

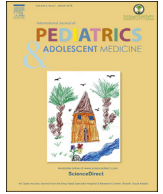
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International Journal of Pediatrics and Adolescent Medicine

journal homepage: <http://www.elsevier.com/locate/ijpam>

Full length article

We don't dare to tell her ... we don't know where to begin: Disclosure experiences and challenges among adolescents living with HIV and their caregivers in China

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ARTICLE INFO

Article history:

Received 20 September 2017

Received in revised form

28 November 2017

Accepted 30 November 2017

Available online 23 February 2018

Keywords:

HIV/AIDS

Disclosure

Adolescent

Caregiver

Stigma

China

ABSTRACT

Background and Objectives: With increasing access to antiretroviral therapy, HIV-infected youth are living longer, but are vulnerable as they navigate the transition to adulthood while managing a highly stigmatized condition. Knowing one's HIV status is critical to assuming responsibility for one's health. The process of disclosure to adolescents living with HIV is not well understood globally, even less so in China. To help address this gap, we explored practices for disclosure to adolescents living with HIV (ALHIV) among Chinese caregivers and clinicians, and the disclosure experiences of the adolescents themselves using qualitative methods.

Design and Setting: The study was conducted in 2014 at the Guangxi Center for Disease Control and Prevention ART (CDC-ART) clinic in Nanning, China. We used a qualitative design, incorporating in-depth interviews (IDIs) and focus group discussions (FGDs).

Patients and Methods: We conducted IDIs with 19 adolescent/caregiver dyads and five FGDs with adolescents and clinicians. Adolescent participants were aged 10–15 years, and had contracted HIV perinatally. Using NVivo™ software, we summarized major themes.

Results: Only 6/19 caregivers reported disclosing to their child; matched adolescents' statements indicate that 9/19 children knew their HIV status. Caregivers planned to disclose when children were 14 years or older. Concerns about stigma toward children and families were associated with reluctance to disclose. **Conclusion:** Disclosure to adolescents living with HIV in China was delayed compared with recommended guidelines. Culturally appropriate disclosure strategies should be developed, focused on supporting caregivers and de-stigmatizing HIV.

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Peer review under responsibility of King Faisal Specialist Hospital & Research Centre (General Organization), Saudi Arabia.

<https://doi.org/10.1016/j.ijpam.2017.11.001>

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1. Background and Objectives

Provision of antiretroviral therapy (ART) for prevention of mother-to-child transmission of HIV (PMTCT) has reduced risk of perinatal transmission to 2–5%, vs. 30–40% without PMTCT [1].

The efficiency of PMTCT has limits, however, as inevitably some children are still infected with HIV, requiring care and support. Indeed, 150,000 children worldwide became infected with HIV in 2015, including 19,000 in Asia and the Pacific, and 190,000 youth now live with HIV in that region [2]. In 2015, 41% of HIV-infected children under age 15 in the region received ART—over a 50% increase compared to 2010 [2,3]. In China, substantial progress has been made in PMTCT among mother-infant child pairs registered in care, but there are still concerning gaps in access, as in 2013, the overall HIV perinatal transmission rate was 17.4% when including transmissions outside the PMTCT care continuum [4]. Pediatric ART is widely available in the country, and it is estimated that 59% of all HIV-infected children accessed ART in 2015, compared to 52% in 2013 [5]. There is also a rising concern in China about new infections among youth; in 2015, 14.7% of all new infections in the country were among young people aged 15 to 24 [6].

With increasing access to ART, HIV-infected youth are living well through adolescence and into adulthood [7]. While a relatively small group, youth face unique challenges in receiving care and support, particularly adolescents. Adolescents living with HIV (ALHIV) must navigate the transition from childhood to adulthood while managing a highly stigmatized condition. Given both ethical considerations surrounding an individual's 'right to know' and public health concerns about HIV transmission [8,9], it is critical that ALHIV know their HIV status. Although international guidelines such as those published by the World Health Organization recommend disclosure of HIV to school-aged children [10,11], disclosure is inherently difficult. Consequently, in many contexts, complete disclosure is often delayed through adolescence [12].

Caregivers may be reluctant to disclose to adolescents for numerous reasons, including concerns about negative emotional impacts on children [12–16]; fear of resentment [16,17]; feelings of guilt in transmitting the virus [12,16,18,19]; and discomfort in discussing HIV transmission [20]. For HIV-positive parents, informing an older child of his/her status may entail disclosure of their own HIV infection [21]. Parents may fear that the adolescent will be unable to maintain secrecy [13–15,17,19], risking stigma and isolation for the entire family [13–15,19,22]. Moreover, some parents may avoid discussion of HIV with their adolescent child because of their own denial, struggles coping with HIV, and negative experiences with disclosure and stigma [11,13,18,22]. Finally, many caregivers report feeling that they lack the skills necessary to disclose, especially answering questions in an accurate, age-appropriate manner [13,14,16,18,23].

In China, where culture emphasizes family honor ("face"), disclosure may be particularly daunting for families and health care providers [15,24,25]. Although several studies in China have focused on parental disclosure of their own HIV status to their children [21,25,26], there is no published evidence regarding disclosure of HIV-infected children's HIV status to the children themselves. Given the increasing numbers of ALHIV in China, and indications from providers that ALHIV face numerous challenges including poor ART adherence, we conducted a study in Nanning, China that included piloting use of adherence monitoring devices among ALHIV [27]. Using qualitative methods, we also explored issues related to medication adherence, understanding of HIV, and disclosure of HIV status to ALHIV with clinicians, parents of ALHIV, and the ALHIV themselves. To help fill the gap in understanding of HIV disclosure issues with ALHIV, here we provide findings from our investigation of practices for disclosure to ALHIV among Chinese caregivers and clinicians, and the disclosure experiences of the adolescents themselves.

2. Methods and materials

2.1. Design and Setting

The study was conducted in 2014 at the Guangxi Center for Disease Control and Prevention ART (CDC-ART) clinic in Nanning, China, where at the time of the study, 370 children aged 15 years and younger were in HIV care and treatment. All adolescent patients had contracted HIV perinatally, were on three-drug NNRTI-based regimens taken twice daily, and obtained their medications monthly. We planned four focus group discussions (FGDs) with adolescents in two age groups (10–12 years; 13 years and older) and one with HIV clinicians; and forty in-depth interviews (IDIs) with twenty adolescent/caregiver dyads.

2.2. Procedures

With assistance from clinicians, we purposively sampled ALHIV aged 10 years and older who were receiving care at the study clinic for both IDIs and FGDs. All patients aged 10 years and older were eligible to participate, along with their caregivers. Knowledge of HIV status was not a prerequisite for participation. Adolescents participated in an IDI, a FGD, or both. All clinic personnel involved in patient care were eligible to participate in the clinician FGD. IDIs and FGDs were conducted in Mandarin Chinese by two trained interviewers in a private room at the CDC-ART clinic using semi-structured interview guides. Sessions were audio-recorded; one interviewer took notes. Respondents were given a small stipend to cover transport.

Adolescent IDIs explored youths' understanding of their medication, how they had learned about their condition, and their challenges taking medications. FGDs with adolescents focused on respondents' understanding of their condition and medication-taking, including challenges and strategies. As not all adolescents knew their HIV status, interviewers did not refer explicitly to HIV unless participants themselves spoke openly about it, indicating awareness of their status. IDIs with caregivers explored disclosure to the participant's child and future plans for disclosure, in addition to challenges related to adherence. The FGD with clinicians focused on perceptions of challenges faced by ALHIV and caregivers related to medication-taking, adherence, stigma, and disclosure, in addition to clinicians' role in supporting adherence and disclosure.

2.3. Data analysis

Recordings were transcribed, supplemented by written notes, and translated into English by a bilingual translator. We coded and analyzed the English-language transcripts using NVivo™ software. Following a grounded theory approach, we summarized major themes related to disclosure, and explored all reports of disclosure experiences and challenges. While our analysis highlighted important themes based on how often they were raised by participants, we considered the full spectrum of experiences, including divergent accounts.

2.4. Ethical considerations

Institutional Review Boards at Boston University Medical Center; the National Center for AIDS/STD Control and Prevention, Chinese Center for Disease Control and Prevention in Beijing; and the Guangxi Provincial Center for Disease Control in Nanning approved the study. Caregivers provided written informed consent prior to enrollment for their own and their child's participation, adolescents provided written assent, and clinicians provided written consent.

3. Results

We conducted five FGDs (four with adolescents, one with clinicians) and thirty-eight IDIs with 19 adolescent/caregiver dyads. A total of 61 individuals participated. Five ALHIV participated in both an IDI and a FGD. Demographic features of adolescent and caregiver participants are summarized in Tables 1 and 2. The mean age of adolescent participants was 12.0 years (SD 1.9 years); the majority (21/35) were male. Most caregivers (11/19) were mothers of ALHIV and had primary school education. Participants in the older FGDs all knew their status; the proportion of participants in younger FGDs that knew their status is uncertain. Participants in the clinician FGD were all female and included four nurses, one physician, one counselor, and the clinic's administrative director.

Analysis of IDIs and FGDs revealed several clear themes, encompassing: disclosure as a process, fear of stigma, concern about children's reactions on the part of caregivers and clinicians, and caregivers' feelings of inadequate preparedness and skills to carry out full disclosure. Additional issues encompassed debate about who is the most appropriate party to lead disclosure to a child and recognition of disclosure and the importance of understanding one's status to promote successful treatment and good adherence. We present the main themes below, with supplementary statements organized by theme in Table 3.

3.1. The process of disclosure

Among the IDI dyads, only 6/19 caregivers reported having disclosed to their child (5/9 caregivers of ALHIV aged 13 years and older; 1/10 caregivers of ALHIV aged 10–12 years). From matched adolescents' statements, we estimated that 9/19 children actually knew their HIV status (6/9 older ALHIV; 3/10 younger ALHIV). Most caregivers who had not disclosed said they planned to do so when their child was 14 years or older.

Many caregivers (13/19) referred to disclosure as a process, requiring attention to a child's developmental stage and maturity (Table 3). Typical descriptions included:

I should tell her slowly and little by little. After all, she is growing up and she will learn a lot of things on her own. (IDI, mother of 12 year-old girl)

She won't be able to understand now even if I told her. All she knows is to take her medicine. She doesn't understand this condition at all. (IDI, mother of 11 year-old girl)

Both caregivers and clinicians stated that they began disclosure by telling children that they had a less-stigmatized condition, such as eye problems or chronic respiratory issues. Clinicians often described HIV to younger children as "bugs in the belly"; ART medications were frequently called vitamins or calcium tablets by both clinicians and caregivers. Adolescents' responses confirmed this stage of the process; one gave this typical explanation:

Table 2

Characteristics of caregiver respondents (N = 19).

Characteristic	N (%) or Mean (SD)
Gender (female)	10 (52.6)
Age (years)	42.1 (11.7)
Relationship to child	
Mother	11 (57.9)
Father	5 (26.3)
Grandparent	3 (15.8)
Education level	
Primary	11 (57.9)
Middle school	5 (26.3)
Secondary school or higher	3 (15.8)

Yes, my eyes will get worse if I don't take my medicine. My other eye will be affected and I won't be able to see. (IDI, 10 year-old girl)

In one case, an adolescent's status was withheld from the child's caregivers, her grandparents:

I told them that she was ill, but not exactly what she had. I told them to watch her take her medicine ... I'm not going to tell her now. She is living with her grandpa now and she tells him everything. (IDI, mother of 12 year-old girl)

Sometimes children wanted more information about their condition. One clinician described a parent whose daughter frequently asked why she had to take so many calcium tablets: "Now this has become her [the mother's] biggest concern, and she doesn't know how to answer it." (FGD, clinician). A 13 year-old boy described being thwarted by caregivers and clinicians: "I asked them what disease I had, but they wouldn't tell me." Instead, numerous children described learning their status independently in a variety of ways (Table 3), including from medication labels and eavesdropping on parents.

Only one caregiver reported full disclosure at a young age:

He knows everything. We have already explained [it] to him when he was little ... We just said that this disease was serious. (IDI, father of 14 year-old boy)

3.2. Challenges to disclosure: stigma, anxiety about children's reaction, and lack of preparedness

3.2.1. Stigma

Caregivers' fear of stigma, both for their child and for the family, represented a main challenge to disclosure. These were typical statements (also see Table 3):

For the time being, we don't plan to [disclose]. He is still too young to keep a secret, so we cannot tell him. If he knows now and tells other people, I don't know what other people will think

Table 1

Characteristics of adolescent respondents (N = 35).

Characteristics	In-depth interviews (IDIs) only (N = 14)	Focus group discussions (FGDs) only (4 FGDs; n = 16)	Both IDIs and FGDs (n = 5)
	N (%) or Mean (SD)	N (%) or Mean (SD)	N (%) or Mean (SD)
Gender (female)	3 (21.4)	9 (56.2)	2 (40.0)
Age (years)	12.1 (1.6)	11.6 (2.1)	13.0 (1.6)

Table 3
Supplementary statements by theme.

Caregivers' impressions of disclosure as a process

He is still young now. I have the feeling that he may not be able to understand this, and that's why we haven't told him yet. (IDI, mother of 10 year-old boy)
 I should tell her slowly and little by little. After all, she is growing up and she will learn a lot of things on her own. (IDI, mother of 12 year-old girl)
 We have told her this. When she grew up, and began to understand a little. She knows that she has this disease. We told her how she got infected, and she understood. However, she is a kid after all, and cannot understand this disease very well. That's probably why she doesn't take her medication seriously enough. I plan to tell her clearly when she gets a little older. (IDI, mother of 14 year-old girl)
 I have told her about her condition. But she doesn't really understand about the harm of this disease. I'll probably tell her when she is 14 or 15. She will have better understanding then. (IDI, mother of 11 y-o girl)
 Some older kids asked me why they were on medication, because they did not know about their condition. They wonder why they were taking so many drugs every day and when they could stop. (FGD, clinician)
 She won't be able to understand now even if I told her. All she knows is to take her medicine. She doesn't understand this condition at all. (IDI, mother of 11 year-old girl)
 ... he is too young now. He wouldn't understand even if we tell him. (IDI, mother of 10 year-old boy)
 We don't let her read those materials displayed in the clinic. We are afraid that she might know. Let her learn about it gradually when she grows up. (IDI, grandmother of 10 year-old girl)
 He is 14 now. We plan to wait and discuss with him when he is 18 or 19. At that time, we would talk to him about having a girlfriend. We will probably tell him to be careful and not to infect his girlfriend. (IDI, mother of 14 year-old boy)
 He should be able to understand slowly. I ask the counselors here and she told me to discuss this with him little by little. (IDI, mother of 14 year-old boy)
 He does, a little. We have told him some vaguely since two or three years ago, but he is probably not 100 per cent clear. (IDI, mother of 14 year-old boy)

Full disclosure to young child: one example

He knows everything. We have already explained to him when he was little ... We just said that this disease was serious. (IDI, father of 14 year-old boy)

Adolescents' accounts of learning HIV status themselves

I read the label on my pill bottles and the instructions. (IDI, boy, age 13)
 I learned about it when I went to the hospital, in recent years. I read [the results] myself, and I learned more about it later, slowly. (FGD, girl, age 17)
 Eavesdropping. On my parents. (FGD, 13 year-old boy)
 [I learned when I was] about 6 or 7 years old. [My parents] dared not to tell me at the beginning, but I found out myself later. I didn't learn from here. I learned it from promos on TV. I asked my mum what that disease was, and my mum told me that's what we have. At that time, I didn't know exactly what it was, I learned about it later slowly. (FGD, boy, age 15)
 We haven't talked about this officially, but he loves internet, so he has probably looked them up on the Internet. There are labels on the pill bottle, he should know. He never asked me, but I didn't talk to him about this either ... I think he knew two years ago. Once when we argued, he asked 'do you really think I don't know why I have to take medicine every day?' I stopped yelling at him then. (IDI, father of 13 year-old boy)
 When I was 6 or 7 ... all my classmates were talking, and they wouldn't play with me. (FGD, 13 year-old girl)

Fear of stigma by caregivers and children

My mum told me not to tell anyone that I was on medication. They won't play with me anymore if I tell them. (IDI, girl, age 10)
 I also told him to avoid being seen when he takes his dose (IDI, mother of 13 year-old boy)
 He is still too young to keep a secret, so we cannot tell him. If he knows now and tells other people, I don't know what other people will think of him, nor how other people will treat us. (IDI, mother of 12 year-old boy)
 I told her not to tell her classmates. (IDI, grandmother of 10 year-old girl)
 He doesn't know about it yet. I plan to tell him when he is older, probably when he is about 16. He won't understand even if I tell him now. If I do tell, I'll worry that he tells other people. (IDI, mother of 12 year-old boy)
 Some children in the facilities are orphans, and they were told clearly about their conditions ... They are worried that they might be discriminated against ... when they have to go to school. (FGD, clinician)
 Some parents also worry that their children may tell other people about their conditions. Once, one child overheard his parents' conversation and learned about his condition. When he went to see a doctor for his cold, he told the doctor really loudly that he was HIV-positive when the doctor asked what was wrong. His mum was shocked and ... worried that the child hadn't had any idea about the discrimination against this disease. (FGD, clinician)
 The school he use to go to won't take him because his teachers know about his condition. (IDI, father of 14 year-old boy)
 Some children living on campus are worried that their classmates may see them take drugs. (FGD, clinician)
 It's most difficult at school. Those people would ask me why I took those pills when I was taking my medicine. I told them that I had a cold. After one semester, no one talked to me. Then I had a cold [more recently] and went to see the doctor for my rhinitis, I would then lie to them that they were for my rhinitis. I then had this idea together with my teacher, and communicated with my teacher. It got better. (IDI, 13 year-old boy)

Caregivers' worries about children's reactions to disclosure

He blamed me. He blamed me for infecting him. His dad was gone then, he probably heard of it from his grandma. He heard that his dad contracted and infected his mum, and then mum infected him. Once when we came here to see the doctor, he also said that he blamed me for giving him the disease. Later I explained to him, and he understood. Please ask whether he still blames me for it. (IDI, mother of 13 year-old boy)
 I am just worried that she cannot accept it. She has to be on medication for life. (IDI, mother of 13 year-old girl)
 No, he did not ask. I'm worried that he might have some thoughts or attitudes towards his parents when he knows. I'll tell him when the time is right. (IDI, father of 12 year-old boy)
 Just don't tell her everything at one time. I'm afraid that she can't handle it. (IDI, mother of 10 year-old girl)
 Not yet. I think he is still too young. I'm afraid that he would carry it as a psychological burden. (IDI, father of 13 year-old boy)

Caregivers' sense of lack of preparedness

No [we have never talked with her about her condition]. We don't know how to begin. We don't dare to tell her either. (IDI, mother of 10 year-old girl)
 I can tell him when he is 15 or older. I don't know where to start, and I'm both worried and scared. (IDI, mother of 12 year-old boy)
 I have the feeling that the biggest problem we have now is we don't know how to tell her. (IDI, mother of 10 year-old girl)
 I'm not entirely sure [whether he knows his status], but we have never talked about this, and I'm not ready either. I don't plan to tell him now, and I thought about telling him in two or three years. (IDI, mother of 13 year-old boy)
 I'm not well educated myself, so I'm not able to explain to him clearly. (IDI, mother of 14 year-old boy)
 To be honest, I, for myself, also wish that this disease can be cured one day. With this wish in my mind, I don't know how to talk to him about this. (IDI, father of 13 year-old boy)
 At this age, he could easily get into something bad without proper education. That's why I'm so concerned about how to tell him. (IDI, mother of 13 year-old boy)

Table 3 (continued)**Ownership of disclosure: dialogue between caregivers and clinicians**

I haven't told him about his condition ... the doctor has told him some. I don't know how to tell him. You [clinicians] can say however much you want to. It's better if you tell him. (IDI, grandfather of 10 year-old boy)

I think it's better if you can tell her. You're professionals, and she may listen to you more. (IDI, mother of 14 year-old girl)

I think you will be more suitable, because he may not pay attention to what I say to him. He may ignore it or never take it seriously. He may listen to you more. (IDI, mother of 11 year-old boy)

There are not many people at home. His grandma is too old, and I'm the only one left, but I can't really explain it clearly. It would be best if you can help me with this. It would be rather easy for him to understand if the counselor could tell him a little every time when we are here. (IDI, mother of 14 year-old boy)

I haven't decided which way I'm going to use to tell them, but I think it would be better if they learn about it from their parents. It might be easier to take it if they are told by someone close to them. (IDI, mother of 11 year-old girl)

I think it would be better to let us tell him. He is quite good with us. (IDI, mother of 10 year-old boy)

It must be me. Who else could tell him that? (IDI, mother of 12 year-old boy)

I think it is the obligation of both parents and medical workers to tell the children. (FGD, clinician)

Some parents believe that they should tell their children when they are older, and some children were told by their counselors. Most of them before were told by counselors. (FGD, clinician)

We haven't developed any standard on exactly when is a good time to tell and how. This is also part of what we would like to explore in the future. It is rather difficult as, domestically, relevant people also don't have any good experience about when and how to tell. (FGD, clinician)

of him, nor how other people will treat us. (IDI, mother of 12 year-old boy)

No [we have never told her about her condition]. We don't know how to begin. We don't dare to tell her either. (IDI, mother of 10 year-old girl)

School and peer relationships presented particular challenges stemming from fear of stigma. Caregivers worried about interactions with teachers and classmates; ALHIV reported problems when peers learned about their status. Here are illustrative accounts (additional statements in Table 3):

My mum told me not to tell anyone that I was on medication. They won't play with me anymore if I tell them. (IDI, 10 year-old girl)

It's most difficult at school. Those people would ask me why I took those pills ... After one semester, no one talked to me. (IDI, 13 year-old boy)

Some children in the orphan facilities ... were told clearly about their conditions ... They are worried that they might be discriminated against when they have to go to school (FGD, clinician)

The school he use to go to won't take him because his teachers know about his condition. (IDI, father of 14 year-old boy)

One clinician described the challenges of the school environment:

Besides home, school is the children's main environment. It is also very important to conduct HIV campaign and education for normal healthy children ... It would have great impact on children if teachers at school didn't discriminate against HIV patients. It is certain that children will be affected if teachers at school treat those [HIV+] children differently. If teachers don't have discrimination, then children won't be treated unfairly even if they are infected. However, this is a social issue, and it is complex. (FGD, clinician)

Several caregivers went to great lengths to protect their child from potential stigmatization, which seemed related to their own status. For example:

I was rather sensitive when I just learned about my condition, and I distanced myself from both my own family and my in-law's family. That's why I have always stayed in Guangdong with

my child during Spring Festival, rather than going home. I have the feeling that their attitudes towards the child have changed. (IDI, mother of 13 year-old boy)

Conversely, one family reported disclosing to an adolescent in order to prevent stigma and its consequences:

He [knows} his status. He knew when he came here for treatment. We have told him, so he won't tell other people. We have also given him examples from the brochures. For example, when the people in the village learned about a kid's infection, they isolated him in a cave on the mountain. His grandma tried to send food to him, but the villagers prohibited her from doing this, so the child died in the cave. (IDI, mother of 13 year-old boy)

3.2.2. Children's reactions

Caregivers also worried about their children's anticipated and actual reactions when they learned of their status. These fell into two categories: fear of blaming the parents for infection, and concern about the child's ability to handle information emotionally. The following passages describe fear of blame and actual experience of resentment by two caregivers:

... he did not ask [about how he was infected]. I'm worried that he might have some thoughts or attitudes towards his parents when he knows. I'll tell him when the time is right. (IDI, father of 12 year-old boy)

He blamed me for infecting him. His dad was gone then, [and] he probably heard of it from his grandma. He heard that his dad contracted HIV and infected his mum, and then mum infected him. Once, when we came here to see the doctor, he also said that he blamed me for giving him the disease. Later I explained it to him, and he understood ... (IDI, mother of 13 year-old boy)

Here, two caregivers share their worries about the psychosocial impact of disclosure on their children:

Not yet. I think he is still too young. I'm afraid that he would carry it as a psychological burden. (IDI, father of 10 year-old boy)

Just don't tell her everything at one time. I'm afraid that she can't handle it (IDI, mother of 10 year-old girl)

One parent reported anger on the part of his child during a

disclosure conversation:

I was going to talk to him over this vacation. I tried twice to slowly lead to this topic, but he stopped me and said that I was really mean. (IDI, father of 13 year-old boy)

Additional statements regarding adolescents' reactions (actual and anticipated) to learning their HIV status appear in [Table 3](#).

3.2.3. Lack of preparedness

The final major barrier to disclosure described by caregivers involved feeling emotionally unprepared and lacking the necessary knowledge and skills:

I don't know where to start, and I'm both worried and scared. (IDI, mother of 12 year-old boy)

... the biggest problem we have now is we don't know how to tell her. (IDI, mother of 10 year-old girl)

I'm not entirely sure [whether he knows his status], but we have never talked about this, and I'm not ready either. (IDI, mother of 13 year-old boy)

I'm not well educated myself, so I'm not able to explain to him clearly. (IDI, mother of 14 year-old boy)

3.3. Ownership of disclosure process

There was some debate among caregivers about who should lead the disclosure process. Several caregivers requested assistance with disclosure from clinicians. Typical statements included: "I think it's better if you can tell her. You're professionals, and she may listen to you more." (IDI, mother of 14 year-old girl). Conversely, several caregivers insisted that caregivers are best suited to disclose. As one mother stated,

I haven't decided which way I'm going to use to tell them, but I think it would be better if they learn about it from their parents. It might be easier to take it if they are told by someone close to them. (IDI, mother of 11 year-old girl)

Finally, although clinicians expressed frustration at not knowing how best to advise caregivers, one expressed the opinion that caregivers and clinicians have an obligation to tell children.

Based on my experience, telling the child why he is on medication and the importance of adherence is very important. If you just keep on holding back the truth, you can keep them from knowing for one day, or two days, but eventually, they will know. If the child knows that their parents have kept the truth from them for so long, they may also become resentful. I think it is the obligation of parents and medical workers to tell the children. (FGD, clinician)

3.4. Importance of disclosure to good adherence

Several older adolescents expressed the view that knowing one's disease status was important to good ART adherence. For example:

I would secretly throw away my medicine when I was in Grade 5 or 6 because I didn't want to take it, but I won't throw them

away now. I stopped since I got to middle school and learned that I have HIV. (FGD, boy, age 14)

My mum told me that I had AIDS, so if I don't take my medicine on time, the virus will spread all over my body. That's why I must take my medicine. (IDI, girl, age 10)

Others appeared motivated to take their medication due to knowledge of their status. In response to queries about what is helpful for adherence, older ALHIV participants in a FGD responded with statements such as "Correct understanding of HIV/AIDS" (FGD, boy, age 14) and "Understanding of the consequences of not taking the medicine" (FGD, boy age 15).

4. Discussion

To our knowledge, this is the first study examining issues surrounding disclosure to HIV-infected children in China. Several notable themes emerged among these HIV-positive adolescent patients and their caregivers. With respect to WHO guidelines, disclosure of HIV status to children occurred late. Concerns about a child's maturity and ability to understand his/her condition, stigma and discrimination toward the child and family, in addition to caregivers' feelings of unpreparedness and worries about the child's reaction (blame and burden), were associated with a reluctance to disclose. However, children expressed a desire to understand their disease status, and some who knew their status considered disclosure important for medication adherence. A compelling aspect of our study was the use of caregiver-child dyads for the IDIs, which allowed us to see vivid cases in which the caregiver was concerned about what the child might know, when in fact, the child already was aware of his or her status. This dyad approach has been used to a limited extent in a very few previous studies of HIV disclosure in sub-Saharan Africa [28,29], but never in an Asian setting, and without our interviewers' emphasis on trying to elicit and understand the child's understanding of disease.

Late disclosure is common in the literature. Caregivers in sub-Saharan Africa, Thailand, and elsewhere frequently report avoiding disclosure of infected children's status, using deception and secrecy to avoid informing youth of their diagnosis [13,18,30]. Concerns of inadequate caregiver knowledge or skills are also seen throughout the literature [11,13,14,17], as is fear of children's inability to maintain secrecy of HIV status [14,16,19]. In addition to school-related concerns shared in our study, several caregivers reported withholding the child's status from family for fear of differential treatment of the child. Similar social dynamics to those identified in our study have been found in studies of disclosure of parental HIV status to children in China, including fears of stigma, psychological burden for the child, and negative social consequences for family [21,25,26,31].

Despite the challenges, timely disclosure of children's status may have benefits for children and caregivers. Youth who know their HIV status can play a greater role in their medical care [32], seek social support [23,32], and benefit from more open communication with caregivers [17,33,34]. In several studies, children who knew their status demonstrated improved medication adherence [16,35], more autonomous self-care [23,33], and reduced psychological distress [33,36,37]. In addition to benefits for children, some caregivers report reduced anxiety and depression following disclosure [17,36,38], in addition to greater trust of the caregiver, strengthened of relationships with their child via more open communication, and less perceived need for deception [17,33,34]. Although no children or caregivers in our sample explicitly mentioned distrust, clinicians observed that withholding HIV status from some children appeared to result in these patients'

resentment towards their caregivers, and other studies have suggested that inadvertent disclosure can create mistrust of caregivers, especially among older children who may feel “lied to” [23,39].

Quite distinct from settings where caregivers conceptualize disclosure to HIV-infected children as a discrete event centered on the naming of HIV [18], in this Chinese context, the “process” of disclosure described by caregivers resembled the preferred approach described in behavioral literature [13,14,18,33,40], which portrays disclosure as a dialogue beginning months to years culminating in the naming of HIV [33] that evolves alongside the child's cognitive development over time [26]. In determining each conversation's timing and content, caregivers and providers assess the child's age, maturity, medication adherence, and likelihood of soon learning his/her diagnosis elsewhere, as well as caregivers' fears and family factors, that will inform the disclosure experience [13,32]. This model provides multiple opportunities for the child to ask questions and express concerns; caregivers and providers can reiterate educational concepts and stress importance of medication adherence [33,39], while reinforcing support. Such an approach is believed to benefit both the child's acceptance of the disease and his/her psychological adjustment [41].

Gradual disclosure should be distinguished from deception, however. Our study found that caregivers and clinicians sometimes use alternative or narrow explanations for acute illnesses to explain the need for daily medications. Similar patterns are seen in other studies, including selective disclosure and provision of misleading information [15,16,42]. In the short term, such strategies may be useful to caregivers, but long-term deception may mislead and harm children, rather than enhance understanding of their illness. It may be that caregivers require substantial help learning how to disclose a child's HIV status and more interventions, such as one focused on the decision-making process surrounding disclosure piloted recently in China among HIV-positive parents considering disclosing their own status to their children [43]. Our qualitative findings also suggest that children seem to be discovering their status at earlier ages on their own, contrary to what clinicians and caregivers believe—a tendency which is unlikely to change.

In China, the honor of the family (“face”) is often prioritized over an individual's right to know their HIV diagnosis [44]. Traditionally it has been commonplace for providers to disclose an HIV diagnosis to an adult patient's family prior to the individual [44]. Providers tend to use subjective judgment, considering the family's best interests and illness severity when deciding whether to inform a patient of his/her HIV status [44]. In one study, Chinese providers felt that hiding an HIV diagnosis from an adult patient was protective of his/her physical and psychological health [45]. Furthermore, in Chinese culture, death, sex and other emotional topics are often taboo [25,46]. and HIV is still a highly stigmatized and emotional subject [47]. In the context of youth with HIV, these cultural dimensions may explain why health professionals in China have historically disclosed status to children unilaterally; having a provider tell the child first is an indirect, more traditional approach for families. In this evolving context (caregivers' increasing role in disclosure but commonly cited feelings of unpreparedness), healthcare providers, who tend to be highly respected and trusted in China [44], will likely continue to play a critical role in facilitating disclosure to HIV-infected youth, although they, too, need adequate training to improve their counseling skills so that they can better support both caregivers and children in the disclosure process.

5. Limitations

There are several limitations to this study. First, the clinician FGD was dominated to some extent by one clinician, and it is possible that some participants' views were expressed

inadequately. Second, the CDC-ART clinic is a specialized facility that cares for HIV patients in Guangxi province, and participants may not be representative of adolescent ART patients in China. Finally, because participants were purposively selected by clinicians, cooperative patients with supportive caregivers may have been disproportionately represented.

6. Conclusions

Disclosure of HIV status occurred late in this group of adolescents living with HIV in China. Fear of stigma, toward not only the caregiver and child but also the broader family, was an important factor underlying delayed disclosure. Caregivers, clinicians, and adolescents identified school and peer interactions as a particularly concerning environment for discrimination, and an important target for interventions aimed to reduce HIV stigma. Clinicians voiced the need to better educate teachers, as teachers' modeled behaviors influenced the behavior of children.

As the population of HIV-infected pediatric patients in China surviving beyond adolescence to adulthood grows, culturally appropriate guidelines for clinician-supported disclosure should be adapted and developed, focusing on ways of supporting caregivers in the disclosure process. The potential to use peer support strategies for both caregivers and adolescents in this process might also be explored. Because individual patients are viewed within the context of the family, and the reputation (“face”) of families is so critical in China, efforts to de-stigmatize HIV in China more broadly, and in schools in particular, will help with the process of HIV disclosure to adolescents.

Conflict of interest

The authors declare that they have no conflicts of interest.

Funding

The study was made possible by a grant from Boston University School of Public Health.

Acknowledgments

We thank the adolescent patients, their caregivers, and clinicians who participated in the study, as well as the staff of the Guangxi CDC STI/AIDS clinic in Nanning.

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