Stigma and Discrimination among Perinatally HIV-Infected Adolescents Receiving HAART in Thailand

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Abstract

Human immunodeficiency virus (HIV)-related stigma and discrimination are important barriers to HIV prevention and treatment. There is scant data on this topic for children or adolescents born with HIV. A cross-sectional study was conducted among perinatally HIV-infected adolescents with access to highly active anti-retroviral therapy (HAART) in Chiang Mai, Thailand. HAART is used to reduce HIV viral replication and consists of a combination of oral medications including nucleoside reverse transcriptase inhibitors (NRTIs), protease inhibitors (PIs) and non-nucleoside reverse transcriptase inhibitors (NNRTIs). A standardized questionnaire and focus groups were used to assess HIV-related stigma and discrimination in the home, community, school, and healthcare settings. A total of 86 adolescents (median age: 13 years; range: 10-18.9; 55% females) participated in the study. Ninety-nine percent were on HAART. Sixty-two percent reported that they had to use their own drinking glass at home, and one-third reported that they had been teased. Approximately one-fourth reported that surrounding people had ended their friendship because they were infected with HIV. Ninety-seven percent of adolescents perceived stigma and 32% said that an HIV-infected person had no hope for the future. The initiation of HAART markedly decreased the physical manifestations of HIV and transformed HIV into a chronic disease for the adolescents. HIV-related stigma and discrimination were identified in all aspects of the adolescents’ lives, most commonly found in healthcare settings. Almost all adolescents perceived stigma and having to use their own drinking glass was the primary mode of discrimination. Peer-to-peer counseling, group meetings, and education of those comprising the support network around the HIV-infected adolescent may be ways that we can decrease the burden of HIV infection.

Keywords

Adolescents; Discrimination; Highly Active Antiretroviral Therapy; Human Immunodeficiency Virus; Social Stigma

Introduction

The HIV pandemic continually presents new challenges for people living with HIV/AIDS (PLWHA) and their communities. HIV-related stigma and discrimination are barriers to prevention and treatment (Parker and Aggleton, 2003; UNAIDS, 2003b; Weiss and Ramakrishna, 2001). UNAIDS (UNAIDS, 2003b) defines stigma as a “process of devaluation” that can be experienced (enacted) and/or perceived (anticipated) (Goffman, 1963; Health and Development Networks, 2006). Discrimination is defined as the harmful treatment of a specific group of people (Giddens, Duneier, Appelbaum, Carr, 2009). PLWHA can suffer from social rejection, financial insecurity, shame, guilt, low self-esteem, and depression (Bennet, 1990; Kalichman, et al., 2005). HIV-related stigma and discrimination have been associated with increased HIV risk behavior, and can originate from family members, people in the community, classmates, and healthcare workers (Alonzo and Reynolds, 1995; Brown, Macintyre, and Trujillo, 2003; Cao, Sullivan, Xu, and Wu, 2006; de Bruyn, 2002; Fortenberry et al., 2002; Herek, Capitanio Widaman, 2002; Herek et al., 1998; Kittikorn, Street, Blackford, 2006; Malcolm et al., 1998; Parker and Aggleton, 2003; UNAIDS, 2003b; Valdiserri, 2002; Yang et al., 2004). A Thai study found that some families asked their HIV-infected relatives to stay
hidden when people came to the house (Kittikorn, Street, Blackford, 2006). HIV-related stigma and discrimination impact all aspects of the individual’s life and need to be addressed on multiple levels.

HIV-related stigma and discrimination research has primarily occurred in adult populations. There is a focus on groups with HIV ‘risk behaviors’, such as sex workers, injecting drug users and men who have sex with men (Chan, Yang, Zhang, Reidpath, 2007; Fortenberry et al., 2002; Parker and Aggleton, 2003; United States Centers for Disease Control and Prevention, 2000). Subsequently, stigma scales, such as the scale created by Berger et al, primarily involve adults with ‘risk behaviors’ (Berger, Ferrans, Lashley, 2001). In these articles it is difficult to disentangle the etiology of stigma and discrimination in the adult’s life in relation to their ‘risk behaviors’, as they are often intertwined.

Studies among HIV-infected children and adolescents are sparse. Wright et al (2007) studied HIV-infected youth (16-25 years) in the United States, who primarily acquired HIV through sexual contact (86%) (Wright Naar-King, Lam, Templin, Frey, 2007). The authors described and validated an abbreviated stigma scale including disclosure, self-image, public attitudes, mental health, and associations with substance use. A 2006 Brazilian ethnographic study followed 50 children (1-14 years) who were infected or affected by HIV living in 2 support houses (Abadia-Barrero and Castro, 2006). HIV-related stigma and discrimination were associated with poverty, social inequality, racism, orphan status, access to resources, age, geographic region, and gender. HAART reduced HIV-related stigma, although the children subsequently faced new challenges such as sexuality and adherence. These two studies offer insight into complexities of HIV-related stigma in children and adolescents.

It is difficult to generalize these studies to Thai adolescents, as prior studies took place in very different settings (developed countries, lack of HAART access, among adults, or in groups with high ‘risk behaviors’). Thus, while Thailand’s response to its HIV epidemic is widely cited as a successful international model, there remain several gaps, including lack of data on stigma and discrimination (Marais, 2004; UNAIDS, 2003a). Characterization of adolescents’ experience with HIV-related stigma and discrimination is needed in order to improve clinical management and community programs. This study aimed to explore stigma and discrimination among perinatally HIV-infected adolescents, as one step to help address this discrepancy.

**Methods**

**Study Location & Population**

A cross-sectional survey of HIV-related stigma and discrimination among the approximately 200 perinatally HIV-infected adolescents under routine HIV care at the Pediatric Infectious Disease Clinic, Chiang Mai University Hospital (CMUH), Chiang Mai, Thailand was implemented. Chiang Mai is a city of 1.5 million people in northern Thailand and was at the epicenter of the initial Thai HIV epidemic. CMUH is a 1,000-bed tertiary care center providing HIV care for children, adolescents, and adults. Adolescents and their caregivers were invited to participate during a regularly scheduled HIV clinic appointment. Study participants were between 10 and 19 years old and had been diagnosed with laboratory confirmed (HIV antibody, PCR, Western Blot) perinatal HIV infection. All study participants and their caregivers previously underwent a multi-step disclosure process of their HIV infection by an infectious diseases pediatrician. If either the adolescent or caregiver were non-Thai speaking the adolescent was excluded (this population makes up approximately 1% of the total number of HIV-positive adolescents). Informed consent of the adolescents and their caregivers were obtained. Each patient was assigned a unique study number. Participants were provided transportation fees on the day of the interview (200 Thai baht, approximately US $6).

**Questionnaire Development**

Questionnaire development drew from questionnaires designed to measure adult HIV-related stigma and discrimination, and to measure stigma and discrimination in children/adolescents with chronic conditions (epilepsy, body image disorder, hemophilia, and mental illness) (Austin, MacLeod J, Dunn DW, Shen J, Perkins, 2004; Berger, Ferrans, Lashley, 2001; Bunn, Solomon, Miller, Forehand, 2007; Corrigan et al., 2005; Fernandes et al., 2007; Holzemer et al., 2007; Warwick, Aggleton, Douglas, 2001; Wright, Naar-King, Lam, Templin, Frey, 2007). Through discussions, editing, translations, back translations, and field-testing, the questions were refined and reduced to create a standardized questionnaire assessing HIV-related stigma and discrimination. Four focus groups were lead by an infectious disease pediatrician with a
standardized questionnaire and conducted in age-related groups of 5-6 adolescents. The study was approved by the Research Ethics Committee of the Faculty of Medicine, CMUH.

**Study Measures and Analysis**

Questionnaires collected demographic data, recent laboratory data, HAART regimen, stigma and discrimination in four settings (home, 11 items; community, 11 items; school, 11 items; healthcare settings, 10 items), and perceived stigma (31 items). The questionnaires took about 30 minutes to complete. Quantitative data were entered with Epi Info, version 6 (Centers for Disease Control and Prevention, Atlanta, GA, USA) and analyzed with Stata SE, version 10 (StataCorp, College Station, TX, USA). Focus groups discussions, which were about 45 minutes in length, were recorded, transcribed verbatim from the audio recordings, and translated into English. Questions used to guide focus groups are shown in Table 1.

**Results**

**Demographics**

Eighty-six adolescents participated in the study. The median age of the adolescents was 13 years old (range: 10-18.9), 55% (47/86) were female, and 97% (83/86) were Thai (Table 2). Median time of knowledge of HIV infection was 6 years (range: 0-16). Ninety-five percent (82/86) were in school from grade 1 to vocational or bachelor’s degree with a mean grade point average of 2.9 (1.5-4.0). Twenty-two percent (17/79) had both parents alive. Of adolescents whose had at least one parent die, 57% (29/51) had a father die and 48% (26/54) had a mother die. Most adolescents lived with their maternal grandparents (24%), other relatives (23%), or parents (16%). When they had a problem the adolescents were most likely to talk with their parents (32%), friends (20%), or teachers (14%).

<table>
<thead>
<tr>
<th>TABLE 1: QUESTIONS USED TO GUIDE FOCUS GROUPS</th>
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<tr>
<td>General questions:</td>
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<tr>
<td>Where do you live?</td>
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<tr>
<td>How did you get here?</td>
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<tr>
<td>How long have you been taking HAART?</td>
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<td>How do you take HAART?</td>
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<td>Who reminds you to take HAART?</td>
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<td>Do you ever forget to take HAART? If yes why?</td>
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<td>Stigma and discrimination:</td>
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<td>Who else knows you are infected?</td>
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<td>Who told you that you were infected with HIV?</td>
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<td>When did you find out that you were infected?</td>
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<td>Do people tease you because of your because of your HIV?</td>
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<td>What do you think about solving the problem?</td>
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<td>How are HIV-infected adolescents treated differently from the non-infected children?</td>
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<td>Do you think there is stigma and discrimination regarding HIV?</td>
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<td>Have you ever had problems in school?</td>
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</table>

**Therapy and Immunologic Data**

Ninety-nine percent of the adolescents were on HAART (85/86), with a median time on HAART of 41 weeks (range: 11-45). Eighty-two percent of the HAART were NNRTI-based regimens (70/85). The median last CD4 count and percentage were 655 cells/mm\(^3\) (range: 46-1189) and 27% (range: 2.5-43), respectively. The median last viral load was 50 copies/mL (range: 55-22,900).

**Stigma and Discrimination**

1) **In the home**

In the home, the most common manifestations of HIV-related stigma and discrimination were
adolescents having to use their own drinking glass (62%, 53/86), being told to keep their infection a secret (35%, 30/86), telling others to keep their infection a secret (30%, 26/86), or being teased about being HIV-positive (28%, 24/86; Table 3). Adolescents were unlikely to say that people did not want to talk to them due to their HIV status (4%, 3/86), expressed disgust toward them (6%, 5/86), they were left to eat alone (7%, 6/86), or their clothes were washed separately (8%, 7/86).

2) In the Community

In the community, the most common manifestations of HIV-related stigma and discrimination were adolescents having to use their own drinking glass (26%, 22/86), telling others to keep their infection a secret (22%, 19/86), ending a friendship after a negative reaction to their infection (22%, 19/86), or being teased (16%, 14/86; Table 3). A few adolescents said that people did not eat near them (5%, 4/86), told them that they had no future (5%, 4/86), prohibited them from joining a trip or sport group (6%, 5/86), or others stopped being friends with the adolescent (7%, 6/86).

3) In School

In school, the most common manifestations of HIV-related stigma were adolescents having to use their own drinking glasses (14%, 12/85), telling their teachers to keep their infection a secret (12%, 10/85), or not being allowed to play sports with other students (9%, 8/85; Table 4). However, there were no adolescents who reported being teased by their teachers about their infection (0/85); and very few were told by their teachers that they had no future (2%, 2/85), not allowed to go to school (2%, 2/85), or not allowed to answer questions (2%, 2/85).

4) In Healthcare Settings

The adolescents reported that the most common manifestations of HIV-related stigma and discrimination in healthcare settings were they did not receive the same care as other adolescents (51%, 43/85), providers wore gloves to treat them (49%, 42/85), or providers washed their hands more often (33%, 28/85; Table 3). However, only a few adolescents were teased (1%, 1/85), not touched (1%, 1/85), had their pain untreated (2%, 2/85), or their treatments withheld (2%, 2/85) due to their HIV infection.

Perceived Stigma

Ninety-seven percent (82/85) of adolescents perceived stigma. Thirty-eight percent (32/85) of adolescents said that an HIV-infected person could not live in community normally, and 32% (27/85) said that an HIV-infected person had no hope for the future (Table 4). Twenty-seven percent (23/85) of adolescents said that they felt that they had to hide their infection from others.

Qualitative Analysis

Four focus groups were conducted, which included 22 adolescents (10 males, 12 females) between 11 and 17 years of age. The adolescents discussed stigma and
discrimination themes at home, in the community, at school and in healthcare facilities (Table 5). They also discussed perceived stigma, which included knowledge of their HIV positive status, fear of HIV transmission, fear of unintentional disclosure, decreased self-disclosure, future outlook, and resistance to stigma and discrimination. Additionally, initiation of HAART was a major positive theme in the lives of the adolescents. HAART initiation improved their interactions with others and their view of their place in society.

**Table 5: Selected quotations from focus groups presented by the discussion theme (external stigma and discrimination, perceived stigma, and HAART)**

<table>
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<th>Discussion</th>
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<td>Our study assessed HIV-related stigma and discrimination in perinatally HIV-infected adolescents. Adolescents who were perinatally infected were chosen to reduce the stigma and discrimination associated with other modes of HIV transmission. HIV-related stigma and discrimination were identified in all aspects of the adolescents’ lives and were both experienced and perceived. Overall stigma and discrimination were most common in healthcare settings, followed by the home, the community, and schools. In healthcare settings approximately half of the adolescents felt that they were treated differently from other patients. In their homes, communities, and schools HIV-related stigma and discrimination primarily occurred when the adolescents experienced using their own drinking glass or keeping their diagnosis of HIV a secret. While almost all adolescents had perceived stigma, approximately 2/3rd of adolescents felt hope and felt they were able to live a ‘normal’ life. Additionally, we found marked reduction in stigma and discrimination with initiation of HAART.</td>
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Our study confirms the results of related research. A study by Abadia-Barrero and Castro (2006) was the first to examine the relationship between access to HAART and the experiences of stigma from HIV-infected children (Abadia-Barrero and Castro, 2006). They reported that access to HAART changed HIV to a chronic disease and reduced stigma of HIV, but they also found that HAART presented new challenges such as adherence and their sexuality. Participants in our study reported the reduction of the physical manifestations of HIV and the change to a chronic disease. Additionally, similar difficulties regarding adherence were found among our study population; “Sometimes it annoys me...taking the medicine interrupts me when I am busy with an activity” (16 yo female); when I take the medicine “I feel sick...the pill is so big” (14 yo female). The authors also describe the associations between HIV-related stigma, structural violence and social inequalities, which we did not observe. Another study by Wright et al described a stigma scale for HIV-infected adolescents in the United States, with good reported reliability and validity (Wright, Naar-King, Lam, Templin, Frey, 2007). Although our study populations were different, we found similar results in the association of HIV-related stigma with anxiety and depression. Among HIV-infected adults in Asia, one study found half experienced some type of discrimination, such as breaches of confidentiality, refusal of treatment, coercion into abortion or sterilization, denial of health insurance, experience of harassment in the community, exclusion from household activities, desertion by their spouse, or forced removal of their children (Asia Pacific Network of Positive People, 2005). Many of these same themes came up repeatedly in discussions with the adolescents. A study of Thai legislation found no policy discrimination, but did find marked reduction in stigma and discrimination with initiation of HAART.
based on HIV status in the healthcare field including refusal of treatment, difficulty receiving treatment, or being tested without their knowledge (Sringernyuang, Thaweetei, Nakapiew, 2005). These findings correlate with our results that healthcare was a primary location of HIV-related stigma and discrimination. Despite the differences between the current and previous studies, our findings are consistent.

The results identified three important HIV-related stigma and discrimination themes, the: most common location, most common mode, and relationship to HAART initiation. The most common location of stigma and discrimination was in the healthcare settings. This seems counterintuitive, as the people with the most HIV knowledge have primarily perpetuated these negative experiences. Initially, we thought the questions were misunderstood by the adolescents and were associated with standard precautions in healthcare settings. Unfortunately, these findings are supported by studies in healthcare workers in China, Ethiopia, Iran, and Turkey that have reported high levels HIV-related stigma (Li et al., 2007; Feyissa, Abebe, Girma, Wolde, 2012; Kasapoglu, Saillard, Kaya, Turan, 2011; Rahmati-Najarkolaei et al., 2010). Anecdotally, in our study population this occurred mostly in the rural clinics and hospitals. The second important theme involves the common misconception of HIV transmission by a shared drinking glass. This misconception is widely reported in the literature and was the most common mode of discrimination both in the quantitative and qualitative parts of our study (Bos, Kok, Dijker, 2001; Ekstrand, Bharat, Ramakrishna, Heylen, 2012; Kaiser Family Foundation, 2009; Kisinza et al., 2002; Stutterheim et al., 2012; United States Centers for Disease Control and Prevention, 2007; Unnikrishnan, Mithra, Rekha, Reshmi, 2010). In Thailand, sharing of drinking glasses is a common practice and many members of the adolescents’ families, communities, and schools feel that this is a primary route of HIV transmission. These results were similar to the findings of our study on perceived stigma among caregivers of HIV-infected adolescents, where 49% of caregivers forbade sharing of the adolescent’s drinking glass (Washington and Oberdorfer, In press). The third important theme identified was the reduction in HIV-related stigma and discrimination by HAART initiation in the qualitative interviews, which has been previously described in the adolescent and adult literature. These themes highlight opportunities and challenges of addressing HIV-related stigma and discrimination. This study has some limitations. The quantitative questions were typically started with “Have you ever..?” This allows for a snapshot of the adolescents’ opinions and views, while we know that these are changing. Recall bias may also play a larger role in the adolescent’s responses as compared to adults’. Additionally, due to the sensitive nature of the questions, we expected behaviors to be underreported. Learning their HIV status and starting HAART were major events in these adolescents’ lives and were major times of change in terms of stigma and discrimination, which were not assessed in our questionnaire. Unfortunately, our survey was not designed to capture change pre- and post-initiation of HAART. Other authors have argued that stigma should be looked at on the societal level, but our study did not attempt to assess the larger constructs of stigma (Alonzo and Reynolds, 1995; Castro and Farmer, 2005; Farmer et al., 2001). Finally, we excluded subjects or caregivers who do not speak or understand Thai. Although this population makes up a small percent of the HIV-positive adolescents at CMUH, they are likely to be more vulnerable and stigmatized. HIV-related stigma and discrimination are a fluid paradigm in lives of HIV-infected adolescents. Adolescence is a time of enormous changes, making assessing perceptions in this age group challenging. Our results highlight the pervasive amounts of HIV-related stigma and discrimination faced by these adolescents despite access to HAART, successful national programs, and lack of specific HIV policy discrimination. Better understanding of their stigma and discrimination will allow better integration into the community and healthcare system, and will assist them in the transition to adulthood. These results have substantial implications for the health and wellbeing of HIV-infected adolescents and highlights issues that need to be addressed beyond HAART access. Additional approaches are needed to address stigma and discrimination in HIV-infected adolescents, as well as understand their changes after initiation of HAART and the challenges adolescents face when HIV-infected adolescents transition to adulthood. We have begun to incorporate the adolescents’ recommendations, such as peer counseling and support groups, into the services offered by the pediatric HIV clinic at CMUH. Additionally, education of caregivers, teachers and members of the community, along with ongoing assessment of the adolescents’ HIV knowledge are a few ways we are trying to decrease the burden of HIV on these
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Conflict of interest: None

REFERENCES


Ekstrand, Maria L., Shalini Bharat, Jayashree Ramakrishna, and Elsa Heylen. “Blame, Symbolic Stigma and HIV Misconceptions are Associated with Support for


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