HIV infected children : where are we in 2007 ?

Philippe Msellati
UMR 145, IRD, Montpellier
CReCSS, Université Paul Cézanne d'Aix-Marseille

25 years into the HIV epidemic

Despite progress in preventing HIV transmission from pregnant mothers to their babies, more than 1,000 children around the world were infected with the disease each day in 2006

In 2006, children constitute:

- **5.8 percent** (2.3 million of 39.5 million) of the persons living with HIV
- **12 percent** (530,000 of 4.3 million) of new global HIV/AIDS infections
- **13 percent** (380,000 of 2.9 million) of HIV/AIDS deaths
- Only 10 percent in need of antiretroviral drugs have access to them (UNICEF).

HIV in children

- Ten years ago, HIV in children was an « invisible epidemic » (A. Desclaux)
- Today, HIV infected child became at last visible, with a chronical disease instead of a death sentence
- BUT
  - Few resources in social sciences (except in clinical psychology) on HIV in children
  - Even if they are much more studies on chronical diseases in children but not in developing countries

Medical care management and research

- In the last ten years :
  - Pediatric AIDS has been eradicated or is nearly eradicated in western Europe, USA, Brazil and Thailande
  - In other countries, there has been real progress in access to HAART and care management even if there are still a lot of things to do
  - Studies have shown that cotrimoxazole prophylaxis in HIV infected children is very useful and that HAART are as good in the south than in the North
- Networks exist
  - Penta in Europe, PACTG in USA for a long time in the field of clinical trials
  - Anecca in Africa from the early 2000's

Non medical care management

For several years, there is a management of social and psychological needs of HIV infected and affected children by non gouvernemental associations.

- Without these aspects, medical care management is of limited interest
- Often implication of women living with HIV and involved directly in care of HIV infected/affected children
  - Importance of home visits
  - Places where to harbour children and families
    - School support, nutritional support, income generating activities (families and teenagers)…
    - Discussion Groups (teenagers, parents)

But most of the time there is a very scarse spreading of locally acquired experience

Associations have often little time or skills to communicate or share on field practices and experiences.

10-Point Package for Comprehensive Care of an exposed/infected child

1. **Early infant diagnosis**
2. **Growth and development monitoring.**
3. **Routine health maintenance**
4. **Prophylaxis for OI's**
5. **Early diagnosis and treatment of infections**
6. **Nutrition counseling**
7. **HIV disease staging**
8. **ART for eligible children**
9. **Psychosocial support to the child and family**
10. **Referral for additional care**

Source: Handbook for Pediatric AIDS in Africa, 2004

A Framework for Comprehensive Care for Children Affected by HIV/AIDS & their Families

Source: Handbook for Pediatric AIDS in Africa, 2004

Paediatric HIV diagnosis

- Diagnosis in children is difficult before loss of maternal antibodies BUT we need diagnosis in children as earlier as possible
  - ➢ because of the very important mortality in HIV infected infants that shows the necessity to treat by ART early those in need of it
  - ➢ Because of the heavy burden/stress on parents waiting for this diagnosis and maybe going away from PMTCT programmes
- Barriers :
  - Laboratory infrastructure, lack of policies for testing young children
  - Skills gap in health workers, challenges of disclosure
  - Exclusion of children from existing testing services

Treatment and compliance

- ➢ How parents and children integrate and manage treatment and care
- ➢ Compliance with usual difficulties
  - Taste of drugs, adverse effects, intake hours inadapted to school schedule, problems of confidentiality, social events, travels,
- ➢ And specific aspects in relation with childhood
  - Relation to parents, parents skills in care, HIV status knowledge, absence of pediatric forms of drugs, parents as intermediate for the oldest
  - Children often forget to take pills, simplify themselves the intake (suppression of noon intake for example)
- ➢ How to improve compliance ?

Disclosure of HIV status

- Disclosure to parents of the child HIV status
  - Always a trauma for parents and especially the mother (reveals her own status)
  - Still more difficult when parents have been involved in PMTCT programs (« failure »)
- Announcement to the child
  - Of his own infection, of his/her parents HIV infection
  - At what age ? How ?
  - It is a major event in the life of the children
  - A lot of anxiety and culpability for parents
- Parents are quite anxious about secrecy and possible disclosure by the child
- Children know they are not like other children (disease, treatments, health care frequentation…).
  - The oldest know it is HIV/AIDS but need words from parents, adults, care givers to name the disease and accept it (and its treatment)
  - Disclosure is a traumatic event but in the same time the child knows at last what is his disease and is proud of the trust of parents who share the HIV status with them.
  - Care givers often have to help parents to announce

Families

- Educational difficulties of parents in front of an HIV infected child
  - ➢Treatment and health improvement give a future to infected children
  - ➢BUT Unability to put limits to these children
- Substitute families
  - ➢Often less informed than parents
  - ➢Afraid of HIV infection, specially for very young children
  - ➢Important to address these problems with specific counselling for families
- Children head of families

Newborns and infants

- Even for treatment, many still untreated (because of difficulties in diagnosis and treatment : absence of drugs or difficulties of intake)
- Disclosure of diagnosis to parents (specially difficult if parents were involved in PMTCT programs : failure)
- One of the most difficult problem for mothers and care givers is about very important failure to thrive in 6-12 months children after a normal growth.

Teenagers

Most of HIV infected Children in the North countries are now teenagers
They will be more and more numerous in South
Special life period with body and mind transformations for children living with HIV from birth
Beginning of sexual relations, way to adult life

Disclosure has to be done
For treatment the worst time : Compliance Problems !
Difficulties to live between secret and knowledge
Some refuse to invest themselves in social life, deny theinfection
Conflicts with parents

Discussion Groups are very important : allow to meet peers in the same situation, a place to speak, to share problems and questions, to help on treatments and compliance

Orphans and Vulnerable Children

- Estimated to 15-20 millions in 2010
- Taken in charge often by broad families but overwhelming their capacities
- Problem of definition and identification
- Risk of stigma
- Need equity in education, nutrition and health access
- Loss of learning environment (for work but also for living abilities)

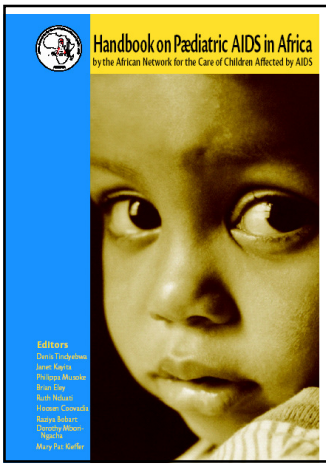
Research and information ongoing

- Penta, PACTG (but children in South)
- ANECCA
- 3C's for Kids, Ped Art Link,
- Coalition on Children Affected by AIDS
- Grandir

grandir info

Vulnerable Children and Youth Studies, April 2006; 1(1): 1

Routledge Taylor & Francis Group



- Distributed in over 15 countries in Africa
- English & French editions
- Companion training curriculum available
- Handbook available on www.rcghc.org

Other questions

- How the child lives his infection, his parents infection, deaths ?
- How to help the child to be resilient ?
- What about psychiatric and psychological disorders : depression, behaviour troubles ?
- How to prevent « burn out » of health workers and care givers ?
- Haart for children are now often free but there is a need for free care and support
- Need for economic analysis of care and management costs (and savings).

Acknowledgements

- Special thanks to my colleagues
  - Aka Dago Hortense, Cacou Chantal
  - Dossou Rose, Hejoaka Fabienne
- Thanks to the teams from Abidjan and Bobo Dioulasso and to the associations AED, Amepouh and CHIGATA
- Thanks to ANECCA