Pediatric HIV/AIDS treatment in Chiang Rai, Thailand

Achieving good adherence through a comprehensive team approach

Edited by
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"Toady, we treat more than 200 children by antiretroviral therapy in Chiang Rai Regional Hospital, and more than 90% of them are doing very well. This is really a blessing for them because they are now free from the risk of getting and dying from AIDS. We help them keep their adherence to more than 95%. This is not an easy task but the patients achieve it through a comprehensive team approach." Dr.Rawiwan Hansudewechakul, pediatrician at Chiang Rai Regional Hospital.

Background

Chiang Rai is the northernmost province in Thailand bordering Lao PDR and Myanmar, featuring the famous Golden Triangle. Agriculture is the predominant industry in the area, and many people migrate to Bangkok or Chiang Mai for work. The poor rural and hill tribe populations in Chiang Rai are especially vulnerable to HIV infection due to the prevalence of sexual labor, drug use and seasonal migration.

Map of Thailand

After the first AIDS case was identified in 1988, Chiang Rai became one of the worst HIV-affected provinces in Thailand. The disease spread rapidly into the society. Many men visited brothels at that time without knowing much about HIV/AIDS. The prevalence among male military conscripts was as high as 18.7% in 1992.

Thai people were quick to realize the severity of the problem and took it as their own problem. Many men stopped going to sex workers and condom use has become a norm at brothels. Health staff, NGOs and some local leaders tried to raise awareness and reduce discrimination towards people living with HIV and AIDS(PHA). Society started to accept and support those who are infected. PHAs started to get together and established support groups to help each other and to establish a voice. The rate of HIV infections started to come down quickly.

However, it was too late. By 1994, 3,826 people had been reported as HIV-positive. Infected men had already passed the virus to their wives and HIV prevalence among pregnant women had risen to 8.5% in 1994. Those women in turn passed the virus on to their babies.

Trends of HIV prevalence among pregnant women in Chiang Rai

Children suffered

The number of HIV-positive children under age 15 increased, and currently there are 1,518 children estimated living with HIV/AIDS in Chiang Rai. Many more have already died and at least 4,836 children lost one or both of their parents to HIV/AIDS. Currently 51.4% of these orphans receive support from NGOs and 3.9% from the government.

The increasing number of children who were born HIV-positive would fall ill and die at a very young age. For those who survived, life was even harder as they were orphaned and had to face severe social stigma and discrimination. Some of them were refused at schools and in communities. There was very little that health services could offer. The infected children developed AIDS and died one after another.

Evolution of Pediatric AIDS care

Chiang Rai Regional Hospital is one of the referral hospitals in the northernmost region of Thailand with 120 pediatric beds among 756 beds in total. The hospital started to receive an increasing number of AIDS children in the late 90's. There are 11 pediatricians and 37 nurses, involved in HIV care in Chiang Rai Hospital. In the early days, there was no one in the pediatric team with experience in pediatric AIDS care and in fact there was very little that they could do. Symptomatic treatment with limited prophylaxis and treatment of opportunistic infection was the best that they could provide.

Prevention of mother-to-child transmission (PMCT)

The government introduced an intervention in 1997 to prevent the vertical transmission of HIV. The effect was remarkable. The HIV transmission rate, the number of HIV positive babies started to decline significantly. Even though the effective intervention for HIV-positive pregnant women had been widely implemented, there was still no hope for those already infected. There were many infected children remaining from the past and a few from new infections.

Chiang Rai Regional Hospital

Pediatric ARV treatment

Antiretroviral (ARV) mono and dual therapy has been in use in Thailand since 1992, but it was limited to research and few private patients who could afford it. In the period from 1997 to 2001, 22 pediatric cases were treated with mono and dual therapy in Chiang Rai, but all for research purposes and most of them had to discontinue the treatment when the research finished. PMCT was the only antiretroviral therapy (ART) available as a routine service before 2002.

In February 2002 with the donation from the AIDS Access Foundation (local NGO), 8 children were started on ART. At the same time, the ARV Care Team was formed consisting of a doctor, two nurses, two NGO staff and three PHAs to work together in hospital and home visit care. Only one child stopped ART, but the others surprisingly showed 100% adherence in the first five consecutive monthly visit. An additional 18 cases were started with more confidence in the second half of the year. In 2003, with the Thai government policy to provide free ART to all

PHAs using GPOvir ® (locally produced generic "three-in-one" drug), 80 new pediatric cases started receiving ART. To date, 10-15 cases newly start ART every month. A pediatric ARV clinic was opened in one of the consultation rooms at general pediatric outpatient department (OPD), to which all the pediatricians send the children who need ARV treatment in accordance with the Thai guidelines. The clinic is not separate or indicated as an "ARV clinic". People may or may not know it. Around 15-25 cases are consulted at the ARV clinic every Thursday and Friday.

ART is a lifelong treatment and requires a very high level of adherence. It cannot be successful without a good understanding of the treatment by the patient and caregivers, as well as a good supportive environment both in the community and at health facilities. It is well known that the key to the success in ART is good adherence.

Preparation for ART

Caregivers

Once a child is considered for ART, two caregivers have to be identified for each child as soon as possible. Forty percent of the caregivers are grandparents, 30% are parents, 20% are an aunt or uncle, 3% are sisters and 6% are foster home caregivers. Once caregivers are identified, their role becomes accompanying the children to the hospital, attending the preparation meeting, practicing preparing the drugs with the children and directly observing the children when they are taking the drugs.

Important roles of the caregivers

- Come with the children to the hospital
- Attend the one day preparation meeting
- Practice preparing drugs with the children in every visit
- Directly observe the children when taking drugs

Disclosure

The basic rule is that all the children should always be informed of the truth according to their level of understanding. Younger ones do not need to know the diagnosis but have to be told of their health condition and the need for medication. The diagnosis of HIV or AIDS is usually gradually informed to the child after the age of 7 or 8, although it depends on the individual. In such case, it is better to disclose their HIV status before starting ART.

"A child should correctly know his/her disease. But it is not the responsibility of health staff to disclose the status to a child. I revealed information in only two exceptional cases, but one of the children later blamed his/her parents for not telling him/her themselves. We can help but a child needs to be informed of the disease by the people they trust most, which usually means their family or caregiver." says Dr.Rawiwan. "Various techniques are used here to make the disclosure easier for both parents and children before starting ART. If the caregivers can not disclose by themselves we offer our help by starting to hint to the child in front of the caregiver that there are some micro organisms in its body that cause chronic illness, which is the reason they need to be taking medication and explain that the organism will not be dangerous if kept under control by taking drugs regularly at the same time each day. We also intentionally let them play with those who already know their status. We leave picture books around to teach them about HIV/AIDS. It takes some time before they are finally informed of everything but they usually already know by then."

Disclosure

- Children must know their HIV status at their perception according to age.
- Always tell the truth. Start gradually and indirectly for younger children, add more information relative to the child's age and needs. Discuss more and more to help the child cope with problems.
- At school age (7-10 years or above), children are capable of understanding the fact and keep it secret.
- Disclosure is a continuing process and need to be informed day by day, by people close enough whom the child trust and ready to talk at any time in a private place.
- Medical teams can help the family to disclose by adding the communication skill and give example.

Pre-ART sessions

Before starting the treatment, patients have to visit the hospital two to three times with their caregivers for preparation (blood examination, Chest X-ray and Tuberculosis (TB) check). There will be one home visit by the NGO team to evaluate the readiness of the family. A one-day preparation session is conducted for families who are scheduled to be on ART in the following month. The session involves basic knowledge of HIV disease, how ART works, how to disclose or communicate HIV problems to the child, and adherence techniques. Patients and caregivers have to decide the most suitable time for medication and how to arrange observed medication (directly observed treatment:DOT). This session is given by the NGO staff nurses, and pediatricians. We have developed a various teaching materials for this education session.

A home visit by the home care team is conducted a few days after the preparation session.

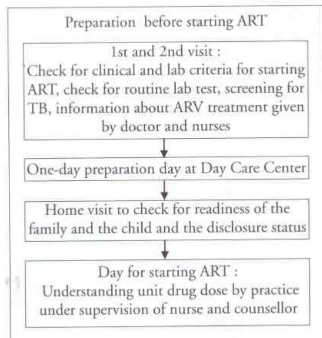
On the first day, after meeting with the doctor and nurses for a check-up and receiving the drugs, the caregivers are divided into three or four groups to practice preparing the drugs. They are introduced to the practice of drug preparation, using the pill cutter*, alarm clock, pill boxes and given a booklet. In some cases, sessions on preparing unit dose drugs are conducted for one week or in a few problematic cases for one month until they can confidently prepare the dose.

Caregivers learning and practicing how to prepare the drugs.

An NGO social worker reading a picture book about HIV to an infected child.

Pediatric regimen (pill cutter*)

At the moment, generic pediatric formulation is not available in Thailand, although the government recognizes the need for it. Therefore, splitting the adult-dose pills is the only way to deliver the appropriate dosage for children. We train caregivers to split the pills rather than for pharmacists to split them in advance. It must be correctly split in order to avoid over-dosing or under-dosing.



The one-day preparation session for caregivers moderated by an NGO social worker and a nurse.

Ongoing adherence support

ARV treatment is not like other medication for common pediatric illnesses because it is a life long treatment and requires a very high level of adherence for success. It is known that more than 95% of adherence (not even one dose of medication can be missed in one week in case of a twice-daily regimen). The Chiang Rai Hospital pediatric team places adherence support at the center of its ART management.

Measuring adherence

Correctly measuring ARV adherence is not an easy task. In fact, there is no single perfect way for it. At Chiang Rai Hospital, therefore, non-adherence is continuously monitored by measuring adherence at every visit in several ways as follows:

1. Pill count by a PHA volunteer in front of the patient and caregiver. This should not be done in an inspecting or judgmental manner but should rather be an opportunity to discuss and remind of the importance of adherence.

2. Patient recitation by a pediatrician asking a child such questions as "Tell me, when did you take your medicine this morning? Which one? How did you take it? How many pills each? How about yesterday? "

3. Checking the 7-day pill boxes whether the remaining pills are left in the boxes correctly and correspond to the actual date.

4. Reviewing the self-record booklet, which patients have to fill in every time they take medicine.

5. Ask for DOT practice and support to have 100% DOT by using open questions to the child such as "How many times in the last ten times have you taken drugs without anybody seeing you? " Then ask the caregiver "The last ten times how many times have you seen the child swallow down the pills? "

ART within comprehensive care and support

In Chiang Rai Hospital, ART is delivered as a part of comprehensive care and support rather than as specialized medical care. It sometimes goes beyond the scope of a hospital's role, but we are convinced that it is preferable for ensuring good adherence as well. As mentioned earlier, health staffs collaborate with PHA peer volunteers and NGOs to realize it. Such attempts include the following activities.

1. Continue group process and counselling

Patients and caregivers are encouraged to join group process at the Day Care Center in the afternoon after finishing up their consultation at the clinic to strengthen their knowledge on HIV, ARV, and disclosure, practice preparing drugs and following weight gain. They learn by exchanging information and experiences with each other.

2. Day Care activities for children

Children can further spend time in the afternoon having fun in a place other than the hospital after the outpatient department follow-up. A nurse together with NGO staff will organize and supervise the meeting. Sometimes there is an organized talk or meeting, but other times there are just casual exchanges. The children learn from nurses, books, and friends. With good facilitation and supervision by staff, older and experienced children can be very good and influential teachers to those new in the group and younger patients. It is a good idea to prepare books and pictures on HIV or medication so that they can naturally read and learn about them. "Very interestingly, we observe the tendency that if a child shows good adherence, the caregivers (mostly parents) show good adherence, too." says Dr.Rawiwan.

3. Care team meeting

A regular case conference is held before starting each clinic day. The meeting is attended by a pediatrician, nurses, NGO and PHA staff, and each case is presented to the team. Any kind of problems are raised and discussed. In addition, the pediatrician, chief nurse, and NGO chief meet every 1-2 months to review results, indicators and direction of the team for continuous improvement.

4. Home visit

The hospital is closely working with the home visit team (NGO and PHA) to arrange and make home visits before and just after starting the ART, and extra visits for those who have problems or who missed an appointment.

5. ART camp

With the support of UNICEF and other NGOs, a recreational camp trip to a beach was organized. It was designed not only as a fun event but also as incorporated health educational activities and skills building for self care and adolescent health.

Afternoon group session for patients and caregivers following the clinic visit in the morning.

An older child on ART is explaining about HIV and ARV to younger patients.

Day Care Centers have various activities. Children learn through playing, and caregivers as well learn and exchange.

Case review among care team

Home visiting by a NGO staff

Response to poor adherence

Poor adherence should be corrected in a timely manner. With the combination of various adherence measurements, health staff and home visit staff try to identify cases of poor adherence as early as possible. If the cause of poor adherence is understood, every possible resources are approached, such as people in the community, health centers, school teachers and NGOs in order to rectify the cause of non-adherence.

There are some cases that require particular attention for adherence support. These include cases that involve old caregivers, illiteracy, changing caregivers, sickness and death of caregivers, school problems and problems related to discrimination. In such cases, we send a visiting team of local PHA peer group, community hospital or NGO to help them to solve the problems accordingly and report back to the team.

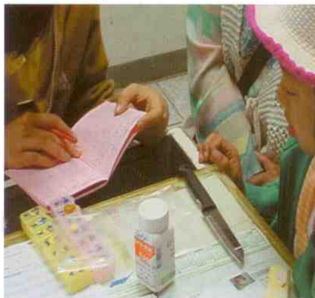
Non-adherence events (as of Nov 2004)

- 30 episodes in 25 children
- 5 children have 2 episodes
- 4 have already developed resistance

Adherence team

Chiang Rai Hospital is currently in the process of expanding its network of pediatric ART adherence support by involving eight district hospitals and creating care teams consisting of health staff and PHA peers for each district hospital. So far, 17 children have been successfully referred back to three district hospitals for ART follow-up and 8 out of 16 PHA networks can do home visit in their area.

PHA group networks build own capacity for peer support including ARV adherence and follow-up.

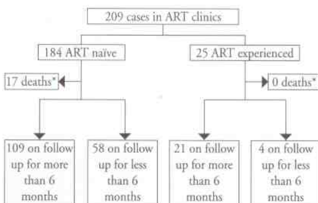


Review of self-record medication books and 7-day pill box is a routine process on each visit.

Self-recorded medication book

So far so good, but challenge continues

Up to now, 209 pediatric HIV cases have started receiving ART, of which 17 have died, but the rest are still on treatment. Thirty episodes of poor adherence(<95%) was observed in 25 individuals. Most of them could be corrected and so far there is no one who dropped out. Fifteen children had to be switched from the Nevirapine-based GPOvir ® regimen to the Efavirenz-based regimen. Three cases were due to drug side effects and 12 due to concurrent TB treatment.



Follow-up of pediatric ART at Chiang Rai Regional Hospital

So far things seem to be going well, but it is just the beginning of a new treatment and there is no second-line medicine or viral load monitoring available in routine service. Nobody is certain of what will happen even in the next 3-5 years. We should not forget that ART is only one part of HIV/AIDS care and always seek to provide comprehensive care for children living with HIV/AIDS. We hope these children will be the ones who will lead the HIV/AIDS control efforts in the future.

This document was created based on the presentation
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