

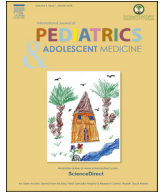
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Full length article

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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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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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.

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