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Reproductive health, social life and plans for the future of adolescents growing-up with HIV: a case-control study in Thailand

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ABSTRACT

Most perinatally HIV-infected children receiving antiretroviral treatment now survive into adolescence. This is a period when young people experience puberty, shape their sexual identity and initiate their own social life. The aim of our analysis was to compare aspects of the sexual and reproductive health, social life and plans for the future of perinatally HIVinfected adolescents (PHIVAs) with a control group from the general population. We used data from the Teens Living with Antiretrovirals (TEEWA) survey carried out from 2010 to 2012 in Thailand among PHIVAs aged 12-19 years. Adolescents completed a self-administered questionnaire focusing on their daily life. Each PHIVA (case) was matched on sex, age and place of residence with a randomly selected adolescent from the general population (control). Analysis was stratified by gender and age; McNemar's test was used to compare cases and controls. A total of 1142 adolescents (571 cases and 571 controls) were included in the analysis, 42% boys and 58% girls. Cases experienced puberty delay compared to controls (p < 0.01). Cases and controls did not differ in terms of sex education, sexual initiation, romantic relationships or friendships, and risky behaviours. However, PHIVAs were less likely to attend the education system (p < 0.01), to plan for marriage (p < 0.01) or parenthood (p < 0.01). PHIVAs do not differ substantially from controls in terms of sexual and social life. Yet, affirmative action policies could help counterbalance their educational handicap. Provision of psychosocial support could enhance their ability to make informed decisions with regards to family formation.

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Introduction

With antiretroviral therapy (ART), HIV infection has become a chronic disease and perinatally HIV-infected children are now able to survive and reach adolescence. Yet, they are entering this troubled period, often after a traumatic childhood: family history frequently disrupted by the illness or death of one or both parents; periods of serious illness; disclosure of their HIV status. Also, at a time when they initiate their sexuality, they have to learn how to manage their social, romantic and sexual life as an HIV-infected individual. Adolescence is a period of risk-taking behaviours, and sexual behaviours such as intercourse without condom in this population could increase sexual transmission of HIV.

At the end of the 1980s, Thailand has been the country most affected by HIV in South-east Asia (UNDP, 2004). As a result, of the National programme for the prevention of mother-to-child transmission of

HIV launched in 2000 (Thisyakorn, 2017), perinatal transmission has affected only one generation of children in Thailand, mostly those born from the beginning of the 1990s until the beginning of the 2000s. With generalized access to ART, since 2003, these perinatally HIV-infected children are now entering adolescence.

In resource-limited settings, only a few studies have described the reproductive health, social life and plan for the future of perinatally HIV-infected adolescents (PHIVAs) taken all together, and included a comparison group of HIV-negative youth (Bauermeister, Elkington, Brackis-Cott, Dolezal, & Mellins, 2009; Mu et al., 2015; Mutumba et al., 2015). In this national case-control survey, we aimed to compare some aspects of the reproductive health, risky behaviours, social life, family environment and plans for the future of PHIVAs, with uninfected adolescents from the general population.

Material and methods

TEEWA survey

The TEEns Living With ARV (TEEWA) survey was carried out from 2011 to 2012 in 20 hospitals throughout Thailand among PHIVAs (12-19 years) receiving ART. A similar survey was carried out from 2012 to 2013 among a control group in the general population matched (one control per case) on sex, age and place of residence. Controls were randomly selected from the population register of the community.

The study was approved by the Ethics Committee, Faculty of Associate Medical Sciences, Chiang Mai University. All participants provided written informed consent/assent. They were assured that the information provided was kept confidential.

The whole survey procedure has been described in details elsewhere (Le Coeur, Lelièvre, Kanabkaew, & Sirirungsi, 2017).

Population study selection

Among the 941 PHIVAs receiving ART in the study hospitals, 709 (75%) adolescents aged 12-19 years could be interviewed. For this analysis, PHIVAs living in orphanages (n = 136) were excluded because their lifestyle mostly depends on the orphanage's rules. Three additional PHIVAs who had no appropriate control in the general population were also excluded leading to a total of 571 PHIVAs and 571 uninfected controls.

Data collection

Self-administered questionnaires were completed by the cases and the controls, coupled with face-to-face interviews of their caregiver. Since some PHIVAs were not aware of their HIV status there was no reference to HIV, AIDS or ART in the self-administered questionnaire in order to prevent unintended disclosure.

The adolescent self-administered questionnaire was documenting aspects of their everyday life including school, work and self-reported happiness. Adolescents were interviewed on their puberty experience - voice change for boys and first menstruation for girls - sex education, romantic relationships (girl/boyfriend) and sexual activity. They were also interviewed on their relationship with their peers (hang out with peers), with parents/caregivers (conflicts in the last year), risk behaviours (smoking and alcohol drinking) and plans for the future in terms of high education, family formation and children. Caregivers were interviewed on the household's financial situation and the vital status of the adolescent's parents.

Analysis

The analysis was stratified by gender and age: boys, aged 12-14 years and 15-19 years; girls, aged 12-14 years and 15-19 years. All variables were dichotomized. For this case-control study, the McNemar test was used to compare matched cases and controls. Data were analysed using SAS® version 9.4 software.

Results

The study population was composed of 571 PHIVAs matched with 571 controls. Both groups (cases and controls) were composed of 42% of boys and 58% of girls, 48% aged 12-14 years and 52% aged 15-19 years. Fifty-nine percent of the adolescents were living in Northern Thailand, and 41% in the North-east, Centre and South.

Tables compare the characteristics of the adolescents in each age group, Table 1 for boys and Table 2 for girls. PHIVAs were significantly more often orphan loss of one or both parents – (p < 0.01), out of the education system (p < 0.01), and lone children than the controls (p < 0.01). Also, except for boys aged 15–19 years, the financial situation of their household was significantly more often perceived as "difficult" than the controls (p < 0.01).

PHIVAs had experienced puberty later than the controls as indicated by the significantly lower percentage of boys and girls aged 12-14 years who had been through puberty (p < 0.01). There was no difference between PHIVAs and controls in terms of frequency of sexual education and sexual initiation. Among PHI-VAs aged 15-19 years, 16% of boys and 8% of girls reported sexual debut versus 19% of boys and 10% of girls in controls. Among PHIVAs and controls, the median age at first sex was 15 years. Condom use at first sex was higher in PHIVAs than in controls (84% vs. 74%). There was no difference between PHI-VAs and controls for tobacco use and alcohol drinking.

The social life of PHIVAs was not different from that of the controls as indicated by the percentage of those who declared that they hanged out with friends or who had a girl/boyfriend. However, in PHIVAs aged 15-19 years, only 74% of boys and 79% of girls perceived themselves as happy versus 89% and 94%, respectively, in the controls (p < 0.01).

Finally, PHIVAs declared less frequently planning for high education, marrying or having a life-partner and



Table 1. Characteristics of boys born with HIV (cases) compared with the general population (controls).

	12–14 years					15–19 years					
	Cases ($n = 136$) Born with HIV		Controls (n = 136) General population			Cases (n = 102) Born with HIV		Controls n = 102) General population			
	%	(95% CI)	%	(95% CI)	<i>p</i> -value	%	(95% CI)	%	(95% CI)	<i>p</i> -value	
Social environment											
One or both parents dead or of unknown status	77	(70%-84%)	10	(5-15%)	<.001	91	(86-97%)	12	(6-18%)	<.001	
Not attending school	11	(6-16%)	1	(0-3%)	<.001	38	(29-48%)	20	(12-27%)	0.004	
No sibling	67	(59-75%)	28	(20-35%)	<.001	77	(69-86%)	30	(21-39%)	<.001	
Financial situation perceived as difficult/very difficult ^a	36	(28-44%)	20	(13-27%)	0.003	26	(18-35%)	23	(14-31%)	0.527	
Reproductive health											
Have experienced puberty ^b	41	(33-49%)	64	(56-72%)	<.001	79	(71-87%)	75	(66-83%)	0.411	
Have had sex education	79	(72-86%)	82	(76-89%)	0.446	89	(83-95%)	85	(78-92%)	0.433	
Have had sexual intercourse ^c		(0-2%)	1	(0-2%)	1.000	16	(8-23%)	19	(11-27%)	0.439	
Risk behaviors											
Tobacco use	5	(1-9%)	9	(4-14%)	0.225	29	(21-38%)	29	(21-38%)	1.000	
Drink alcohol	9	(4-14%)	13	(7-18%)	0.297	33	(24-42%)	37	(28-47%)	0.446	
Social life and happiness											
Hang out with friends ^d	54	(45-62%)	51	(42-59%)	0.541	78	(70-86%)	82	(75-90%)	0.433	
Have Girl/boy friend	12	(6-17%)	15	(9-22%)	0.369	30	(21-39%)	39	(30-49%)	0.150	
Have arguments with caregivers or parents	74	(66-81%)	83	(77-89%)	0.074	78	(70-86%)	86	(80-93%)	0.131	
Feel very happy/ happy/average	81	(74-87%)	90	(85-95%)	0.034	74	(65-82%)	89	(83-95%)	0.008	
Plans for the future											
Plan for high education in children still at school ^e	34	(25-42%)	54	(46-63%)	<.001	62	(50-74%)	76	(66-85%)	0.075	
Plan to marry or live with a partner	26	(19–34%)	41	(33-49%)	0.011	18	(10-25%)	60	(50-69%)	<.001	
Plan to have children	15	(9-22%)	40	(32-49%)	<.001	14	(7-20%)	58	(48-67%)	<.001	

^aThe financial situation was declared by the caregiver;

children. Among female PHIVAs aged 15-19 and still attending school, only 72% reported planning for high education compared to 87% in the general population (p < 0.01). The difference was not significant for boys in the same age group. Only 17% of female PHIVAs aged 15-19 planned to marry and 12% to have children compared to 39% and 35% in the controls (p < 0.01). In male PHIVAs aged 15-19, 18% planned to marry and 14% to have children compared to 60% and 58% in the controls (p < 0.01).

Discussion

Our results indicate that in Thailand, the sexual, reproductive and social life of PHIVAs does not differ substantially from that of adolescents in the general population. However, PHIVAs appear to have lower expectations in terms of education and family formation.

As in other studies, we found that PHIVAs experienced puberty later than adolescents from the general population (Buchacz et al., 2003; Szubert et al., 2015) (Bellavia et al., 2017; de Martino et al., 2001; Williams et al., 2013a). Puberty delay in PHIVAs has been found to be associated with older age at ART initiation, growth retardation and HIV disease severity (Bellavia et al., 2017; Szubert et al., 2015; Williams et al., 2013a).

After age 15, the proportion of adolescents - either cases or controls - reporting having experienced sex was low: less than 10% for girls and 20% for boys. However, there was a lack of power to ascertain a possible statistical difference between cases and controls. Similarly, low rates of sexual initiation had been found in Thailand (Lee & Oberdorfer, 2009) (Ruangkanchanasetr, Plitponkarnpim, Hetrakul, & Kongsakon, 2005).

When comparing PHIVAs with controls, the most striking difference was their lower aspirations with regards to education, family formation and parenthood. Planning the future can be difficult for adolescents with life-long disease. These self-restrictions could be related to depression, more frequent in AIDS-orphans (Cluver, Orkin, Gardner, & Boyes, 2012). Indeed, in our study, PHIVAs reported a lower level of happiness than the controls.

PHIVAs could be reluctant to continue their studies because of their disadvantaged socio-economic situation. Indeed, our study indicates that their households, lacking the income of the deceased parents, are facing more financial hardship compared to controls. Heavier pressures to become breadwinners for their household may explain the boys' lower willingness for high education. Other reasons for school dropout could be neurocognitive impairments related to HIV, school absenteeism due to severe illnesses (Mu et al., 2015) or discrimination

^bMissing responses: boys born with HIV, n = 1;

^cMissing responses or did not want to answer: boys born with HIV, n = 18; boys from the general population, n = 12;

^dMissing responses: boys born with HIV, n = 1;

^eKhi2 test was used because the matching could not be maintained since some individuals had already dropped of school.

Table 2. Characteristics of girls born with HIV (cases) compared with the general population (controls).

	12–14 years					15–19 years					
	Case	es (n = 172)	(Controls (n = 172) General		Cases ($n = 161$) Born with HIV		Controls (n = 161) General			
	Born with HIV			pulation				р	population		
	%	95% CI	%	95% CI	<i>p</i> -value	%	95% CI	%	95% CI	<i>p</i> -value	
Social environment											
One or both parents dead or of unknown status	85	(80-90%)	11	(6-16%)	<.001	93	(89-97%)	13	(8-18%)	<.001	
Not attending school	8	(4-12%)	1	(0-2%)	<.001	19	(13-25%)	6	(2-10%)	<.001	
No sibling ^a	71	(64-78%)	27	(20-33%)	<.001	70	(63-77%)	27	(20-34%)	<.001	
Financial situation perceived as difficult/very difficult ^b	37	(29-44%)	16	(10-21%)	<.001	42	(35-50%)	20	(14-26%)	<.001	
Reproductive health											
Have experienced puberty ^c	55	(48-63%)	83	(77-88%)	<.001	93	(89-97%)	99	(97-100%)	0.013	
Have had sex education	88	(83-93%)	88	(83-93%)	1.000	96	(93-99%)	94	(90-98%)	0.467	
Have had sexual intercourse ^d		(0-2%)	1	(0-2%)	1.000	8	(3-12%)	10	(5-15%)	0.317	
Risk behaviors											
Tobacco use ^e	2	(0-5%)	1	(0-2%)	0.180	2	(0-5%)	3	(0-6%)	0.739	
Drink alcohol ^f		(1-7%)	4	(1-7%)	1.000	20	(14-27%)	20	(14-26%)	0.891	
Social life and happiness											
Hang out with friends ^g	47	(40-55%)	52	(44-59%)	0.352	70	(63-77%)	77	(71-84%)	0.172	
Have Girl/boy friend ^h	10	(5-14%)	16	(11-22%)	0.101	39	(31-46%)	39	(31-46%)	0.908	
Have arguments with caregivers or parents ⁱ	74	(68-81%)	81	(76-87%)	0.096	84	(78-90%)	91	(87-96%)	0.040	
Feel very happy/ happy/average		(83-93%)	90	(86-95%)	0.516	79	(73-85%)	94	(90-98%)	<.001	
Plans for the future											
Plan for high education in children still at school ^j		(43-58%)	75	(69-82%)	<.001	72	(65-80%)	87	(82-93%)	0.002	
Plan to marry or live with a partner		(4–12%)	22	(16-28%)	<.001	17	(12–23%)	39	(32-47%)	<.001	
Plan to have children		(2-9%)	17	(12-23%)	<.001	12	(7–18%)	35	(27-42%)	<.001	

^aMissing responses: girls born with HIV, n = 2;

from their peers or from the school staff (Mutumba et al., 2015).

The desire for family formation was lower than in a study in northern Thailand, in which 30% of PHIVAs reported desiring a marital life (17% in our study) and 24% a willingness to have children in the future (11% in our study) (Lee & Oberdorfer, 2009). Several qualitative studies among HIV-infected patients reported reluctance to building a family, following the difficult experience of one's disrupted family or fear of HIV status disclosure to partner (Hosek, Harper, & Domanico, 2000; Troussier & Tourette-Turgis, 2006).

The disinclination of PHIVAs with regards to parenthood could be related to their own difficult experience as a perinatally HIV-infected child or the strong family planning counselling from the medical staff (Fair, Sullivan, Dizney, & Stackpole, 2012). In a low-fertility country (Tu, Yan, & Zhao, 2017), social desirability is against having children when HIV-infected, though the risk of mother-to-child transmission is quasi-eliminated (Lolekha R, et al. 2016).

One limitation of our study is that despite its casecontrol design, we did not control for socio-economic background. Also, in the self-administered questionnaires, answers might have been affected by cultural bias, but there is no reason to believe that these biases affected the cases and controls differently.

Despite the constraint plans for their future and their disadvantaged socio-economic situation, PHIVAs in Thailand adopted similar social, sexual and risky behaviours than their peers from the general population. Social science studies indicate that Thai youth are prone to adopt behaviours from the Western teenagers' culture (Dubus, 2011; Siriyuvasak, 2004). However, they are also influenced by Buddhism that encourages self-acceptance and acceptance of the destiny (karma) (Gabaude, 2001) and emphasizes gender differences (Pongsapich, 2001).

Planning for the future is a vital aspect of identity development relying on socialization factors such as family and school (Nurmi, 1991). Although PHIVAs behave like any other adolescents of their age, they might fear that their prospect will change in their adult life. It may be advisable that policy-makers provide affirmative action policies to help counterbalance PHI-VAs' educational handicap. Psychosocial and medical

^bThe financial situation was declared by the caregiver;

^cMissing responses: girls born with HIV, n = 1;

^dMissing responses or did not want to answer: girls born with HIV, n = 53; girls from the general population, n = 44;

^eMissing responses: girls born with HIV, n = 1;

^fMissing responses: girls born with HIV, n = 1;

⁹Missing responses: girls born with HIV, n = 6; girls from the general population, n = 1;

^hMissing responses: girls born with HIV, n = 1;

ⁱMissing responses: girls born with HIV, n = 1;

^jKhi-2 test was used because the matching could not be maintained since some individuals had already dropped of school.



services may also deliver comprehensive information to ensure that PHIVAs are able to make informed decisions with regards to family formation.

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