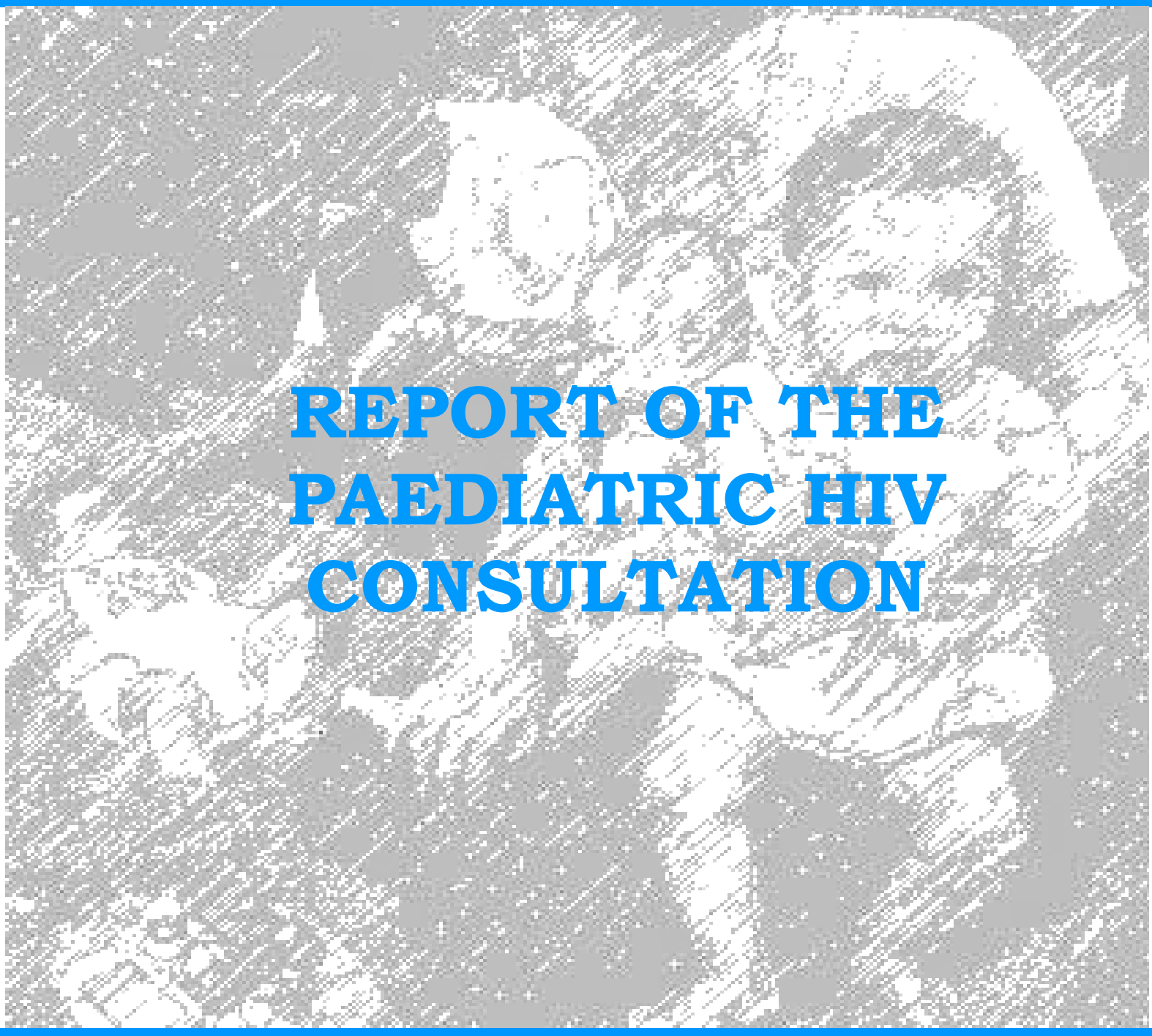
Consultation on Accelerating Support for Paediatric HIV Care, Support and Treatment in Thailand and Neighbouring Countries within the Context of the 3 x 5 Initiative



REPORT OF THE PAEDIATRIC HIV CONSULTATION

Organized by HIV/AIDS Section
UNICEF East Asia & Pacific Regional Office
Bangkok, Thailand, 20th October 2004

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INTRODUCTION

On October 20, 2004, 29 representatives from three countries and more than a dozen international and supranational organizations and hospitals attended the Consultation on Accelerating Support for Paediatric HIV Care, Support and Treatment in Thailand and Neighboring Countries within the Context of the 3 x 5 Initiative. (For details see the participants list in Annex C)

This important one-day meeting was convened in Bangkok by UNICEF and involved paediatricians along with other doctors, researchers and administrative officials from various countries and organizations.

The meeting was intended to update those working on issues concerning Pediatric HIV/AIDS in the region on progress being made by their colleagues. It also aimed to strengthen communication and cooperation among those working on PMTCT and pediatric HIV/AIDS-related issues in the region through sharing country experiences and technical updates from global experts. Reporting on progress toward reaching the 3 x 5 goals, including increasing access to pediatric antiretroviral treatment, was also a cornerstone of the meeting's agenda.

Also highlighted were:

- Needs and support for paediatricians and other caregivers
- Integrating paediatric HIV/AIDS issues with the larger goals of protecting and improving children's health
- Advocacy required for attention to be paid to pediatric formulations
- Addressing psychosocial problems and needs of children living with HIV/AIDS

SUMMARY OF CHALLENGES, LESSONS LEARNED AND RECOMMENDATIONS ON PAEDIATRIC HIV
Arjan de Wagt, UNICEF EAPRO

HIV disease progresses among young children is more rapidly than in adults and so survival time for children is shorter. But there is also good news as the impact of PMTCT is started being seen, for instance one physician from Thailand said that in the past much fewer cases.

The consultation shared many lessons learned so far on the care, support and treatment for children infected with HIV. Below you can find a summary of the main issues and suggested improvements as presented and discussed during the consultation.

Diagnosis

- Diagnosis before 18 months is difficult without viral load testing capacity available.
- CD4 and VL testing expensive, often not available, decision on when to treat therefore difficult
- Counseling of families on having an HIV infected child is complex

Stigma and discrimination

- Even in Thailand with a well developed HIV/AIDS response there are still deep-seated problems with discrimination and stigma and these can extend to health care workers as well as the general public.
- Because of stigma and discrimination children living with HIV suffer from many psychosocial problems. The four main causes of those problems are misconceptions about HIV/AIDS, lack of knowledge and skill among caregivers, lack of adult care and economic problems. Those conditions can lead to no access to treatment, psychological distress and hopelessness, and not achieving adherence to medication

Psychological and social issues of children

- Psychological and social issues HIV infected children have to deal with receive too little attention in most pediatric HIV programs.
- Sleep problems among HIV infected children are significant. They can cause cognitive impairment in school. The younger and more inarticulate they are, they can't express their problems. When you put that together with HIV and language delay then the problem is much greater.
- Psychological pathology in kids is more severe than in adults and often goes undiagnosed or misdiagnosed. It is hard to determine how much is related to the disease and how much to situational factors.
- Children's problems include illness even after starting ART; physical and psychological trauma from neighborhood discrimination; adherence to ARV; disclosure -- children don't know why they need to take ARVs.
- Telling a child he or she has HIV is very challenging. Guidelines need to be developed to help parents and care givers with deciding when and how to tell the child about HIV and being HIV positive.

Psychological and social issues of older children

- Adolescents need to have better access (incl. legal) to services like testing and treatment
- Because of stigma and discrimination access to schooling for HIV infected children is a major concern.
- An increasing number of HIV infected children are growing up and will become sexual interested and active. They will need guidance and support on sexual and reproductive health, disclosure of HIV and protection of their own health and that of their partner.
- "Our oldest child is 14, and we're trying to prepare him for the outside world. It will be difficult."

Psychological and social issues of women

- "People living with HIV should have unrestricted access to solutions that are available and be able to make the choices that are most appropriate to them and not have a choice imposed by doctors and other caregivers. That ability to make a decision is one of the most empowering things that can happen, and gives quality of life to people with HIV. Making decisions helps them regain self esteem and dignity."
- "Also for the HIV infected woman support needs to go beyond care for illness and symptoms, to looking at identity both as a social and psychological need as mother and wives. Women particularly are stigmatized as being bad women who deserved the disease."
- HIV affected families have socioeconomic problems and need to take care of children and care givers and this is inadequately included in the services presently provided.

Pediatric ART

- Some of the challenges with pediatric ART include:
    - Uncertain dosing, limited pharma kinetic data available
    - Formulations including simplified dosing schedules are poorly available and expensive and this is in particular the case with second line treatment
    - Palatability of drugs (including bad taste)
    - Prior exposure to NVP and potential resistance: surveillance and management need to be established

Drug supply management

- The difficulties in meeting the needs and demands for drugs are mainly a matter of logistics and is often due to poor supply planning and management
- In principle to supply ARVs is no different than supplying paracetamol. Good to reflect on past performance with other pharmaceuticals.
- Ensuring access to ARVs is one whole big circular chain and it's as strong as the weakest link.

Management of HIV in children

- High levels of malnutrition is seen among infected children, management is complex and clear guidelines are not available.
- Clear guidelines on micronutrient supplementation among HIV infected children are needed

- Pediatric care and treatment needs to be part of a more holistic family response
- Psychosocial impact and support to families and children is too limited
- Follow-up in PMTCT programs simply isn't happening in many places. Despite clear evidence that children should be put on prophylaxis, they aren't. Programs also must provide entry points for care for the mother.

Prevention

- It is important to ensure that resources for treatment are not being taken from prevention activities
- Better guidance is needed on how to use 3by5 as an opportunity of primary prevention
- PMTCT follow up needs to be improved to ensure a continuum of care including PCP prophylaxis

Program management

- Better guidance is needed on how to accelerate PMTCT as part of 3by5.
- We need to be very efficient with very good PMTCT services first. The problem of HIV infection among young children will decrease with good PMTCT. There is a need for innovative approaches and more efficacious PMTCT services.
- The programming indicators, benchmarks and targets are not there, we don't know how interventions are performing. The dearth of information is quite frightening.

Staffing issues

- Need to strength knowledge and skills on HIV care/treatment among health care workers
- Attitudes / discrimination by health workers are still a major challenge. Many health care workers still fear getting HIV from kids. Some also don't believe these children can get much better, so it's for them hard to be motivated.
- Lack of adequately trained physicians and counselors - both quality and quantity. There are huge needs for training health care workers at various levels of the health care system on pediatric HIV and this does receive inadequate attention in treatment programs.
- What additional support (technical, psycho-social etc.) do health care workers dealing with paediatric HIV cases need, e.g. how to prevent burn out?

OPENING REMARKS

"The issues of children and health go beyond HIV/AIDS to children's health in general." – Dr. Stephen Atwood

The meeting opened with remarks by Dr. Stephen Atwood, UNICEF Regional Advisor on Health and Nutrition. In laying out he meeting's objectives and expected outcomes, Dr. Atwood, who would also serve as moderator throughout the day, noted that the gathering was a meeting of paediatricians and those who are providing care and support for children and families dealing with HIV/AIDS.

Other points made by Dr. Atwood during his opening remarks included:

- The number of pediatric HIV deaths is underestimated especially children under the age of 15 months. This is a reporting challenge.
- There is a lack of simple and cheap screening methodologies.
- There is a need for pediatric formulations; children can't swallow pills.
- Closer follow-up is needed to monitor drug toxicities.
- HIV infection is a chronic illness.

PRESENTATIONS

1. Approaching Paediatric Care, Support and Treatment; Presented by Dr. Usa Thisyakorn, President – Paediatric Society of Thailand and Deputy Director, Thai Red Cross AIDS Research Centre.

Dr. Usa noted that the one-day meeting was especially important because it was part of the agenda for several organizations such as UNICEF, WHO, UN and the Thai Red Cross Society and Paediatric Society of Thailand. She detailed the history of HIV/AIDS in Thailand and the country's early response to the disease and its early concern for how children would be affected by the epidemic, and spoke about problems she and her colleagues have encountered in combating the spread of the disease.

Other points made by Dr. Usa in her presentation were:

- Doctors have been working on PMTCT in Thailand since 1995. The country now has several programs to prevent mother-to-child transmission
- Since 1984, when AIDS first appeared in Thailand, doctors began considering what to do for children. The next consideration was how to gear more programs toward teenagers.
- The spread of HIV/AIDS has left Thailand with an increasing number of orphans.
- The country has introduced PMTCT-plus.
- An important element of Thai programs is to help parents stay alive longer and care for their children, so there will be fewer orphans.

2. 3 x 5; National Responses presented by Dr. Ying Ru-Lo, WHO SEARO, and Siobhan Crowley, WHO Geneva

In a dual presentation, Dr. Siobhan Crowley and Dr. Ying Ru-Lo reviewed progress toward achieving the 3 x 5 goals and obstacles that still remain. 3 X 5 means 3 million people on treatment by 2005 with the ultimate goal being universal access to treatment as a universal right. Nonetheless, even the more modest target of 3 million people on treatment doesn't appear to be obtainable by the deadline considering the levels of support currently being provided by most countries.

Among the important points made by Dr. Crowley were:

- The goal is universal access to treatment as a universal right. The way to achieve that is to scale up national programs for treatment, but also improving prevention. Treatment provides us with a huge opportunity to improve prevention.
- Two key things are to simplify and standardize the tools that are there instead of asking what each country needs and specializing it for them. We need to be supporting countries to meet their goals. Helping them to fill the gaps and do whatever is required.

- A major obstacle in many countries is that the drugs aren't there even if people on the ground are ready to use them.
- Moving to document cases where scaling up of treatment has occurred.
- Moved to a full-stage system which broadly harmonizes with the CDC. Early suggestions are that it stands up.
- Real lack of access to any formulations. Thailand is ahead of the field. Illustrated here is scored pill. With a scored pediatric tablet you're more likely to get the right dosages. With syrups the volume needed is huge.
- Trying to support countries that have been trying to scale up and build capacity.
- The programming indicators are not there, we don't know how they are performing. The dearth of information is quite frightening.
- We must make sure on the ground that national coordination is much better to make a difference.

Points made by Dr. Ying Ru-Lo included:

- The number of children on treatment is not yet known, data has not been validated in Thailand. In Myanmar there is only one site providing ARV therapy. It's run by the FHM, the Fund for HIV/AIDS in Myanmar. Less than 50 children infected are coming to hospital and less than 10 are on ARV. India just started. In Indonesia, no children are on ARV therapy.
- Regional, guidelines are being revised and will have a section on paediatric care and support of HIV/AIDS.
- Lack of trained physicians remains a problem. Even in Thailand there are considerable gaps. Access to schooling for HIV infected children is a major issue even here in Thailand.

3. Paediatric Care and ART for Children with HIV - Dr. Sam Sophan, National Paediatric Hospital, Phnom Penh, Cambodia

Dr. Sam Sophan is the director of Cambodia's National Paediatric Hospital, a modest institution making important contributions in the fight against HIV/AIDS in one of the world's poorest countries. Originally built in 1975, the hospital was open for just two months before the radical Marxist Khmer Rouge took control of the country. The Khmer Rouge shut down the hospital. It reopened after the country was liberated in 1980 and had 75 beds. Today it has 114 and treats between 7,000 and 10,000 patients a year.

Other points made by Dr. Sam were:

- Since 2002 every infected child at the hospital has received VCT service.
- More infections are being reported now because more people understand through education, television and newspapers not to keep quiet about the disease.

- The guidelines from the hospital became the guidelines for the whole country after consultation with partners and NGOs.
- There are two flows for anti-HIV testing and treatment. Less than, and older than 18 months.
- Cd4 testing is so complicated for hospitals in Cambodia because of lack of resources and sophistication of the labs. Some samples are sent to Thailand.
- The hospital set up a malnutrition subunit because treatment can't support malnutrition. The hospital also supports an IMCI program.

Panel discussion / Q&A with previous speakers

During the question and answer session, it was posited that despite the general belief that treatment works to support prevention, there is scant or no evidence to back that up. Dr. Crowley responded that by normalizing HIV management through health services, prevention will be improved, and that the divide between treatment and prevention is an artificial one. Dr. Ying Ru-Lo commented that it is important to ensure that money allocated for treatment isn't being taken away from prevention. One participant asked how can PMTCT and treatment for children work together. Dr. Crowley observed that the problem in this area was that follow-up in PMTCT programs simply isn't happening in many places. Despite clear evidence that children should be put on prophylaxis, they aren't. Programs also must provide entry points for care for the mother. The fact that they haven't been, is resulting in more orphans.

Questions were also raised about when VCT should take place and the role of social and cultural considerations in programming and counseling. Dr. Crowley said that UNICEF is trying to be consistent about how and when VCT being offered. It can be done in different ways in different models in different places but all women should have the offer of knowing their status and receive counseling. That helps prevent infections being passed to children, and the most important thing is to prevent as many infections as possible. Sr. Sam noted that in Cambodian provinces where male partners participate in testing and counseling, the transmission rates are lower. A speaker asked if any countries were providing post-exposure prophylaxis to child sex abuse victims. Dr. Ying Ru-Lo said that that hasn't been specifically built in to any country's ARV guidelines yet, although South Africa has experience with this, and she hoped Asia would be moving towards guidelines for it next year.

4. Khon Kaen Integrated Response - Dr. Pope Kosalaraksa, Faculty of Medicine, Khon Kaen University

Srinagarind is a university hospital in the northeastern Thai province of Khon Kaen, and it also serves patients from neighboring Udon Thani and Nong Khai provinces. The hospital uses a holistic approach model and integrated response as part of a two-year program from UNICEF. It's a two-year program and its objectives are to improve care of HIV-infected children and families and to develop a holistic approach for the entire northeastern

area, the most populous region of Thailand. Another goal is to get adherence up to more than 95% among those taking ARV. Dr. Pope noted that there are still deep-seated problems with discrimination and stigma in northeastern Thailand and these can extend to health care workers as well as the general public.

Additional points made by Dr. Pope included:

- Groups on dual therapy showed a lot of resistance and had to move on to protease inhibitors.
- Experience shows that medical therapy in hospital is not enough to provide a happy life. Families still have socioeconomic problems and need to take care of children and care givers.
- When parents are ill, they suffer from fear and depression. Some kids have to take care of their own parents. Some children suffer from over-protection from the family and are not allowed to do anything.
- Children's problems include illness even after starting ART; physical and psychological trauma from neighborhood discrimination; adherence to ARV; disclosure -- children don't know why they need to take ARV; and prevention of sexually transmitted diseases.
- The hospital is still trying to set up a system to produce good workers. Attitude is most important. Some caregivers cause problems. The problems come from fear from not enough knowledge. No confidence to take care of the child. Teamwork is needed.
- Activities; strengthen health care team and network; find out baseline problems of each family; group support, art and play therapy; home visits; HIV camp for children and families.

5. Paediatric ART - Professor Tawee Chotpitayasunondh, Queen Sirikit National Institute of Child Health

The Queen Sirikit National Institute of Child Health is the only children's hospital in Thailand. It has 538 beds and treats 50,000 babies a year. The hospital started HIV activities in 1992. At that time the only drug available was AZT. The hospital has treated 220 patients infected with HIV, 96% of who are on ARV. Only 5% are on dual therapy, most are on triple therapy and a small portion are on protease inhibitors. Because each test costs about $100, the hospital can't afford viral load assessments. Queen Sirikit National Institute of Child Health is engaged in long-term cooperation with the U.S. CDC and NIH. It has a research program on PMTCT and is working with Sririaj Hospital in Bangkok.

Other points made by Prof. Tawee included:

- Of those infected, 15% are more than 10 years old. Our oldest infected child is almost 16.
- Most PMTCT originates from the paediatricians. Without them it would be a big burden. Some paediatricians are trying to force obstetricians to do it instead.

- The number of patients has decreased because of the PMTCT program. In the past there were more than 300 or 400. Now there are fewer cases because of more protection, less opportunistic infections and more healthy children. People are happier.
- There are still problems. ARV formulations are a big burden. Some pills or capsules are a problem to divide or crush. The second problem is adherence, although it is improving. Patients are surviving longer, getting older. Disclosure is a big problem. They're in a program with the CDC to look at these adherence and disclosure problems.

Panel discussion / Q&A with previous speakers

With most deaths the result of inability to meet the high costs of treatment, participants wanted to know who is picking up the costs and how much is passed on to the patient. Dr. Pope responded that while the government pays for ARV, other costs such as transportation, food, visits and overnight stays for families so they can see doctors, falls on the patient. He said it was the hospital's duty to try and help with those expenses, but the problem is that it receives very few donations. If patients can't meet the costs of travel, etc., then adherence and follow up will be weak or nonexistent. The government also does not pay for protease inhibitors.

Participants also wanted advice on disclosure. What is the proper age? Dr. Kulkanya said that the general feeling was that 10 was the proper age. Most parents, relatives and care givers, however, tend to never think any time is the right time. Dr. Rangsima said some hospitals are doing a good job on disclosure, including one in Petchburi province that is using a model established by Harvard Medical School. This year Siriraj and Queen Sirikit will assess a disclosure plan and develop guidelines. If they work, then it will scale up to a national model. Disclosure is a process not a one step thing, Dr. Rangsima added. Concerns include, can the child keep a secret? There is a need to develop guidelines on what to do before disclosing to a child.

Other participants were curious about patients developing resistance to therapies. Dr. Rangsima said that after 3 years 95% show resistance to dual therapy. They develop nucleotide mutations and can't recycle NRTI anymore. If a patients is on ARV more than six months, there is a high risk of mutation. For that reason, Dr. Pope says his hospital is not doing dual therapy anymore. Dr. Siobhan said that there is a need to see that children will be part of an international network tracking resistance, and they will be.

6. Whistle Home Power of Life Group – Ms. Junsuda Suwanjundee or Khun Oom

In a powerful presentation, Khun Junsudda Suwanjundee told participants the story of how as a drug user she contracted HIV, lost her job and family, but eventually found a positive path in life through founding Whistle Home, an organization dedicated to helping others with the disease. Khun Junsudda began using intravenous drugs as a teenager. She did not realize she was HIV positive until years later when she was tested as part of a job

application. When she revealed to her family she had the disease, they threw her out of the house and didn't want her to use the family name. She and a small group of women in similar circumstances started Whistle Home to help other women suffering from HIV/AIDS and the stigma that accompanies the disease. Through helping others, Khun Junsuda found new meaning in her own life. She has married, adopted one child and given birth to another who is now three years old and is expecting one more in January. So far, her three-year-old child has shown no sign of having contracted the disease.

Other points Khun Junsuda made in her presentation included:

- People living with HIV/AIDS lose their identities as human beings. They must regain self esteem and with this they can work and have the ability to manage their own lives.
- Sometimes when services have been provided they are services not needed or requested. Most important is to develop understanding among other people about people living with HIV/AIDS.
- Support needs to go beyond care for illness and symptoms, to looking at identity both as a social and psychological need as mother and wives. Women particularly are stigmatized as being bad women who deserved the disease.
- Many women find out they are positive when they are pregnant. They are rejected by their husbands and turned out of the home. The government had no services. They had nowhere to turn. They became unemployed. Families were resistant to take them in. As the babies were born, no care services or support were provided for children at that time. So they developed Whistle Home with women in similar circumstances.
- The organization has become interested in research. Mothers are the most highly regarded persons in the family. HIV positive mothers should be regarded in the same way. By participating in research Whistle Home can help improve the living circumstances of mothers and children with HIV.
- The conviction of the organization and its members is that living with HIV should be based on choices. People living with HIV should have unrestricted access to solutions that are available and be able to make the choices that are most appropriate to them and not have a choice imposed by doctors and other caregivers. That ability to make a decision is one of the most empowering things that can happen, and gives quality of life to people with HIV. Making decisions helps them regain self esteem and dignity.
- Family encompasses happiness and sorrow. It's about helping one another. Khun Junsuda was rejected by her family, but now they are much closer than before. By opening doors to helping other people they find more avenues to receive help as well.

7. What can MCTC-plus programs contribute to paediatric HIV care in developing countries? - Dr. Nittaya Phanupak, Thai Red Cross AIDS Research Centre

Dr. Nittaya told the meeting that as a model of care for HIV families, MTCT-plus initially started as women-centered and multidisciplinary care. In this model, hospitals set up a family clinic where doctors from different disciplines are available at the same clinic on the same day. It's a team. There are five MTCT-plus hospitals in Thailand: Chulalongkorn, Thammasat, Police General, Sriracha and Queen Sirikit. To broaden activities at the Red Cross they have two parallel programs. The first one is funded by Columbia University. The reason there are two is that Columbia would only allow the Red Cross to enroll currently pregnant women. That's not sufficient for the situation in Thailand, so they set up another program. It was delivered five or six years ago from the PMTCT program.

Other points in Dr. Nittaya's presentation were:

- Sriracha hospital has set up a real family clinic. Family doctors and paediatrics are in the same room. Paediatricians take care of the children and an internist takes care of the mother and father the same day. It's a success story.
- There are regular team meetings every week after the clinic hours. It's proven to be a very successful model for dealing with chronic long-term diseases. It has also been successfully used and repeated in other HIV programs in these hospitals. The guidelines are flexible and practical, adapted to the country although they were originally set up for use in African countries.

8. Guidelines for the management of HIV infection in children in resource-limited settings in Myanmar - Dr. Chris Duncombe, HIV-NAT

Treating and preventing the spread of HIV/AIDS is a particularly difficult challenge in countries such as Myanmar which suffer from limited resources. Myanmar is one of the world's poorest countries and was accorded Least Developed Country status by the United Nations in 1987. Of its 48.36 million people it is estimated that 1.2% has HIV/AIDS. Between 20% and 30% of female sex workers have the disease, while anywhere between 10% and 73% of injecting drugs users do. As Myanmar has limited infrastructure, numerous ethnic minorities and some areas are difficult to access, these figures are merely estimates and difficult to confirm.

Other points made by Dr. Duncombe were:

- Approximately 7,600 children up to the age of 13 are living with HIV/AIDS.
- An ART pilot program was launched in 2003.
- Only 100 adults are participating at this stage, and only 10 children.

- Myanmar is currently reviewing its locally-written guidelines on care and treatment and adapting regional guidelines.

9. From PMCT to PMCT+ Experience from the PHPT Network in Thailand - Dr. Gonzague Jourdain, Perinatal HIV Prevention Trial

In a technical presentation, Dr. Gonzague Jourdain outlined the history of the PHPT Network in Thailand and what the trial has discovered to date. The PHPT Network is a group of hospitals trying to identify problems with PMTCT and PMTCT-plus and find solutions. Forty public, provincial and community hospitals are taking part and a center for clinical research is located in Chiang Mai. The center is looking at protocol development, training, data management, monitoring, statistical analysis, and laboratory dedicated to HIV (virology + pharmacokinetics) As of September 2004 the program had 300 children on ARV treatment

Additional points and questions raised by Dr. Jourdain during his presentation included:

- Are we compromising the treatment of children because of PMTCT? If you use Nevirapine alone you have many children infected and resistant.
- We need to be very efficient with very good PMTCT services first. The problem will decrease with good PMTCT.
- There is a need for innovative approaches and more efficacious PMTCT
- Propose care programs for the family: need for coordination and collaboration between specialists and programs.
- Ensure reliable early diagnosis of HIV-infected children.
- There are huge needs for training (health care workers at various levels and PHA)

10. Psycho-social impact on children and how we respond with counseling and art therapy - Ms. Chutima Saisaengjan, AIDS Access Foundation

In her presentation, Ms. Chutima Saisaengjan of the AIDS Access Foundation, a non-governmental organization, talked about the formation of the We Understand Group, which consists of people who work with children infected by HIV/AIDS. Chutima explained that stigma and discrimination against those infected by HIV, even children, is still strong in many communities throughout Thailand. Consequently, children living with HIV suffer from many psychosocial problems. The four main causes of those problems are misconceptions about HIV/AIDS, lack of knowledge and skill among caregivers, lack of adult care and economic problems. Those conditions can lead to no access to treatment, psychological distress and hopelessness, and not achieving adherence to medication.

Other points made by Ms. Chutima included:

- Understanding the psychological world of the child is important.
- Art, play and peers are useful. They help alleviate psychosocial problems.
- Awareness of issues surrounding HIV/AIDS needs to be raised at all levels.
- Responses of the families and communities needs to be strengthened.

Panel discussion / Q&A with previous speakers

The panel discussion began with one participant asking about the cost-effectiveness of CD4 testing among children. Dr. Jourdain responded that because the number of children infected with HIV is still small that doctors should do the best they can for them despite the costs. If children were tested every three months it wouldn't be a major financial burden in Thailand. He added that because CD4 levels can drop very rapidly in children less than one year old, that children be tested before then.

Another participant asked how children are tolerating side effects like sleep disturbance and nightmares? Dr. Jintanat responded that children can tolerate side effects better than adults and that few showed problems sleeping. Some of the discussion also dealt with the question of micronutrients and whether or not they should be a standard part of the treatment regimen. Dr. Nittaya replied that most doctors in Thailand didn't think they were important. Dr. Jourdain added that while there is no evidence additional vitamins help, the feeling he got from many hospitals is that vitamins are needed. Arjan de Wagt of UNICEF EAPRO said that both too little and too much vitamins could cause problems. Because studies have been limited and there are many micronutrients that might help, figuring out how much to prescribe and which ones are very difficult.

Afternoon Sessions

11. Response to Paediatric HIV Care and Support in Thailand TUC [Thailand MOPH - U.S. CDC Collaboration] - Dr. Rangsima Lolekha, CDC Thailand

In her presentation Dr. Rangsima gave an introduction to the Global AIDS Program initiated by the Thailand-United States Collaboration. GAP/Thailand provides funding and technical collaboration to pilot new approaches in prevention, care, and surveillance for HIV/AIDS, TB, STD; scale up successful pilot projects to the provincial level and nationally; and strengthen existing programs. It also works to develop province-based networks for prevention, care, training, and surveillance. An important part of the program is to expand care and treatment for women, partners and their children. A key part of this is to focus on adherence.

Other points made by Dr. Rangsima included;

- The HIVQual-T program has shown very nice results. It's been expanded to 30 hospitals in Thailand this year.
- Right now it's only for adults, but we want to try to expand it to children.

12. Antiretroviral Therapy in Children - Dr. Kulkanya Chokephaibulkit, Siriraj Hospital

In a technical presentation, Dr. Kulkanya talked about research and findings on when to start ARV in children and what combinations of drugs should be used. She noted that the disease progresses more rapidly than in adults and so survival time for children is shorter. She added that she believed Thai guidelines about when to start and what to use should be revised. Some of the problems of ARV therapy for children include unpalatable drug formulation, limited PK data and clinical trials. Also, some children are very difficult medicine takers and so long-term adherence depends upon the caregiver. It's difficult for most families as ART may disrupt normal family life.

Dr. Rangsima noted that problems still remain, and they include:

- Lack of knowledge
- Chaotic family settings
- Care-givers not available to feed/F/U.
- Side effects
- Poor formulation/bad taste/complexity/etc. of the drugs
- Difficult drug taker children

13. Paediatric projects at HIV-NAT and treatment of orphans with HIV at Baan Gerda - Dr. Jintanat Ananworanich, HIV-NAT

Dr. Jintanat Ananworanich told participants about a unique program in Lopburi, a central province of Thailand that strives to provide a caring family and community atmosphere for children living with HIV/AIDS. Called Baan Gerda, it is eight homes with seven to nine children each. The caregivers also have HIV. They come from Wat Prabat Namphu, a nearby Buddhist temple that has an AIDS hospice. Dr. Jintanat said there are many stories of children who come to Baan Gerda and with love and care they do very well. She said that among the caregivers, coping was quite good. Few used anti anxiety-medicines and none used alcohol. But they aren't well prepared, don't know what to say and are afraid they will harm the child's mental health if he asks what's wrong with him.

Dr. Jintanat also pointed out that:

- When we did pill counts we saw non-adherence more than through the questionnaire.

- It's hard to find these people who are dedicated and willing to stay and take care of these children. When someone dies, all 55 children go to temple for the cremation.
- Our oldest child is 14, and we're trying to prepare him for the outside world. It will be difficult.
- In the future we hope there won't be a need for this and children can live in their communities.

Panel discussion / Q&A with previous speakers

An important topic raised during the discussion was the problems health care professionals and workers have in accepting and working with children living with HIV. One participant asked why 20 years into the epidemic there is still reluctance to provide service, and are there any systematic or institutional attempts to respond to the reluctance. Is it getting worse, or better? Dr. Rangsima responded that Thailand has had a program in place in which guidebooks and other tools have been provided to health care workers for treating children living with HIV, yet many physicians were still reluctant to treat them. Dr. Kulkanya added that commitment from a hospital's administration is important. Many physicians would like to take on treating children with HIV but it means a lot more work, and if they don't have nurses or health care workers to help then the entire burden is on them. Dr. Jintanat said that lack of knowledge is still a major reason. Many health care workers still fear getting HIV from kids. Some also don't believe these children can get much better, so it's for them hard to be motivated.

14. Access to paediatric formulations - Helene Moller, UNICEF Supply Division, Copenhagen

The difficulties in meeting the needs and demands for drugs are mainly a matter of logistics. It's also extremely difficult to deduce from the information she receives how much a particular drug a hospital will need, and so planning remains complicated. Nonetheless, she said that progress has been made as far as access to drugs, although there is still a long way to go.

Ms. Moller also noted that:

- There are 42 formulations in 75 dosaes and 30 to 40% can be used for children. That is good news, it means we have something at least.
- In principle to supply ARV is no different than supplying paracetamol. Good to reflect on past performance.
- We've learned that access is one whole big circular chain and it's as strong as the weakest link.

15. Gaps in responses in Thailand - Kathleen Casey, Family Health International

Thailand's response to the HIV/AIDS epidemic has been held up as a model for other developing nations to follow. While more than a million people have been infected with the virus that causes AIDS since it was first detected in

Thailand in 1984, that's an estimated 400,000 people less than projected thanks to prevention programs. Nonetheless, as the disease has progressed through different sectors of society – finally reaching women and children – new challenges have become apparent, and those working on HIV/AIDS issues are struggling to fill in the gaps where needs aren't being met. A big part of that are the psychological needs of the infected children. Often this is left to NGOs, but Ms. Casey and FHI believe health care workers need to become more involved in this, and that care has to be balanced between the physical and psychological.

Other points made by Ms. Casey included:

- It's important to examine what we're asking often untrained caregivers to manage.
- Psychological pathology in kids is more severe in kids than adults and often goes undiagnosed or misdiagnosed. It is hard to determine how much is related to the disease and how much to situational factors.
- Sleep problems are significant. They can cause cognitive impairment in school. Cognitive problems are a burden for caregivers. The younger and more inarticulate they are, they can't express their problems. When you put that together with HIV and language delay then the problem is much greater.
- There are often beliefs around medicating kids that lead to a lack of adherence. Parents say that when I see my kids having side effects or symptoms it reminds me I infected my child.

Panel discussion / Q&A with previous speakers

One participant said that the Thailand's Government Pharmaceutical Office can't produce Nevirapine because they can't get the ground materials to manufacture it. They asked if WHO or UNICEF can help supply them with the necessary chemicals to make it. Siobhan Crowley from WHO said that UNICEF will hold a meeting in December and will try to and find things to change the landscape of formulations, making them easier to use and pushing for development of a couple of new products.

Another participant asked if anything could be learned from the experiences with stigma and discrimination suffered by children infected with other diseases or afflicted with handicaps and applied to children living with HIV. Kathleen Casey of FHI answered that there are linkages. She sees close parallels in the lack of disclosure by parents. It can be very disturbing for children when they don't know what's wrong. And they come up with their own explanations. And that changes balance of relationships within the family, she said, adding that children operate in a vacuum, and when they hear bits and pieces of information, then their understanding of what is happening becomes distorted and they end up being more disturbed.

GROUP WORK

Participants at the meeting formed two working groups to brainstorm on particular issues and come up with solutions. Each group appointed a facilitator and a rapporteur. The groups were tasked with identifying key concerns / issues / challenges coming from the presentations and discussions, and identifying key steps and actors for addressing the issues.

Group 1 looked at strategies for putting children on the care and treatment agenda; and strategies for fostering partnership and coordination among all involved in the issues of children and HIV/AIDS.

Entry points:
Professional organizations
They can lobby, communicate, and effectively advocate society

NGOs/other networks
Often offer communication strategy

Ensure that MOPH identifies paediatric indicators/targets
This has been done in India and Cambodia.

Political parties. Should these issues be part of a political party's platform? What can be done to raise these issues as part of national elections in Thailand next year? What would be the platform's message?

Partnerships
What/who already advocates for paediatrics? Treat Asia, MSF? Need to gather info on what organizations are active in this area.

Need for cross border TA/exchange
Lessons learned/study tours/some cultural similarities between countries in the region

When we think about partnerships it can go beyond HIV-infected children to HIV-affected children and women. Identify other departments and stakeholders aside from MOPH that can help those affected by HIV.

Laboratories as centers of excellence
Collaboration

Is it possible to stockpile of drugs in a central location so they are available quickly when there are shortages in the region?

Group 2 looked at strategies for ensuring program intelligence; and strategies for accelerating country level support.

There needs to be rationalization of program indicators. (We have different organizations funding different programs and parts of programs. Service delivery has not been the focus, reporting has, and that has led to evaluation fatigue)

- Interagency – donor
- Meeting on development of core data sets
- Interagency – government meetings on data collection needs
- Projections on burden of paediatric care
- rapid appraisals of entry points for services
- entry points for paediatric services
- unified resistance monitoring
- core program indicators needed
- development of core national survey data
    - -women testing positive
    - -orphan burden
    - -orphan burden from HIV/AIDS
    - -children with HIV

(Depends on what can be collected, that has to be taken into account: Aussie, collecting data is distracting people from the job and taking up funding. Thailand has set up fairly sophisticated data collecting, as different donors come in they have different reporting demands and its' distracting and is a major problem)

Closing remarks
Robert Bennoun

ANNEX A: Consultation on Accelerating Support for Pediatric HIV Care, Support and Treatment in Thailand & neighbouring countries within the context of 3x5

Bangkok, Thailand, 20 October 2004 [Immediately after Country mission for the National HIV/AIDS Access to treatment programme]

Objectives

1. Identify ongoing initiatives and expertise in the region with regards to pediatric HIV care, support and treatment – projects, guidelines development, and studies.
2. Identify region specific challenges and opportunities.
3. How to explicitly strengthen the linkage between paediatric care, support and treatment, PMCT Plus, and community care for children interventions [IMCI and ECD]
4. Promote improved coordination and collaboration between regional partners.
5. Preparation for the November 3-4 Geneva meeting on paediatric formulations and diagnostics

Outcomes

1. Suggestions for joint action to address regional specific challenges and use region specific resources and opportunities for the acceleration of pediatric HIV care, support and treatment.
2. Agreement on regional coordination mechanisms and suggestions for strengthening collaboration among regional partners.

Background

Most children with HIV infections need a more intensive course of treatment compared to infected adults and therefore need unique care and support measures. Without care and antiretroviral treatment, a significant proportion of children living with HIV in resource limited settings will die before age five; as many as 30 percent dying before their first birthday and 50 percent before age 2. HIV/AIDS ravages children in a way that is even more overwhelming than observed in adults. Despite most children following a more ravaging course, with sustained care and support these children have a good chance of growing and developing to their full potential. Prospects for expanding access to care and treatment are improving as a result of:

- Global and national efforts to mobilise resources and increase financing of care programmes, including health delivery systems and championing of new innovations WHO 3x5 Initiative, Global Fund; US President's Emergency Plan for AIDS Relief (PEPFAR); private foundations and sector initiatives; World Bank MAP Funds and multilateral and bilateral donors and civil society;
- Reduction in the cost anti-retroviral drugs (ARVs);
- Growing availability of generics.

Children are part of the WHO 3x5 agenda at global regional and country levels. The challenge is to translate this reality into feasible, practical and sustainable actions. At the Bangkok International Conference, the Elizabeth Glaser Paediatric AIDS Foundation recently issued a call to action for paediatric HIV treatment. They reiterated that "each day, more than 8,200 people die of AIDS, most as a result of inadequate care and treatment. Of those, 1,400 are children

Programme issues specific to children

Caring for children born to mothers living with HIV has many challenges, and the care approach will need to overcome some of the issues specific to children and build on existing experiences and approaches:

1. *Quantification of burden of disease.* Although UNAIDS estimates the number of children infected annually and those living with HIV, most programmes have used an estimate of 10 percent of the adult estimates. Further elaboration of this estimate will be needed to guide planning.

2. *Lack of simple and cheap screening methodologies for identifying infected children early to facilitate care planning***.** Antibody tests, available in resource limited settings, can only identify infection in children over 15-18 months. The PCR test is expensive and requires specialised laboratories and technical expertise. WHO has developed new guidelines for laboratory diagnosis and staging of HIV in children. These guidelines will soon become available to countries to guide programming.

3. *Difficulty of identifying children and providing them with basic health care* due to parental and caregiver consent issues and lack of systematic and comprehensive follow up systems despite knowing the mother's HIV status.

4. *Limited expertise in treating children living with HIV with ARVs.* Health care providers at all levels of care need to develop their skills in order to identify children living with HIV, provide ARV treatment and other care services, monitor their progress, and offer psychosocial support.

5. *The youngest children cannot swallow pills and require liquid and simplified formulations currently not widely available*. Some of the formulations also require refrigeration and clean water to mix and have a short shelf life. There are currently no fixed dose combinations for paediatric use; they require dosing guidelines specific to certain age groups. These guidelines are not available for many of the ARVs. MSF, Baylor, PMTCT Plus and the Medical Research Council have developed some guidelines to help with the dosing issue but these will require standardisation.

6. *Children will require closer follow up to monitor drug toxicities and resistance,* which might be different from what is observed in adults and in the different co-morbidities frequently seen in children in resource limited settings. Children, because their bodies are still growing, respond differently to drugs than do adults. Special consideration should be

afforded to children who may not have a primary caregiver because of orphaning or illness in the parent.

7. *HIV infection in children is a chronic illness* requiring a team and ambulatory approach to care. Mechanisms for ensuring other support points (households, schools, community care points) are part of the care and psychosocial support plan, and will need to be defined.

ANNEX B: Agenda

Consultation on Accelerating Support for Paediatric HIV Care, Support and Treatment in Thailand and Neighbouring Countries within the Context of the 3 x 5 Initiative
Date: 20th October 2004

Venue: Pathumwan Princess Hotel, Jamjuree II Room, M Floor

Time	Session/Topic	Speaker
Chair[morning]: Dr. Stephen Atwood - UNICEF Regional Adviser Health & Nutrition		
08.00-08.30	Registration	
08.30-08.40	Introductions	Dr. Atwood
08.40-08.50	Meeting objectives and expected outcomes	Dr. Atwood
08.50-09.00	Approaching paediatric care, support and treatment	Dr. Usa Thisyakorn, President – Paediatric Society of Thailand & Deputy Director, Thai Red Cross AIDS Research Centre
	Presentations – 3x5; National Responses	
09.00-09.20	▪ "3 x 5" Initiative & responding to paediatric needs	Dr. Ying Ru-Lo, WHO SEARO & Dr Siobhan Crowley, WHO Geneva
09.20-09.35	▪ Pediatric Care and ART for Children with HIV	Dr. Sam Sophan, National Paediatric Hospital, Phnom Penh
09.35-09.50	Discussion / Q&A	
	Presentations – Thailand health services	
09.50-10.05	▪ Khon Kaen integrated response	Dr. Pope Faculty of Medicine, Khon Kaen University
10.05-10.20	▪ Paediatric ART	Prof. Tawee Chotepitayasunon, Queen Sirikit National Institute of Child Health, Department of Medical Services,

Time	Session/Topic	Speaker
10.20-10.35	To be advised	MOPH Ms. Junsuda Suwanjundee, Power of Life Organisation
10.35-10.50	Discussion / Q&A	
10.50-11.10	***MORNING BREAK***	
	Presentations – specialised responses	
11.10-11.25	What MTCT- Plus programmes can contribute to paediatric HIV care in developing countries?	Dr. Nittaya Phanupak, Thai Red Cross AIDS Research Centre
11.25-11.40	Guidelines for the Management of HIV infection in children in resource limited settings, Myanmar	Dr. Chris Duncombe, HIV-NAT
11.40-11.55	From PMCT to PMCT + Experience from the PHPT network in Thailand	Dr. Gonzague Jourdain, Perinatal HIV Prevention Trial
11.55-12.10	Psycho-social impact on children and how we respond with counselling and art therapy	Ms. Chutima Saisengjan, AIDS ACCESS Foundation
12.10-12.30	Discussion / Q&A	
12.30-13.30	***LUNCH BREAK***	
Chair [afternoon] Dr. Scott Bamber – Project Officer HIV/AIDS UNICEF Thailand		
13.30-13.45	"TUC [Thailand MOPH-U.S. CDC collaboration} response to pediatric HIV"	Dr. Rangsima Lolekha, CDC Thailand
13.45-14.00	Antiretroviral Therapy in Thai Children	Dr. Kulkanya Chokephaibulkit, Siriraj Hospital
14.00-14.15	Pediatric projects at HIV-NAT and treatment of orphans with HIV at Baan Gerda	Dr. Jintanat Ananworanich, HIV-NAT
14.15-14.30	Discussion / Q&A	

Time	Session/Topic	Speaker
	Presentations – specialised responses	
14.30-14.45	Access to paediatric formulations	Helene Moller, UNICEF Supply Division, Copenhagen
14.45-15.00	Gaps in responses in Thailand	Kathleen Casey, Family Health International [FHI]
15.00-15.15	Discussion / Q&A	
15.15-15.30	Summary of key points from presentations	Arjan de Wagt
15.30-15.40	Introduction to group work	Scott Bamber & Greg Carl
15.40-16.40	Group work – Program strategy inputs	
16.40-17.00	***AFTERNOON BREAK***	
17.00-17.15	Group work presentations	
17.15-17.45	Plenary	

ANNEX C: List of Participants

	Name	Organisation
1.	Ms. Helene Moller Technical Officer PMTCT and HIV/AIDS	Technical Services Centre UNICEF Supply Division, Copenhagen hmoller@unicef.org
2.	Ms. Sedtha Chin Project Officer - HIV/AIDS	UNICEF Cambodia schin@unicef.org
3.	Dr. Sam Sophan IMCE and HIV/AIDS Core Trainer	Cambodian/National Paediatric Hospital, Cambodia eworsnph@camnet.com.kh samsophan@yahoo.com
4.	Dr. Ying Ru-Lo Medical Officer (HIV/AIDS)	WHO, SEARO loy@whosea.org
5.	Dr. Siobhan Crowley Medical Officer HTM/HIV/PRV	WHO, Switzerland crowleys@who.int
6.	Ms. Junsuda Suwanjundee	Power of Life Organisation whistle@ksc.th.com junsuda@yahoo.com
7.	Ms. Chutima Saisaengjan Project Coordinator	We Understand Group AIDS ACCESS Foundation ouichutima@yahoo.com
8.	Ms. Namphung Plangraun Manager	AIDS Access Foundation Chiang Rai accesscr@aidsaccess.com
9.	Dr. Gonzague Jourdain Senior Research Scientist	Perinatal, HIV Prevention Trial - Harvard University - PHPT, Chiang Mai gjourdai@hsph.harvard.edu gonzague@phpt.org
10.	Dr. Pope Kosalaraksa Associate Professor	Department of Pediatrics Faculty of Medicine Khon Kaen University pkosalaraksa@kku.ac.th pkosalaraksa@yahoo.com

	Name	Organisation
11.	Dr. Rangsima Lolekha Medical Research Scientist, Care and Counseling Section	Thailand MOPH-U.S. CDC Collaboration (TUC) rangsimal@tuc.or.th
12.	Ms. Mary Culnane Chief of Perinatal Pediatrics and Family Section	Thailand MOPH-U.S. CDC Collaboration (TUC) MaryC@tuc.or.th
13.	Dr. Kulkanya Chokephaibulkit	Faculty of Medicine Siriraj Hospital Mahidol University sikch@malhidol.ac.th si.mahidol.ac.th
14.	Dr. Tawee Chotpitayasunondh Deputy Director	Research and Development Queen Sirikit National Institute of Child Health gneilsen@fhibkk.org
15.	Ms. Kathleen Casey Senior Technical Officer Testing and Counseling	Family Health International kcasey@fhibkk.org
16.	Dr. Graham Neilsen	Family Health International gneilsen@fhibkk.org
17.	Dr. Nittaya Phanupak MTCT-PLUS Coordinator	Thai Red Cross AIDS Research Centre nittaya.p@chula.ac.th
18.	Dr. Chris Duncombe Senior Trial Physician/Clinical Trials Co-ordinator	HIV Netherlands Australia Thailand Research, Collaboration (HIV-NAT) chris.d@chula.ac.th
19.	Dr. Jintanat Ananworanich Pediatrician, Clinical Trials Co-ordinator	HIV Netherlands Australia Thailand Research, Collaboration (HIV-NAT) jintanat.a@chula.ac.th
20.	Dr. Josephine Anne Sauvarin Adviser on Reproductive Health Family Planning Programme, CST	UNFPA/CST sauvarin@un.org
21.	Mr. Scott Bamber Project Officer - HIV/AIDS	UNICEF Office for Thailand sbamber@unicef.org
22.	Ms. Wanda Krekel Regional Adviser - Supply	UNICEF EAPRO wkrekel@unicef.org

	Name	Organisation
23.	Mr. Robert Bennoun Regional Adviser – HIV/AIDS	UNICEF EAPRO rbennoun@unicef.org
24.	Mr. Arjan De Wagt HIV/AIDS Section UNICEF EAPRO	UNICEF EAPRO adewagt@unicef.org
25.	Mr. Gregory Carl HIV/AIDS Section UNICEFE EAPRO	UNICEF EAPRO gcarl@unicef.org
26.	Dr. Stephen Atwood Health and Nutrition Section UNICEF EAPRO	UNICEF EAPRO satwood@unicef.org
27.	Jo Shetliffe	Save the Children United Kingdom joshetliffe@scuk.org.cn.
28.	Dr. Alessio Panza Regional Adviser for HIV & AIDS	European Commission Alessio.PANZA@cec.eu.int
29.	Ms Wannee Kunchornratana Programme Assistant	HIV Health Office USAID wkunchornratana@usaid.gov
30.	Dr. Tara Chinakarn	Bureau of AIDS TB and STIs, DOC, MoPH tara@aidsthai.org
31.	Prof. Dr. Usa Thisyakorn Deputy Director	Chairman, Paediatric Society of Thailand Thai Red Cross AIDS Research Centre smeduty@md2.md.chula.a.cth

ANNEX D: Presentations

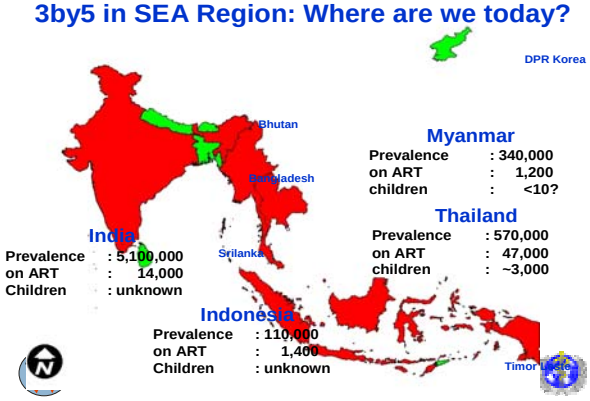
1. "3 x 5" Initiative & responding to paediatric needs – Dr Ying-Ru Lo

"3 x 5" Initiative &
responding to paediatric needs

Dr Ying-Ru Lo
World Health Organization Regional Office for South-East Asia

Consultation on Accelerating Support for Paediatric HIV Care, Support and Treatment in Thailand and Neighbouring Countries within the Context of the 3 x 5 Initiative
20th October 2004, Bangkok

3by5 in SEA Region: Where are we today?



Paediatric AIDS has been addressed on request of service providers in countries of the South-East Asia region

National

- Thailand: National expert consultations and treatment guidelines on paediatric AIDS in since many years
- India: first national expert consultation on paediatric formulations in Sep 2004
- Myanmar: Draft paediatric antiretroviral treatment guidelines

Regional

- Regional training modules on: Voluntary HIV counselling and testing, 2004
- Draft revised regional antiretroviral treatment guidelines
- Draft regional training modules on HIV/AIDS care including ART

Issues

Drugs

- High cost of paediatric formulations if available
- Prior exposure to NVP for PMTCT
- Poor palatability of medication
- Side effects of medication
- Crushing of tablets and partitioning of content of capsules

Diagnosis

- Diagnosis of HIV status in infants born to HIV+ mothers
- Counselling for families and their children is complex (disclosure to child and family and outside)

Access to paediatric care and support

- Lack of trained physicians familiar with management of HIV/AIDS and ART in children at health facilities in most countries
- Primary prophylaxis of pneumocystis pneumonia for babies born to HIV+ mothers
- Adherence in children
- Psychosocial issues, family support, schools

2. The "3 by 5" initiative - Reaching out to children in '3 by 5' HIV care and Treatment for children – Dr. Siobhan Crowley

The "3 by 5" initiative

Reaching out to children in '3by5' HIV care and treatment for children

Siobhan Crowley
Treatment and prevention scale-up team
HIV/AIDS Department, WHO Geneva

UNICEF, Bangkok, 20th Nov 2004

'3X5' -what do we mean?

3by5 is a *target*: 3 million on treatment by end 2005

- **The *goal* is universal access to ART as a human right**
- **The process is *scale-up* of national treatment action and acceleration of prevention**

10-17% of treatment burden is in children

Delivering on 3 x 5

WHO seeks to catalyse rapid uptake of ART in communities where it is needed now but not widely accessible

Simplifying and standardizing ART as far as possible without compromising effectiveness to enable widespread scale up and delivery in resource constrained settings

Supporting countries to recognise and respond to their HIV/AIDS treatment gap and leveraging the necessary resources to enable ART to be scaled up rapidly in line with 3x5 targets AND accelerate HIV prevention

Expected results - Global goods

- **Recommendations for clinical staging of HIV infection in and children** (& adults)
- **Recommendations on care treatment and support of HIV infected women and their children** (Sections :- Infected children, exposed children and diagnosis)
- **Appropriate Paediatric ARV Formulations** (incl. Standardised simplified paediatric dosing schedules)
- **Simplified standardised training tools for interated HIV care (IMAI)**
- **Case studies of successful scale up of ART for children and families**
- **Operational guidance of scaling up entry to ART treatment through ANC and child health services**

WHO revised clinical staging

- Better defines the clinical condition and sets out presumptive and clinical diagnosis
- Expanded list of conditions in children
- Harmonises adult and paediatric staging (4 stages and closer to CDC)
- Designed for assessment of current clinical events
- Organised as hierarchy based upon prognosis
- Linked to clinical decision triggers for starting, switching, stopping ARV treatment

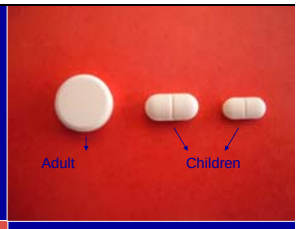
CDC vs Revised WHO clinical staging

N = Asymptomatic	**Stage 1** - asymptomatic,PGL, HSM,
A = Mildly symptomatic – Parotitis, diarrhea	**Stage 2** - Parotid swelling, mucocutanoues manifestations, Recurrent URTI
B = Moderately symptomatic Anaemia, pulmonary TB, sepsis	**Stage 3** -TB, oral candida, OHL, LIP
C = Severely symptomatic (AIDS) Wasting syndrome, encephalopathy PCP, Cryptococcosis, MAC, MOT	**Stage 4 (AIDS)** -Wasting, PCP, KS oesophageal candida, MOT, PML

ART IN FIXED DOSE COMBINATIONS:

ADULT AND PAEDIATRIC FORMULATIONS

d4T + 3TC + NVP



FORMULATIONS

Adult: d4T (30 mg or 40mg), 3TC 150mg, NVP 200 mg)

Children
- "Junior" (10 - 30 Kg):d4T 12mg, 3TC 60mg, NVP 100 mg
- "Baby" (3 – 10 Kg): d4T 6mg, 3TC 30mg, NVP 50mg

Global goods - other priorities

- Operational guidance;
  - for follow-up of exposed children in PMTCT
  - scaling up PMTCT/child health as entry points to care
- Case management of common childhood illnesses in HIV infected children
- Adherence and counselling (children, parent and carers)
- Policy guidance on HIV testing and counselling (for children and adolescents)
- Nutrition and HIV

Country capacity building (RO and CO)

Support to development and use of :

- National ARV & HIV care guidelines (children)
- National programme indicators
- Training for integrated management (e.g. IMAI)
- HIV adaptation of IMCI

OP research, knowledge management & strategic information

- Develop and support regional and national hubs of excellence (technical networks, training and research, & regional knowledge hubs)

Key areas where UNICEF & WHO need to move together

1. Advocacy (esp. paediatric formulations, equitable access, OVC)
2. Coordination: global, (TRG) regional **(e.g**. Inter-Agency Task Teams on Care, Treatment and Support, OVC and PMTCT, Child Survival Partnership and regional groupings including UNAIDS Inter-country Teams (ICTs)
3. Paediatric HIV care programme indicators/care benchmarks and targets, demand forecasting
4. Research: simplified formulations, dosing schedules & aids, diagnostic and monitoring tools and technologies
5. National coordination: scale up of integrated programmes (PMTCT & IMCI & ART) including M & E

Regional perspectives

Dr Ying-Ru Lo, WHO SEARO

3. Accelerating Support for Pediatric HIV Care, Support and Treatment – Dr. Sam Sophan

Consultation Workshop

Accelerating Support for Pediatric HIV Care, Support and Treatment

20 October, 2004
Bangkok, Thailand

Sam Sophan, MD, DTM&H, Cambodia

1

THE NATIONAL PEDIATRIC HOSPITAL

Phnom Penh, Cambodia

Background of National Pediatric Hospital

- 1974 : Word Vision built the hospital, completed in March 1975
- 1975-1979 : Khmer Rouge Regime, was closed
- 1980: WVI and MoH renovated and opened on October 15, 1980
- 75 beds in 1980
- Currently 114 beds
- Over 70,000 to 120,000 consultations per year
- 7,000 to 10,000 admissions per year

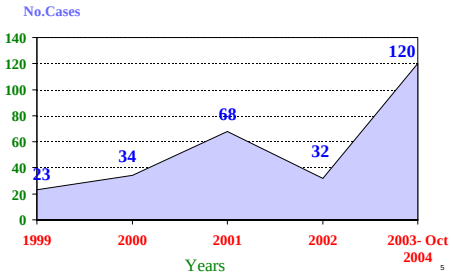
3

Brief Info of HIV/AIDS Infected Children

- Received first case of HIV infected child in 1999 among admitted patients
- From 1999 to 2002, suspected children were tested on HIV without counseling with parents because at that time the VCT service was not available.
- From 2002 to the present time: Infected children have been tested through VCT service in the hospital.

4

Distribution of HIV Positive Children by Years in National Pediatric Hospital



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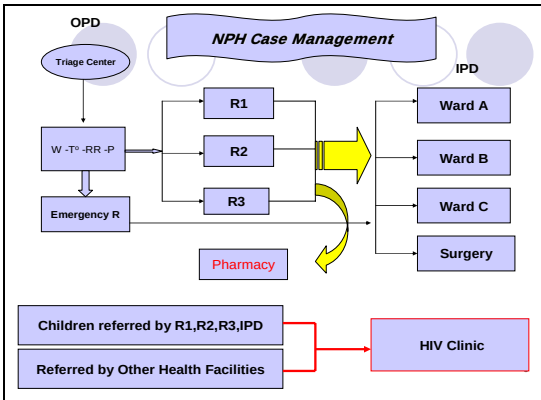

Inpatient and Outpatient Pediatric care services cover

HIV/AIDS Infected Children as follows:

- Children who know the HIV status in advance
- Children who know the status during their stay in the hospital
- Infected children referred from other NGOs (some cases just suspected)
- Children referred from PMTCT program (National Maternal and Child Health Center and Calmette Hospital)

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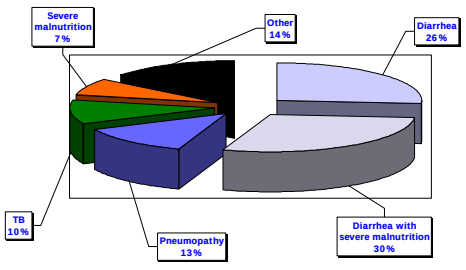
Clinical Manifestations of HIV infected Children NPH, 1999-2001 (n=125)



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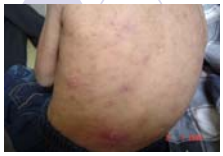
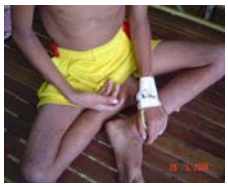
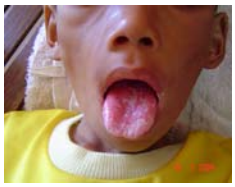


Girl 12ys,Wt. 12kg; CD4:2%





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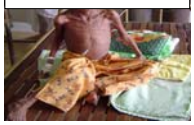
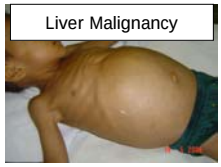
Severe Pneumonia



Herpes

Liver Malignancy



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Follow-up the infants from PMTCT Program

- Start at NPH from October, 2002
- So far: 150 cases
  - 80 children reached 18 months
  - 2 (1.6%) are infected
  - 4 died before 6 months old

11

ARV Treatment for HIV Infected Children

- Start providing ARV service from March 2004, supported by UNICEF
- 48 children were receiving HAART
- Mean age at treatment initiation:7.3 years; range:13 months - 12 years
- Mean CD4%: 7.16; Range: 0.2 – 19
- First line regimen: 3TC+d4T+NVP
- The First Edition of National Guideline for use of Pediatric ARV was published in October 2004

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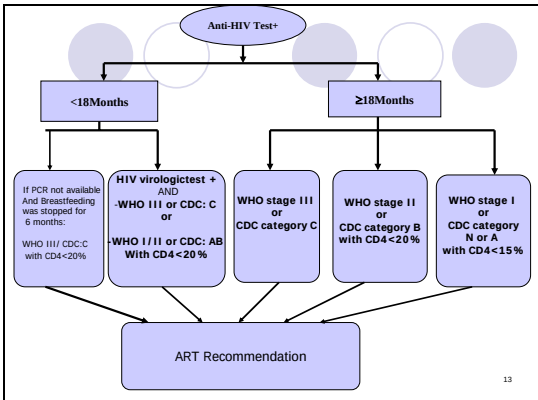

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ARV Treatment Follow Up

14

Preliminary results

- 3 children died while taking ART, after a mean treatment duration 3 months; all had <2% CD4 cells at recruitment.
- Causes of death were: lower respiratory tract infection, cachexia.

15

4. Khon Kaen integrated response for HIV-infected children and families – Dr. Pope Kosalaraksa

Khon Kaen integrated response for HIV-infected children and families

Pope Kosalaraksa, M.D.
Associate Professor
Department of Pediatrics
Faculty of Medicine
Khon Kaen University

October 20,2004

Srinagarind Hospital

- University hospital
- Referral center in northeast area
- Take care of HIV-infected children
  - : out-patients
  - : orphanages

Patient information

Dual NRTI therapy	**15**
HAART	**99**
: NNRTI	77
: Protease inhibitor	22
No ARV	**43**
: good CD4+	39
: wait for new regimen	4
Referred to other hospitals	**8**
Dead	**16**
Lost follow-up	**54**
Total	**235**

Past experience

- Medical therapy in the hospital
  - : not enough to provide a happy life
- Family and socioeconomic problems
- Take care of both children and caregivers

Problems in taking care of HIV-infected children and families

- Family/Caregiver
- Child
- Medication
- Health-care worker

Family problems

- HIV-infected mother/father
- Northeast : caregiver - elderly grandparent
- Face to family crisis ─ fear, depress
- Child : over responsibility
  - : over protection

Child's problems

- Illness
- Physical/psychological trauma
- Adherence to ARV
- Disclosure

Medication problems

- Pediatric preparation
- Taste
- Side effects

Health-care worker

- Attitude
- Knowledge
- Lack of confidence
- Teamwork

Integrated response

- 2 year-support : UNICEF
- Holistic approach model

Objective

- To improve care of HIV-infected children and families
- To develop a holistic approach model for northeast area
- To get the adherence more than 95% in ARV treated group

Activities

- Strengthening of HCW team and network
- Find out baseline problems of each family
- Group support, art and play therapy
- Home visit
- HIV camp for children and families

Group counseling

Children group process

TEAM MEETING

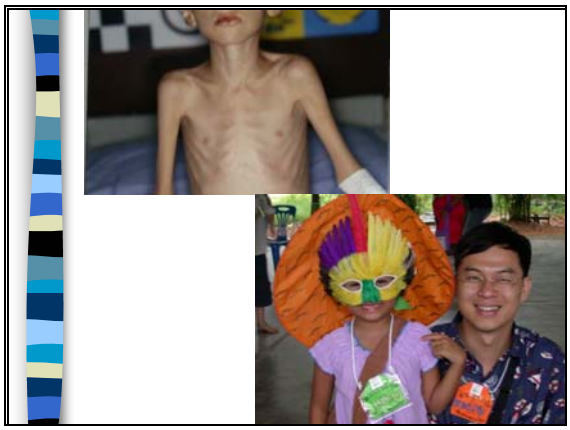
Health-care worker team

- Medical Doctors
  - : Prof. Pagakrong Lumbiganon
  - : Assoc. Prof Pope Kosalaraksa
  - : Assist Prof Chulaparn Engchanil
- Nurses
  - : Suthanom Kamolert
  - : Somjai Rattanamani
  - : Pornipa Hanlakorn
- Pharmacist
  - : Ratchadaporn Wisai
  - : Tanittha Udompanich

Health-care worker team

- Research assistances
  : Manita Kanka
  : Wannapha Ourkit
- Laboratory
  : Dr. Weerapon Lulitanon
  : Central laboratory
- Social worker
  : Mathinee Chaousup
- NGO
  : AIDSNET
  : WE UNDERSTAND
- Government part

Family camp




Thank you for your attention

5. Power of Life Group – Ms. Junsuda Suwanjundee

Power of Life Group

www.thaicities.net/whistle

AIDS and Myself

- 14 years ago, I did not understand AIDS – I did not think it applied to me.
- I did not know about my rights in terms of having my blood tested – I had my blood tested 2 times
- I lost my job, my home, my family – I had no place to go
- Although I was surrounded by people and still alive and well, I felt lonely, devastated and hopeless

??????????

What Can I Do? How Can I Survive??? [Needs]

- Problem: death is not now……
- Need information about AIDS
- No home, no job, no nothing

Answer for today or tomorrow and……

Basic Needs: Friends, Living and doing activities together in regular society

The Power of Life Group

- Formed POL because we needed to make people understand that PWAs needed to be and could still be productive in society
- In our PWA group, we had could think and talk more freely because we shared similar problems
- We needed to work because we wanted others to see that we could work and live successfully - PWA groups needed more than just support
- In the future, we want to be equal to others in society

Problems facing HIV infected women

- Receive news during pregnancy (telling your partner, making decisions concerning your child)
- Information received from health workers concerning pregnancy and abortion
- Emotional and social problems
- Being left behind, death and sickness

Women Facing Problems Alone

- **Needs of the women:**
- *Emotional support
- *Updated information on HIV
- *Support/help with present problems
- *Support on child issues
- *Advice on; planning her own and her child's life and future, telling other about her HIV infection

Whistle Home

- **Child care services for children under 3 years of age.**
- **Peer support groups.**
- **Advise and counseling.**
- **Health advice and support, liaison with the hospitals for optimal health care.**
- **Referral and advise concerning presenting problems.**

Why the name "Whistle Home"?

The home was opened to support the many women who face a similar problem, a problem that affected their child; there were no NGOs specifically offering help and support for the children born to HIV infected mothers. No one seemed to really understand or care.

We devised a symbol 'a whistle made out of clay'; children can't speak out and don't understand why it is they face problems like rejection or being avoided. They need someone to blow the whistle for them, an adult who understands their problems. Their needs are no different from the needs of other children, they need love, care, educational opportunities, and they need a society that understands and accepts them.

They need a life just like any other child.

MEETING THE NEEDS OF CLINICAL TRIAL PARTICIPANTS: A SURVEY OF CLINICAL TRIAL PARTICIPANTS CONDUCTED BY HIV SUPPORT GROUP LEADERS

Issue

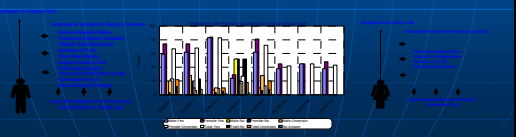
HIV positive persons enrolled in clinical trials for drug therapies are raising questions concerning the lack of information provided to them and inadequate follow-up after the completion of drug trials.

Project Description

Twenty interviews were conducted and 100 questionnaires were answered among HIV positive persons who had been enrolled in clinical trials. Questions examined their level of satisfaction with information provided prior, during and after the trials, as well as the enrollee's degree of involvement in decision making.

Questionnaire

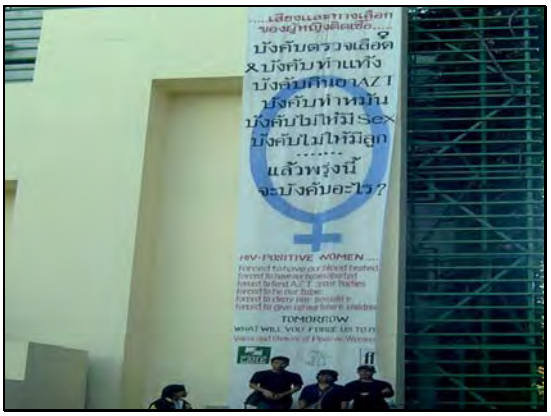
- Do you know the details or the specifications of the drugs in the trial?
- Did you receive information on how long you would take the drugs?
- Did you receive information on periodic bodily changes?
- If you experienced any side effects could you decided to stop taking the drugs?
- Did you receive a high level of information and care during the study?
- Did you receive adequate information on the following during the study:
  - Consequences of stopping medications?
  - Care, treatment and consistent reporting of results?
  - Overall progress and results of the study?



Results

A significant number of clinical trial participants expressed dissatisfaction with the information they received. They felt that the drug therapy offered through clinical trials was their only choice in order to prolong their life. They particularly felt there were limited treatment options available on a continual basis, and therefore were willing to take the drug therapy for the limited time period. Problems arose when drug trials were completed and participants had to continue taking these costly drugs at their own expense. Some of the participants had their periods of therapy reduced without explanation. They felt the drug companies should be responsible in supplying the drug therapies throughout their life, since clinical trial participants were relatively few in number and were risking their health to participate in the drug trial. They were also aware of drug trials being conducted in developed countries where trial participants were provided the drugs on a life-long bases, even after the trial was completed. Pregnant women in the study felt that they should receive equal attention as that given to their unborn children because they wish to spend their lives with their children.

Voices & Choices Of positive woman



PWAs want the same happiness as other people

6. What MTCT-Plus programs can contribute to pediatric HIV care? – Dr. Nittaya Phanuphak

What MTCT-Plus programs can contribute to pediatric HIV care?

Nittaya Phanuphak, M.D.
The Thai Red Cross AIDS Research Centre

MTCT-Plus Initiative

- Save mothers, save families
- Women-centered, family-oriented, multidisciplinary care for HIV-infected families

MTCT-Plus Initiative

- Pregnant women received TRCARC PMTCT regimen (not provided through MTCT-Plus)
  - Before April 2004:
    AZT 32 wk + SD-NVP / AZT 6 wk + SD-NVP (infants)
  - After April 2004:
    AZT/3TC/NVP 14 wk or 28 wk / AZT 6 wk (infants)
- Post-partum women / male partners
  - AZT/3TC/NVP or d4T/3TC/NVP as first-line regimen

Infants exposed to HIV

- Formula feeding & AZT 6 wk (not provided through MTCT-Plus)
- CTM 6 wk – 6 mo
- DNA-PCR at 8 wk, if positive → confirmed by another DNA-PCR (to early identify infection rather than to confirm the absence)
- F/U according to national immunization schedule
- Anti-HIV at 12 mo (18 mo.)

Infants with HIV infection

- CD4 at the time of diagnosis
  - 0-6 mo: q 2 mo, f/u monthly
  - 6-18 mo: q 3 mo, f/u q 3 mo
  - 18-24 mo: q 6 mo, f/u q 3 mo
  - >24 mo: q 6 mo, f/u q 3 mo if symptomatic
    f/u q 6 mo if asymptomatic
  - On ARV: q 6 mo, f/u at wk 0, 2, 4, 6, 8, mo 3, 4, 5, 6 then q 2 mo
- CTM for all <12 mo and CD4 <15% if >12 mo
- TST annually starting at 12 mo
- Immunization according to national guidelines

Indications for initiation of ARV in children

- Failure-to-thrive (no wt gain or wt loss or z score < -2)
- Advanced symptomatic disease (WHO stage II, CDC cat B)
- AIDS (WHO stage III, CDC cat C)
- <12 mo: CD4 percentage <20%
  1-12 yr: CD4 percentage <15% (≥6 yr may wait until <10% with more frequent CD4 check)

ARV regimens

- Recommended first-line regimens
  ≤ 3 yr: AZT/3TC/NVP
  > 3 yr >10 kg: AZT/3TC/EFV
- Recommended second-line regimens*
  ABC/ddI/LPV/r

**therapeutic failure of ARV treatment*

- *no improvement or worsening of clinical status after 3 mo*
- *inadequate immune response*
  - *<50 cells increase or <3% increase of CD4 at 6 mo*
  - *return of CD4 % to or below baseline*
  - *fall of >30% in CD4 % from peak*

HIV status of infants/children

HIV status	*Number (%)*
Indeterminate	75 (31%)
HIV negative	146 (60%)
HIV positive	15 (6%)
HIV-infected at enrollment	7 (3%)
Total	243 (100%)

Infants/children on ARV

- 9/22 HIV-infected infants/children (41%) currently on ARV
- AZT/3TC/NVP 5
- AZT/3TC/EFV 1 (NVP intolerance)
- d4T/3TC/NVP 3 (1 AZT intolerance)

MTCT-Plus Initiative

- Family-oriented model of care for HIV-infected families
- Practical and flexible guidelines for pediatric HIV care
- Free ARV and OI prophylaxis meds
- Early detection of HIV infection in infants

THANK YOU

7. Guidelines for the Management of HIV infection in Children in Resource Limited Settings – Dr. Chris Duncombe

Guidelines for the Management of HIV infection in Children in Resource Limited Settings

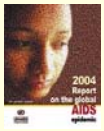
Chris Duncombe
October 20th 2004

UNAIDS at Country Level – Progress Report

MYANMAR

Country Situation Analysis

- Population 48.36 million
- Gross Domestic Product per capita of US$ 730
- LDC (least developed country) by United Nations
- HIV sero-prevalence 1.2% (adults)
- 2002
  - female sex workers
  - 20.4% - 30.1%
  - injecting drug users
  - 10% to 73%



1. Estimated number of people living with HIV

Country	Adults and children, end 2003 Estimate	Adults and children, end 2003 [low estimate - high estimate]	Adults and children, end 2001 Estimate	Adults and children, end 2001 [low estimate - high estimate]	Adults (15–49), end 2003 Estimate	Adults (15–49), end 2003 [low estimate - high estimate]
South & South-East Asia	6,500,000	[4,100,000 - 9,600,000]	5,900,000	[3,700,000 - 8,700,000]	6,300,000	[4,000,000 - 9,300,000]
Afghanistan	...	...	...	...	...	...
Bangladesh **	...	[2,500 - 15,000]	...	[2,200 - 13,000]	...	[2,400 - 15,000]
Bhutan	...	...	...	...	...	...
Brunei Darussalam	<200	[<400]	<200	[<400]	<200	[<400]
Cambodia	170,000	[100,000 - 290,000]	170,000	[100,000 - 270,000]	170,000	[99,000 - 280,000]
India	5,100,000	[2,500,000 - 8,500,000]	3,970,000	[2,100,000 - 7,100,000]	5,000,000	[2,500,000 - 8,200,000]
Indonesia	110,000	[52,000 - 190,000]	56,000	[28,000 - 95,000]	110,000	[53,000 - 190,000]
Iran (Islamic Republic of)	31,000	[10,000 - 61,000]	18,000	[6,000 - 35,000]	31,000	[10,000 - 60,000]
Lao People's Dem. Rep.	1,700	[600 - 3,600]	800	[300 - 1,600]	1,700	[550 - 3,300]
Malaysia	52,000	[25,000 - 86,000]	42,000	[20,000 - 70,000]	51,000	[25,000 - 84,000]
Maldives	...	...	...	...	...	...
Myanmar **	330,000	[170,000 - 620,000]	280,000	[150,000 - 510,000]	320,000	[170,000 - 610,000]
Nepal	61,000	[29,000 - 110,000]	45,000	[22,000 - 78,000]	60,000	[29,000 - 96,000]
Pakistan	74,000	[34,000 - 150,000]	63,000	[31,000 - 130,000]	73,000	[34,000 - 140,000]
Philippines	9,000	[3,000 - 18,000]	4,400	[1,400 - 8,700]	8,900	[2,900 - 18,000]
Singapore	4,100	[1,300 - 8,000]	3,400	[1,100 - 6,700]	4,100	[1,300 - 8,000]
Sri Lanka	3,800	[1,200 - 6,900]	2,200	[700 - 4,300]	3,800	[1,100 - 6,800]
Thailand	570,000	[310,000 - 1,000,000]	630,000	[360,000 - 1,100,000]	560,000	[310,000 - 1,000,000]
Viet Nam	220,000	[110,000 - 360,000]	150,000	[75,000 - 250,000]	200,000	[100,000 - 350,000]

Estimated PLHA in Mynamar end 2003 - 330,000

1. Estimated number of people living with HIV (continued)

Country	Women (15–49), end 2001 Estimate	Women (15–49), end 2001 [low estimate - high estimate]	Children (0–14), end 2003 Estimate	Children (0–14), end 2003 [low estimate - high estimate]
South & South-East Asia	1,600,000	[1,000,000 - 2,300,000]	160,000	[91,000 - 300,000]
Afghanistan	...	...	...	...
Bangladesh **	...	[300 - 2,100]	...	...
Bhutan	...	...	...	...
Brunei Darussalam	<200	[<400]	...	...
Cambodia	46,000	[30,000 - 77,000]	7,300	[3,900 - 14,000]
India	1,500,000	[570,000 - 1,900,000]	120,000	[55,000 - 260,000]
Indonesia	6,900	[1,400 - 11,000]	...	...
Iran (Islamic Republic of)	1,900	[600 - 3,800]	...	...
Lao People's Dem. Rep.	<200	[<400]	...	...
Malaysia	6,300	[3,100 - 10,000]	...	...
Maldives	...	...	...	...
Myanmar **	78,000	[42,000 - 140,000]	7,600	[3,600 - 16,000]
Nepal	9,100	[4,500 - 15,000]	...	...
Pakistan	4,300	[1,400 - 8,300]	...	...
Philippines	900	[300 - 1,800]	...	...
Singapore	800	[300 - 1,500]	...	...
Sri Lanka	<500	[<1,000]	...	...
Thailand	200,000	[110,000 - 340,000]	12,000	[5,700 - 24,000]
Viet Nam	41,000	[21,000 - 69,000]	...	...

Estimated children with HIV/AIDS end 2003 – 7,600

ART in Myanmar

- Pilot ART started in 2003
- 100 patients mostly adults
- Few (10) children

Guidelines

- In process July 2004
- Review of locally written guidelines
- Adaptation of regional guidelines
- Consensus workshop
- Draft document
- Final workshop

Issues

- Diagnostic testing algorithms
  - 18 < months >18
  - countries where PCR is limited
- Infant feeding counselling
- Starting and stopping PCP prophylaxis
- Syndromic approach
  - OI diagnosis and management
  - limited laboratory diagnostic capacity

Issues

- Role of TLC in initiation of ART
- Staging
- NVP regimens in women exposed to PMCT
- ARV dosing tables
  - weight-based not validated
  - use of adult formulations not validated

Pediatric Dosing in Resource Constrained Settings

Pediatric Antiretroviral and Cotrimoxazole Dosing

Developed collaboratively by:

Global AIDS Program
Division of HIV/AIDS Prevention
National Center for HIV, STD, & TB Prevention
Centers for Disease Control and Prevention (CDC)
Atlanta, Georgia, USA

Home-based AIDS Care Program – Tororo, Uganda
Global AIDS Program, CDC - Uganda
Entebbe, Uganda

Baylor International Pediatric AIDS Initiative
Baylor College of Medicine
Houston, Texas, USA

The MTCT-Plus Initiative
Columbia University Mailman School of Public Health
New York, New York, USA

Weight based dosing schedule

Weight	Stavudine (Zerit®, d4T)	Lamivudine (Epivir®, 3TC)		Zidovudine (Retrovir®, ZDV, AZT)		Didanosine (Videx®, DDI)	Nevirapine (Viramune®, NVP)						Efavirenz (Sustiva®, Stocrin®, EFV)	
	1 mg/KG twice daily	4 mg/KG twice daily		240 mg/m² twice daily		120 mg/m² twice daily	Induction dose: 4 mg/KG once daily for 14 days, then give maintenance dose ➔		Maintenance dose				Dose as shown once daily	
									< 8 yrs 7 mg/KG twice daily		≥ 8 yrs 4 mg/KG twice daily			
KG	Capsules 15, 20, 30 mg	Liquid 10 mg/ml	Tablet 150 mg	Liquid 10 mg/ml	Capsule 100 mg	Chewable tablets 25, 50, 100 mg	Liquid 10 mg/ml	Tab 200 mg	Liquid 10 mg/ml	Tablet 200 mg	Liquid 10 mg/ml	Tablet 200 mg	Liquid 30 mg/ml	Capsules 50, 100, 200 mg
5 – 6.9		2 ml		7 ml			2 ml		4 ml					
7 – 9.9	15 mg	3 ml		9 ml	1 cap	25mg + 25mg	3 ml		6 ml					
10 – 11.9	15 mg or (20 mg†)	4 ml		12 ml	1 cap	25mg + 25mg	4 ml		8 ml	½ tab			9 ml	200 mg
12 – 14.9	15 mg or (20 mg†)	5 ml		14 ml	1 cap	50mg + 25mg	5 ml		8 ml	½ tab			9 ml	200 mg
15 - 16.9	15 mg or (20 mg†)	6 ml	¼ tab	15 ml	2 caps	50mg + 25mg	6 ml		10 ml	½ tab			10 ml	200 mg + 50 mg
17 – 19.9	20 mg	7 ml	¼ tab	17 ml	2 caps	50mg + 50mg	7 ml		12 ml	1 tab AM + ½ tab PM†			10 ml	200 mg + 50 mg

8. From PMTCT to PMTCT+ Experience from the PHPT network in Thailand – Dr. Gonzague Jourdain

From PMTCT to PMTCT + Experience from the PHPT network in Thailand

0ctober 20, 2004
Gonzague Jourdain, MD, MSc
PHPT, Thailand
gjourdai@hsph.harvard.edu

PHPT network

40 public provincial and community hospitals in Thailand:
- Physicians, Nurses, Counselors, Laboratory Technicians, Pharmacists
- ANC-OB-GYN, Pediatrics, Internal Medicine

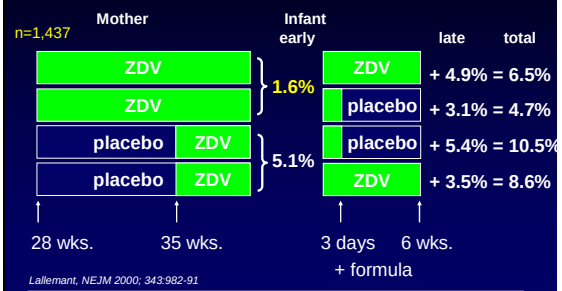
+ A center for clinical research located in Chiang Mai: protocol development, trainings, data management, monitoring, statistical analysis, and laboratory dedicated to HIV (virology + pharmacokinetics)

PHPT and ARV treatment: from PMTCT to PMTCT +

- 1997-1999: PHPT-1
- 1999: Antiretroviral treatment for the immunocompromised mothers and infected children (Thai Ministry of Public Health's support)
- 2001-2003: PHPT-2
- 2002: Oxfam supported ART program in 3 community hospitals in Chiang Mai province
- 2003: Sub-Recipient of the Global Fund for expanded PMTCT+ program
- Sep 2004: 300 children on ARV treatment

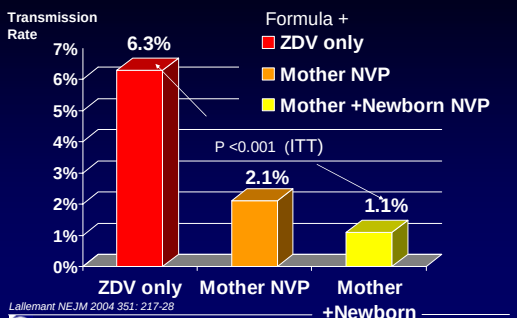
PHPT network

PHPT-1: ZDV 28 wks' gestation better than shorter course



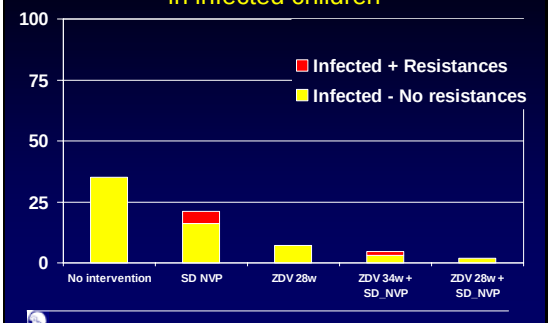
Lallemant, NEJM 2000; 343:982-91

2003: PHPT-2: ZDV 28 weeks' gestation + peripartum NVP for PMTCT



Lallemant NEJM 2004 351: 217-28

NVP resistances in children occur only in infected children



Transparency and collaboration

- Trainings
- Evidence based medicine and use of guidelines, discussion of medical decisions
- PHA networks and community involvement
- Collection of data and evaluation
- Regular reports to the members of the network and to the Ministry of Public Health
- Focus on patients, not on number of treatments dispensed

Origin of the two groups of infected children on treatment

- From perinatal trials (n=180 infected children) 106 started antiretroviral treatment
- From HIV clinics (n=261) 261 other infected children in urgent need of treatment who started treatment in one of the HIV clinics (median 8 years of age)

Cohort of children on ART

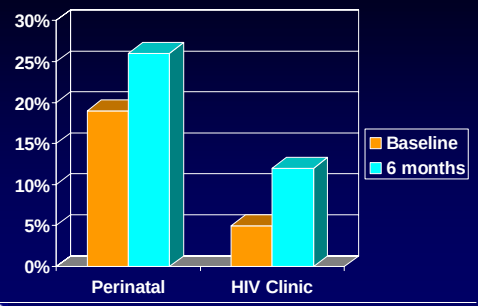
	Perinatal trials (n=106)	HIV clinics (n=261)
Age started ART	1 year	8 years
CD4% at ARV baseline	19%	5%
Viral load at ARV baseline (log_{10})	5.4	5.1
First line	Dual Nucs: 54%	NNRTI based: 83%
Age (Aug 2004)	4.7 years	9.2 years

Outcome on ART: preliminary data

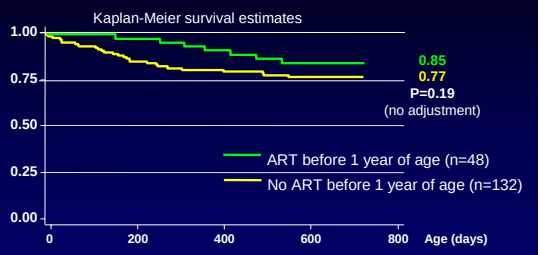
(median)	Perinatal	HIV clinics
Risk of death (Kaplan Meier) during the first 2 years of ART	5.5%	2.9%
CD4 increase at 6 months	7%	7%
VL decrease (log_{10}) at 6 months	- 2.1*	- 3.4
Undetectable <400 copies	32%*	84%
<50 copies	14%*	46%

* 54% of children initiated dual NRTIs as first line in 1999-2001

CD4 after 6 months of ART



Initiating antiretroviral therapy early?



Preliminary survival analysis at 2 years in 180 infected children on follow up since birth

Urgently needed

- Convenient and palatable pediatric formulations, simple dosing guidelines, simple administration
- Evaluation of interventions to promote adherence, especially for NNRTI based regimens (only one chance)

Opportunities

- PHA and community involvement
- PMTCT+
- Early diagnosis
- Training and evaluation of trainings
- Research

PHA and community support

- Promotion of local community support and PHA involvement in the design and the implementation of the programs
- Need for innovative approaches

PMTCT +

- More of more efficacious PMTCT
- Children and parents = family
- Propose care programs for the family: need for coordination/collaboration between specialists and programs

PHPT: Perinatal HIV Prevention Trial, Thailand

Early diagnosis of HIV infection

Ensure reliable early diagnosis of HIV infected children:

- Ensure specialized care for infected children
- Discontinue PCP prophylaxis in uninfected children
- DNA PCR (real time PCR) on Dried Blood Spots (on filter paper) performed in regional/national centers?

A pilot program to make available early HIV diagnosis in all hospitals in northern Thailand (collaboration Faculty of Associated Medical Science - PHPT - CDC Region 10; support: Sidaction)

PHPT: Perinatal HIV Prevention Trial, Thailand

Trainings

- Huge needs for training (health care workers at various levels and PHA)
- Lots of trainings have been developed: what is the effectiveness of the trainings? How individuals can evaluate their own knowledge?
- Need for evaluation kits (minimum knowledge for specific responsibilities)
- Web based resources

PHPT: Perinatal HIV Prevention Trial, Thailand

Research

In addition to operational research, basic questions remain unanswered:

- Who and when to start antiretroviral treatment?
- Second line regimens after failure on NNRTI based regimens
- How and when stop/restart therapy ("STIs")?
- What regimens after perinatal nevirapine?
- Natural history of TREATED children (cohort follow up)

Evaluate now the use of drugs that children will need tomorrow: need for mechanisms linking GF-ATM and research programs (funding the drugs used in clinical trials)

PHPT: Perinatal HIV Prevention Trial, Thailand

9. Coping with Psychosocial Impact – Ms. Chutima Saisaengjan and Nampung Plaengruan

"Coping with Psychosocial Impact"

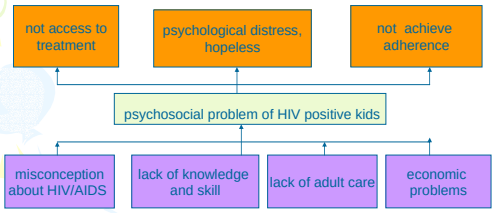
Consultation on Accelerating Support for Pediatric HIV Care, Support and Treatment in Thailand and Neighbouring Countries within the Context of 3x5 Initiative

20 October 2004

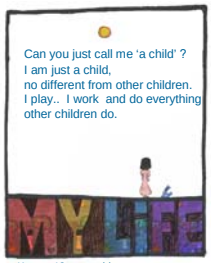
Chutima Saisaengjan
Nampung Plaengruan
"WE UNDERSTAND" Group
AIDS Access Foundation

Psychosocial impact : One of the main obstacles to access the treatment and to achieve adherence

Causes and Effects



Implementation



Kaeng, 13 years old

Raise awareness
- Media workshop
- Media campaign
- Communities forum

Implementation

- Develop the methodology dealing with the psychological problem; counseling, disclosure, art therapy, group support, and camp

Implementation

- Strengthen community and family capacity to response the impact on children

Implementation

- Strengthen the capacity of the social workers; sharing experience and networking

Lesson Learned

Discrimination
- Understanding world

I am not living with a 'deadly disease' like what people think but rather living in a 'deadly world' with people who don't understand and are unwelcoming.
I have a hope that one day this misunderstood world will become an understanding one.
Let's help each other.Change the world.
Kaeng 13 years old

Bua 13 years old

Lesson Learned

Discrimination

- Strengthen the capacity of children to cope the discrimination

"When people ask questions and stared at me strangely, I just walk away and stay calm."
Kaeng 13 years old

Lesson Learned

Fah 11 years old

Disclosure

- Fact information
- Process for supportive

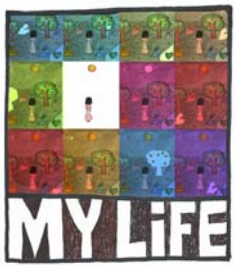
"When adults tell children about HIV, say it gently. Don't frighten them, don't scare them. Be supportive to them.."
Kaeng 13 years old

Lesson Learned : Psychological Problem

Paint brightness into the night, paint my life becomes weakness.
My father said we have to fight and don't give up. He loves me. He is good to me and supports me. When he is with me while I am sick, I feel comfortable.
From now on, I think I have to keep walking and fight. Sadness will not make it better. Body may not be dead but the heart is dead.
I am stepping out from the darkness. My father is like the moon who takes me out from darkness.

At first, I didn't know how to get out but when there was a light, I found the entrance. And it is important for me to step out too.
I am stepping out from my dark past to the bright, healthy and strong future with a society that will accept and understand.
Bua, 13 years old

Lesson Learned

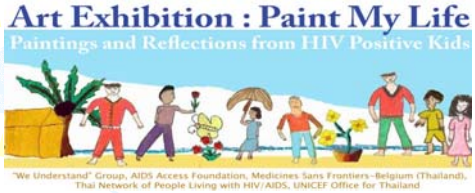


"Even though I can't forget about unpleasant things in life, I feel better when I draw or write. I don't have to think of unpleasant matters."
Kaeng 13 years old

Challenges

- Holistic approach; physical and psychological care, social inclusion, protection, and economics
- Expanding working with children and aware of the children participation
- Raise awareness at all levels
- Strengthen the communities and families.
- Children participation.

Thanks



10. Response to Pediatric HIV Care and Support in Thailand - Dr. Rangsima Lolekha

Response to Pediatric HIV Care and Support in Thailand

Thailand MOPH – U.S. CDC Collaboration

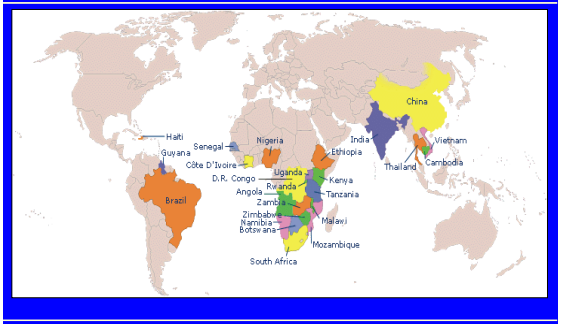
Prepared for the UNICEF Pediatric HIV Consultation
October 20, 2004

Rangsima Lolekha
Global AIDS Program

Objectives of this Talk

- Introduction to the Global AIDS Program, Thailand MOPH – U.S. CDC Collaboration
- Describe TUC's pediatric programs

GAP Countries



GAP/Thailand provides funding and technical collaboration to:

- Pilot new approaches in prevention, care, and surveillance for HIV/AIDS, TB, STD
- Scale up successful pilot projects to the provincial level and nationally
- Strengthen existing programs

Develop province-based networks for prevention, care, training, and surveillance

Networks

- Bangkok Metropolitan Administration
- Chiang Rai
- Ubon Ratchathani
- Phuket

Main Areas of Work for GAP/Thailand

- Training and health communications
- Care and counseling
- Prevention and care for families
- Prevention and care for special populations
- Surveillance, monitoring, and evaluation
- Laboratory services
- Information systems
- TB prevention and control

Pediatric HIV

Several GAP Strategies Focus on the Pediatric Population

1. Diagnosis of pediatric HIV disease
2. Improving care and treatment services
3. Evaluating performance

1. Diagnosis of Pediatric HIV Disease

Outcome and Diagnosis of Pediatric HIV Disease

Bureau of Epidemiology

Outcome or impact monitoring

Perinatal HIV Outcome Monitoring (PHOMS)

Surveillance system started in January 2001

6 sites are currently supported: Ubolratchathanee, Chiang Rai, Petchaburi, Songkla, Prae, Nhongkai

Objectives of the Surveillance System

- To report mother-to-child HIV transmission rate
- To monitor number of HIV-infected children who receive PMTCT regimen according to Thai national PMTCT guidelines
- To facilitate referral system for HIV-infected children to receive care and treatment through NAPHA program

Bureau of Epidemiology is now receiving support to use PCR for diagnosis of pediatric HIV infection through this program

2. Improving Care and Treatment Services

2.1 Expanded Care and Treatment (ECAT) for Women, Partners and Children

Appropriate care for mothers and children

Enhancing HIV-Related and Treatment of HIV-infected Mothers and Their families (ECAT)

Develop model for care and counseling of HIV-infected women, their partners and children

TUC supports pilot in 4 provinces
Department of Health expanding model to other regions

HIV-infected women

Enrolled at 6wks postpartum

Health check up, CD4 count test and access to treatment and counseling

Medicine - HIV Care

- Treatment for patients with CD4≤200 or symptomatic
- Supportive counseling
- Health promotion education
- Vitamin and iron supplement
- OI prevention and treatment
- CD4 count every 6 months
- Family planning

HIV-infected partners

HIV exposed infant

- Follow-up
- Supportive counseling
- Diagnosis of HIV infection
- OI prophylaxis
- Treatment as indicated HIV-infected children
- Supportive care for children affected by HIV

2. Improving Care and Treatment Services (cont.)

2.1 Expanded Care and Treatment (ECAT) for Women, Partners and Children

2.2 Care and Treatment Programs for HIV-Infected Children

- ❖ Chiang Rai
- ❖ Siriraj and Queen Sirikit National Institute of Child Health
- ❖ Ubolratchathanee

Network Model for Pediatric HIV Care from the Regional Hospital to District Hospitals

Chiang Rai Regional Hospital follows 170 children on ARVs)

Observational and follow-up training will be provided to 16 district hospital teams

Approximately 70 children on ARVs will begin to receive care and treatment at their district hospitals

1. Develop provincial care and treatment guidelines
2. Improve capacity of health care workers in district hospital to care for HIV-infected children on ARVs
3. Monitor performance

Key Component: Focus on Adherence

Dr Rawiwan Hansudewechakul, Chiang Rai regional hospital

Adherence strategies implemented before children starts ARVs

1. Preparation before ARVs

2. Caregivers practice preparing drugs

Adherence Emphasized at Every Clinic Visit

Monitoring for non adherence

1. Pill count

2. Patient recitation

3. Pill box

4. Diary

5. DOT

Additional Adherence Strategies

Continue group process and counseling

Day care activities

Care team meeting

Home visit

ART camp

Pediatric Adherence and Disclosure

Siriraj and Queen Sirikit National Institute of Child Health

- New project
- Assess baseline data on ARV access, antiretroviral adherence and disclosure status and practice of HIV-infected children and families in QSNICH and Siriraj hospital
- Develop disclosure guidelines/protocol for HIV-infected children and their care givers
- Develop adherence tool kit (e.g. educational materials etc) for health care providers, caretakers and children

Improving QOL for Children and their Families: Sappasitthipasong, Ubolratchathanee

Family camp activities

System Development for HIV/AIDS Care in Day Care Centers, Chiang Rai province

Home visit

PLHA group activities

HIV education for students in schools by HIV peer leaders

3. Evaluating Performance

HIVQUAL

- New York State AIDS Institute project for HIV clinical care improvement
- Began in 1995
- Widely applied in U.S.

Participating Sites, 1997-2003

HIVQUAL-T

2002-2004 Pilot in 8 hospitals in Chiang Mai, Chiang Rai, Payoa

2004→ Expand to more than 30 hospitals in Northern Thailand

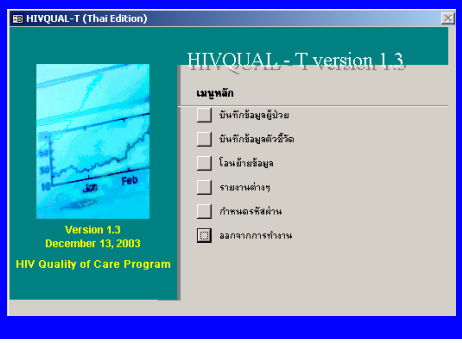
HIVQUAL-T: An Approach to Quality Improvement

The HIVQUAL-T Project: Goals

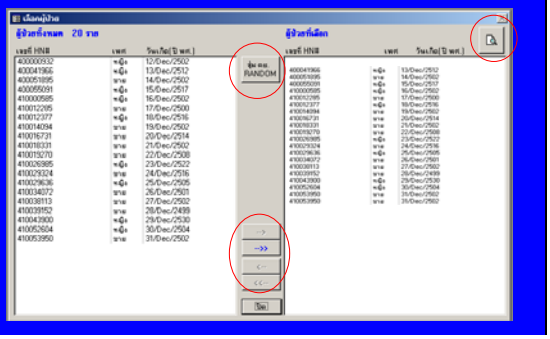
- Build capacity and capability to sustain quality improvement
- Develop a sustainable quality improvement program structure that supports ongoing improvement in the quality of HIV care
- Promote quality improvement activities and self-reporting of HIV performance data

Improve the quality of care for persons with HIV

Main Menu



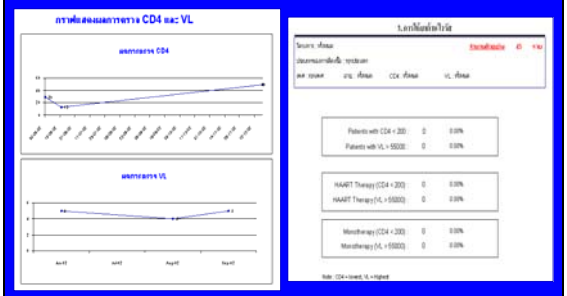
Enter Patient Identification and Random Samples



Example: HIVQUAL-T adult
6 main indicators

1. Monitoring HIV status
2. ARV treatment
3. OI prophylaxis
4. TB/HIV
5. Syphilis
6. Care for women with HIV

Report on ARV and laboratory data *(example)*



President's Emergency Plan for AIDS Relief

- Announced January 28, 2003
- 15 focus countries
- Goals:
  - Prevent 7 million new HIV infections
  - Treat 2 million HIV-infected people
  - Provide care for 10 million HIV-infected people and AIDS orphans

Photo: Robert Mulder

- Overall budget for global AIDS: $15 billion over 5 years ($10 billion new money, including $1billion for Global Fund)

Summary

- TUC will continue to focus pediatric care and treatment issues
- The Global AIDS Program activities throughout the world are expanding rapidly in this area

11. Antiretroviral Therapy in Thai Children
Dr. Kulkanya Chokephaibulkit

Antiretroviral Therapy in Thai Children

BY

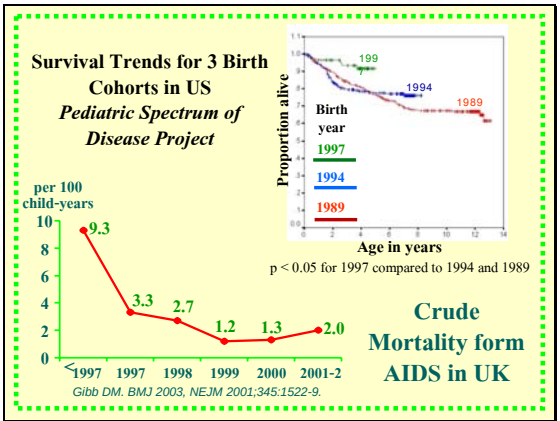
Kulkanya Chokephaibulkit, MD.
Department of Pediatrics
Faculty of Medicine Siriraj Hospital
Mahidol University

Some Important Facts about HIV-Infected Children

- Infection in young infants is equivalent to primary infection
- Viral load in infants is high and slowly decline
- Disease mostly run faster than adult but 40-50% survive to 10 year without ART *(but mostly symptomatic)*

Some Important Facts about HIV-Infected Children

- It takes longer time and less likely to achieve undetectable VL by HAART even in naïve children(<50% vs >70% in adults)
- Great restoration and regenerative capacity (CD4 naïve recovery) if viral replication is under control
- Serrogate markers have different predictive values compared to adults



The Goal of Treatment in Children

- **To maintain good immunological status**
- **To prevent disease progression**
- **To maintain good quality of life**
- **To maintain good family function**

(Regardless of achieving undetectable VL)

Problems of Antiretroviral therapy in Children

- Unpalatable drug formulation
- Limited PK data
- Limited clinical trials
- Some children are very difficult meds takers
- Long-term adherence depend upon caregiver and difficult to most families
  - →ART May disrupt normal family life
- Dysfunctional family (psychosocial/economic)

Before Initiating ART

- Take time to evaluate the indications
- Take time to evaluate caregivers / family status to ensure long-term adherence
- Take time to explain to caregivers / family comprehensively, and make them participate in decision of ART
- ART is not urgent, but need long-term commitment
- Defer ART if adherence is questionable

Start ARV 3 x 5

Salvage ARV 3 x 6

When to Start Treatment

Early Initiation

Advantage

- Better immune reconstitution with CD4 naïve cell
- Possible improved long-term outcome
- Prevent morbidity (illnesses/hospitalization)

Disadvantage

- Long-term adherence
- Resistance
- Toxicity
- Uncertain dosing (Limited PK data)
- Loss HIV specific immune response
- Cost

CDC Staging of Pediatric HIV

Clinical categories

N = Asymptomatic
A = Mildly symptomaic
B = Moderately symptomatic
C = Severely symptomatic (= AIDS)
"E" = Exposed (perinatally)

Immunological categories

1 = Normal
2 = Moderate suppression
3 = Severe suppression

MMWR 1994;43:1-19

Pediatric HIV Classification Immunologic Category

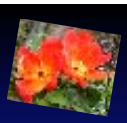
Immunologic Definition	Age-Specific CD4 Count / Percentage					
	< 12 mo		1- 5 yo		6-12 yo	
	x10⁹/L	%	x10⁹/L	%	x10⁹/L	%
1: No suppression	≥ 1500	≥ 25	≥ 1000	≥25	≥ 500	≥ 25
2: Moderate suppression	750-1499	15-24	500-999	15-24	200-499	15-24
3: Severe suppression	< 750	< 15	< 500	< 15	< 200	< 15

Classification for Children < 13 years of age

Clinical Classifications

Immune Suppression	Signs and symptoms N:No	A:Mild	B:Moderate	C:Severe
1: No evidence (CD4 > 25%)	N1	A1	B1	C1
2: Moderate (CD4 15-24 %)	N2	A2	B2	C2
3: Severe (CD4 < 15%)	N3	A3	B3	C3

Natural Course



Barnhart et al. Pediatrics 1996;97:710-6.

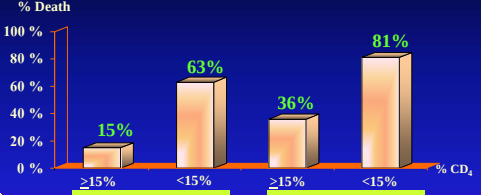
Mean age (months) at transition in each staging

Non AIDS (58)			AIDS (55)	
N (10)	A (4)	B (65)		C (34)
0	10	14	79	113
Birth	*At stage "B", 65% survive more than 5 years*			Death

- Stage "C" is good predictor for poor outcome
- Stage "B" included various predictive values

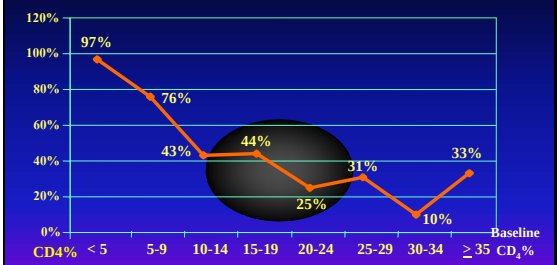
Galli L. Int J Epidemiol 2002;29:573-8.

Baseline CD4/VL vs Long-Term Risk for Death (mean F/U 5.1 yr)



Mofenson LM. JID 1997;175:1029.

Baseline CD4% and Long-term Risk for Death (mean F/U 5.1 yr)



Mofenson LM, JID 1997;175:1029.

CD4 Predicts Survival in Thai Children without ART

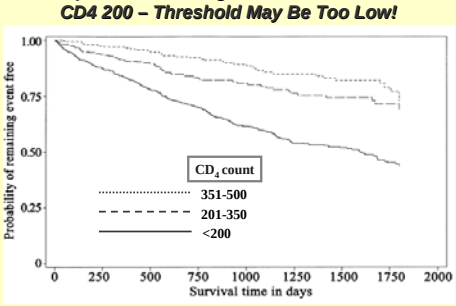
At any time point	Risk of death before 5 yo
CD4 < 22%	79% (N=24)
CD4 > 22%	0 (N=11)

Vanprapar.J Med Assoc Thai 2002;85 (suppl 2):S690-3

Earlier HAART Initiation is Better

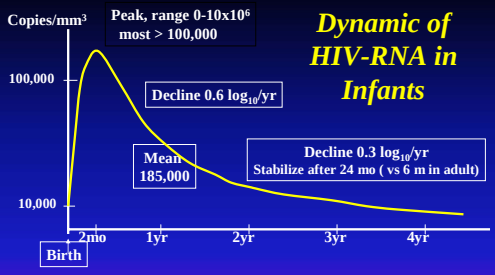
1173 patients initiating HAART at various CD4

CD4 200 – Threshold May Be Too Low!



Sterling TR. JID 2003;188:1659

Dynamic of HIV-RNA in Infants



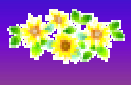
HIV-RNA has low predictive value for subsequent disease progression/mortality
∴VL decision to start ARV is uncertain

Initiation of ARV In Infants *From Various Guidelines*

US	EU	WHO
Recommend	Recommend	Recommend
Stage A,B,C	Stage C	Stage III
CD4 <25%	CD4 <20%	CD4 <20%
	Rapid CD4 fall	Stage II with
Consider all esp. < 6M	VL > 6 log	total L<2,500 /mm3
	Consider all esp. < 6M	

Initiation of ARV In Children *From Various Guidelines*

US	EU	WHO
Recommend	Recommend	Recommend
Stage C	Stage C	Stage III
CD4 <15%	CD4 <15%	CD4 <15%
		Stage II with
Consider	*Consider*	total L<1,500 /mm3
Stage A, B	*Stage B*	
CD4 15-25%	*CD4 15-20%*	
VL>5 log	*VL>5 log*	



When to Start Antiretroviral Therapy to Thai Children

- What is the appropriate clinical staging to start ?
  - Stage B or C (Consider A)
  - All infants <12 M
- What is the appropriate CD4 level to start?

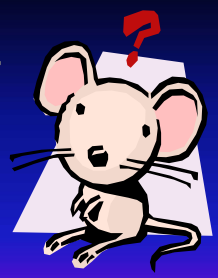
≤ 20%
(Consider 20-25%)

National Guideline 2002

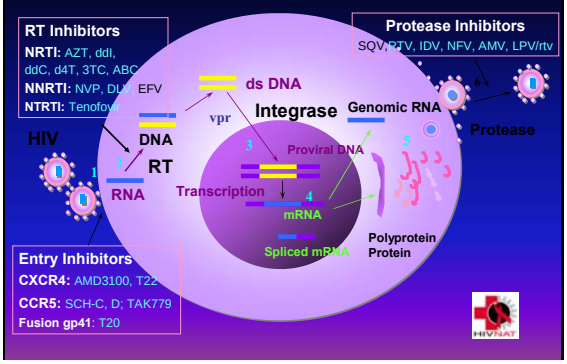
Recommendation of When to Start ART

USA(2003)	EU	Thailand
Recommend	**Recommend**	**Recommend**
•Stage <12M: A,B,C	• Stage "C" any age	• Stage B,C
>12M: C	• CD4 <12 M: <20%	• CD4 < 20%
•CD4 < 12M: < 25%	>12 M: <15%	• All infants < 12 M
>12M: < 15%	• Rapid fall CD4 and/or VL>10^6	**Consider**
Consider	**Consider**	• Stage A
•All infants < 12 M (esp. < 6M)	• All infants < 12 M	• CD4 20-24%
• >12M: Stage A, B CD4 15-25% VL>5 log	• > 12M: Stage "B" CD4 15-20% VL > 5 log	*Consider other factors*
Defer	**Defer**	
Stage N CD4 > 25% VL < 5 log	• Stage N, A • CD4 > 20% • VL < 5 log	

What to Start



Major Targets of Antiretroviral Agents

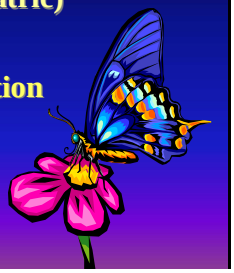


ARV drugs

- **NRTIs**
  - –Zidovudine (*AZT*)
  - –Didanosine (*ddI*)
  - –Zalcitabine (ddC)
  - –Stavudine (*d4T*)
  - –Lamivudine (*3TC*)
  - –Abacavir (ABC)
- **NNRTIs**
  - -Nevirapine (*NVP*)
  - -Efavirenz (EFV)
  - -Delavirdine (DLV)
- **PIs**
  - – Saquinavir (SQV)
  - – Fortovase (SGC)
  - – Ritonavir (RTV)
  - – Indinavir (IDV)
  - – Nelfinavir (*NFV*)
  - – Lopinavir (LPV)
  - – Amprenavir (APV)
- Others
  - - Tenofovir (TDF)
  - - T-20 (Enfuvirtide)

Drug Regimen Consideration

- Schedule
- Formulation (Pediatric)
- Taste
- Drug-drug interaction
- Tolerability, S/E
- Efficacy
- Cost



CSF Penetration of ARV Drugs

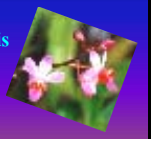
NRTI	NNRTI	PI
AZT 60%	NVP 45%	SQV, RTV poor
d4T 55%	DLV 0.4%	IDV, NFV mod.
ddI 20%	EFV 0.7%	
ddC 20%		
3TC 10%		
ABC 18%		

Common side effects of NRTIs

Suspected mitochondrial toxicities

- AZT: anemia, neutropenia, nausea, hepatitis headache, malaise, myopathy
- 3TC: peripheral neuropathy
- d4T: peripheral neuropathy, lipodystrophy (cheek atrophy, limb atrophy, bitemporal atrophy).
- ddI: peripheral neuropathy, pancreatitis

Lactic acidosis in all NRTIs (esp. d4T)



Common side effects of NNRTIs

- Nevirapine : rash, hepatitis
- Efavirenz : dizziness, nightmare, transient rash (18%)

Common side effects of PIs

- Lopinavir, Ritonavir: nausea, vomiting, circumoral paresthesia, diarrhea, bitter taste
- Indinavir: kidney stone, hyperbilirubinemia (indirect), metallic taste
- Nelfinavir: diarrhea

Problems of HAART in Children

	Liquid available	Taste	Cost	Schedule	S/E
RTV	y	Bad	High	BID	GI
LPV/r	y	Bad	High	BID	GI
NFV	y (powder)	OK	High-Med	TID	Diarrhea
IDV	N	OK	High	TID	Renal Stone
SQV	N	OK	OK	TID	Poor PK
EFV	N	OK	Med	OD	CNS
NVP	y	OK	LOW (GPO)	BID	20% rash (mod efficacy)
ABC	y	OK	High	BID	Hypersens
ddI	y (powder)	Bad (powder) OK (tab)	Med	BID	GI (powder)

Nelfinavir

Ad - Powder formulation available
- Effective
- Different resistance pattern
- Well studied in children

Disad - Diarrhea
- Expensive (GPO may produce)

Ritonavir & Lopinavir/r

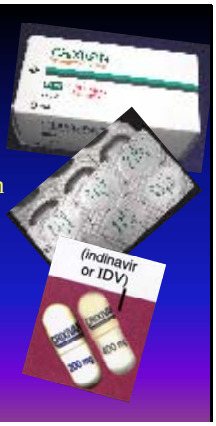
Ad - Liquid formulation available
- Effective
- High resistance barrier
- Well studied in children

Disad - Bad taste, GI S/E
- Expensive

Indinavir

Ad - Highly
- Effective
- High resistance barrier

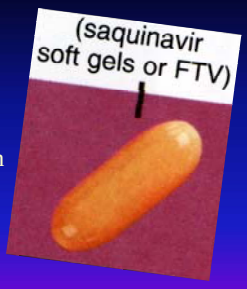
Disad - No pediatric formulation
- Less studied in young children
- Nephrolithiasis
- TID dosing (unless combine with RTV)
- Expensive



Saquinavir

Ad - Effective

Disad - No pediatric formulation
- Less studied in children
- Poor PK
- TID dosing



Efavirenz

Ad - Once daily dosing
- Highly effective
- Well tolerate

Disad - No liquid formulation
- Not approve in < 3y.o.
- Low resistance barrier
- CNS S/E

Nevirapine

Ad - Cheap (by GPO)
- Liquid formulation available

Disad - Low resistance barrier
- S/E esp. rash in 20%
- Less effective on viral suppression

Abacavir

- **Ad**
  - **Liquid formulation available**
  - **Convenient bid dosing with AZT/3TC**
  - **Well tolerated**
  - **In interfere with Cy P450**
- **Disad**
  - **Hypersensitivity reaction in 5%**
  - **Less effective viral suppression in pediatric trial (VL<400 in only 10%)**

What Regimen to Start For Thai Children

- **Stage ≤ B and CD4 ≥ 15%**
  - **Triple : 2NRTI + PI or 2 NRTI + NNRTI**
  - **Dual 2NRTI if complicance for HAART is questionable**
- **Stage C or CD4 < 15%**
  - **Insist Triple: 2NRTI + PI or 2 NRTI + NNRTI**
- **Choices**
  - **PI : LPV/r, NFV, IDV/±r (older children)**
  - **NNRTI : EFV, NVP**

National Guideline 2002

Recommended Drug Regimen to Start

USA (2003)	EU	Thailand
Strongly • 2NRTIs+ LPV/r or NFV or RTV or EFV (or NVP in < 3Y) • 1NRTI+NFV+EFV ***Alternative*** • 2NRTIs+ APV (in >4Y) or IDV •2NRTIs+ NVP (in >3Y) • ABC+AZT+3TC ***Special Circumstances*** • 2NRTIs	***First choice*** • 2NRTIs+ NFV or RTV or LPV/r or NVP or EFV ***Second choice*** • 2NRTIs+ABC	***Stage ≤B and CD_4 ≥15%*** • 2NRTIs+ PI or NNRTI • 2NRTIs (if adherence for HAART is unsured) ***Stage C or CD_4 < 15%*** • 2NRTIs+ PI or NNRTI ***Choices*** PI : LPV/r, NFV, IDV±r (older kids) NNRTI : EFV, NVP

NVP-Resistance in Infants After Perinatal Single Dose Regimen Exposure

• HIVNET 012 *Eshleman S. AIDS 2001;15:1951-7.*

11/29 (46%) developed NVP-R at 6-8 week-old

>> 82% Y181C : higher resistance level

>> 18% K103N *(Predominate in mothers)*

Mutation disappeared by 14-16 week-old

•Standard (NVP-NVP) >>33% (all Y181C)
• PEP (O-NVP) >> 13% (various)

CCN. Pillay WeOrB1290. XV IAC Bangkok July 11-16, 2004

In 11 infected mother-child pairs

received NVP-NVP

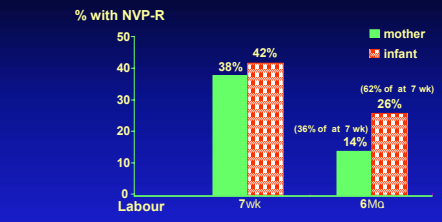
1 mother had K103N

4 infants had Y181C, 1 had K103N

Resistant in infants occur more frequent than mothers. Probably by *de novo*.

M. Gordon. ThPeB7045. xv IAC Bangkok July 11-16, 2004

Persistance of NVP-Resistance After SD of NVP-NVP for Perinatal Prevention



Mother	N=	623	157	56
Infants	N=	-	21	13
Mutation in moms				K103N, G190A
Mutation in infants				Y181C, K103N

L. Morris TuOrB1353. XV IAC Bangkok July 11-16, 2004

Follow Up

- **Clinical and adherence check up Q 1-2 mo**
- **Lab - CBC, CD4, (VL) Q 6 M**
  - **SGPT at 1 , 6 M if take NVP**
  - **U/A if take IDV**

Criteria For Failure (US)

Clinical

- Neurodevelopmental deterioration
- Growth failure
- Disease stage progression
  - A → B
  - B → C
  - C → new OI

Immunologic

- Immuno stage progression
- CD4 count decline > 30% in 6 mo
- % CD4 decline > 5 % If baseline CD_4% < 15%
- Persistent increase VL

However, VL failure only is not an absolute indication

When to switch?

Definitions of treatment failure in HIV + infants and children 2003

Clinical signs

- Lack of or decline of growth after initial response
- Loss of neurodevelopmental milestones or development of encephalopathy
- Occurrence of new OI/ malignancy
- Recurrence of prior OI

CD4 cell criteria

- Return of CD4% to pre-treatment level
- >= 50% decrease of CD4 during treatment without other concomitant infection

(use CD4 cell count > 6 years)

What to Switch To ?

Failed Regimens	Regimens to switch to
• 2NRTI	• NNRTI + (boosted) PIs
• 2NRTI+NNRTI*	• (double) boosted PI±NRTI*
• 2NRTI+PI*	• NNRTI+ boosted PI±NRTI*
• 3 class resistance*	• Mega HAART (≥ 5drugs)*

* Resistant test affect the decision

Ensure that the treatment failure is not from poor adherence

Changing of Regimen After treatment failure

- Check of adherence
- Only if adherence is good ⇒ change regimen

Dual → Triple

Triple → boosted PI

→ Mega HAART (≥5 drugs)

Change at least 2 new drugs

WHO Guidelines

WHO STAGING for Resource Limited Settings

Clinical stage I

1. Asymptomatic
2. Generalized lymphadenopathy

Clinical stage II

3. Unexplained chronic diarrhoea
4. Severe persistent or recurrent candidiasis outside the neonatal period
5. Weight loss or failure to thrive
6. Persistent fever
7. Recurrent severe bacterial infections

Clinical stage III

8. AIDS-defining opportunistic infections
9. Severe failure to thrive
10. Progressive encephalopathy
11. Malignancy
12. Recurrent septicaemia or meningitis

Recommendation for Initiating ART by WHO in Resource Limited Setting 2003

CD_4 available		
< 18 mo	PCR⊕	Stage III or CD_4 < 20%
	No PCR	Stage III with CD_4 < 20%
≥ 18 mo	Anti-HIV ⊕	Stage III or CD_4 < 15%
CD_4 not available		
< 18 mo	PCR⊕	Stage III only
	No PCR	No Rx at any stage
≥ 18 mo	Anti-HIV ⊕	Stage III only

Regimen: AZTord4T + 3TC + EFVorNVP

(NVP if <3 yo or < 10 kg)

First-Line Regimen

First line regimens	Comment
d4T or ZDV	
Plus	NNRTI choice:
3TC	□ if age <3 yr or wt <10 kg, use NVP
Plus	□ if age >3 yr or wt >10 kg, use NVP or EFV
NVP or EFV	*Regardless of perinatal NVP exposure*

Concurrent RIF therapy, if age > 3 yo -> EFV

if age < 3yo -> ZDV/3TC/ABC

Comments: What if the < 3 yo child unable to tolerate NVP
Suggestions >> Use NFV >> use ABC (not avail in liquid, expensive)
>> Use dual NRTI if no other drug available in symptomatic pts.?

Changing ARV

- **Clinical failure**
- **Immunological failure : CD4 counts/percentage**
  - **CD4 dropped ≤ baseline**
  - **> 50% fall from peak**

Comments - **> 50% drop is OK in most cases but may be too much in those with low peak response, or too less for the growing children with physiologic drop, esp without time frame**

Suggest:
- **>50% drop should be confined to only CD4 percentage and only among those with the peak response >20%**
- **Other criteria should be added to help :**
  - **>> Rapid drop e.g. >30% in 6 months**
  - **>> Limited CD4 peak (< 15%) after 6 M**

Second-line Treatment Regimens for Infants and Children with Treatment Failure, 2003

- All drugs should be replaced

d4T or ZDV
+
3TC
+
NVP or EFZ

Change to →

ABC
+
ddI
+
LPV/r or NFV, or SQV/r >= 25 kg

Draft: Scaling-Up Antiretroviral Therapy in Resource-Limited Settings, 2003

Comment - ABC may not be available

Suggestions - Other regimens should be included as alternatives; e.g.
ddI+LPV/r+NFV
ddI+NFV+SQV/r
ddI+NFV+RTV

Depending upon availability locally !

TB Disease and HIV Co-infection, 2003

CD4 (mm3)	TB and ART	Recommend
< 200	1. Start TB Rx 2. Start ART as soon TB Rx tolerated	Recommend ART
<200 - 350	1. Start TB Rx 2. Start ART after initiation phase	Consider ART
> 350	1. Start TB Rx	Defer ART

Draft: Scaling-Up Antiretroviral Therapy in Resource-Limited Settings, 2003

TB Disease and HIV Co-infection, 2003

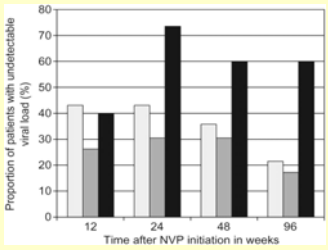
- Treatment of TB remains central priority and should not be compromised by ART!
- The optimal time to initiate ARV in patients with TB is not known!
- NVP may be used in place of EFZ in absence of other options

ZDV		EFZ
or	+ 3TC +	Or SQV/r
D4T		Or ABC

Draft: Scaling-Up Antiretroviral Therapy in Resource-Limited Settings, 2003

Virological Response Correlate with NVP dosage

Proportion of patients achieving undetectable VL(< 400 copies/ml) on high (> 300 mg/m2/day), recommended (240–300 mg/m2/day) and low (< 240 mg/m2/day) dosage of NVP

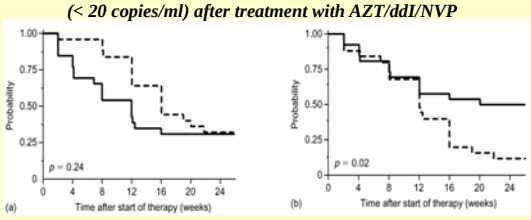


, intention-to-treat analysis, missing equals failure, last value carried forward.

Verweel: AIDS, Volume 17(11).July 25, 2003.1639-1647

Virological response correlate with NVP level

KM curves for the time to undetectable HIV-1 RNA (< 20 copies/ml) after treatment with AZT/ddI/NVP



Patients starting Rx with high [> 15 800 copies/ml (– – –)] or low [<= 15 800 copies/ml (—)]

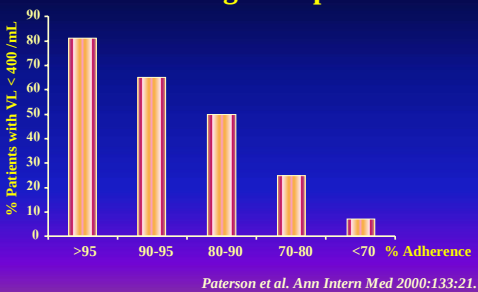
Patients with low [<= 3.4 µg/ml (— or high [> 3.4 µg/ml (– – –)] plasma NVP concentrations

Veldkamp. AIDS 2001;15:1089-1095

Suggestions:

- **NVP should be acceptable with RIF if no alternative available**
- **If RIF is co-administered with NVP, increased NVP around 20% would be prudent**

Correlation Between Adherence and Virologic Response



Paterson et al. Ann Intern Med 2000:133:21.

Patient's relationships with care providers

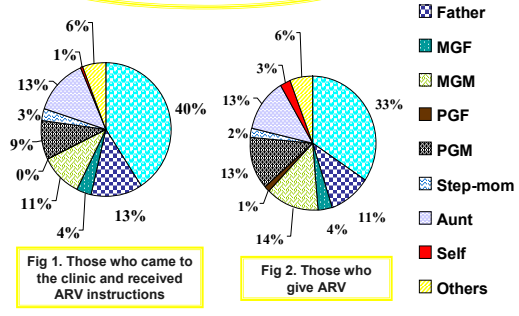
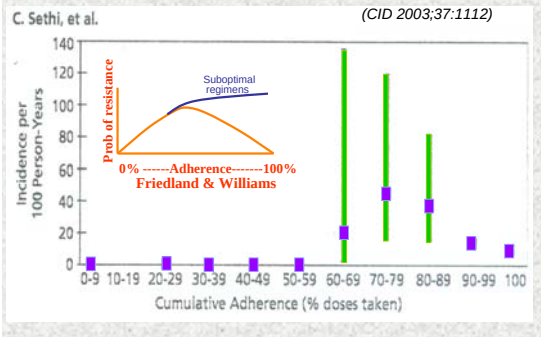


Fig 1. Those who came to the clinic and received ARV instructions

Fig 2. Those who give ARV

Adherence vs Resistance



Problems Causing Poor Adherence

- Lack of knowledge
- Chaotic family setting
- Care-givers not available to feed/F/U.
- Side effects
- Poor formulation/bad taste/complexity/etc.
- Difficult drug taker child

Problems Facing

- Growing children → Adolescent
  - Disclosure
  - Sexuality issues
  - High risk behaviors (less in perinatal cohort)
- Unstable family. Changes of care-takers.
- What's the next regimens? Who is going to pay?

12. Pediatric HIV Projects at HIV-NAT and the Treatment of Orphans with HIV at Baan Gerda – Dr. Jintanat Ananworanich

Pediatric HIV Projects at HIV-NAT and The Treatment of Orphans with HIV at Baan Gerda

October 20, 2004

Jintanat Ananworanich
HIV-NAT
Jintanat.a@chula.ac.th

1

Pediatric Projects at HIV-NAT

- HIV-NAT and Chulalongkorn University
  - Standard HIV care
    - PATC program/HIV-NAT 015
    - HIV care for fathers and mothers
    - Financial support for families in need
  - Research projects
    - Partners
      - Khon Kaen University
      - Queen Sirikit National Institute of Child Health

2

Research Projects

- When to start ARV?
  - An on-going pilot study of 43 children
  - Awarded 5-year U19 NIH grant to perform the full study with 300 children
- How common is resistance in children treated with dual NRTI?
- What to do when children fail GPO-vir?

3

Research Projects

- What is the correct dosing of ARV in children?
  - Dual boosted PI with LPV/r/SQV
  - NFV based on either BSA or BW
- How well does HAART work in children?
- What are the factors that affect adherence and disclosure of HIV diagnosis to children?

4

Prevalence of NRTI resistance on dual NRTI for at least 6 months (N = 95)

5

What to do when children fail GPO-vir?

- 20 children
- Failed NRTI/NNRTI
- PI-naïve
- Sick
  - CDC B and C
  - CD4 6.5% (129)
  - VL 4.9 log
- Started LPV/r + SQV
- 12-hours PK
- 2-year follow up
  - CD4, VL, TDM
- Acceptable PK
  - Identify threshold for VL suppression and toxicity
- At 24 weeks
  - Significant wt/ht gain
  - CD4 rise of 6% (216)
  - VL drop 2.5 log
  - VL undetectability in 80%
  - No PI resistance
  - Significant rises of cholesterol and triglyceride

6

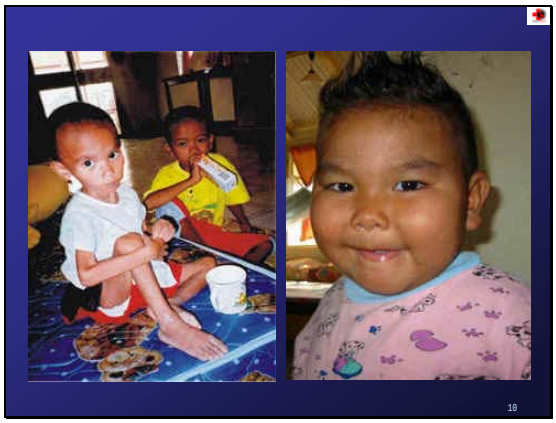
Coping and Living Issues Caregivers

- Stress, ability to cope and social support
  - Coping mechanisms
- Disclosure
- Adherence
  - Barriers to adherence
  - Methods to assess adherence
  - Biological vs non-biological caregivers

7

Baan Gerda
A family-style Thai community for orphans with HIV infection In Lopburi

8



Issues

- Medical care
  - OI prophylaxis
  - ARV
  - Laboratory monitoring
  - Resistance
  - Medical care for opportunistic infections and other illnesses
  - Immunization, dental care
- Finding foster parents and change of parents
- Death in adults and children
- School, teenagers

11

13. Ensuring Secure and Reliable Supply and Distribution System in Developing Countries, in the Context of HIV/AIDS and PMTCT – Helene Moller

ENSURING SECURE and RELIABLE SUPPLY and DISTRIBUTION SYSTEMS in DEVELOPING COUNTRIES, in the CONTEXT OF HIV/AIDS and PMTCT

Access to Paediatric ARV Formulations The plight of Children ….

Bangkok

October 2004

Helene Möller
M.Pharm, PhD
Supply Division

unicef

Overview of Presentation

- **Background:**
  - Access to ARVs, Access to Medicines
  - Supply Division involvement from 1997 to date
- **Paediatric Formulations available (in the context of WHO guidelines for prevention and treatment)**
- **Procurement and Supply Logistics**

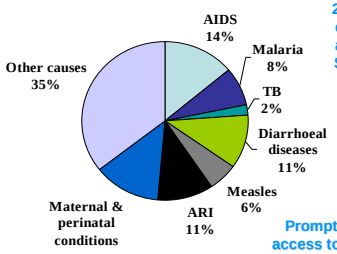
BACKGROUND
Overview of HIV supply history

- **1997: UNICEF lead agency in PMTCT pilot programme: Implications for Supply Division**
  - Zidovudine, nevirapine
  - HIV diagnostic tests
  - Breast Milk Substitute
- **2001/2002: MOU with Columbia University, to provide supply support to 8 countries, including Thailand:**
  - Capacity to provide first, second line ARVs established
- **GFATM, WHO 3 x 5, other NGOs: Product portfolio expanded:**
  - ARVS ⇨ 42 formulations in 75 different presentations, ⇨ 30 - 40% can be used for children
  - HIV tests, CD4, CD8, Viral load including PCR equipment

UNICEF has provided ARVs to 37 countries in last 18 months
– has contracts with 22 companies, both innovators and generic

Cuba	Benin	Mozambique	Albania	Cambodia
Haiti	Burkina Faso	Niger	Tajikistan	Fiji
Honduras	Burundi	Nigeria		Indonesia
Nicaragua	CAR	Rwanda		Mongolia
	Chad	S. Africa		Myanmar
	DR Congo	Swaziland		Papua New Guinea
	Cote d'Ivoire	Tanzania		Thailand
	Guinea	Togo		Vietnam
	Kenya	Uganda		
	Liberia	**Zambia**		
	Madagascar	Zimbabwe		
	Malawi			

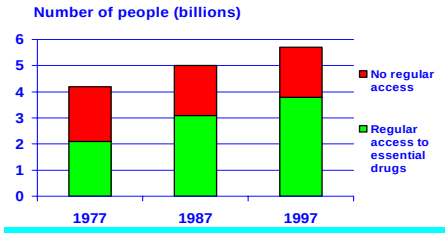
CHALLENGE
Child mortality and morbidity



2/3 of deaths among children and young adults in Africa and South East Asia are due to 7 causes

Prompt diagnosis and access to essential drugs could save 4 million lives a year in Africa and SE Asia alone

ACCESS to DRUGS IMPROVED
but large gaps remain …..



In 32 countries 50% of the population lacks regular access:
- public spending is insufficient and decreasing
- limited health insurance coverage
- new essential drugs are costly
- supply systems are often unreliable and poorly managed

What do we mean with

' there is no access to Paediatric ARV Formulations ' ?

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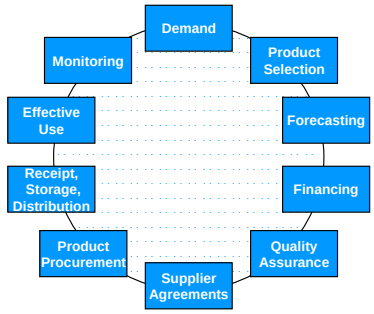
Access to paediatric ARV formulations depends on effective supply chain management



DEMAND :
When to start ; What to start with ….

WHO Guidelines exist

- **For Prevention of Mother to Child Transmission:**
  - Guideline for mothers with indications for initiation of treatment who may become pregnant
  - Mothers on ART who become pregnant, and infants
  - HIV infected pregnant women with or without indications for ART, and infants etc
- **For Treatment and Care: First Line**
  - Preferred option for children ⇨ (zdv or d4T) + 3TC + NVP
  - Guideline for children on TB treatment regiments containing rifampicin, substitute NVP for EFV
- **For Treatment and Care: Second Line**
  - Guidelines for children with treatment failure ⇨ ABC + ddI + PI

FIRST LINE / PMTCT
ARV Formulations are available ……

Treatment	Products available		Price (US $ / 100ml)	
PMTCT/ 1st Line	Innovator	Generic	Innovator *	Generic #
D4T	Yes	No	4.23 – 18.66	
ZDV	Yes	Yes	2.96	1.53 - 2.10
3TC	Yes	Yes	2.80	1.68 - 2.00
NVP	Yes	Yes #	8.75	2.00 - 2.45
EFV	Yes	No	9.45 - 15.12	

* Mostly current ACCESS prices unless range indicated , # Not necessarily WHO prequalified

SECOND LINE / PMTCT
ARV Formulations are available ……

Treatment	Products available		Price (US $ / 100ml)	
2nd Line	Innovator	Generic	Innovator *	Generic #
ABC	Yes	No	13.05	
ddI	Yes	No	9.64	
LPV/r	Yes	No	13.70 – 136.70	
NFV	Yes	No	35.00 / 144g	

* Mostly current ACCESS prices unless range indicated , # Not necessarily WHO prequalified

If we have the formulations, how can we still say

‘ there is no access to Paediatric ARV Formulations ’ ?

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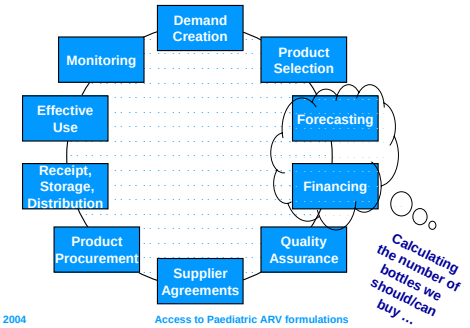
Access to paediatric ARV formulations depends on effective supply chain management



DEMAND :
When to start ; What to start with ….

- **For Prevention of Mother to Child Transmission:**

For infant:

Zidovudine (ZDV)	4mg/kg 2x daily, for 1 week, 4-6 weeks
Nevirapine (NVP)	single dose 0,6ml
Lamivudine (3TC)	2mg/kg 2x daily, for 1 week

DEMAND :
When to start ; What to start with ….

- **For Treatment and Care: First Line**

Variations of

Zidovudine (ZDV)	< 4 weeks: 4mg/kg 2x daily 4 wks – 13 years: 180mg/m²/dose 2x daily
Stavudine (d4T)	< 30kg: 1mg/kg/dose 2x daily
Lamivudine (3TC)	< 30 days: 2mg/kg 2x daily, then 4mg/kg 2x daily
Nevirapine (NVP)	15 – 30 days: once daily dose 5mg/kg 30 days – 13 years: 120mg/m²/dose once a day for 2 weeks, then 120-200mg/m²/dose 2x daily
Efavirenz (EFV)	Only > 3 years, > 10kg

DEMAND :
When to start ; What to start with ….

- **For Treatment and Care: Second Line**

Variations of

Abacavir (ABC)	< 16yrs or < 37,5kg: 8mg/kg 2x daily
Didanosine (ddI)	< 3 months : 50mg/m²/dose 2x daily 3 months – 13 yrs : 90-120 mg/m²/dose 2x daily, or 240mg/m²/dose once a day
Lopinavir/ritonavir (LPV/r)	6 months – 13 years: 225mg/m² LPV, plus 57,5 mg/m² ritonavir 2x daily, or weight based
Nelfinavir (NFV)	< 1 yr: 50mg/kg/dose 3x daily, or 75mg/kg/dose bd 1 yr - 13 yrs: 55 – 65 mg/kg/dose 2x daily

Based on these recommended doses, how many bottles of ARVs do we need to buy if 100 children will need ART in 2005

?

unicef

FIRST LINE / PMTCT
Operational Characteristics of available ARV Formulations

Treatment	Products available (volume)		Storage & other considerations	
PMTCT/ 1st Line	**Innovator**	**Generic**	**Fridge ?**	**Other**
ZDV	240ml	100, 200ml	No	
d4T	200ml	-	Yes	Supplied as pwdr
3TC	240ml	100, 240ml	No	
NVP	240ml	20*, 25,100ml	No	Need 0,6ml for PMTCT
EFV	180ml	No	No	
* Only available in donation programme, with dispensing syringe				

SECOND LINE
Operational Characteristics of available ARV Formulations

Treatment	Products available (volume)		Storage & other considerations	
2nd Line	**Innovator**	**Generic**	**Fridge ?**	**Other**
ABC	240ml	-	No	
ddI	237ml	-	No	May need antacid, 4g in 237ml
LPV/r	5x60ml	-	Yes	Need cold shipment
NFV	144g pwd	-	No	Crushed tablets cheaper
* Only available in donation programme, with dispensing syringe				

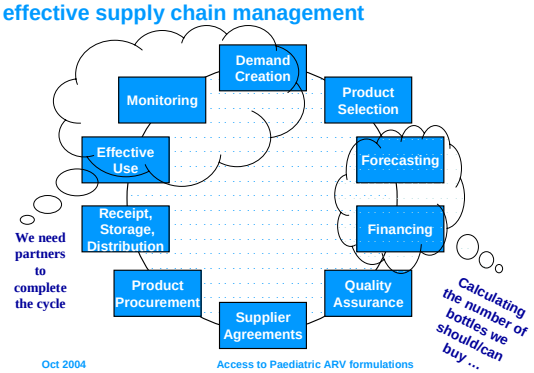
ARV liquid formulations can become expensive ..

Regimen Paediatric	Cost per month		Cost per day		Total Costs	
	original	generic	original	generic	1 year	5 years
ZDV+3TC+NVP (±3kg)	21.69	16.91	0.72	0.56	200.67	1,003
ZDV syr +3TC+NVP (±10kg)	53.61	43.35	1.79	1.44	514.36	2,572
ZDV caps +3TC+NVP (±10kg)	24.94	18.35	0.83	0.61	217.75	1,089

ARV Formulations available, but ....

- More expensive than adult formulations
- No fixed dose combinations
- Estimating needs are problematic
- Weight guided dosing will assist care-givers
- Some need cold storage, shipment
- Distributing glass bottles has it's problems
- Taste of formulations, bulk of supplies

Access to paediatric ARV formulations depends on effective supply chain management



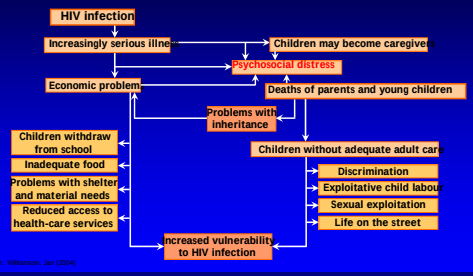
14. Ensuring comprehensive care of children? - Kathleen Casey

Ensuring comprehensive care of children ?

The unmet psychological needs of infected and affected children and their carers.

Kathleen Casey
Senior Technical Officer,
Testing & Counseling

Challenges in caring children and families affected by HIV/AIDS



Balancing physical and psychological support

- Common psychological and behavioral presentations in pediatric infection
- Common issues confronting counsellors
- Children and treatment adherence
- Gaps in services in Thailand (case study)
- Implementation strategies: supporting comprehensive care

Psychological impact-behavioral

- Psychopathological abnormalities
  63% of cases
  - Hyperactivity
  - Delayed adaptive behavioural skills
  - Oppositional disorders
  - Avoidant disorders
  - Depression/withdrawal/anxiety
  - Autistic like behaviours
  - Substance dependence

Psychological impact-behavioral

- HIV related sleep disorders
- Cognitive impairment (70-80% of all cases)
  - visual – spatial reasoning
  - attention
  - short term memory
  - language delay
  - gross motor skill retardation

Psychological and developmental impact

- Communication deficits in 80% cases
  - Expressive language delays
  - Receptive language delays
  - Impaired vocal capacity, oral-motor problems (articulation)

Infected children present special communication challenges to the counsellor and parents!

Key counseling tasks-children

- Supporting children - post disclosure
- Help the child work through feelings and beliefs about the illness
- Help children express feelings of grief and loss.
- Address issues around medical visits and hospitalisation (preparation strategies)
- Address issues around death and dying

Key counseling tasks -parents & carers

- Assisting parents & carers manage challenging behavioral disturbances
- Informed decision making –disclosure
- Family counseling post disclosure
- Managing treatment adherence challenges

Key counseling tasks -parents & carers

- Should the child be told (pros & cons)?
- When and by whom ?
- How much information should be given?
- What if questions about death arise ?
- What about the child's capacity to manage the information and manage the "secret" ?
- Should the school be told?

Our counsellors are unprepared!

- Most counselor training in the region is VCT
- Where counsellors are trained to deliver on-going counseling they are prepared for adult clients
- There is a widespread failure to address the psychological needs of both children & adults who are caring for them

Adherence counseling tasks

- Improving treatment literacy –carers
- Exploring parent & caregiver attitudes & beliefs related to treatment
- Problem solving adherence constraints
  - Planning schedules
  - Memory cues
  - Problem solving e.g. gag reflex

A review of HIV/AIDS Voluntary Counselling and Testing & psychosocial support Report of the Ministry of Public Health Thailand

Rapid appraisal and response HIV VCT and Psychosocial & support (RAR_VCT P&S) Thailand

Burden of care in Thailand

- "Global ORPHANS Study for Thailand" I estimated that in 1998 there were 34,372 children under the age of 15 who had lost their mothers to AIDS, and 420,731 whose mothers were HIV positive but asymptomatic.
- A second data collection in the year 2000 counted 10,270 children, 35% of which are double orphans
- There are limited specialist services offered by NGOs.
- Orphan homes for HIV infected children provide psychosocial care and encourage volunteer support.

UNICEF EAPRO "Estimating the numbers of children affected" Mekong children and AIDS 2000

Study size

- 16 regional hospitals
- 50 general
- 451 community hospitals health centers
- 82 private hospitals
- 90 NGOs
- PLWHA 192

Testing of children

- Lack of clarity relating to policies related to testing of minors without parental consent
  - 43.8% of regional hospitals
  - 42% of general
  - 40% of community hospitals
  - 19% of private hospitals
  - Unattached minors and testing - No policy.

Counselling of children

- Institutions reporting staff trained to counsel children
- 37.5% (n=16) regional hospitals
- 38.0% (n=50) general hospitals
- 37.9% (n=451) community
- 22.3% (n=350) health center
- 13.8% (n=80) private
- 41.4% (n=185) NGOs
- 51.8% (n=85) PLWHA

The burden of care in Thailand

- In the year 2003 - 4% of AIDS cases are children and 4,000 children are infected every year.
- >1/7th of all new infections are children

Strategies

- ✓ Clarify policies related to testing of minors, unattached minors and orphans
- ✓ Scale up "care counselor" training
- ✓ Develop curricula for counseling of children and parents
- ✓ Develop child support volunteer support & supervision networks programs
- ✓ Peer support facilitator curriculum to include child support and care issues
- ✓ Teacher HIV awareness programs

15. Challenges in paediatric HIV care, support and treatment – Arjan de Wagt

Technical issues - Diagnosis

- Diagnosis before 18 months is difficult without VL
- CD4 and VL testing expensive, often not available, decision on when to treat therefore difficult
- If VL available how to set up system for test analysis
- Counseling of families is complex
- How to test more women to identify exposed children: routine, pre-pregnancy etc?
- Guidance of disclosure of HIV status to children themselves, relatives, teachers

Technical issues - Management

- High levels of PEM among infected children, management is complex
- Guidelines on micronutrient supplementation among HIV infected children
- Pediatric care and treatment as part of a family response
- Support on how to care for infected children to care providers, e.g. grandparents
- Psychosocial impact and support to families and children is too limited

Programme issues – Prevention

- How to ensure that resources for treatment are not being taken from prevention
- How to use 3by5 as an opportunity of primary prevention
- How to accelerate PMTCT as part of 3by5
- Improve PMTCT follow up incl. PCP prophylaxis

Programme issues – Program management

- Regional coordination
- Programme indicators, benchmarks and targets are weak

Programme issues - Access

- Psychosocial issues, family support, access to education (discrimination)
- Post exposure prophylaxis for sexual assaulted children
- How to provide orphans with a home

Programme issues - Staff

- Need to strength knowledge and skills on HIV care/treatment
- Attitudes / discrimination by health workers
- Lack of adequately trained physicians and counselors
- What additional support (technical, psycho-social etc.) do health care workers dealing with paediatric HIV cases need. E.g. how to prevent burn out?

Programme issues - Adolescents

- Access (incl. legal) to services like testing and treatment
- HIV infected children growing up: sexual health, behavior and guidance

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