

PATIENT SUPPORT FOR CHILDREN LIVING WITH HIV/AIDS



MSF – OCB David Goetghebuer, July 2008

PATIENT SUPPORT

- A definition:

All the activities aiming at supporting the patient facing his disease and his treatment, beyond the purely medical care aspects.

- This includes 3 areas:

- Education : *Health education, explaining the disease, OI's, treatment literacy, ...*
- Emotional support : *psychosocial support, living positively*
- Social support : *community follow-up, home visits, in kind support, ...*

- Performed by :

Counsellors, Educators, Social Workers, Volunteers, Lay Counsellors, Peer Educators, ...

Problems encountered on the field

- Patient Support Staff not at ease with children, not trained, sometimes even not motivated.
- Lack of specific tools and methods, appropriate for children of different ages, and their care-takers.
- Parents / care-takers afraid of testing the children, or to disclose their status to them, and participate to the treatment.
- Not many children patients, no specific recruitment measures
- Poor adherence, defaulting, psychological problems.

Responses developed by the field

- Train the Patient Support Staff : counsellors, educators, social workers, ...
- Develop specific tools and activities : books, games, creative activities, support groups, ... for children of different ages, and their care-takers.
- Work with the parents / care-takers on supporting the child.
- Improve recruitment of child-patients

Compiling experiences from the projects and from other organisations, we now propose :

- A minimal package of specific tools and activities for children
- A recommended package
- And an ideal package

Patient Support for children : The minimal package / 1

1) Age categories : 0-2 / 3-7 / 8-12 / 13-17

2) Children consultation day at the clinic

3) A child-friendly environment in the clinic:
Reception, consultation rooms, lab, ...



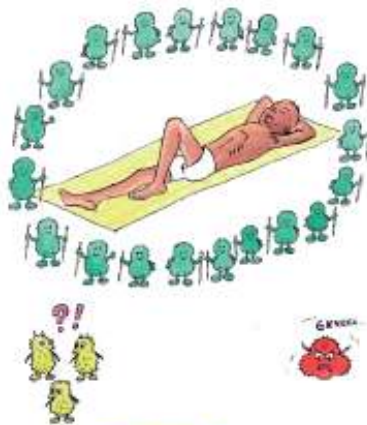
4) Child-friendly and competent staff, specifically trained on patient support for children

The minimal package for Patient Support / 2

5) Individual Counselling : for the child and his care-taker, adapted to the age, progressive disclosure.



6) A set of counseling cards / flipcharts, present in each consultation room

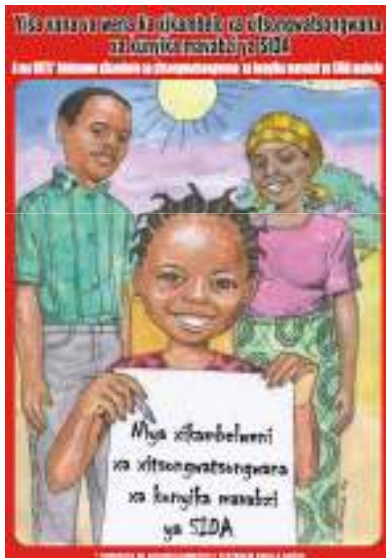


7) A pill-taking tool for children



The recommended package / 1

(= The minimal package, plus :)



1) A strategy of recruitment of HIV infected children.

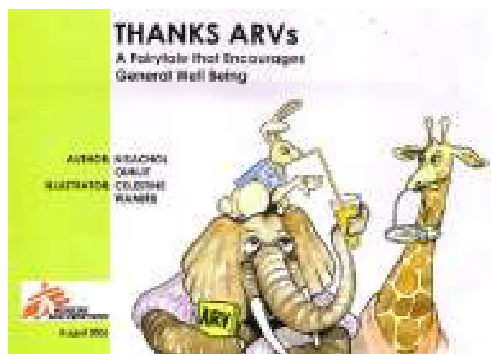
2) A children space in the clinic, with toys, and with adults in charge.



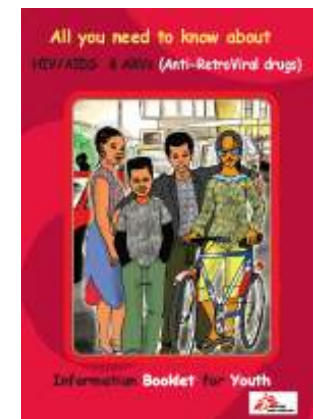
The recommended package / 2

Books about the disease and the treatment :

- 1- A book or leaflet for the care-taker of an infected child, explaining the basics about the care and support for the child
- 2- one book for non disclosed children (not naming the disease)



- 3- and one book for the disclosed children (naming HIV/Aids)



The recommended package / 3

- * Group sessions (educative and supportive) for children.

A group should have only children from the same age category and the same level of disclosure.

- * Group sessions (educative and supportive) for care-takers.

- * Social consultations

- * Community follow-up, possibly through partners



The ideal package options / 1

(= The minimal plus recommended, plus :)

Creative activities

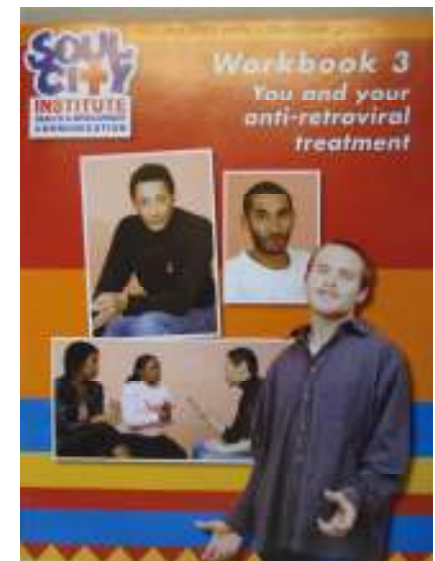


Hero Books



Handbook

Workbook



The ideal options / 2

Films



Games



Performances



Party /
Day out



Results

- Too soon to tell ...
- Not many studies on impact of patient support on adherence and well-being of infected children
- But we get encouraging results:
 - * *increasing number of children in the projects*
 - * *improved adherence, less defaulters*
 - * *happier children*

Challenges ahead

- Decentralization and integration :

implement the minimal package in many health structures, with less patients and less staff

- Early treatment of infants :

Improve the patient support through care-takers, for an increasing nr of babies under ART

- Patient Support for Adolescents :

Find new ways with this increasing category of patients

Let's GO!

