Care for HIV positive adolescents

Rama Diagne
Symposium at the 10th INTEREST Workshop
Wednesday 4th May 2016, 11:00-13:00

Martin Freeman, Universal
An active artist and California native, Martin Freeman was kind enough to donate his extraordinary artwork to Janssen. Martin was diagnosed with AIDS in 1990.
SUPPORTING BEYOND TREATMENT – CARE FOR HIV POSITIVE ADOLESCENTS IN CHNEAR (SENEGAL)

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General

Adolescence: Latin origin "adolescere" means "grow up to."

- Transition period:
  - Children → adult
  - 10 to 19 years old according to WHO

- Maturation and complex psychological evolution period:
  - Deep changes

- Difficult management of chronic disease
Epidemiology

- **HIV burden:** 2.1 million adolescents


- **Modes of infection:** Transmission from mother to child / Sexually
Survey conducted in Thailand / Institute for Research and Development: TEEWA


« Teenagers living with antiretrovirals »

- 800 teenagers from 12 - 19 years, as well as parents and / or legal tutors
  - Necessity of information to remove fears and avoid stigmatization
  - Needs expressed by families: respect confidentiality, economic and social support
  - Measures for ART: daily intake, therapeutic treatment during weekend
  - Accidental disclosure: indiscreet adults, classmates, other
How Did We Develop Adolescent Friendly Services?

- Transitional Consultation
- Psychosocial Care
  - Status disclosure
  - Therapeutic education
  - Discussion groups
  - Psychological listening
- Reproductive Health
Transitional “Consultation”

Infectious Diseases Service at the University Hospital of Fann: April 2011

- **Teens >16 years old** monitored at ARNHC (Albert Royer National Hospital of Children),

- **Multidisciplinary**: Infectious disease specialists, (adult / pediatric ward), pharmacists, sex therapist, social workers, mediators,

- **Monthly consultation**

- **Beyond ART**: discussion group, therapeutic education, sex education...
Transition in ARNHC: Baseline Characteristics

- **Between 2011 and 2015:** 38 teenagers went in transition
  - Median age: 18 years
  - Sex–ratio: 1.92 (25 male and 13 female)
  - No lost to follow up
  - Deceased: 3
    - Severe acute malnutrition, renal lymphoma, progressive multifocal leukoencephalopathy
  - Adult consultation in June 2015: 27 (18 male and 9 female)
Medical monitoring

- **Patients on ART at the time of transition:** 20
  - Undetectable viral load: 11 (55%)
  - Virologic failure (HIV-RNA > 1000 copies/ml): 9 (45%)

- **Immunovirological state changes:** 20
  - Undetectable viral load for 18 patients (90%)
  - All 11 patients are still undetectable: N=11 (85%)
  - Improved biological test results for 6/9 patients who were failing at beginning

- Transition did not succeed for only 3, who are in 2nd line failure
Mortality in perinatally HIV-infected young people in England following transition to adult care: an HIV Young Persons Network (HYPNet) audit

- 11 deaths
- Transfer: median age 17 yrs, CD4 120. At death: 21 yrs, CD4 27
- Causes: suicide (2), end stage AIDS (3), respiratory infections (2) PML, CNS lymphoma, ICH and Toxoplasmosis.
- All had treatable virus in year of death
- 9/11 mental health diagnosis


Aging and loss to follow-up among youth living with human immunodeficiency virus in the HIV Research Network.

19.8% were LTFU in the year after turning 22 years. Receiving care at an adult versus pediatric HIV clinic (AOR, 2.91; 95% CI, 1.42-5.93),

C. Dollfuss, EVA 2015
Is the Operation of Medicine Services for Adults Suitable for Youth/Young Adults Monitoring?

- Over 287 youth from 12 to 24 years infected in adolescence
  - 69% initiated treatment
  - Relative risk of interrupting treatment with adult medicines compared to pediatrics: 3.64

- **Single-center study** case-control comparing problems monitoring young between 17-24 years versus adult > 24 years

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<th>17 – 24 years</th>
<th>&gt; 24 years</th>
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<tr>
<td>Virological failure by M6</td>
<td>43 %</td>
<td>22 %</td>
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<tr>
<td>Virological rebound</td>
<td>56 %</td>
<td>13 %</td>
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<td>Lost to follow up</td>
<td>44 %</td>
<td>11 %</td>
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- Adult medicine services must also improve their practice to better meet the needs of young patients

References:
2 RYSCAVAGE  P. J Acquir Immune Defic Syndr 2011;58:193–197

C. Dollfuss, EVA 2015
How Do We Provide Psycho-Social Support?

- Therapeutic Education
- Disclosure
- Discussion Groups
- Psychological Listening
Therapeutic Education: Age >7 years

- **Educational Diagnosis**
  - Family environment
  - Scholastic
  - Life projects

- **Information: Immunity basics**
  - Microbes: Disease
  - White blood cells
  - Importance of medication and treatment monitoring
Disclosure Process: Age >12 years

- Preparing children may require several sessions
- Prior consent of parents / tutors +++
  - If possible in their presence
- Test their knowledge on:
  - Microbes and diseases
    - Acute: malaria (paludism)....
    - Chronic: cancer, diabetes, HIV infection (100% refer to AIDS)
Disclosure Conditions

- **Individual disclosure**
  - Individual preparation and disclosure
  - Number of sessions: generally 3-4 sessions
  - Session length: 20 min / session
Group Disclosure

- Grouped preparation → time saving
- Connection between children / parents
- Psycho-emotional support, peer group ++

  !!! But homogeneous group

- Same age children
- Concerned parents or tutor
- Evaluation of each step

- **Individually** assessing knowledge before group disclosure
Post-disclosure: Recall of information and evaluation of emotions after 15 days

For children
- Information return is better with children individually prepared
- Disclosure “accepted” for the majority
- 9 children are in denial (10%)

Among parents / tutors
- All feel more comfortable with their child more involved in treatment
- 27 tutors
- 53 Concerned parents
  - 30 revealed their own status at disclosure time
  - 3/4 unaffected parents: "relieved" by the disclosure (not vertically transmitted)
Discussion Groups

- Some tutors have often hostile attitudes stigmatizing orphaned teens under their supervision
- Difficult living / acceptance of infection exacerbated by misinformation
- Poor self-esteem of some teens related to body image (delayed height and weight)
- Questions related to their love life: sharing status, how to protect themselves
- Wedding desire and ability to have healthy children
- Importance of treatment adherence in achieving life
Impact

- Mutual psycho-emotional support; strengthening links between peers
- Deconstruction of misrepresentations on infection
- Better treatment adherence
- Enhancing self-esteem
- Appeasing fears / anxieties of teenagers
- Teen's reconciliation with itself and its immediate environment
- Preventing risky behavior
Psychological Listening

- Social and family background often difficult: Insecurity / conflict between parents or tutors ...
- Overprotective attitudes of teens developed by some parents, while teens aspire to independence / freedom
- Fear, anxiety, questions about their future
- Questioning related to sharing their infection
- Denial of infection
How Do We Address the Issue of Reproductive Health?

Number of adolescents living with HIV by mode of infection in the 25 countries which contribute to the majority of AIDS-related deaths among this age group.

Source: Futures Institute analysis of UNAIDS estimates.
Proportion of teenagers, 15-19 years, who have started their reproductive life in Senegal

Agence Nationale de la Statistique et de la Démographie (ANSD) [Sénégal], et ICF International. 2014. Enquête Démographique et de Santé Continue (EDS-Continue 2014). Rockville, Maryland, USA : ANSD et ICFInternational.
In Practice?

- **Between 2013 and 2014:**
  - 40 adolescents and their parents / tutors have been trained in reproductive health

- **Actors:**
  - Reproductive health direction, psychologists, social workers

- **Topics:**
  - Adolescence, puberty and body changes
  - HIV, definition and modes of transmission, risks related to sexuality
  - Reproductive and sexual health
  - Self-esteem, Human rights, the daily hygiene to respect…

- **Methodology:**
  - Oral presentations, discussion groups, focus groups with parents, role plays…
Results

- **March 2016**: Assessment of the impact of these trainings
- **Targets**: 40 children (10 in each group)
- **Surveyed to date**: 27

**First conclusions**:
- This training was the first channel of information on reproductive health for many teenagers
- HIV requires discretion and constant medication
Results

Findings

- Desire not to have sex until marriage to keep the secret, but also because of religious prohibitions and health risks
- Condom cited as a priority means for protection
- This training enabled them to speak with their peers especially during discussion groups to talk about their fears

Recommendations

- Increase number of training days
- Setting up an Internet connection to facilitate research on this topic
- Would like to be contacted directly for this type of activity
What are the Challenges?
What are the Opportunities?

- Schooling/ socio-professional integration
- Management of disclosure: on time, psychosocial support
- Assistance in transition
- Integration of services: medical care, reproductive health
- Support services for teens