A SURVEY OF ADOLESCENTS BORN WITH HIV: THE TEEWA PROJECT IN THAILAND
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A Survey of Adolescents Born with HIV: The TEEWA project in Thailand

For surveys that cover sensitive topics or target vulnerable populations, specific protocols must be developed to ensure both high-quality results and strict compliance with ethical standards. For example, a survey of adolescents infected with HIV at birth and who are not necessarily aware of their serological status poses a very specific set of problems. This was the population covered by the TEEns Living With ARV (TEEWA) survey conducted in Thailand from 2010 to 2012. Sophie Le Coeur, Éva Lelièvre, Cheeraya Kanabkaew and Wasna Sirirungsri describe in detail their survey protocol, including the methods used to access the population and to guarantee confidentiality, and the matching of the sample of infected persons with a random control group drawn from the general population. Addressing key issues of public health and survey methodology, this original survey protocol provides a new tool for understanding the effects of HIV/AIDS on the lives of young people infected with the disease from birth.

Over the last decade, with the introduction of antiretroviral therapy, the life expectancy of children born with HIV has improved remarkably (Brady et al. 2010; Collins et al. 2010; Goetghebuer et al. 2009). Children infected with HIV at birth who are receiving antiretroviral treatment now reach adolescence, albeit carrying a chronic disease that is still very difficult to manage on a daily basis. While the biomedical aspects and therapeutic challenges of HIV are well documented, in particular the requirement to take medication at set times and without interruption, little is known about the family and social situations and the living conditions of these children. The few existing studies are qualitative (Ferrand et al., 2010; Orban et al., 2010; Punpanich et al., 2008)
and are based on small samples (Frederick et al., 2000; Rogers et al., 1996). They rarely offer comparisons with adolescents in the general population who are living in the same context.

Thailand was severely affected by the HIV/AIDS epidemic in the late 1990s, and the government of Thailand quickly set up an extensive prevention programme to contain the disease (Ainsworth et al., 2003; Thanprasertsuk et al., 2004). Preventing mother-to-child HIV transmission was one of the main achievements of this programme and very few children are born with HIV in Thailand today (Amornwichet et al., 2002; Le Coeur et al., 2003). Children infected prior to this programme are now reaching the critical age of adolescence and often have a difficult life-history. This may include a family environment disrupted by the disease; in many cases, the death of one or both parents; the experience of coping with a disease that sometimes gives rise to severe pathologies (Ferrand et al., 2010); the need to take medicine several times a day and continuously; the shock of learning that they are HIV-positive; and stigmatization by other children and adults in their social circle. In this particularly difficult family and social context, families, caregivers, members of patient associations and policy makers are reflecting on the situation and future of these children in order to develop an appropriate public health response.

As part of the Living with Antiretrovirals (LIWA)(1) research project, whose objective was to study the impact of antiretroviral therapy on the family and social life of adult patients, two life-event history surveys were conducted in 2007. The first involved all the patients treated with antiretrovirals in four district hospitals in the region of Chiang Mai (N = 513), and the second a matched sample of the general population (N = 500). Among other findings, this research showed a significant difference in access to HIV testing and treatment depending on gender, with women having better access than men, in particular because of the medical care they received during pregnancy and childbirth (Le Coeur et al., 2009, 2011). When the results were presented to groups of patients, families and caregivers, they suggested that we apply the same approach to explore the particularly worrisome situation of adolescents born with HIV.

The Teens Living with Antiretrovirals (TEEWA) study was designed in response to this request. Its main objective was to evaluate the family and social situation, and to pinpoint the needs of Thai children who were reaching adolescence, had been infected with HIV at birth and were receiving antiviral therapy. The aim was to find out more about their situation, including their aspirations, behaviours and quality of life with reference to their life history and medical care. To this end, an original data collection approach was developed to take account of the methodological and ethical considerations specific to a survey of adolescents whose life histories are marked by severe material and emotional difficulties.

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(1) Project funded by the Agence nationale de recherches sur le sida et les hépatites virales (ANRS, 12141), the French national agency for research on AIDS and viral hepatitis.
Faced with the need for sensitive collection methods and accurate information, for validated data and confidentiality, this article presents our methodological explorations and the solutions adopted for gathering data from an adolescent population born with HIV. We begin with a description of these challenges and the ways in which the survey responds to them. We then describe the survey protocol and the data collection process. We also discuss the advantages and limitations of the sampling method and briefly describe the sample obtained.

I. Designing a survey of HIV-infected adolescents: the challenges of data collection

To shed light on the situation of these adolescents born with HIV, the study had to capture the diversity of their life histories, family situations and living conditions, as well as regional differences, by means of an approach that, in a context of vulnerability, would not stir up memories of painful experiences. In addition, we had to ensure that the procedure was confidential and that anonymity was respected. Finally, it was important to avoid any risk that adolescents who were not necessarily aware of their serological status might find out that they were HIV-positive.

In-depth interviews with adolescents born with HIV were at first envisaged, but a qualitative approach did not necessarily address the reservations identified above. Such an approach, limited out of necessity to a small number of selected (non-representative) adolescents, would have delved deeply, but only into individual lives, without necessarily revealing the full diversity of situations. It would therefore not have responded to the request we had received, namely to provide an overall assessment of the more general situation of such children in Thai society. Given the number of HIV-infected people in the country, their geographical distribution and the wide diversity of their care situations, we needed to design a quantitative survey on a national scale with a sample that was as representative as possible of all children born with HIV.

1. Deciding whom to approach

At first, we thought that only young people who were fully aware of their HIV-infection status should be included in the study. However, in addition to the bias that such a selection would have introduced, it soon emerged, through our interviews with paediatricians and families, that the adults were sometimes unsure about whether the children had actually been informed about their status. And when this was indeed the case, they could not be sure that the children fully understood the information they had been given. In fact, unlike adults who become aware of their serological status after a test, generally as part of an explicit protocol, children born with HIV do not necessarily have
complete and objective information about the details of the infection that they carry, and are sometimes totally ignorant of their status. Telling a child that he or she was infected at birth is a complex process; it involves various people such as parents, doctors, the people who care for the child, and the family circle – whose response may not necessarily be supportive. It is particularly painful for the parents and, above all, the mothers because they feel responsible for the transmission. Depending on the circumstances, children may learn of their status at different ages, with varying degrees of receptivity. It is often a gradual process during which the child’s understanding of the infection and related issues develops little by little. These observations showed us that while it was feasible to interview a sub-population of HIV-infected adolescents, it was practically impossible to know for certain before the survey whether the children were aware of their HIV status. We therefore had to find a means of addressing all the children (whether or not they knew that they were infected) without running the risk of revealing their HIV status to them.

2. Trajectories with HIV

Assessing the children's situations involved retracing their family, schooling, residential and medical histories. As shown by the LIWA survey of HIV-infected adults in northern Thailand, families reconfigure their support systems in response to the disease and ensuing deaths (Lelièvre and Le Coeur, 2012). The situation of adolescents born with HIV is the result of a personal history marked by the onset of the epidemic that struck down their parents and by their access to treatment, whether early or late. A life-history approach therefore seemed to be the best strategy for understanding the circumstances and difficulties relating to the care of these children and their transition from adolescence to adulthood. Nonetheless, given the specificity of this population, life-history data collection can run into problems arising from the very nature of the disease. In interviews, it is important to avoid rekindling memories of painful events such as the illness or death of one or both parents, or experience of discrimination. Moreover, adolescents are not necessarily the best observers of the exact circumstances of their childhood, their family history or the history of their disease, transmitted by their mother at birth.

As in the LIWA survey of adults, we decided to carry out a survey with a hospital-based starting point. The chosen strategy consisted of finding a wide range of different respondents to obtain contrasting perspectives on the adolescents' lives. The adolescents(2) themselves were surveyed via a questionnaire that did not mention the infection or the disease. To gather data about family history, we also approached the adolescents’ parents or, when this was not possible, their legal guardians. While this approach worked well for adolescents living in a family setting, it was not as suitable for the many HIV-positive children who live

(2) Whether or not they were aware of their infection status.
in orphanages. For these children, summary information about their life histories was collected from the orphanage. Finally, staff members at the hospital where the adolescents were receiving treatment, who were familiar with their medical history and care management, completed a medical information form.

We thus decided to use a self-administered questionnaire for the adolescents, combined with a face-to-face interview with their parent or guardian (or a shortened questionnaire filled out by the orphanage) along with a short medical form. To account for gender specificities, in particular for questions relating to puberty, two self-administered questionnaires were used, one for girls and another for boys, but the vast majority of questions were identical, allowing for term-to-term comparisons.

It was also important to uphold strict ethical standards and to minimize any risks arising from the survey, to ensure that respondents gave their informed consent before taking part, and that all information obtained remained strictly confidential.

3. Ethical issues relating to data collection

The Declaration of Helsinki (World Medical Association, 2013) states that “all vulnerable groups and individuals should receive specifically considered protection”.(3) Under the recommendations of the Council for International Organizations of Medical Sciences (CIOMS, 2002), before undertaking research involving children researchers must ensure that:

- the research might not equally well be carried out with adults;
- the purpose of the research is to obtain knowledge relevant to the health needs of children;
- a parent or legal representative of each child has given permission;
- the agreement (assent) of each child has been obtained to the extent of the child`s capabilities;
- a child`s refusal to participate or continue in the research will be respected.

The adolescents in our study were doubly vulnerable owing to their age and their HIV status. Our research was justified, however, because its purpose was to learn about these adolescents’ situations and their specific needs.

The vast majority of adolescents in our study were minors (the age of majority is 18 in Thailand), and were not able to give legal consent to take part in the research. Their parents’ authorization was therefore required. In the specific case of our study, however, the parents had often died of AIDS and it was a grandparent, a family member or even someone outside the family who was legally responsible for the child.

(3) The Council for International Organizations of Medical Sciences (CIOMS 2002) defines vulnerable persons as “those who are relatively (or absolutely) incapable of protecting their own interests. More formally, they may have insufficient power, intelligence, education, resources, strength, or other needed attributes to protect their own interests”.
The interviews were therefore necessarily preceded by a consent process. The parent or guardian was informed of the research objectives and the content of the questionnaire and then invited to give consent for the adolescent to participate in the study and for him or herself to be interviewed. The adolescents, for their part, were given an assent form specifying that they would be interviewed about their lifestyle and health.

Confidentiality was also a sensitive issue. Asking a third person, namely the parent or guardian, about the adolescent’s life called for certain precautions. It was of crucial importance to inform the adolescents concerned and obtain their consent for the legally responsible adult to answer questions about them under conditions of complete confidentiality. Likewise, the parent or guardian was informed that his or her answers about the child would remain confidential. In short, both surveyed parties – the adolescent and the adult – were asked to give their assent/consent in writing in order to participate in the survey, after receiving detailed information about the project.

Another ethical issue involved protecting the surveyed adolescents from accidentally discovering their infection status during the survey process, insofar as the survey targeted all adolescents born with HIV receiving antiretroviral therapy, whether or not they had been informed of their HIV status. To this end, documentation about the project had to be precise but selective, corresponding to the topics discussed with each of the respondents. We believed that the risks of accidentally revealing an adolescent’s HIV status during the survey were much greater than any potential risks arising from inadequate information about the real objectives of the study. For this reason, the information sheet about the survey, as well as the questionnaire for the adolescents, contained no mention of HIV.

### II. A matched survey of adolescents, parents or guardians and caregivers

Once the survey had been designed, its efficacy and its capacity to meet the TEEWA project objectives had to be tested. In this section, we describe how the survey was administered and explain how the methodological and ethical questions raised by this approach were handled in practice.

#### 1. A survey in a hospital setting

According to data from the National Health Security Office (NHSO), in November 2012, there were an estimated 17,718 children between the ages of 0 and 19 living with HIV in Thailand, two-thirds of whom (12,119 children) were receiving treatment. At that time, infected children were treated only if they presented symptoms of the disease or signs of advanced immunosuppression (Ministry of Public Health, 2002). For obvious reasons of confidentiality, no
list of names and addresses existed for children born with HIV. To meet our goal of gaining a better understanding of the situation and needs of adolescents born with HIV, our only option was to reach the adolescents through the hospitals where they were receiving care.

As antiretroviral therapy was not available on a large scale until 2003, very few children born with HIV had survived beyond the age of 19 in 2010. Almost all HIV-infected adolescents older than 19 had been infected through sexual transmission or intravenous drug use, and thus represented a very different group, from an epidemiological and socio-behavioural point of view, from those infected at birth. We therefore chose to limit our selection to young people under the age of 20. As the project targeted adolescents born with HIV, the cohort was made up of children who were born before treatments to prevent mother-to-child HIV transmission had become widespread (in 1999) and who had survived into adolescence in 2010. Given the difficulty of obtaining a large sample without introducing too much heterogeneity into the study group, we decided to include only children over 12, an age when they enter puberty and start to become more independent. The adolescents born with HIV in our population sample were thus between the ages of 12 and 19 at the time of the study.

As we could only access adolescents born with HIV in the hospitals where they were treated, our sample was limited to those who were receiving antiretroviral therapy. To obtain our sample, we relied on the hospital network established by the clinical research group in the Program for HIV Prevention and Treatment (IRD174-PHPT). These hospitals are located across Thailand and provide care for a cohort of 2,000 HIV-infected patients, adults and children who are receiving treatment (Collins et al., 2010; Fregonese et al., 2012). This cooperation for the purpose of clinical research on HIV/AIDS has been active for 20 years and strong ties have been forged within this hospital network. Relationships of trust among medical staff, patients and their families made it possible to envisage a survey on the hospital premises under conditions of complete confidentiality and anonymity. A total of 34 hospitals in the IRD-PHPT network treat HIV-infected children. These hospitals, selected for the size of their HIV-infected patient population, voluntarily agreed to join the research network so that their patients could benefit from advances in research and optimal care as members of a structured therapeutic cohort. Of course, they represent only a small proportion of all the public hospitals in Thailand, but their patient populations and geographical distribution reflect those of the HIV-infected population: 12 hospitals in the north, the region the most affected by HIV; 12 in the centre of the country; five in the north-east; three in Bangkok; and two in the south.

(4) Project supported by the Global Fund to Fight AIDS, Tuberculosis and Malaria.
(5) In 2010, Thailand had 1,002 public hospitals including 736 community hospitals (10–30 beds), 70 general hospitals (100–500 beds), 12 health promotion centres (30–90 beds), 25 regional hospitals (400–1,000 beds) and 13 university hospitals (100–2,200 beds).
2. Survey design

All the hospitals in the PHPT network providing care for children and adolescents were invited to take part in the TEEWA survey. Twenty of them accepted.

Given the issues described above, the following strategy was adopted:

- Each adolescent completed a questionnaire about the members of his or her household, his or her personal space, participation in household chores, schooling and/or employment, hobbies, social network and peer group, risk behaviours and relationships with adults. It included questions on how respondents perceived their health, physical appearance, puberty, romantic relationships, sexuality and, lastly, their outlook on the future (Table 1).

- A questionnaire on the adolescent’s life history was administered face to face with their parent or guardian. It explored their family history (separation and/or death of parents, successive guardians), residential mobility, schooling, disease history (date and circumstances of diagnosis, Table 1).

<table>
<thead>
<tr>
<th>Questionnaire completed by adolescent</th>
<th>Face-to-face questionnaire with parent/guardian</th>
<th>Questionnaire for the orphanage</th>
<th>Sociodemographic and medical form</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household composition, personal space, household chores</td>
<td>Child’s family history (death of parents, successive guardians)</td>
<td>Details in the child’s family history (background, successive orphanages, age on entering the orphanage, parents’ deaths)</td>
<td>Sociodemographic characteristics, place of residence, parents’ vital status</td>
</tr>
<tr>
<td>Schooling or employment, hobbies</td>
<td>HIV infection history (diagnosis, treatment start date, disclosure)</td>
<td>HIV infection history (diagnosis, treatment start date, disclosure)</td>
<td>HIV infection history (diagnosis, treatment start date, disclosure)</td>
</tr>
<tr>
<td>Outlook on future</td>
<td>Medication adherence</td>
<td>Medication adherence</td>
<td>Type of treatment</td>
</tr>
<tr>
<td>Perceived state of health</td>
<td>Child’s state of health since birth</td>
<td>Child’s current state of health</td>
<td>Immune and virological status</td>
</tr>
<tr>
<td>Perception of physical appearance</td>
<td>Experiences of discrimination</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social network, peer group</td>
<td>Child’s behaviour, conflicts</td>
<td>Child’s behaviour, conflicts</td>
<td></td>
</tr>
<tr>
<td>Risk behaviours</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Puberty, sexuality</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationships with adults, conflicts</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 1. Topics addressed in the questionnaires

Note: The questionnaire completed by the adolescents did not contain any reference to HIV.

Source: TEEWA survey, 2010-2012.
date when antiretroviral therapy began, disclosure date, treatment conditions (responsibility, assessment of medication adherence), behaviour and well-being, and any reported experiences of discrimination within the family, village or school (Table 1). Data on family, residential, educational and health history were compiled in an event-history table (GRAB, 2009; Le Coeur et al., 2005). A fictitious example is shown in Figure 1.

- A short medical form, filled out by a nurse at the hospital on the basis of medical records, provided information on the type of treatment taken by the adolescents, their immune status and the stage of the disease.

For the children in institutional care, the questionnaire for the children and the medical form were identical, but the information about their life histories collected from the institution was briefer. In Thailand, there are many

Figure 1. Fictitious example of a life-event table of a 17-year-old adolescent girl. It was established with the help of her legal guardian, her maternal grandmother in this case.

<table>
<thead>
<tr>
<th>Year</th>
<th>Age</th>
<th>Parents’ status</th>
<th>Guardians</th>
<th>Residence</th>
<th>School/work</th>
<th>HIV</th>
<th>Health status</th>
</tr>
</thead>
<tbody>
<tr>
<td>2536</td>
<td>0</td>
<td>M+F</td>
<td>Chiang Mai</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2537</td>
<td>1</td>
<td>FM - Sep</td>
<td>M</td>
<td>San Sai</td>
<td>HIV Test</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2538</td>
<td>2</td>
<td>D - F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2539</td>
<td>3</td>
<td>D - M</td>
<td>GM (M)</td>
<td></td>
<td>HIV symptoms</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2540</td>
<td>4</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2541</td>
<td>5</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2542</td>
<td>6</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2543</td>
<td>7</td>
<td>D - M</td>
<td>GM (M)</td>
<td></td>
<td>HIV symptoms</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2544</td>
<td>8</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2545</td>
<td>9</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2546</td>
<td>10</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2547</td>
<td>11</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2548</td>
<td>12</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2549</td>
<td>13</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2550</td>
<td>14</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2551</td>
<td>15</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2552</td>
<td>16</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2553</td>
<td>17</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2554</td>
<td>18</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2555</td>
<td>19</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2556</td>
<td>20</td>
<td>D - M</td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
</tbody>
</table>

These notes correspond to comments made by the respondent and recorded by the interviewer:

1. Father dies of AIDS
2. Mother dies of AIDS
3. Mother returns to live in parents’ home
4. Child refuses to attend school because strongly stigmatized
5. HIV symptoms
6. ARV
7. Disclosure
8. HIV Test
9. Year 1
10. Year 5
11. Year 8
12. Basket-making
13. Year 12

F: Father
M: Mother
FM: Separation of father and mother
D: Death of father
GM (M): Maternal grandmother

(a) Buddhist calendar year (+543 years with respect to the Gregorian calendar).
(b) Perceived health status on a scale of 1 to 5 (1 = very poor, 2 = poor, 3 = fair, 4 = good, 5 = excellent).

baan deck, which are public or private “children’s homes” that take in not only orphans, but sometimes also children entrusted to their care by parents, often from ethnic minorities living in remote areas, wishing to provide their children with an education. The children return to stay with their parents for holidays. These “children’s homes”, often run by international Christian charities (Catholic or Protestant), are described as “orphanages” to encourage the generosity of donors moved by the plight of orphans.

The questionnaires were first tested on a small number of adolescent members of the Youth Community Advisory Board (Youth CAB, see Box) set up by the PHPT, and their parents/guardians. Members of the Youth CAB also suggested topics and helped to adapt the wording of questions for the adolescents. For example, they suggested adding questions on how the adolescents saw themselves in the future and, more specifically, on their desire to start a family and have children.

For the institutions, the questionnaire to be completed by staff members was first tested and then adapted to ask only for information generally known by the personnel.

3. Comparing the situation of adolescents born with HIV with that of a group from the general population

One difficulty with this type of survey is to obtain comparable information from a reference population group who live in the same general environment as the children born with HIV but who were not infected at birth. Some studies on HIV-infected adolescents in Europe (AALPHI, COVERTE) have used the uninfected brothers and sisters of children born with HIV as a control group. In a country with a very low fertility rate, however, not everyone has siblings and for those who do, the siblings’ ages may be too far apart for the purposes of the study.

In the LIWA project we were able to match the sample of HIV-infected people with a random sample from the general population based on their place of residence, sex and age (Le Coeur et al., 2011). Likewise, for TEEWA, for every district represented in the survey, we selected a village where the majority of the surveyed adolescents born with HIV lived with their families. In the health centre in this village, we randomly selected adolescents of the same age and sex as those born with HIV from an exhaustive population list. The aim was to obtain a comparable group of adolescents from the general population who would also be surveyed after data collection among the HIV-infected adolescents was completed. Since this strategy was not feasible for those living in institutions, the reference group in that case comprised all the other adolescents living in the same institution who had not been infected with HIV and who were all surveyed at the same time. In some cases, one or both of the parents of these adolescents were HIV-positive. We thus had another very

(6) Every health centre has a computerized file of the whole population for the village in question.
interesting reference group made up of children born to HIV-infected parents, but themselves uninfected.

4. Anonymization, consent forms and the ethics committee

For reasons of confidentiality, no names were made available to the research team, and the various questionnaires could be identified only through a number, thus ensuring anonymized data collection. In their self-completed questionnaire, the adolescents did, however, write the initials of their first name and surname, which provided an additional key for subsequent linkage of the adolescent’s questionnaire with the parent/guardian’s questionnaire and the medical form. The participants were, of course, informed of the confidential and anonymous nature of the information gathered.
The consent and assent forms were reviewed by the Patient Advisory Committee or the Community Advisory Board (CAB) (see Box) to ensure that they were complete and readily understandable by the lay population.\(^7\)

The protocol was submitted for review and approval to the Ethics Committee at the Faculty of Associated Medical Sciences, Chiang Mai University and the local hospital.

5.Administering the survey of adolescents born with HIV and their parents/guardians

In each of the hospitals involved in the survey, a list of all the HIV-infected children aged 12-19 who were receiving antiretroviral therapy was drawn up by the nursing staff but not communicated to the research team. Adolescents who had been infected through sexual transmission or intravenous drug use were excluded. Using this list of eligible adolescents, the head nurse contacted the parents or guardians to ask them to take part in the survey. The medical staff often have a special relationship with these young patients receiving antiretroviral therapy, who go to the hospital every three months for a check-up and a renewal of their medical prescription. The adolescents completed their questionnaires in the hospital, in a private room of the service they attend for their regular visits. For the adolescents who lived with their family, the interviews with the parent/guardian were conducted at the same time, in another room and under conditions of strict confidentiality. In consultation with the families, it was decided to schedule the interviews mostly at weekends to avoid disrupting the adolescents’ schooling. For the adolescents living in institutions, the staff were interviewed and the self-completed questionnaires administered under the same conditions, but within the institution itself.

The interviewers explained the research project objectives to the parents/guardians on an individual basis, providing them with an information sheet about the study and asking for their written agreement to take part. Only when the consent form had been signed by the parent/guardian was assent requested from the adolescent. Copies of the consent and assent forms were given to the signatory participants.

Quantitative surveys are commonly administered by a team of interviewers. For the survey of HIV-infected adolescents and their parents or guardians, some special precautions were taken to adapt the approach already applied in the LIWA project (Le Coeur et al., 2005), and two interviewers were recruited from the previous research project team.\(^8\) In the field, supervised by a research professional, a psychiatric nurse and a social scientist, both trained in event-history data collection and in counselling and physiological support for HIV/AIDS patients. In addition, they received training in the specific treatments and epidemiological profiles of children with HIV.

\(^7\) The consent and assent forms were first written in English, then translated into Thai and finally retranslated into English in order to check the accuracy of the translation.

\(^8\) A psychiatric nurse and a social scientist, both trained in event-history data collection and in counselling and physiological support for HIV/AIDS patients. In addition, they received training in the specific treatments and epidemiological profiles of children with HIV.
assistant who had also been trained as a nurse, they were able to identify
difficult situations for which a psycho-medical approach would be required.

At the same time, the medical form was filled out by the hospital nurse in
charge of the adolescent. It asked for information about the medications taken,
the date of diagnosis, the therapy start date, and the adolescent’s virological
and immunological response.

6. Collecting data from adolescents in the general population
and their parents or guardians

The survey was organized in much the same way as for the adolescents
born with HIV: the self-administered questionnaire was practically the same;
the face-to-face questionnaire for the parents/guardians/institution staff was
the same except for the omission of questions about HIV infection, and there
was no medical form.

For the adolescents living with their families, a list was drawn up in every
selected health centre, and the adolescents’ parents were contacted by the head
of the centre. The interviews with parents and administration of the adolescents’
self-completed questionnaires took place at weekends in village health centres,
with precautions identical to those for data collection among adolescents born
with HIV and their parents in order to respect confidentiality in all the study
groups. The interviews were carried out by the same interviewers as for the
survey of adolescents born with HIV.

For the control group of adolescents living in institutions, the survey took
place during the same session as for the adolescents born with HIV.

III. A national sample of adolescents born with HIV
and receiving antiretroviral therapy

Given the specific nature of the target population (vulnerable minors) and
the theme of the study, a concerted approach with the medical institutions
was necessary. The 20 hospitals that participated in the study are spread across
the country: 11 hospitals in the north, the region most affected by HIV; three
in the north-east; three in the east and centre; two in the south; and one in
Bangkok. These hospitals are also of different sizes, reflecting the diversity of
medical care for HIV-infected patients in Thailand: nine community hospitals
that treat exclusively rural populations, seven general hospitals, three regional
hospitals and a military hospital receiving patients from both urban and rural
populations (Figure 2).

From March 2010 to July 2012, all the adolescents born with HIV aged
12-19 who had been identified as receiving antiretroviral therapy in one of the
20 hospitals – a total of 944 adolescents – were approached. Out of this number,
712 adolescents (75%) were surveyed with their parent or legal guardian, 376
(81%) of whom were living with their family and 136 (19%) in an institution (Figure 3). Three adolescents initially identified were later excluded from the sample because they were not receiving therapy at the time of the survey. For all the other adolescents from the 20 hospitals who could not be interviewed owing to their absence on the day of the survey, we nonetheless obtained information from the nurse on certain sociodemographic characteristics such as their birth date, their knowledge of their HIV status and their parents’ vital status, in addition to medical data. We were thus able to assess the characteristics of the non-respondents. We do not know, however, whether the parents/guardians or the adolescents themselves were responsible for these “refusals”. It was clearly more difficult for the adolescents living in orphanages to avoid participating in the survey, as all the children in the same orphanage were collectively subject to decisions made by the institution staff.

As regards the group from the general population, from July 2012 to January 2014, 576 adolescents presumed not to be HIV-positive and living with their

Figure 2. Geographical distribution of adolescents (12–19 years old) receiving ART in the general population and in the TEEWA survey

families in the same areas, who were the same age and sex as the adolescents born with HIV, were surveyed. One adolescent randomly drawn from the general population who knew that he was HIV-infected was excluded from the sample and not interviewed. In addition, 118 non-infected adolescents living in the same institutions as the 136 adolescents born with HIV made up the control group in institutions (Figure 3). The reference group of young people living in institutions was not balanced because, as the survey targeted the total number of adolescents residing in each institution, the sample size depended on how many adolescents were living there. Note that among these 118 non-infected adolescents living in institutions, 16 (14%) were born to a HIV-positive mother.

1. Sampling procedure

According to data from the National Health Security Office (NHSO), out of the 12,543 HIV-infected adolescents aged 12-19 across Thailand in 2012, 9,174 were receiving antiretroviral therapy. The available data provide very few details to evaluate the characteristics of the sample. The number of HIV-infected adolescents varies across regions, which themselves have populations of different sizes (Table 2). When the geographical distribution of adolescents aged 12-19 who were receiving therapy is compared with that of the survey sample (Figure 2), adolescents living in northern Thailand are found to represent nearly half of the survey sample versus only a quarter in the total population.
This fact can be explained by the proximity to the research centre (located in Chiang Mai) and special links with hospitals in the region. This is the region most affected by HIV in Thailand, and the survey coverage rate was high, at 21%. It was lower in the other regions (between 6% and 8%). Southern Thailand, where HIV prevalence is the lowest, is not easily accessible from Chiang Mai. It is represented by two hospitals, in Songkla and in Hat-Yai (together on the map), where 6% of infected adolescents in the region were surveyed. In the north-east, which is also difficult to access from Chiang Mai, 6% of infected adolescents were surveyed. This region, on the border with Cambodia, is the point of departure for many temporary migrations to Bangkok. Lastly, in the central and south-eastern regions, which are highly industrialized, 8% of infected adolescents were surveyed.

### Table 2. Comparison of the regional distributions of HIV-infected adolescents (12–19 years) receiving treatment (NHSO) and of the TEEWA sample

<table>
<thead>
<tr>
<th>Regions</th>
<th>North</th>
<th>North-east</th>
<th>Centre(a) and East</th>
<th>South</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population in millions</td>
<td>11.5</td>
<td>18.8</td>
<td>18.1</td>
<td>8.9</td>
<td>57.3</td>
</tr>
<tr>
<td>Adolescents receiving treatment (% of total)</td>
<td>2,251 (24.5%)</td>
<td>2,803 (30.5%)</td>
<td>3,125 (34.1%)</td>
<td>995 (10.8%)</td>
<td>9,174 (100%)</td>
</tr>
<tr>
<td>Surveyed adolescents (% of total)</td>
<td>463 (49.2%)</td>
<td>170 (18.1%)</td>
<td>245 (6.0%)</td>
<td>63 (6.7%)</td>
<td>941 (100%)</td>
</tr>
<tr>
<td>Coverage rate</td>
<td>20.6%</td>
<td>6.1%</td>
<td>7.8%</td>
<td>6.3%</td>
<td></td>
</tr>
</tbody>
</table>

(a) Excluding Bangkok (8.2 million inhabitants); the large hospitals in the capital are not part of the network.

**Sources:** National Health Statistical Office (NHSO), National Statistical Office (NSO), the 2010 Population and Housing Census, TEEWA, 2012.

Randomly including hospitals of each region in line with levels of HIV prevalence would certainly have provided better population representativeness. Nonetheless, the relationships of trust forged over many years with the institutions and their active collaboration in the study enabled us to survey all the adolescents treated in the hospitals in question, with a very high participation rate.

### 2. Sample characteristics

Here we will describe some of the sample characteristics to give an overall picture of the HIV-infected adolescents in the TEEWA survey (Table 3). The total sample contained slightly more girls (56%) than boys (44%), reflecting the distribution observed at national level. Their average age was 14, with 8% of adolescents being 18 or older, and only 2% being 19 or older. In all, 84% of the adolescents were living with their families and 16% in institutions. The reasons why some adolescents were with their families and others in institutions will be explored below. Many of the adolescents were orphans: half (50%) had
Table 3. Demographic and family situations of all the adolescents born with HIV and of the reference group from the general population

<table>
<thead>
<tr>
<th></th>
<th>Born with HIV with family (N=573)</th>
<th>Born with HIV in institution (N=136)</th>
<th>Born with HIV not interviewed (N=232)</th>
<th>Born with HIV Total (N=941)</th>
<th>General population with family (N=576)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>% or CI(^{(a)})</td>
<td>N</td>
<td>% or CI(^{(a)})</td>
<td>N</td>
<td>% or CI(^{(a)})</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>239</td>
<td>41.7</td>
<td>68</td>
<td>50.0</td>
<td>112</td>
<td>48.3</td>
</tr>
<tr>
<td>Female</td>
<td>334</td>
<td>58.3</td>
<td>68</td>
<td>50.0</td>
<td>120</td>
<td>51.7</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age</td>
<td>14</td>
<td>13-16</td>
<td>14</td>
<td>13-16</td>
<td>15</td>
<td>13-17</td>
</tr>
<tr>
<td>12-13</td>
<td>249</td>
<td>43.5</td>
<td>49</td>
<td>36.0</td>
<td>66</td>
<td>28.4</td>
</tr>
<tr>
<td>14-15</td>
<td>179</td>
<td>31.2</td>
<td>46</td>
<td>33.8</td>
<td>61</td>
<td>26.3</td>
</tr>
<tr>
<td>&gt;15</td>
<td>145</td>
<td>25.3</td>
<td>41</td>
<td>30.2</td>
<td>105</td>
<td>45.3</td>
</tr>
<tr>
<td><strong>Parents’ vital status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Both parents alive</td>
<td>79</td>
<td>13.8</td>
<td>5</td>
<td>3.7</td>
<td>34</td>
<td>14.7</td>
</tr>
<tr>
<td>Mother deceased or status unknown</td>
<td>139</td>
<td>24.3</td>
<td>18</td>
<td>13.2</td>
<td>26</td>
<td>11.2</td>
</tr>
<tr>
<td>Father deceased or status unknown</td>
<td>109</td>
<td>19.0</td>
<td>9</td>
<td>6.6</td>
<td>47</td>
<td>20.3</td>
</tr>
<tr>
<td>Both parents deceased or status unknown</td>
<td>246</td>
<td>42.9</td>
<td>104</td>
<td>76.5</td>
<td>125</td>
<td>53.9</td>
</tr>
<tr>
<td><strong>Legal guardian</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent(s)</td>
<td>180</td>
<td>31.4</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Grandparent(s)</td>
<td>215</td>
<td>37.5</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Uncle(s) or aunt(s)</td>
<td>115</td>
<td>20.1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>63</td>
<td>11.0</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Income of parent/guardian (Thai baht)(^{(c)})</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 2,800</td>
<td>159</td>
<td>36.8</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>2,800–5,000</td>
<td>146</td>
<td>33.8</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>5,001–9,000</td>
<td>73</td>
<td>16.9</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>&gt; 9,000</td>
<td>54</td>
<td>12.5</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

(a) 95% confidence interval.
(b) Comparison between adolescents born with HIV living in families and the reference population.
(c) Local unit of currency.
Source: Enquête TEEWA.
lost their mother and father, 19% their mother and 17% their father. Those living in family settings were, in most cases, in the care of their grandparents (37%), one of their parents (31%), or more distant relatives such as aunts and uncles (20%). As can be expected, the majority of adolescents residing in institutions were orphans who had lost both parents (76%). A quarter still had at least one parent who was alive. This fact attests to the openness of these institutions in accepting children “to give them a better chance in life”. These children generally remain in contact with their family. Note that the adolescents who refused to participate in the survey and about whom information was obtained indirectly were slightly older on average. Probably enjoying more personal freedom than the younger participants, they did not answer our invitation to take part.

Table 3 also compares some characteristics of the adolescents born with HIV with those of the reference group from the general population. The populations are matched, so the age-sex distribution is identical. As we have just seen, however, the majority of adolescents born with HIV had lost one or both parents (87%), whereas in the reference group, both parents were generally alive (89%). Compared with adolescents born with HIV, a much smaller proportion of adolescents in the reference group were not in the care of their parents (27% versus 67%). The proportion of adolescents in the general population entrusted to someone else’s care is nonetheless high. This may reflect the growing number of “missing generation” households in poor regions of Thailand, whose young adult members migrate to industrial areas to find work, leaving their children in the care of their grandparents. We have observed elsewhere that the AIDS epidemic has also given rise to this type of household configuration by taking the lives of young adults (Lelièvre and Le Coeur, 2012). Lastly, the income of the parents or guardians was also much lower in households that included adolescents born with HIV. This situation shows how the HIV infection that has killed young adults (the parents of the surveyed adolescents) has also contributed to the impoverishment of the affected families, whose head, in most cases, is an elderly person (grandparent) with a very modest income.

3. Limitations of the data collection method

The challenges of event-history data collection

The life-history aspect of this study hinged upon obtaining information, not only about the adolescent’s daily life but also about his or her past, from the parent/guardian, or the person who accompanied the adolescent on the day of the survey.

Event-history tables (Lelièvre and Vivier, 2001; GRAB, 2010) were used to reconstitute the adolescents’ life history since birth, situating events chronologically and in relation to one another (Figure 1). When asked about

(9) 2007 Survey of Older Persons (Knodel and Chayovan, 2008).
the moment when the adolescent was diagnosed, the parent or guardian in more than one case went through a recall process such as this: “My daughter died in 2543 [in the Buddhist calendar, corresponding to 2000 in the Gregorian calendar]. Before her death, she found out that her child was infected, so the diagnosis was made before […]”. Clearly, the family history and that of the disease are inextricably connected across generations.

That said, the person who was taking care of the child at the time of the survey had not necessarily witnessed past events personally, so it was sometimes difficult to reconstitute the child’s life events. The children had often been entrusted successively to several people, sometimes shunted between the paternal and maternal families, from the grandmother to the aunt or elder sister. Certain events such as experiences of discrimination, of which parents/guardians are not always aware, may well have been under-reported. Likewise, when there was no direct information about the adolescent’s degree of awareness of his or her HIV status, the impact of disclosure on certain behaviours, such as medication adherence or risk-taking, was more difficult to interpret.

Lastly, since the legal guardians of adolescents born with HIV were, in the majority of cases, their elderly grandparents (Table 3), we sometimes encountered problems gathering data from them. In addition, while we tried to protect the adolescents from having to recall painful childhood events, it was also emotionally difficult for a grandparent responsible for the surveyed adolescent to talk about the death of his or her adult child (the father or mother of the adolescent) when reconstituting the family history.

Our data collection strategy functioned well, and the parallel completion of questionnaires by the adolescents and the interviews of their parents went smoothly in the hospitals for the children born with HIV and in the health centres for the adolescents from the general population. Consistent reconstructions of the adolescents’ life histories were obtained, although the information on the tables was sometimes vague and imprecise. At the very least, this type of data collection allows for a chronological ordering of events – and sometimes the pinpointing of exact dates – thus making it possible to use the data for quantitative analysis (GRAB, 2006).

Creating a general population reference sample

Creating a matched control group, based on the criteria of place of residence, sex and age, provided a frame of reference, albeit imperfect, for comparing the situation of adolescents born with HIV with that of adolescents in the general population. However, it was impossible to determine whether the observed dissimilarities between, for example, household income levels, were a cause or a consequence of HIV infection. In a country like Thailand, where economic growth has been very rapid, the time lag of two years between the survey of adolescents born with HIV and that of the general population could partly explain this income gap.
Two levels of non-participation

For this type of survey covering a sensitive target population best approached through collaboration with hospital services, we were obliged to resort to convenience sampling in the hospitals. HIV infection is a major research topic, and hospitals are frequently solicited. Some hospitals, already taking part in large epidemiological studies, did not wish to involve their young patients in an additional study.

Finally, we were able to evaluate non-participation bias for a certain number of adolescents because the medical staff collected data on the adolescents’ demographic characteristics. The full diversity of the target population could thus be described exhaustively in every hospital.

Conclusion

Surveying a population of adolescents born with HIV about their life history, care and living conditions called for a survey design that took the vulnerability of their situations into consideration. The fact that they were not always fully aware of their infection status, were minors and in the care of institutions (orphanages), relatives (grandparents, uncles and aunts, etc.) or their parents, also called for data collection methods that were adapted to such needs while respecting anonymity and confidentiality. The TEEWA survey brought together information from three sources: the young person, his or her parent or guardian, and a medical caregiver. If the adolescent was residing in an institution, a form to be completed by the orphanage replaced the questionnaire for the parent/guardian.

We designed the TEEWA national survey of adolescents born with HIV on the basis of lessons learnt during the LIWA study of adults receiving antiretroviral therapy in northern Thailand. In addition to the issues of questionnaire design, access to young people born with HIV was also a major difficulty because we needed to work in close collaboration with the hospitals providing their medical treatment. While provincial HIV-patient counts are available, there is no sampling frame, and setting up such a large-scale survey\(^{(10)}\) required the trust and cooperation of the institutions where the adolescents were receiving care. This survey, conducted within a network of 20 hospitals that were not randomly selected, nonetheless successfully provided data for 10% of the population of children across Thailand who were born with HIV and were receiving antiretroviral therapy at the time of the study. This approach was complemented by a survey of a matched reference sample from the general population, thus providing valuable data for comparative purposes.

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\(^{(10)}\) The LIWA project surveys covered the total patient population in just four hospitals.
Of course, the adolescents born with HIV in this survey are those who have survived the disease. These children were born between 1993 and 2002. Some were born before programmes to prevent mother-to-child transmission became widespread in Thailand beginning in 1999–2000 (Amornwichet et al., 2002), although the majority were able to benefit from antiretroviral therapy after the age of six. Without treatment, the mortality rate is extremely high in the first two years of life, with more than 50% of HIV-infected children dying before age two (Newell et al., 2004). The survey population therefore represents a selected surviving population who, because of delayed access to treatment, had already paid a heavy tribute to the disease, sometimes with lasting after-effects.

Today, the mother-to-child transmission prevention programme is widespread, and the HIV-transmission risk has been reduced to less than 2% (Lallemand et al., 2004). As a result, very few children are now infected at birth. Resources must be found to support previous generations of children born with HIV, i.e. those represented in this survey.

As we had expected, disclosure of a child’s HIV status may take a variety of forms. While in the majority of cases (87%), the parents/guardians reported that the adolescents had been informed of their HIV status, in 9% of cases they had not been informed, and in 3% the parents or guardians did not know if this was the case. Disclosure is sometimes brutal, occurring by chance, for example, when a child who is unaware of being infected is mocked for having AIDS by his or her school playmates.

Analysis of the data will enable us to describe the process whereby these children find out about their HIV status, and to identify the factors that favour good medication adherence. Indeed, as in the case of other chronic diseases, treatment compliance, while crucial for the adolescent’s survival, is often problematic during adolescence.

The integration of these children into society and their future working careers depend on their educational trajectories. How well have they been accepted at school? To what extent has the infection disrupted their education? The data from this survey will also enable researchers to identify the consequences of the disease for the families who care for their HIV-infected children and to assess how state intervention can complement family solidarity.
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Thailand is one of the Asian countries hardest hit by the HIV/AIDS epidemic. Before the widespread implementation, beginning in 1999, of programmes to prevent mother-to-child HIV transmission, many children were born with HIV in Thailand. They now reach adolescence thanks to antiretroviral treatments. While some qualitative studies have documented the family situation and the living conditions of these adolescents, the TEEWA (Teens Living With ARV) project has, for the first time, conducted a national quantitative survey among 10% of adolescents aged 12-19 infected with HIV at birth, under antiretroviral treatment, in order to assess their situation and compare it with that of adolescents in the general population. This article presents an original survey approach that takes into account the methodological and ethical issues specific to the situation of a population rendered doubly vulnerable by age and HIV status.

Keywords: HIV, adolescents, Thailand, living arrangements, survey

Translated by Lynda Stringer