



WHY I TAKE MY MEDICINE



Interagency Task Team

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Overview

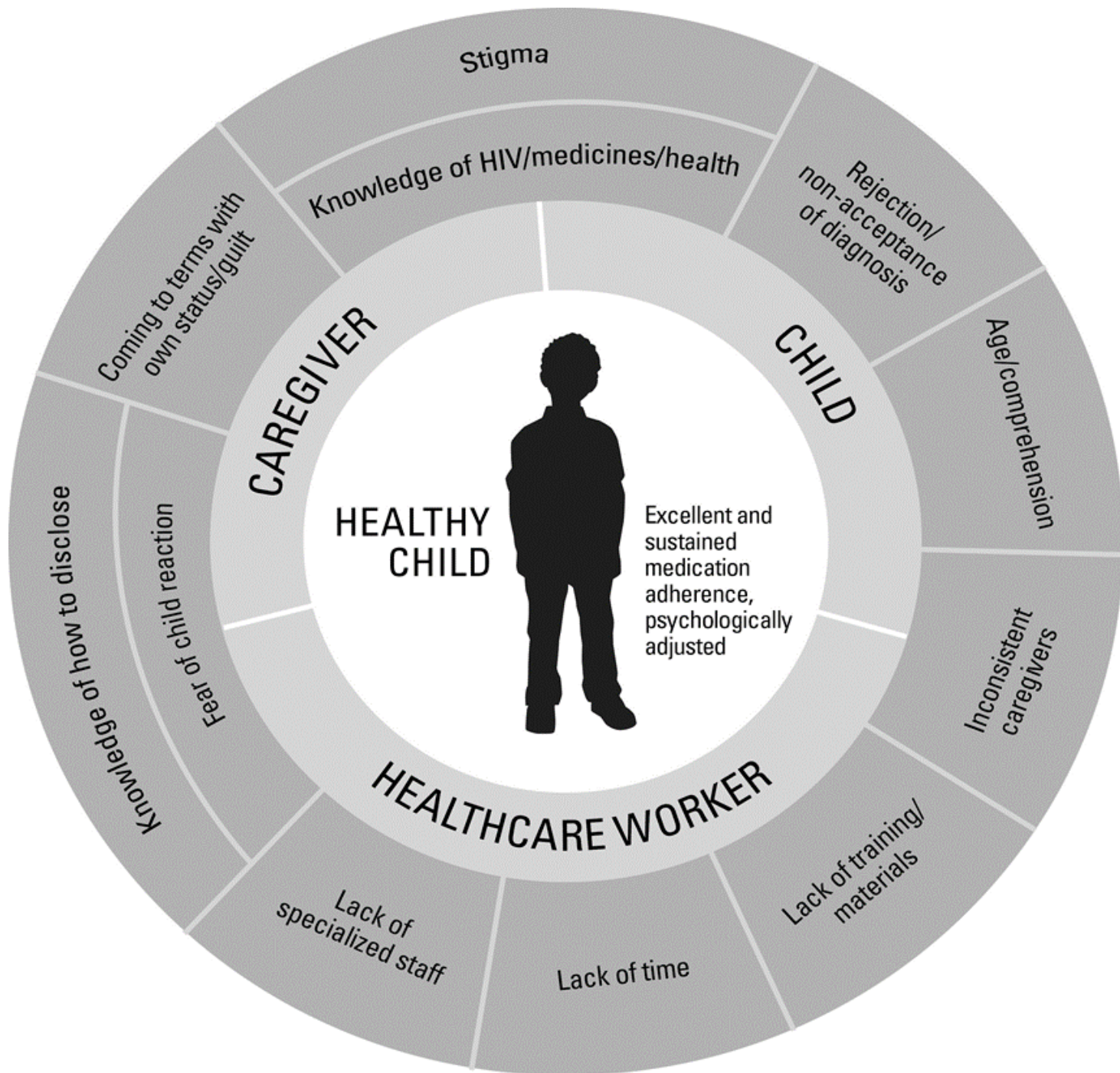


- Background
- The intervention itself
- Evaluation of the intervention

Barriers to disclosing HIV status



- Health care workers don't know how
- Caregiver reluctance
- Impacts health care worker capacity to counsel their pediatric patients
- Needed support materials feasible for use in busy clinic settings



Solution



- Disclosure program developed and integrated into routine paediatric HIV care
- Rolled-out to all health facilities managing children on ART
 - ▣ Doctors, nurses and counselors trained as teams

Pediatric Disclosure Form

Paediatric Disclosure Form

Health Facility: _____

Name: _____ Unique No.: _____ Date of birth: _____ Gender: ____ Discos. Reg. No.: _____

Primary Caregiver: _____ Relationship to child: _____

Parent or guardian (if not Primary Caregiver): _____ Relationship to child: _____

Attach this form to the child's patient care booklet to assist with the child's disclosure process. Record child's details in the Paediatric Disclosure Register and copy the register number to the space on this form. At each visit the HCW should determine a child's understanding of the disease as this re-enforces correct understanding, and complete the information below. Record the date of full disclosure in the box below, on p.2 of this form and in the Paediatric Disclosure Register.

Does the child know HIV status before introduction of the book?

____ Yes ____ No

If no, record date HIV status is fully disclosed: Date of full HIV disclosure _____

Remember to record this date on page 2 of this form and in the Paediatric Disclosure Register. Then **turn to page 2 to record post-HIV disclosure assessments**

Date of visit	Age (yrs/mths)	Mths on HAART	Adherence since last visit	Child's response to "why are you taking your medicines"	*Disclosure discussions today	Adult who is with child at this visit (name and relationship)	What child wants to be:
							Other comments

Health Facility:

Ministry of Health and Social Services, Namibia, Feb 2012 version

Readiness Assessment

Assessment of Family and Child Readiness for full HIV disclosure

The information on this form should be collected over several visits. Issues should be addressed as needed before full HIV disclosure takes place.

Name of Child..... **Name of Primary Caregiver**.....

Can be asked in the presence of the child:

1. Who else is in the household?.....
.....
2. Who gives medications to the child?.....
.....
3. Who takes the child to appointments?.....
.....

Should not be asked in the presence of the child:

4. Who knows the child's HIV status?.....
.....
5. Do any other household members also have HIV and if so, are they taking ARVs?
.....

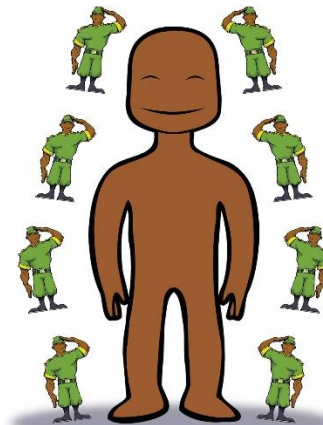
The Disclosure Book

Health Care Worker:

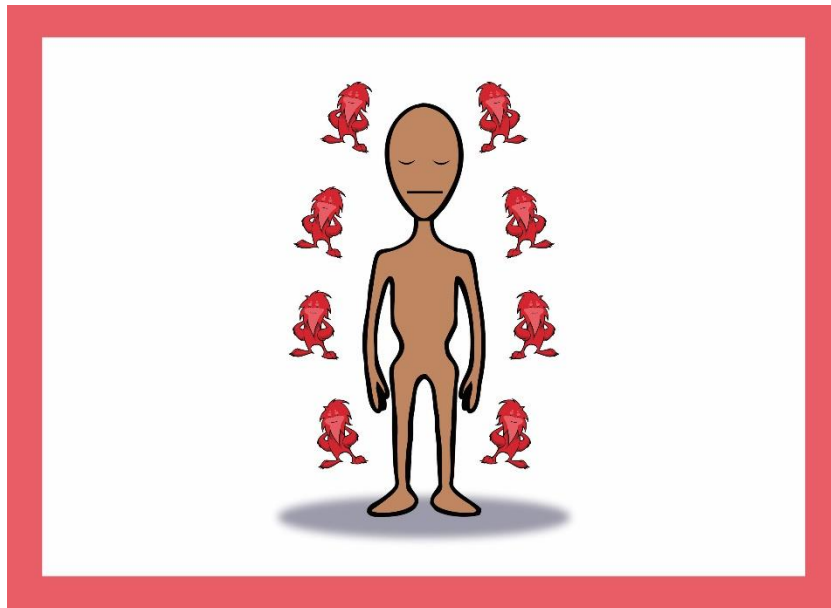
- First read this page to the child and while reading, point to the soldiers around the body.
- After reading ask, "Does the child look healthy?" The child should say, "Yes."
- Then ask, "Are you feeling healthy today? What do you think your body soldiers are doing?"
- If the child feels healthy he/she should explain that the soldiers are protecting him/her from getting sick.

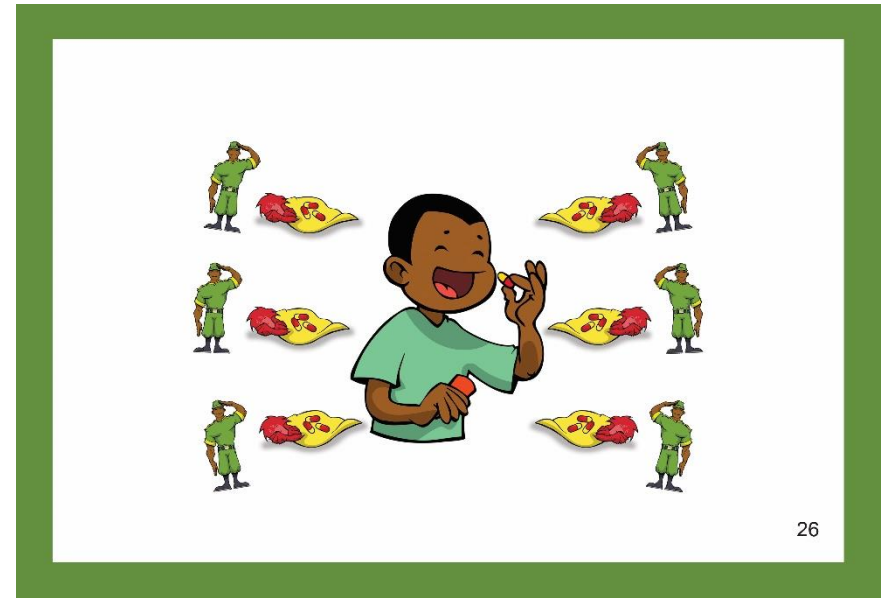
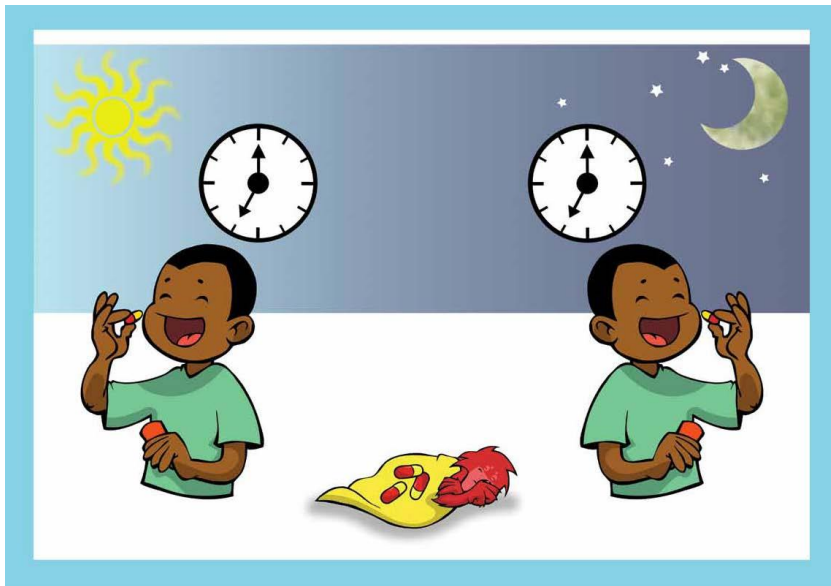
When you are healthy there are many strong body soldiers inside of you protecting you from getting sick.

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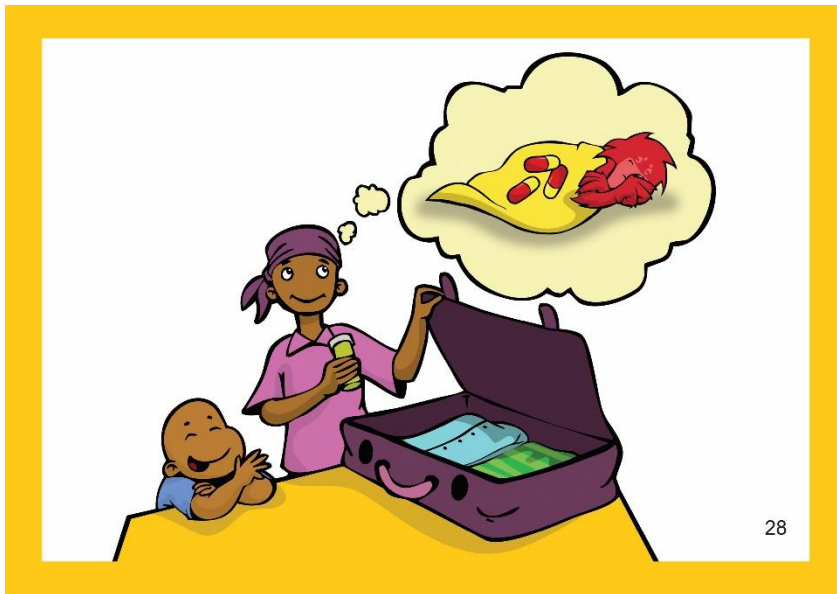


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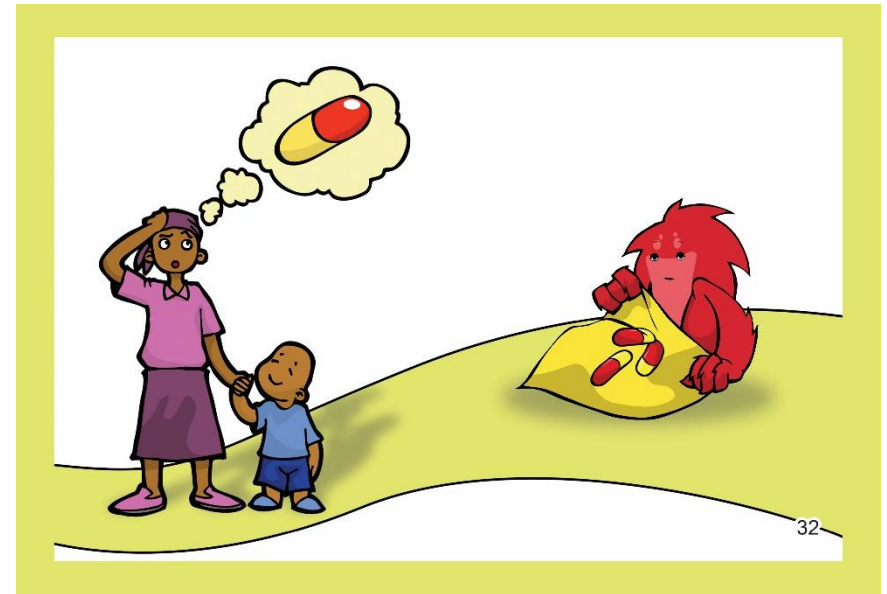




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38



40



Evaluation Questions



- Does the disclosure program help caregivers and health care workers engage in the disclosure process with children?
- Does the disclosure program help children adhere to their medication?
- Does the disclosure intervention succeed in bringing children to full disclosure?

Methods: 4 study sites



- 35 HCW interviews
- 64 CG interviews
- Reviewed over 1018 patient charts
- All qualitative data dual coded, managed with Atlis.TI

Findings



- 31 of the 35 HCWs reported regularly using some component of the intervention with children and/or caregivers
- Disclosure book most highly valued in addressing barriers to disclosure

Accessible shared language



“The book simplifies the disclosure process because... it is arranged stage-wise.. you are building a story and you reach full disclosure, it’s not haphazard. And if maybe we were to do it from our own heads, we can jumble things and mix things and actually create problems with the kids that we are disclosing to. It builds the story as you go for the kids to understand.” (HCW)

Accessible shared language



- *[E]ven when you ask them why they are taking the medication, that child will tell you that ‘there are some bad guys in my body and I want my anti bodies to be strong and destroy these bad guys.’ (HCW)*

Caregivers learn



“They [CG] generally like the book. It also makes the caregiver understand the virus, you would assume that they already know, but once you use that book you will see the interest of the parent go higher. They will say that I did not understand this myself, so it also works both ways.” (HCW)

Reduces CG reluctance



“When you ask those [resistant caregivers], ‘Does your child know why she or he is taking medication, do you want us to tell the child?’ they used to say ‘no’, but now when you bring in that book, you tell them at first we are not going to talk about HIV, everyone says ‘I like that kind of book.’” (HCW)

Reduces CG reluctance



“I like it because it’s nice. There is nothing that can scare the child, where the child might think that if I continue to take the medication I might die like my uncle. The book encourages the kids that if they continue to take their medication and go to school they can become whatever I want to be.” (mother of an 11 year old boy)

Reported behavior change

“[The book is] very helpful...kids... easily forget why they are taking medications ... and decide not to, but if you bring in the book, you will see that it will come back to them that yes, I have to drink my medication and like that book you will see there is a picture of when you grow up, what do you want to do? You know they get so excited, so they say I have to go to school, I have to play with my friends, I want to be a teacher, whatever, that is when they will decide, ok, I will drink my medication from now onwards.” (HCW)

Reported behavior change



“The child always talks about bad guys. Sometimes, when he almost forgets his medication he says, “no, I am going to take my medication because these bad guys are trying to fight me.” (mother of 7 year old boy)

Quantitative data – analysis in process



- Very large increases in children's awareness of why they are taking their medicine
- Preliminary analysis shows reduction in VL pre/post intervention

Important steps for success



- Systematic adaptation of materials
- Pilot testing and revision
- Training
- Monitoring and Evaluation during roll out

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