

Sharing perspectives from the field : Disclosure to children



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Background of the research

Data collected

- Data were gathered during 18 months of fieldwork in 2005-2007 in the urban zone of Bobo-Dioulasso in Burkina Faso, in West Africa
- HIV prevalence = 2% in 2007



Qualitative methods as participative observation and Interviews were used

- Interviews were conducted with
 - 52 parents and caregivers,
 - 35 HIV-infected children and adolescents aged from 8 to 18 years - 20/35 were aware of their status - Drawings used as support for interviews
 - 20 children from OBCs, unaware of parental status and 20 children in the general population
 - 15 healthcare providers (doctors and counselors)

Toward a holistic approach

- A large body of scientific literature exists on HIV disclosure to children, even if few were conducted in low-resources countries
- Holistic and social approach of disclosure HIV
- Focus on 5 points
 1. Children's awareness of their illness
 2. Children and secrecy
 3. Children's knowledge of HIV/AIDS
 4. Disclosure and affected children
 5. Children and disclosure : a missing point on the AIDS policy Agenda

Background HIV disclosure to children

What does exist ?

- Recommendations and guidelines
- Innovative programmes and localized interventions

In the context of public health

- Lack of materials and support (disclosure + treatment literacy)
- healthcare workers are unskilled on children's issues
- Structured and standardized interventions are exceptions

Consequences

- Parents are not supported to disclose their status and communicate with children about HIV/AIDS

I. CHILDREN'S AWARENESS ON THEIR ILLNESS

Children's awareness

- Children's HIV disclosure issue is often seen as a binary situation : **Disclosure versus non-disclosure**.
- Some children are not formally told but may suspect their parents or their own HIV status
- Children's awareness is underestimated by adults :
 - children did not dare to speak plainly and ask questions to their parents and healthcare workers
 - children make a pretence of being unaware

Children bear the burden of secrecy alone

How do children become aware ?

- Witnesses to some revealing acts (*e.g. overhear conversations about their illness, HIV test result given in their back or gossip*).
- They also suspect their illness by cross-checking information : poor health for many years, regular visits to hospital or pills needed to be carefully taken every day ...
- Some others children are told by third persons, without parental agreement – “Traumatic disclosure”

Quotes from children's

- «Mummy tells me to take my pills otherwise I would die, and to not tell anybody [...]. If mummy tells me not to tell anybody, it's because it must AIDS». Esther, 8-year-old-girl.
- «When mummy told me that I had AIDS, I told her that I knew that. When the doctor gave her the results of the test in his office, I saw her face and had understood...». Adama, 14-year-old boy.
- «Where I live, people insulted me... They were saying that I had AIDS». Farid 11-year-old boy.

II.Children, secrecy and stigmatization

Children and Secrecy

- One of the most common barriers to disclose is parent's fear that children may reveal "their secrecy" to others if they were informed

Parents underestimate that children children's knowledge and understanding of HIV/AIDS.

Children facing Stigma

- When I asked children as to whether they talk about, or would like to disclose parental or their own status, a common response given by them was: *“I don’t want the others children to know; otherwise they will not play with me anymore”*.
- Parents do not understand that children know that HIV/AIDS is highly stigmatized and want to keep scrupulously the family secret.
- Children don’t want to be stigmatized.

How children conceal their status

- Children develop strategies to conceal pills-taking or visits to hospital (*eg. they hide themselves to take their pills, or discreetly remind their mothers of the hour, by raising their hand to mouth and tap on their lips to signify that they have to swallow their pills, make a light movement with their head and glance at the place where medicines are put away. They can also whisper to their mother "It is time".*)
- Children's develop concealment strategies because their parents tell them to hide their pills and "to not to tell anybody".
- Many others children who are neither aware nor told to hide, know of the secret dimension surrounding their illness, also adopt concealment strategies

III.Children's knowledge of HIV

Children's knowledge of HIV

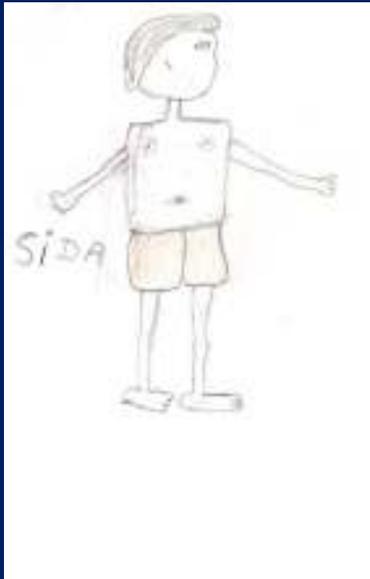
- Contrary to parents' and caregiver's perceptions, most of the children interviewed know HIV/AIDS and its symptoms.

As a result of wide media coverage of HIV/AIDS in Burkina Faso, clinical signs of AIDS are well known by adults as well as by children. "Social disclosure"

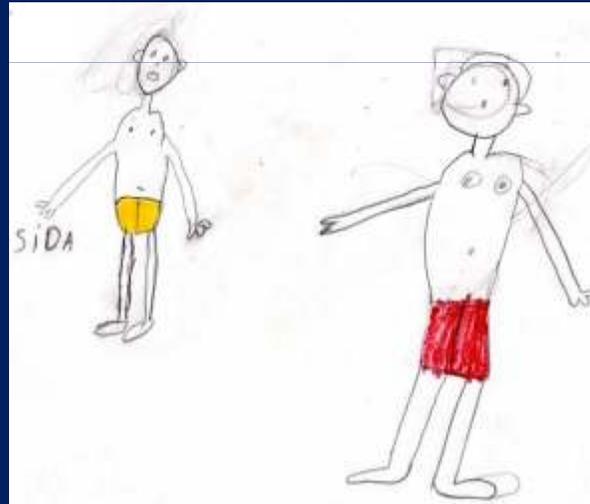
Slim and weak bodies

Children depict in their drawings weak and lean bodies

Slimness



11-year-old boy



10-year-old boy

Weakness



8-year-old girl

Skin rash and diarrhea

Skin rash



,10-year-old girl

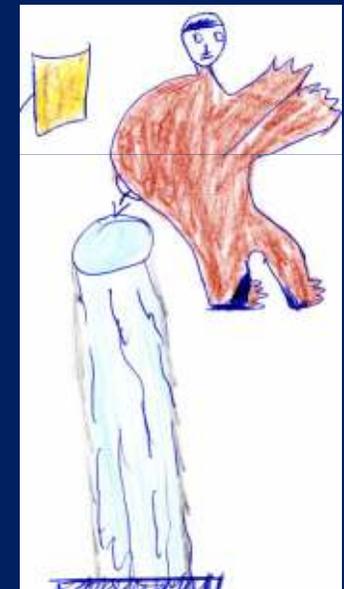


12-year-old girl

Diarrhea

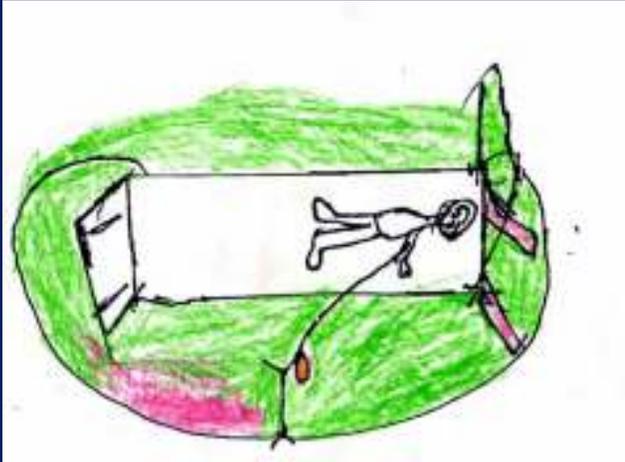


10-year-old boy

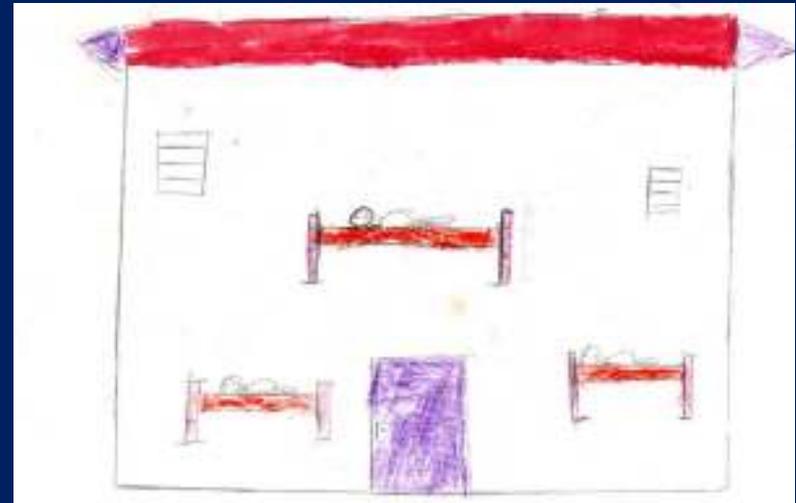


12-year-old boy

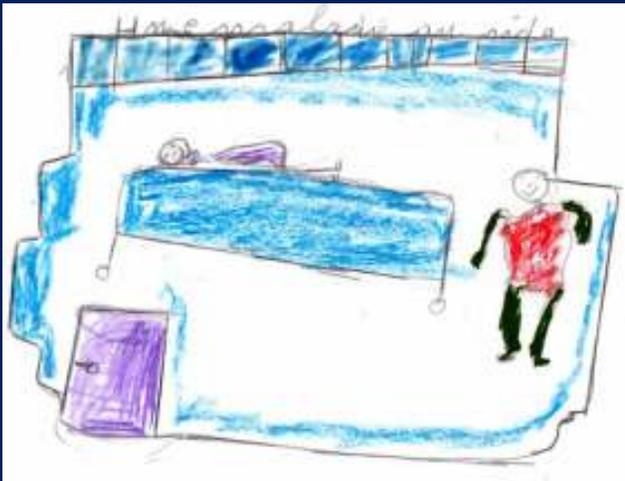
Bedridden people,



Farid, 11-year-old boy



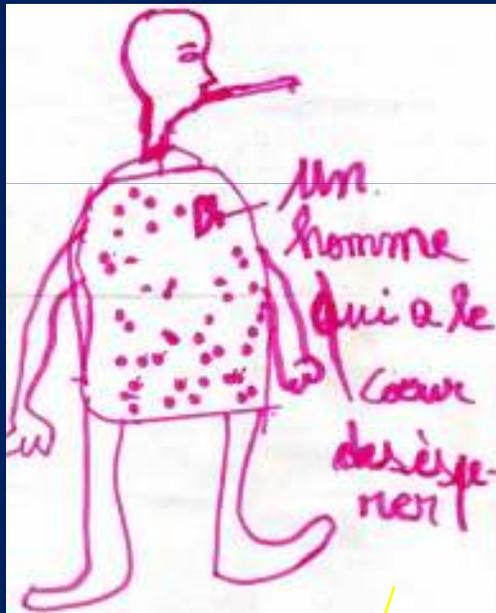
Madou, 11-year-old boy



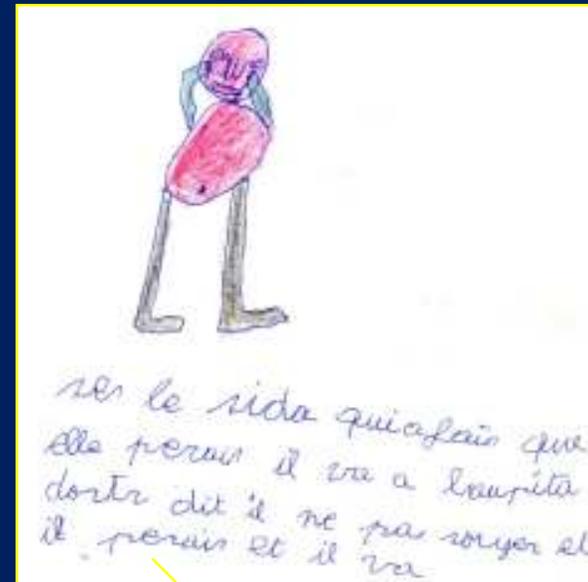
Souleyman , 9-year-old boy

A “serious”, “deadly” and “incurable” disease

They finally associate HIV/AIDS with death and are not well informed on access to and efficacy of ARV treatment – even in the case of those aware of their status.



« A man with a desperate heart because he has AIDS »



« He is crying because of AIDS. He went to hospital and doctor said he can't treat. He is crying and ... »

When children are well informed

Without HAART



“When you don’t take your medicine, AIDS kill your soldiers”

With HAART

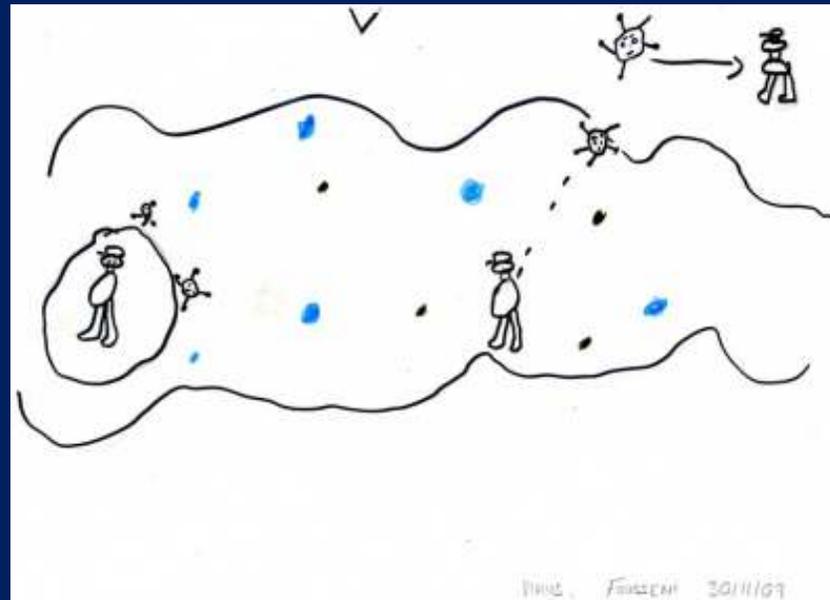


“When you take your medicine, soldiers are strong to fight AIDS”

Children and therapeutic literacy



Hélène , 8-year-old girl



Farid, 11-year-old boy

IV. How about affected children ?

How about affected children ?

- **HIV disclosure to children also concerned affected children**
- **Affected children may be less informed but**
 - Preferential care of infected children may cause jealousy with siblings who don't understand why
 - Affected children are also anxious because of parents poor health and parents taking pills daily
 - Children play a proactive role in their parents' or siblings' treatment (role of reminding and caring)
 - For orphans children, parent's grief and bereavement

V. HIV disclosure to children :

**A missing point from AIDS
policy agenda**

Adults disclosure *versus* children disclosure

Why a double standard?

HIV counseling and diagnosis disclosure

- For adults : 😊
 - Delivered by well-trained healthcare workers
 - Within an institutionalized and standardized framework
- For children : ☹️
 - Parents are not supported to disclose their status and/or communicate with children about HIV/AIDS
 - Healthcare workers are ill-trained on and lack guidance on child-related issues
 - Lack of evidences-based, standardized and assessed interventions

Toward a “disclosure partnership”

- Need to set up a “disclosure partnership” with children, parents and healthcare workers
- Need for trainings for counselors and healthcare workers on counseling and communicating with children
- Need for providing communication supports, including children’s and adolescents’ friendly supports

Conclusion

- Holistic and dynamic and age-appropriate approach of HIV disclosure
- HIV infected AND affected children
- “Disclosure partnership”
- Training of healthcare workers on child-related issues
- Don't forget voluntary counseling and testing

No double standard : National and international AIDS policies have to take significant steps to offer strategic frameworks to increase and improve the disclosure process of HIV/AIDS to infected and affected children and adolescents

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Children, adolescents , parents and caregivers





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