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A Qualitative Exploration of Psychosocial Challenges of Perinatally HIV-Infected Adolescents and Families in Bangkok, Thailand

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Abstract

Thailand has the highest HIV prevalence in Asia, with 9,600 HIV+ adolescents and thousands additional younger HIV+ children (World Bank, 2015; UNICEF, 2015). Studies from other settings suggest perinatally HIV-infected (PHIV+) adolescents are at high risk for mental health problems and engagement in risk behaviors that threaten individual and public health. Yet, few studies exist in Thailand, and few evidence-based psychosocial interventions have been developed for and studied in this population, despite great need. The current study qualitatively explored psychosocial issues among Thai PHIV+ adolescents to inform development or adaptation of interventions. Thai and US-based researchers and clinicians conducted two focus group discussions with PHIV+ adolescents aged 12-16 and their adult caregivers, and six in-depth key informant interviews with health/social work providers at a large clinic for PHIV+ youth in Bangkok, Thailand. Data were analyzed thematically using framework analysis. Multiple challenges for PHIV+ youth and caregivers were identified. Adherence to antiretroviral treatment was a significant challenge attributed to lack of adult support, side effects, feeling too well to take medicines, and avoiding acknowledging sickness. Poor child-caregiver communication and conflict was a key concern, explained in part by cultural expectation of obedience and generation gaps. Concerns about societal stigma and discrimination emerged strongly and influenced delay or

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avoidance of disclosing HIV status to children and others. Respondents identified positive approaches to addressing these issues and highlighted the need for interventions to improve child-caregiver communication and generate peer and community support for PHIV+ youth. Thai PHIV+ adolescents and families experience significant psychosocial challenges, similar to those seen in other contexts. Cultural adaptation of an existing evidence-based clinic-based family group intervention is recommended to rapidly address these needs.

Keywords

perinatal HIV infection; adolescents; psychosocial support; Thailand; adherence

Introduction

Improved access to antiretroviral therapy [ART] has dramatically reduced perinatal transmission of HIV [PHIV], and infants with HIV, once not expected to survive childhood, are reaching adolescence in large numbers. Globally, two-thirds of HIV+ children are between the ages of 10 and 19 years, creating a pressing need for information about this growing population (Sohn & Hazra, 2013; UNAIDS, 2014). While most HIV+ children live in sub-Saharan Africa, a sizeable, less studied population lives in Asia. Among Asian countries, Thailand has the highest HIV prevalence at 1.2% (World Bank, 2015), including 9,600 adolescents 10 to 19 years old and thousands more children soon to enter adolescence (UNICEF, 2015). With the near elimination of mother to child transmission of HIV in Thailand, pediatric HIV will be further concentrated among adolescents (Lolekha, 2016).

PHIV+ youth face vulnerabilities beyond those that affect all adolescents. They have lived with a chronic, stigmatized illness since birth. Lacking access to optimal treatment in early childhood, they may have experienced multiple hospitalizations, missed substantial time in school, and experienced significant adversity related to trauma, stigma, and discrimination. They have faced parental illness and sometimes parental/family death, substance abuse, and mental illness; the majority live in impoverished communities (Mellins & Malee, 2013). Studies from both high- and low-and-middle-income countries have consistently found high rates of mental health problems and some engagement in risk behaviors among PHIV+ youth (Bomba et al., 2010; Mellins et al., 2012; Mellins & Malee, 2013; Puthanakit et al., 2013), including substance use, sexual risk-taking, and inconsistent condom use (Bauermeister, Elkington, Robbins, Kang, & Mellins, 2012; Mellins et al., 2011; Tassiopoulos et al., 2013). Studies have found PHIV+ adolescents' ART adherence rates are lower than adults and younger children (Van Dyke et al., 2014). Non-adherence increases risk to individual health and, if unsafe sex, of HIV transmission to others.

Limited studies on PHIV+ youth in Thailand suggests considerable psychosocial need. One study found limited knowledge about family planning, reproductive health, and STIs, with about one-third reporting sexual risk behaviors including lack of condom use (Lolekha et al., 2015). More than half of another study's sample reported clinically significant mental health problems (Rongkavilit et al., 2010). Finally, lack of disclosure may influence health and

psychosocial wellbeing with less than a third of Thai PHIV+ children over age six aware of their HIV status in one study (Oberdorfer et al., 2006).

Despite clinical efforts, there are few published studies of interventions with Thai PHIV+ youth. One exception is a trial of a brief intervention to improve health knowledge and reduce sexual risk for youth, primarily 12 years or older. However, no significant differences were found between the intervention and control group (Chokephaibulkit et al., 2015).

An evidence-informed mental health and HIV prevention program may provide a helpful model in Thailand. The ‘Collaborative HIV Prevention and Adolescent Mental Health Program’ [CHAMP] is a multiple family-based group intervention originally developed in the US to promote mental health and prevent sexual and drug use risk behavior in young HIV-negative adolescents, before risk behaviors emerge (Paikoff & McKay, 1995). The CHAMP intervention model has been replicated and validated with PHIV+ (referred to as ‘CHAMP+’) and HIV-negative youth in New York, South Africa, Trinidad, and Argentina. All iterations of CHAMP/CHAMP+ engage youth-caregiver pairs in approximately ten sessions combining learning and discussion, aiming to strengthen parent–child communication, adolescent problem-solving and peer negotiation skills, and support within and between families. Trials of the CHAMP/CHAMP+ model show significant improvements in HIV knowledge, family communication and monitoring of youth, youth mental health, and reduced risk behavior, with high levels of acceptability, and improved ART adherence (Bell et al., 2008; Bhana et al., 2010; Bhana et al., 2014; McKay et al., 2007; Mellins et al., 2014).

A team of US-based and Thai researchers and providers hypothesized the model might also be beneficial in Thailand. To inform intervention adaptation, this study aimed to qualitatively examine psychosocial needs and strengths of Thai PHIV+ adolescents and their families through focus group discussions (FGD) and in-depth interviews. We explored social, cultural, and environmental conditions that impact coping, perceptions about HIV, and family communication, critical target areas of the CHAMP+ program.

Methods

Site

All FGD and interviews were conducted at the Thai Red Cross AIDS Research Centre, a clinic that provides health care to approximately 250 PHIV+ children and families in Bangkok. Institutional Review Board approval was obtained from New York University (#13-9748) and Chulalongkorn University, Bangkok (#213/56).

Participants

Purposive sampling methods were used. Inclusion criteria for adolescents were: PHIV+, 12-16 years old (most younger youth did not know their HIV status), receiving care at the Thai Red Cross, and aware of HIV diagnosis. Caregiver inclusion criteria were: age 18 years, living with and responsible for a PHIV+ adolescent’s care, and aware of the adolescent’s HIV status. Of 55 eligible clinic families, 12 were randomly selected; all consented to participate; ten children and eight adults attended FGD in July 2013.

Participants were demographically similar to the overall clinic population. Caregivers provided informed consent for themselves and their children.

Data Collection

Two FGD were conducted, one each for caregivers and adolescents. Ten adolescents and eight caregivers participated. Two Thai staff members, a social worker and a researcher moderated two hour long groups in Thai in private rooms. Facilitators used semi-structured interview guides based on those used by CHAMP+ researchers previously (Nestadt et al., 2013; Petersen et al., 2010). They were linguistically and culturally adapted to explore key themes including living with HIV, coping, mental health, risk behaviors, parent-child communication, stress, loss, religion and culture, peer relationships, and HIV knowledge, medication adherence, disclosure, and stigma.

Six individual 45-to-60-minute key-informant interviews were also conducted with key stakeholders, including one parent and clinic staff. All pediatric clinic staff (two pediatricians, three nurses, and three social workers) were considered eligible; one physician, one nurse, and all social workers were selected, given time and funding limitations. The interviewed parent was interested in helping with intervention design but did not have a child in the eligible age range for FGD. Interviews were conducted by a US-based researcher with experience developing PHIV+ youth interventions in multiple settings, with a Thai translator using a semi-structured interview guide similar to those used in FGD, with additional questions about staff roles and perceived needs for psychosocial/behavioral interventions.

Data Management and Analysis

Interviews and FGD were audio recorded. Interviews were transcribed, and FGD summarized in Thai with direct quotes from participants; all data were translated into English. Data were analyzed using a collaborative, iterative process based on framework analysis (Ritchie & Spencer, 1994), involving immersion in and familiarization with the transcripts; development of a thematic coding framework based on interview questions and emergent themes; indexing and coding of transcripts by two researchers using NVivo 10 software (QSR International, VIC, Australia); and identification of emerging associations and patterns by English- and Thai-speaking clinicians and researchers.

Results

Analysis revealed psychosocial challenges and coping strategies faced by PHIV+ youth and their caregivers/families.

Sample Description

Caregivers were 44-70 years old (mean 58.25 years), primarily female (75%), and included birth mothers, adoptive parents, and grandmothers. Youth were 13-16 years old (mean 14.4 years), with gender evenly distributed. Two attended vocational school; one had left school; the rest were in grades seven to nine.

Adherence

Adherence emerged as a major challenge. Some adolescents lack adult support for taking medications properly, due to orphaning, discrimination within and outside of their homes/families, or caregivers' time being consumed by income generation. One provider described adherence challenges, saying, *'[They are] on their own,'* and *"If there is discrimination in the house then [it's] hard to take meds and there is no support.'* Side effects, number of pills, and medication forms, also present obstacles. Also, some adolescents stop taking medication when they don't feel sick, and start again when they get sick. Many youth and caregivers reported forgetting to take medication because of distractions, participation in activities outside home and, occasionally, sleeping through their prescribed medication times. One child explained, *I have a big problem taking my medication [when I'm supposed to]. When I go out with my friends...I don't take [medicine] with me either because I forget to...I have to try to get home on time [to take it] and then go out again. But I'm not sure whether or not my friends will let me go.*

Relatedly, some adolescents worried about taking medication in front of others during social or school activities.

Respondents identified strategies to maintain adherence, including caregiver support and encouragement, and use of reminders. Some reported that fear of sickness and death motivated them. One caregiver said, *'I show him pictures of sick people at the hospital and I tell him, "If you don't take your medicine, then you're going to end up like this."'* All groups of participants cited scheduling or organization as effective methods for improving adherence, including rescheduling medication intake times to fit youth/family needs and using pill boxes or alarms. Providers supported adherence efforts through education, reminder calls, devising organization strategies, and home visits. Several caregivers indicated the critical role of providers in adherence. One said, *'Once, my daughter's viral load went up, and the doctor explained to her [what would happen if she didn't take her medicine]. She listened to the doctor more than she does when I explain things to her.'*

Child-Caregiver Communication

'Communication is difficult during this age. The translation of words and feelings are different for each. Caregivers are ordering teens around out of love. Teens feel "they are just ordering me around.'"

Youth and caregivers identified challenges effectively communicating with one another, including general conflict, such as complaining, sarcasm, yelling, irritability, saying mean things, and arguing. Several youth and caregivers described ignoring one another or keeping silent rather than communicating about difficult topics or conflicts arising from the cultural expectation that children do as their parents/caregivers tell them. One provider said, *'Parents just tell them what to do. Hierarchy in Thai culture is a strong power... You cannot question or doubt your caregiver. [There are] high expectations of children to be good.'*

Yet, youth often have different ideas, do not want to obey caregivers, or feel there is a generation gap. One provider said, *'Caregivers grew up in a different era and teens are in a modern world. They don't understand each other.'* Several topics were identified as 'taboo'

or difficult for caregivers and youth to discuss, including sex. Others reported that caregivers and children do not generally discuss feelings. As one provider stated, *'A child cannot tell a parent how they really feel about the parent, like...you are mad at them.'*

However, many youth and caregivers described positive approaches to handling conflict, such as apologizing, taking time to calm down before responding, calmly explaining caregiver reasoning, and being open and honest and trying to improve communication.

Disclosure

Perhaps the most significant challenge that emerged for all respondents was disclosure of HIV status—both to the infected youth and to others.

Disclosure to youth—Though all caregivers had disclosed to their children, many recalled concerns that their children were too young to understand or keep HIV a secret, or it would be too upsetting. One mother said, *'It was difficult because I was afraid that she would think too much about it. Society is repulsed by this disease.'* Providers struggled with believing youth should know their status and caregivers' readiness to disclose: *'Once children know their HIV we can move forward and address adherence; 12 to 14 is the average age parents tell...Providers want to tell but need permission from parents to disclose.'*

Many reported that providers play a key role in disclosure to children, including being present for the first disclosure. Caregivers also reported that they found support and inspiration from other parents. When disclosing to children, caregivers emphasized they could live long, healthy lives by taking medication: *'I told her that if she takes her medicine, then she will be fine. She won't die.'*

Disclosure to others—Most youth and caregivers had disclosed the child's HIV to few or no people. They expressed fears and experiences of rejection, stigma and discrimination. One child said, *'I still don't want to tell anyone. I'm afraid that my friends won't want to look at me, talk to me, or let me hang out with them.'*

Few adolescents had disclosed to any friend, and those who had said they had told trusted, long-time friends. One caregiver said she had lost a friend after disclosing.

Disclosure to boyfriends/girlfriends/sexual partners was raised frequently as difficult, with participants torn about when, how, and if to disclose. Generally, caregivers and youth believed it was important to use condoms to avoid infecting partners with HIV, but some felt disclosure was unnecessary. Youth and caregivers said partner disclosure depended on whether they were trustworthy, kind, understanding, and likely to be accepting. As one child said: *'[The person you tell] has to be the person who is clearly your soul mate...someone who loves you ...[and] willing to accept you.'* Youth and caregivers both feared rejection and that partners might use the information against them, or tell others. Most respondents believed that indirect disclosure was best, first posing a hypothetical situation to feel out how the partner would respond. One caregiver described disclosing to her partner, *'For me,*

it was hard to tell my status to him. I had to imagine [what it would be like to be in] his shoes...I also gave information to him that HIV and AIDS are different.'

There was consensus that HIV-related stigma was widespread in society. In some cases, youth and caregivers attributed this to misinformation or misunderstanding because *'the disease was presented in [the] media as [a] bad and promiscuous disease.'* Families were concerned about workplace discrimination. All respondents knew about companies testing their employees for HIV and firing those who tested positive. Some had left jobs pre-emptively to avoid discrimination. While they agreed that this practice was wrong, respondents felt powerless to change policies and worried about impact on their children's future.

Social Support

Most youth identified family members as their primary source of social support with HIV-related problems. One child expressed a common feeling: *'My encouragement comes from father, mother, and sister and brother.'* Another specifically said that family members *'cheer me up to fight [my] sickness.'* Caregivers mentioned receiving support from partners, relatives, and from the children they cared for.

Need for Services

Several providers said caregivers needed financial support, help finding employment, and planning for their children's education and future. Both caregivers and providers expressed a strong desire for improving parent-youth communication. This emerged as the most important caregiver need. Providers also expressed a desire to build greater caregiver and community support and understanding of youth, including peer support so, as one provider noted, *'[teens] know they are not alone.'*

Discussion

Pediatric HIV in Thailand is increasingly an adolescent epidemic. This study revealed a significant need for psychosocial interventions to address difficulties with adherence, disclosure, communication, and other stressors. Yet there is a lack of evidence-based interventions in Thailand and Asia. Despite significant cultural differences, Thai PHIV+ youth had many of the same psychosocial and prevention needs as their counterparts in other countries. Therefore, family-based interventions developed for PHIV+ youth in other contexts may be appropriate for this setting, particularly if adapted to reflect culturally-bound family relationship norms and social practices.

Psychosocial challenges faced by Thai PHIV+ youth and their families also identified in other countries included struggles with adherence, disclosure, and communication about HIV, sexual behavior and other sensitive topics (McKay et al., 2007; Mellins et al., 2014; Nestadt et al., 2013; Petersen et al., 2010). However, key cultural nuances that affect how these struggles manifest and impact respondents' lives also emerged, including well-documented hierarchical expectations that children obey their parents without question or criticism (Cameron, Tapanya, & Gillen, 2006; Limanonda, 1995). Yet, youth want to assert

independence related to HIV and other areas, leading to conflict and communication barriers.

Respondents suggested that HIV/AIDS-related stigma and discrimination creates disclosure-related anxiety. Few reported disclosing their HIV status to others, particularly outside family, similar to a previous study of older Thai HIV+ youth, in which only 20% reported disclosing to friends (Rongkavilit et al., 2010). Also, institutionalized testing in some Thai professional settings, though designed to be voluntary and to protect employee rights (International Labour Organization, 2013), was of concern. Participants reported that it contributes to stress, feeling lack of control over disclosure, fears of rejection, job loss, and financial insecurity, uncertainty about the future, and concerns about identity defined by HIV. Studies of Thai HIV+ adults report limited disclosure based on widespread stigmatizing views of HIV+ individuals as promiscuous, contagious, and terminally ill (Liamputtong, Haritavorn, & Kiatying-Angsulee, 2009; Songwathana & Manderson, 2001). Stigma and public attitudes about HIV have been associated with mental health problems and poorer quality of life among HIV+ youth (Rongkavilit et al., 2010). Respondents' discussion of romantic partners suggests fears may lead to engagement in sexual relationships without disclosure. Although there was limited discussion about sex and the use of condoms, the potential for condom-less sex is a challenge in most studies of youth. Given that nearly 20% of 13-17 year olds in one Thai national survey had ever engaged in sexual intercourse (World Health Organization, 2015), addressing risky behaviors needs to be a focus of interventions with youth.

Despite consensus regarding family communication challenges, many youth identified caregivers/family members as their primary source of support, relying on them for medication reminders and motivation to stay healthy. Given limited disclosure to others, caregivers may be the only available support around coping with HIV. Studies have found that the close relationships between Thai parents/caregivers and children persist into adulthood (Knodel & Chayovan, 2008), and HIV+ Thai adults receive medication adherence support from parents (Knodel, Kespichayawattana, Saengtienchai, & Wiwatwanich, 2010). This suggests a need and an opportunity for family-based interventions, as supportive relationships are a critical foundation of HIV-related prevention efforts (Remien & Mellins, 2007).

Limitations

There are limitations to this study. The sample is small and from only one Bangkok clinic where one FGD was conducted with caregivers and youth, respectively, because of funding limitations. Findings may not represent all Thai PHIV+ youth and families, particularly those in remote areas. FGD summaries do not identify individual speakers, precluding comparisons of themes by respondent characteristics or matching of caregiver and child responses. Additionally, a translator was used for individual interviews, possibly affecting interviewer-respondent rapport or altering the meaning of questions or responses. Interestingly respondents did not mention Buddhism, which comprises 93.5% of the population (UN Data, 2012), and maybe an important cultural consideration in prevention efforts for future studies to consider.

Conclusions

Despite the limitations, we believe this exploratory study adds critical information to the very limited knowledge base about the psychosocial needs of Thai PHIV+ youth. Thai PHIV+ youth and their families have clear psychosocial needs related to adolescence and living with HIV and are interested in interventions, particularly those focused on medication adherence, disclosure support, family relationship and communication, navigating stigma and discrimination, and peer and romantic relationships. Given the support received from medical providers, strength of family bonds, and the expressed need for peer support, a multiple family-based group intervention offered within clinics, might be helpful. With its focus on many of the topics identified, its family- and peer-based approach, and evidence of efficacy in multiple settings, our Thai-American collaborative team and participants felt the CHAMP+ model would provide a useful starting point. Such work is urgently needed to promote health and well-being in Thai youth, and prevent secondary transmission to others. Details about the adaptation process to adapt CHAMP+ for Thailand may be found in a forthcoming publication (Pardo et al., in press). In brief, the Thai intervention retained a cartoon format used in South Africa with a story focused on a Thai adolescent and his mother to address topics such as stigma, disclosure, adherence, and family communication using contextual information gathered in the present study and through additional stakeholder input.

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