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# Growing-up just like everyone else: key components of a successful pediatric HIV disclosure intervention in Namibia

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## Abstract

**Objectives—**To facilitate replication and adaptation of pediatric HIV disclosure interventions, we identified key components of a child-friendly cartoon book used to guide Namibian caregivers and healthcare workers (HCWs) through a gradual, structured disclosure process.

**Design—**Qualitative interviews were conducted with caregivers and HCWs from four high-volume pediatric HIV clinics in Namibia.

**Methods—**Semi-structured in-depth interviews with 35 HCWs and 64 caregivers of HIV+ children aged 7–15 were analyzed using constant comparative and modified grounded theory analysis. Major barriers to disclosure were compared to accounts of intervention success, and themes related to key components were identified.

**Results—**The disclosure book overcomes barriers to disclosure by reducing caregiver resistance, increasing HIV and disclosure knowledge, and providing a gradual, structured framework for disclosure. The delayed mention of HIV-specific terminology overcomes caregiver fears associated with HIV stigma, thus encouraging earlier uptake of disclosure initiation. Caregivers value the book's focus on staying healthy, keeping the body strong, and having a future 'like other kids', thus capitalizing on evidence of the positive benefits of resilience and hopefulness rather than the negative consequences of HIV. The book's concepts and images resonate with children who readily adopt the language of 'body soldiers' and 'bad guys' in describing how important it is for them to take their medicine. Discussion cues ease communication between HCWs, caregivers, and pediatric patients.

**Conclusion—**Given the urgent need for available pediatric HIV disclosure interventions, easily implementable tools like the Namibian disclosure book should be evaluated for utility in similar settings.

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**Keywords**

adherence; disclosure; HIV/AIDS; pediatric HIV; stigma

## Background

Despite WHO recommendations that HIV-infected school-aged children be fully informed of their HIV diagnosis, disclosure rates in sub-Saharan Africa remain extremely low [1–3]. Although healthcare workers (HCWs) and caregivers believe disclosure to be important, significant barriers prevent or delay disclosure from occurring in practice. Caregivers are reluctant to disclose because they lack knowledge about how to discuss HIV, have guilt regarding transmission, worry about the child's possible negative reactions or questions the child may ask, or are concerned with HIV stigma [1,4–10]. In addition, many high-volume pediatric HIV clinics do not have dedicated resources or systematic processes for disclosure, affecting HCW confidence and ability to reliably perform or facilitate parent-led disclosure counseling [10–12]. Nondisclosure has been shown to be associated with lower adherence, poorer psychological adjustment, and increased morbidity [1,13–19]. In addition, delayed disclosure increases the likelihood that the child will learn his/her status accidentally or in an emotionally traumatic way [10,17,20,21], or that the child will maintain a false understanding of illness, including the belief that he/she will be cured [21].

Few studies present disclosure interventions being used in practice and there are currently no published results from randomized control trials testing effects of pediatric HIV disclosure interventions [11,20,22,23]. In addition, cross-sectional and longitudinal studies evaluating health outcomes in children following disclosure interventions are minimal [12]. Programmatic evaluations of pediatric disclosure interventions are too few to generate empirically-based best practices through comparative analysis. Yet, the dangers of delaying disclosure to children necessitate widespread implementation of support programs while evidence accrues.

A lack of child disclosure interventions prompted the Namibian Ministry of Health and Social Services (MOHSS) to develop an intervention aimed at improving the number of children who knew their status, children's understanding of HIV and antiretroviral medication adherence. In addition, the intervention aimed to make the disclosure process easier for caregivers, and to facilitate discussions between HCWs, caregivers, and pediatric patients with HIV. The intervention was developed in collaboration with HCWs in busy HIV clinics in Namibia and responded to recommendations in the literature to develop resources that support disclosure as an ongoing process [8,24–26]. The intervention addresses barriers to disclosure and supports primary caregivers and HCWs in a structured disclosure process that includes assessing caregiver and child readiness for disclosure, and guiding children and their caregivers through the disclosure process. The centerpiece of the intervention is a colorful, child-friendly cartoon book organized into five chapters (Fig. 1). Chapter 1 describes how medicines keep 'body soldiers' strong and protect the child from getting sick, so he can grow up to be a successful adult. Chapter 2 describes the 'bad guy' who can make them sick by attacking their body soldiers. Chapter 3 describes the importance of taking

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medicine regularly to keep the 'bad guys' asleep and thus allow the body soldiers to be strong and numerous. Chapter 4 describes how the 'bad guy' can wake up if medicines are not taken correctly. Chapter 5 leads to full disclosure by explaining that the 'bad guy' is named HIV, that 'body soldiers' are CD4 cells, and the medicines are called antiretrovirals. The book contains prompts to assist HCWs in assessing the child's comprehension and emotional readiness to move to the next chapter, and eventually for full disclosure. The number of months or years spent reviewing chapters varies with the child's age and understanding. The intervention has been integrated into routine outpatient HIV care country-wide and is targeted to begin at age 6 with a goal of achieving full disclosure by age 10.

Understanding how and why existing interventions work is critical for replicating and adapting them to other settings with high pediatric HIV prevalence [12,23, 27–32]. An evaluation of the Namibian disclosure intervention in 2013 provided a detailed description of multiple components of the intervention implementation, demonstrated its success in supporting HCWs, caregivers and children with HIV in the disclosure process, and found that it was also perceived to improve children's adherence [33]. This study explicitly evaluates the cartoon book's facilitation in overcoming specific barriers to pediatric HIV disclosure. We then identify implicit theories underlying the book's success.

## Methods

### Study design and population

We performed a cross-sectional evaluation of the disclosure intervention at four of the highest volume pediatric HIV clinics in Namibia: Onandjokwe, Oshakati, Engela, and Katutura [33]. All HCWs providing pediatric HIV outpatient services were interviewed, including doctors (9), nurses (17), and community counselors (9). HCWs reported having between 2 and 9 years of experience at their respective clinics. Purposive sampling was used to interview 16 caregivers per site ($N = 64$) to reach phenomenal variation and informational redundancy related to the disclosure experience [34]. Caregivers were recruited at the clinic during pediatric outpatient days. Patient charts were pre-screened on the day of clinic visit and caregivers of patients aged 7–15 were flagged and recruitment proceeded sequentially. Caregivers were at least 18 years of age and accompanied by an HIV-positive child on antiretroviral therapy (ART) to clinic that day. Caregivers were mostly the biological mother (59%) or aunt (21%) of the child. At the time of the interview, caregivers reported that approximately half of the children knew their status (54%).

The evaluation protocol was approved by the Namibian MOHSS ethics review committee. Because the intervention is implemented nationally as part of the routine pediatric patient care, the University of Washington Institutional Review Board determined that the evaluation was not human subjects research. Both HCWs and caregivers provided written informed consent for the interview.

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### Data collection

During May and June of 2013, semi-structured in-depth interviews were conducted exploring the nuances and depth of opinions and experiences with pediatric HIV disclosure in general, and with the HIV disclosure intervention components in particular. Interviews were conducted in English or Oshivambo, depending on the interviewee preference. All interviews were digitally recorded and later translated (if applicable) and transcribed.

### Data analyses

Initial codes were applied independently by three investigators to a subset of transcripts, and additional codes were created when new themes emerged. Coded transcripts were compared and differences were discussed and resolved. Investigators then independently coded a portion of the transcripts and reviewed and second-coded transcripts initially coded by other investigators so that all transcripts were coded by at least two investigators. Disagreements with codes were noted and resolved in group discussions [35–37].

A second coding process was then undertaken by two investigators to more specifically understand 'how' the cartoon book influenced HCW and caregiver willingness and capacity to engage in the disclosure process. First, scientific literature was reviewed to identify common barriers preventing or delaying disclosure (Fig. 2).

Second, a constant comparative approach was used to identify whether these barriers were also identified by the Namibian population and whether any novel barriers emerged. Data were synthesized to generate a graphical representation of the common barriers to disclosure (Fig. 3). On the basis of this graphical representation, additional codes were developed that identified whether and how the cartoon book addressed specifically identified barriers. An inductive approach was used to identify themes and patterns emerging from the data relevant to the key components of success. Specifically, we sought to identify important facility contexts, perceived intervention effects, and motivations of caregivers and HCWs to engage in the disclosure process that might moderate uptake of the intervention. Concordance between HCW and caregiver (CG) views was also analyzed. Findings were contextualized within the health communication, resilience, and implementation science literature.

## Results

The disclosure cartoon book is a communication tool that successfully addressed disclosure barriers in four health facilities in Namibia by addressing child, caregiver, and HCW barriers to disclosure (Fig. 2). Barriers identified in the literature [1,4–12,21] were explicitly mentioned in interviews with HCWs and caregivers in Namibia. In addition, one novel barrier – inconsistent caregivers accompanying the child to clinic visits – was mentioned by HCWs as a significant challenge to disclosure initiation. Barriers were grouped under three broad categories, including: caregiver resistance to disclosure, lack of knowledge about HIV and how to talk with children about their HIV status, and a lack of specialized staff (psychologists, social workers) and resources to address sensitive disclosure issues. The disclosure book specifically overcomes these barriers to disclosure by: allaying fears of

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stigma and psychological harm, using accessible and acceptable language, and being easy to implement in low-resource settings.

### Allays fears of stigma and psychological harm by focusing on medication use to keep body strong rather than HIV disease

The disclosure book was perceived to reduce caregiver resistance to disclosure by targeting health behavior (i.e. taking medicine), rather than focusing on a highly stigmatized disease. The focus on medication behavior reduces caregiver fears of potential psychological harm and negative child reactions.

> *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, so really they are appreciating that.* P44: HCW

Caregivers appreciated how the book normalizes taking medicine and frames disclosure as a hopeful, future-oriented process that supports the child to become a normal, healthy, successful adult.

> *[Taking ARVs] is not a problem because it's the same as taking any other medication. But, ….because the ART ones are taken for the rest of someone's life then it must be explained to the child that they should take medication in order for them to grow and also to be able to complete school like other children and get a job so you can buy and drive a car of your own one day. That will help the child to take medication correctly until he reaches a stage where he understands what the medication is for.* P38: mother of 8-year-old boy

The HCWs had similar perspectives on the importance of a future-oriented approach.

> *[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.* P44: HCW

Rather than causing psychological harm, caregivers and HCWs saw the disclosure book empowering children through increasing their understanding of the importance of and motivation to take their medication to strengthen and increase numbers of body soldiers. Following exposure to the book, caregivers and HCWs described children as having confidence in their actions to stay healthy and keep their body strong.

> *[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.'* P19: HCW

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Improved understanding and motivation led children to take responsibility for better adherence.

> *There is a change in his behavior, before he used to be forced to take his medication but now he runs very fast to go take his medication if he is told and sometimes he even remind himself.* P39: mother of 14-year-old boy

Some caregivers reported children's increased attention to their clinic dates, as well.

> *[S]ometimes she is even the one who reminds me when it is close to her next appointment……or she would come to me and tell me that there is not much medication left.* P76: mother of 13-year-old girl

The positive and empowering tone of the disclosure book prepares children and their CG for full HIV disclosure to occur.

> *… by using that method most children will understand what is going on with them, even before you get to the word HIV, … prior to the disclosure tools we used to tell the children that you are HIV positive without…explaining much to them, but with these tools, the important thing is for them to understand what is going on in their bodies, it is only then you can tell them they are also HIV-positive, and then they are able to link up everything.* P47: HCW

### Accessible and acceptable language

Use of the disclosure book provides a common and accessible language for caregivers, children, and HCWs to use.

> *I think the booklet works quite well because it is in such a simplified way that even for the caregivers it works well. The children will understand, and it is quite encouraging because after you have done that then in subsequent visits you ask the children and most of the time they still remember whatever you discussed before.* P42: HCW

The disclosure book outlines very clearly for caregivers what the disclosure process will be, thus developing their confidence that disclosure will not cause a shock, but will influence medicine taking. They respond well to the knowledge that there will be no mention of HIV if the child and caregiver are not ready.

> *[T]here was a grandma…[who] didn't know what to do, and then luckily we had that book… So I spoke to that granny, … she was just fearing. She didn't want us to mention the word HIV. So by letting her know that we don't just start telling the child 'HIV.' This is how we start, slowly, she agreed…..* P91: HCW

Caregivers reported learning from the book as well and adopting the language of the book.

> *My reaction was positive, we… were shown these pictures, and there are these people surrounding him [the child] and those are the body soldiers, if there is only one person around you it means that your defense system is weak, but if you have a lot of soldiers surrounding you, it means that you are well protected.* P53: mother of 12-year-old male

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Once the child is told his HIV status, the caregiver and child can revisit the common language to reinforce important adherence behavior.

> *[W]hen you go to chapter 5 you have to be really specific and show the patient's file and show the child, that when you say CD4, its body soldiers and it's how much, and the viral load, the bad guy, is how much…What you need to do now is work hard, take your medication that we can improve on this, so next time lets work on this and see whether there can be an improvement….Next time the child comes in they can even ask, 'I have taken blood last time, how is it now?'* P67: HCW

By providing a simple narrative the book helps build relationship between the HCW and CG.

> _ *…if you show the book with the parent there you will see they will understand better, especially if it comes to the issue where you don't take your medication on time, the virus comes out of the blanket and wakes up, now if they see that picture of it waking up, one could see it really touches them, it helps them take the medication seriously…* P70: HCW

### Easy to implement in low-resource settings

The book content and instructions are simple enough to be used by non-specialized HCWs. Any available HCW can use it at the health facilities. Caregivers reported ease with using the disclosure book themselves.

> *We talked about when a child takes medication correctly they can be healthy, and that if the child wants to be healthy she needs to take his medication. She was even shown pictures about children that looks healthy. We even asked her to choose which child he would like to look like and then he chose a child who looks healthy.* P38: mother of 8-year-old boy

An added benefit in the Namibian setting, where many children come to the clinic without a caregiver, is that the book can be read without mentioning HIV, similar to adherence counselling one would do with any medication.

> *[If] we see that the child is always coming alone we than go through the booklet with the child alone and show him the importance of taking medication without doing a full disclosure (mentioning HIV*). P72: HCW

## Discussion

Caregivers and HCWs described a reduction of disclosure barriers resulting from the Namibian disclosure book's guided narrative. Given limited information on pediatric disclosure interventions scalable in low-resource settings, situating our findings within the context of relevant theoretical literature can help generalize knowledge by identifying explanatory mechanisms for how the intervention works [27,29–31,38].

One of the key features of the disclosure book is its use of metaphor to explain the importance of taking medicine without having to mention HIV. This focus on impacting

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specific behavior (adherence) rather than the disease itself is consistent with evidence of effective adherence communication strategies [31]. The persuasive power of metaphor results from both cognitive and affective responses [39–43]. Metaphor is frequently used in medical education to clarify complex scientific and medical phenomena because it facilitates information processing by rendering the unfamiliar more understandable and manageable [42,44,45]. Studies have demonstrated that affective response is an important determinant of information acceptance [42] and that negative emotions lead to less careful message processing [46]. Children and their caregivers readily adopt the language of ‘body soldiers’ and ‘bad guys’ in describing the importance of anti-retroviral medication adherence. Establishment of a degree of conceptual congruence among actors can strengthen the physician–patient relationship by transcending the barriers between them [47]. Productive interactions between the provider and the patient can improve the patient understanding and foster positive coping mechanisms and behaviors [12,31,38,48].

Scholars describing the importance of a gradual disclosure process have drawn on Piagerian theory of developmental stages and absorptive capacity of children [11,31,49]. Current guidelines and recommendations have focused on age as a key indicator for disclosure. However, studies have shown that other factors in addition to age may play an important role in determining readiness for disclosure. With the disclosure book, moving from the metaphor of ‘bad guys’ and ‘soldiers’ to the medical names of CD4, antiretroviral medicine, and HIV is based on both the cognitive and emotional readiness of the child rather than a specific age. The flexibility and reliance on caregiver and HCW assessment may facilitate a sense of ownership and agency in implementing the intervention [32].

Researchers have identified the need for interventions that promote resilience in HIV-infected and affected children and adolescents, rather than focus on ‘pathologies’, in order to identify potentially modifiable processes [12,50–52]. Resilience is defined as the capacity for successful coping despite challenging circumstances [12,52–54] and is correlated with better mental health outcomes and desirable health behaviors, including adherence [12,50–52,55–61]. Studies indicate that individual characteristics strongly associated with resilience include having a sense of purpose, belief in a positive future, hopefulness, not feeling alone, and self-efficacy/empowerment [12,50–52,55–58,60,61]. In alignment with these characteristics, the cartoon book taps into the desire to be healthy, lead a normal life, and have a future ‘like other kids’. Caregivers and HCWs reported the disclosure book positively affected children’s motivation to take their medicine and increased their sense of responsibility in tracking their clinical appointment schedules, evidence of children’s sense of empowerment to take control of their own health and future. Studies have shown that patients experience comfort in understanding their condition and participating in their own care [12,21], and that long-term, chronic disease management requires pediatric patients to learn to care for themselves [31,62].

The disclosure intervention fits within both ecological and constructivist approaches to understanding resilience. Social ecological perspectives of resilience draw attention away from single influences and acknowledge a complex interaction between the child, family, and the larger environment [52,63]. The cartoon book facilitates this interaction through strengthening communication between caregiver, HCW, and child. Constructivist

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perspectives on resilience build on strength-based approaches to empowerment [64–67], and emphasize that how people talk about and think about taking their medication has important implications for adherence [57,68]. The cartoon book encourages feelings of self-efficacy and empowers the child with agency to take the medicine to keep the bad guys sleeping and strengthen the body soldiers,

### Strengths and limitations/conclusions

The cross-sectional evaluation does not have the generalizability of a randomized control trial, nor can it yet draw from clinical outcomes to assess intervention effectiveness. Our findings rely on self-reports by healthcare workers and caregivers, and our analysis does not include objective measures of disclosure rates. There are no comparable disclosure intervention evaluations from which to draw to help provide comparative context for our findings. However, triangulating data from healthcare workers, caregivers, and the published literature is a common practice in implementation research and strengthens the reliability of our findings.

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**Conflicts of interest**

The authors report no conflicts of interest.

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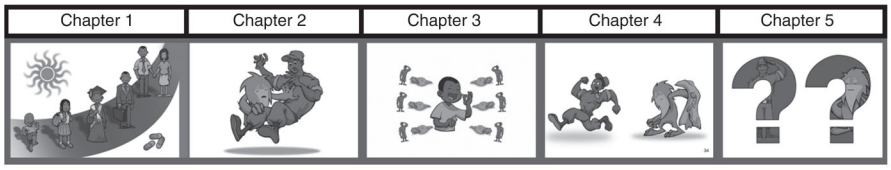


**Fig. 1.**

Example illustrations from a child-friendly cartoon book used by Namibian heathcare workers in performing a gradual, structured pediatric HIV disclosure process.

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| Barriers to Disclosure | Example Quotes | Overcoming Barriers | Example Quotes |
|---|---|---|---|
| **Caregiver Resistance to Disclosure** | | **Allay Fears of Stigma and Psychological Harm** | |
| Child age/comprehension | *'Most caregivers feel that the children are too young to understand what is going on, and some of them feel that their children are not yet emotionally ready to be told about their status.'* **P47 HCW** | Focus on partial disclosure | *'The booklet is a tool that is helping the kids especially because you start with partial disclosure not only for the kids alone, but also for caregivers learn something from it. The pictures and everything is explanatory and clear.'* **P43 HCW**<br><br>*'She [HIV+ child] was excited with the pictures in the book and understood them, because now if she forgets to take medication she will say her soldiers will be eaten up by the bad men.'* (**P83** mother of 11 year old girl) |
| Child rejection/non-acceptance of diagnosis | *'Despair, they will rebel sometimes if you are not careful there are children who will stop the medication, because now they are thinking that the world has ended....'* **P93 HCW** | Gradual structured process | *'....when you mentioned the word HIV, they already think it is AIDS, but if we start telling a child, using simple language, that the child can properly understand and as he is growing up you start adding more information until when he is old enough you can fully disclose to him.'* **P70 HCW** |
| HIV stigma | *'for most of them it is Stigma, from household members, friends, and especially from school.'* **P18 HCW** | Use of alternative language | *'…because now you are just talking about body soldiers, bad guy is really interested to hear what does the body soldier do, what does the bad guy do?...It's no more that stigma.'* **P67 HCW**<br><br>*'[E]ven now when she is around other children, she seems free, one can see that now he feels like she is just like the other kids, … When she is [in] a group with the others she is just normal like the others ...'* (**P53** mother of 12 year old girl) |
| Fear of child reaction | *'...usually they think that if you tell the child they would start crying or worry a lot, or the child would have bad intentions toward themselves, things like suicide, they are always afraid, its not that they don't want the child to know, its just that they fear, if the child knows what will they do to themselves, or tell others at school and people might start mocking him or her.'* **P70 HCW** | Future focused messaging | *'...with the disclosure program we give them information in fact it shows them that there is hope at the end of the tunnel, they get information that having HIV is not a death sentence, you can live with HIV and get old, you can live with HIV and achieve all your dreams in life, get married, have children even who are HIV-free. So they get all that information and then they learn that they have HIV...'* **P42 HCW** |
| Child knowledge of HIV/medicines/health | *'The other thing is the information that they already have before the disclosure of HIV, for instance, they are learning about it in the schools and the message that they get is trying to scare them away from taking risks, so the message is if you get HIV or If you do anything that will give you HIV, then you are going to die.'* **P42 HCW** | Provision of age-appropriate, accurate information | *'For me, the book has made so much difference. With the book, we really speak their [children's] language. It makes a great difference.'* **P16 HCW**<br><br>*'if we start telling a child, using simple language, that the child can properly understand and as he is growing up you start adding more information until when he is old enough you can fully disclose to him.'* **P70 HCW** |
| **Lack of Knowledge** | | **Provides of Accessible and Acceptable Language** | |
| Caregiver knowledge of HIV/medicines/health | *'...sometimes the parents really don't know what HIV is and how to explain or help a child understand it.'* **P23 HCW** | Use of simple terminology | *'most caregivers their biggest shame has been that no one has ever explained to them HIV in the simplest form to an extent that at one point we were considering using the same disclosure booklet for the adult patients, because I think we tend to use big words when we are trying to explain about HIV to patients, but with the HIV disclosure booklet it kind of reduces everything to a language that anyone can simply understand.'* **P47 HCW** |
| Caregivers coming to terms with own status/guilt | *'Some of them they are saying, no it is very hard for me to tell my kids that they are HIV positive because I'm the one who infect them, so it's a shame, some of them they say that they are just not confident to face their child.'* **P24 HCW** | Use of alternative language | *'I think, they are happy because that's not what they expected. Especially with partial disclosure. When they realize, oh here people did not even mention anything about HIV, they are always happy and grinning.'* **P91 HCW** |

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| | | | |
|---|---|---|---|
| Knowledge of how to disclose | *'....caregivers usually reply by saying they really want the child to know but they don't know how to go about telling the child, so they (parents) usually lie to the child that the medication is for TB.'* **P71 HCW**<br><br>*'It was difficult to tell her because I d idn't receive any training on how to disclose to her and I didn't know what ways I should use to tell her.'* (**P83** mother of 11 year old girl) | Provides tool for disclosure | *'Some of them, they [caregivers] are really happy because [they] feel that they have a tool to prepare their children for something serious…'* **P95 HCW** |
| **Lack of Specialized Staff and Resources** | | **Easy to Implement in low-resource settings** | |
| Lack of specialized staff | *'Kids require a lot of attention and care. When you have a shortage of counselor, and you have to call in a counselor, they may not know about kids, and he doesn't know what to say. But if we have a full team, specially trained, with social programs. I think it would make a difference.'* **P16 HCW** | Clear instructions; child-friendly structure | *'Like I mentioned earlier, I think that tool has made it easier for us to be able to discuss these HIV issues with children, because I think it reduces the whole explanation to something that a child can relate to, and you will find that by using that method most children will understand what is going on with them, even before you get to the word HIV.'* **P42 HCW**<br><br>*'I think the book its helping, because first, the instructions that are to be followed, you read to the child, you ask to the child what they see, because there are pictures there, I think it helps the kid understand much better and in a simple way.'* **P89 HCW** |
| Lack of time | *'People really know what should be done but in most cases, why it is not done in most cases is sort of the numbers that we see and the number of staff that we have. They don't dally. The odds are against us in terms of numbers...sometimes you find there is one doctor, and you know the queue's there, and in our case we cannot send any patient without their drugs home. You have to finish the queue. So it makes it very difficult and for people to really commit themselves to say now, today I want to do disclosure to 5 children. You can have it in your heart, but you'll send them without that having been done.'* **P90 HCW** | Barrier minimized but still exists | |
| Lack of training/materials | *' the most difficult thing is, sometimes…..the skills on how to do it. Sometimes we are just scared, like we think maybe the child will react, maybe in a bad way. We might think…yeah, the perception that we have that the child will react like this, even though most of the time it's not the way they think.'* **P91 HCW** | Provides training and tools to promote structure and direction | *'Because before I went there [the HCW training] I tended to want to explain a lot of things and I found that actually can easily confuse kids....So when they taught us how to exactly use it, and ask any questions I have and the kid can ask you questions. For one, I found it very simple to use. And the kids actually understand it better when you do not do things that the book is not telling you to do.'* **P90 HCW**<br><br>*'I think it works very well, because it is nicely described, even the pictures you can easily interpret them to the children, even if you first ask the children just to tell you what they seeing on the pictures you know most of them are able to pick up what is happening.'* **P44 HCW** |
| Inconsistent caregivers | *'Parents who do not bring their children also make it difficult for us because we cannot do it to children without them or their consent."And some parents are careless, they don't come accompany their children to the hospital and if you ask the child to come with treatment-supporters they keep on coming with a different one every time, this make it difficult for us when giving information to different person every time because you have to restart from chapter 1 with every new person bringing the child.'* **P72 HCW** | General terminology allows use in caregiver absence | *'...we used to put them in groups, and then we show them this book, why I take my medicines, and we teach them why they should take their medication.'* **P70 HCW** |

**Fig. 2.**

Barriers to pediatric HIV disclosure and ways the disclosure book helps to overcome these barriers.

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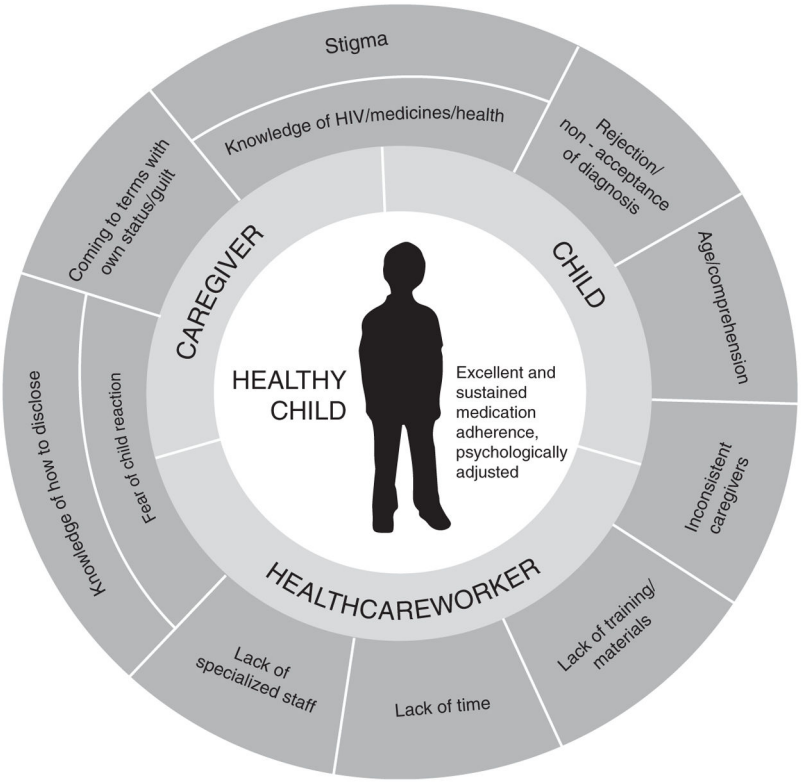


**Fig. 3.**

Barriers to pediatric HIV disclosure identified in the literature and by Namibian caregivers and health workers.