just let her know that she has to take those pills if she doesn't want to die like her parents" (55 years, grandmother)
Opinion on disclosure by service provider	"... It's difficult to disclose the children if they have little knowledge on HIV. So, we need to raise their awareness first ..." (Public service provider)
Opinion on disclosure by adopted parent	"... We have to tell him since he has to go to clinic and don't want to miss the school. We told him "you have to take the drugs till you die and it would be good for his health" (53 years, adopted father)
Opinion on disclosure by parent	"... We just tell my child as he had to take medicine for TB ... till now, he doesn't know that he had HIV" (48 years, mother)
Opinion on disclosure by adult PLHA	"Most parents don't allow disclosing directly to their children. We've to try hard to counsel them only when they are transferred to adult side ..." (35 years, PLHA Network)

During FGDs, about half of the guardians admitted that they did not disclose HIV status to their children properly. They just let them know that they had an illness which needed daily medication for their survival. Most of the adolescents gradually recognized their HIV status without proper counselling before disclosure. Some of the responses to the focus group discussions are shown in Table 4.

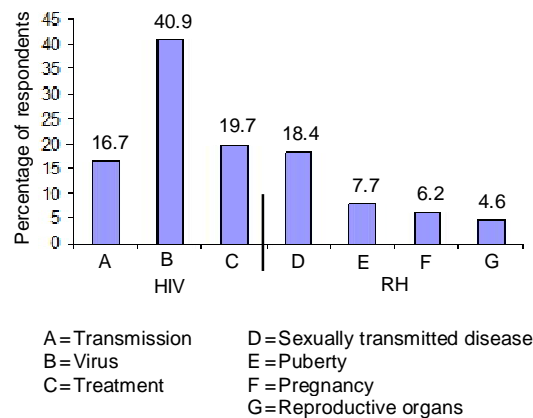


Fig. 1. Information on discussion about HIV and reproductive health information with the adolescents as reported by the guardians

Figure 1 depicts the information on discussion about HIV and reproductive health information with the guardians. Less than half of the adolescents discussed about HIV such as transmission of HIV (16.7%), HIV virus (40.9%) and treatment of HIV (19.7%). Very few adolescents had ever received RH information necessary for them. In particular, 18.5%, 7.7%, 6.2%, and 4.6% of adolescents received discussion about sexually transmitted diseases, puberty changes, pregnancy and reproductive organs, respectively from their parents/ guardians.

## DISCUSSION

Current study aimed to explore the situation of HIV status disclosure among vertically infected adolescents. Of all adolescents, majority knew their HIV status and most of them aware of their status gradually without receiving proper disclosure counselling.

Mean age when they knew their status was around 10 years.

Previous studies have documented the disclosure status of children and adolescents.<sup>6-7, 11</sup> In Nigeria, the mean age at disclosure was just over 10 years and about one third of the children were informed their status.<sup>7</sup> Another study in rural Uganda also recorded that most children were informed their status between the age of 5 to 9 with the mean age at 7 years.<sup>6</sup> Similar age at disclosure was detected in present study, however, higher proportion of adolescents has known their status in comparing to other studies. In a study in Tanzania, among 4-17 years perinatally HIV infected children and adolescent, about 32% of care givers reported that they have disclosed the children's HIV sero-positive status.<sup>11</sup> The discrepancy might be due to the difference in age group of this study population in which only adolescents over 10 years were included in this study whereas other studies included children over 6 years of age.

Adolescents living with HIV in Asia and the Pacific region gain knowledge of their status for the first time at different ages and sources. How and when adolescents receive information about their status plays an important role in how they understand what living with HIV means for their health and well-being.<sup>1</sup> Surprisingly, over 90% of the children from the present study did not express anything at the first time they knew about their HIV status. Children's age, maturity and background knowledge about HIV may contribute their responses towards knowing their status. Likewise, in a study among adolescents aged 9 to 16 years in United States, 70% of them had disclosed and did not shown any psychological consequence after the disclosure.<sup>12</sup>

Communication between caregivers and service providers is essential for smooth and successful disclosure of HIV status to the children. In addition, getting child consent is crucial in disclosing HIV status to children and adolescents according to the United

Nations Convention on the Rights of the Child (CRC). Adolescents' right to privacy is protected in Article 16 of the CRC. It was mentioned that information on the HIV status of children may not be disclosed to third parties, including parents, without the child's consent.<sup>10</sup>

One of the important issues surrounding disclosure is counselling where improper post-test counselling and support may worsen their emotional status.<sup>13</sup> One third of the adolescents from current study had never received any type of counselling. In a study in Nigeria, 11% of HIV disclosure were performed by health staff including counsellor while much higher proportion of adolescents (42%) in the current study were informed by health staff.<sup>6</sup> On the other hand, about one-third of disclosure was done by the caregivers in Tanzania.<sup>11</sup> Adherence to take medicine for HIV is one of the important reasons for disclosure in the current study as reported by the caregivers and similar reason was found in other study.<sup>6</sup>

Regarding reproductive health information, very few adolescents were ever discussed with their guardians in this study. In contrast, previous study in Myanmar documented that 87% of the parents communicated on RH issues at least one time with their children.<sup>14</sup> The difference might be due to the fact that many adolescents in present study were double orphans who are staying in extended family members and they may rarely get chance to discuss about RH with their guardians.

Previous study has highlighted the attitudes and behaviours of caregivers regarding disclosure where 42% of caregivers told their children as they were suffering from a disease other than HIV, with malaria being the most common disease.<sup>15</sup> Similarly, some children from the present study were told that they had to take medicine for TB.

There were certain limitations in current study. Firstly, findings were solely based on

self-reported answers from children and their caregivers. Verification could not be done whether these reported behaviors were really practiced by the participants. Another limitation was about the disclosure process. Although 82% of the adolescents were disclosed, the process of disclosure could not be clarified in this study.

### Conclusion

Comprehensive disclosure counselling is very limited and many guardians do not want to disclose their children's HIV status in this study. About one-third of the adolescents have not received any type of counselling. Additionally, parents/guardians of over half of them have never discussed with their children about HIV related information. More importantly, many adolescents have never received RH information though it is critical for them to have RH knowledge during the adolescent period.

### Recommendation

Strengthening of proper and comprehensive disclosure counselling is suggested for vertically HIV infected adolescents. RH information should be provided to all infected adolescents since very few of them had ever received RH information. Awareness raising activities should be carried out for guardians on advantages of disclosure counselling.

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