

# Paediatric disclosure of HIV diagnosis

Jude Nwakpoke Ogbodo discusses communicating HIV diagnosis to infected children in Africa via cartoon books and video



HIV remains incurable and affects millions of people, especially in low-resource countries.<sup>1</sup> As such, the impact of HIV remains high, especially for children, due to complex medical, economic, psychological, social and emotional burdens associated with it.<sup>2</sup> Some of the affected children in Africa end up as orphans and/or face abject poverty which in turn causes additional burden to the children and their caregivers.<sup>2</sup>

UNICEF estimates that 14.9 million children worldwide have lost one or both parents to AIDS-related causes, and over 74% of these children live in sub-Saharan Africa.<sup>3</sup> Many of them have no knowledge of their status due to fear of stigmatisation or a potential harm for Children Diagnosed with HIV (CDWHIV), and poorly implemented guidelines for disclosure among caregivers and healthcare providers.<sup>4</sup> The right time to inform children about their HIV status has also re-

mained contentious in the literature.<sup>5</sup>

In its 2011 guidance for disclosing the status of CDWHIV from 12 years and under, the WHO specifies that children of school age should be told their HIV-positive status; younger children should be told their status incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure. This broader context is crucial to this review because it addresses disclosure as a culturally sensitive process.

The broad aim of this paper is to evaluate ways of communicating HIV diagnosis to African children. Specifically, the study aims:

- to identify the challenges of paediatric disclosure of HIV to infected children in Africa
- to evaluate cartoon books and videos as emerging models paediatric disclosure in Africa

## The cultural dimensions of disclosure

In order to understand how children are communicated with in matters of their health, it is important to understand their role in family and cultural settings. Con-

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## LUKIA'S STORY

Every Friday, James helped Lukia train Simba. Sometimes Simba came alone.

"How come you miss sometimes?" James asked. Lukia was silent.

"Do you get sick?" James asked.

"I used to be sick all the time and people abused me," James told her.

"That happens to me and I hate it," Lukia answered.

"I sing to myself when they abuse me. That way I see them but I cannot hear them," James told her. "Cruel words will only hurt you if you let them."

"How did you become healthy?" Lukia asked James.

"I started taking medicine everyday," James replied.

"Is it for Fever like me?" Lukia asked.

"Can you keep a secret?" asked James. Lukia nodded.



"I have the HIV virus in my body," James told her. "When there is a lot of it, I fall sick with fever, cough or skin rash. The medicine keeps the virus down. I must take medicine everyday for the rest of my life."

"What kind of medicine?" Lukia asked him.

Source: John Hopkins Centre for Communication Programs (ccp.jhu.edu).

versely, it has been observed that there is a limited empirical research on children and childhood disclosure experiences, especially among those in sub-Saharan Africa.<sup>1</sup> In most African settings, children are perceived as future investment, and the production of children helps a lot in strengthening family ties, lineages and kinship.<sup>6</sup> This perception gives children a sense of importance in society and goes a long way in shaping their behaviour and expectation to adulthood. Within this cultural context, children are expected to be submissive and docile, and must be ready to respect their elders and assist in performing chores without objection.

Although concerns about the social and psychological effects of disclosure for Malawian children have been raised,<sup>7</sup> Krauss, Letteney and Okoro<sup>8</sup> suggests that after disclosure, infected children fare better than those without knowledge of their status. Research further demonstrates that African children whose HIV status has been disclosed have better medical and social supports and seem to overcome depression over the long term.<sup>9</sup> Studies from industrialised (e.g. US, UK), and developing nations (e.g. South Africa, Malawi) suggest that delayed or paediatric nondisclosure to CDWHIV is associated with negative adherence to antiretroviral therapy (ART) and poor psychological and coping outcomes.<sup>10,7</sup>

### Challenges affecting disclosure

Although research<sup>11</sup> has identified nondisclosure as a major barrier to children's adherence to ART in Swaziland, other studies indicate that the low culture of disclosure in South Africa has remained due to fear of discrimination and stigma.<sup>12</sup> Similarly, parents or caregivers in Africa might decide to withhold information regarding the HIV status of children for fear of being judged or blamed by the child, in addition to the assumption that children are too young to know the implications of their HIV status in relation to taking their ART.<sup>11,12</sup>

A common feature observed in the literature regarding the positions of both the healthcare professionals and the caregivers is that they have difficulty identifying the 'age-appropriate' timing and language as well as the appropriate responses to questions emerging from the process and support given.<sup>5</sup> Empirical findings also suggests that when this support is offered, it helps to improve the healthcare providers' and caregivers' confidence in the disclosure process and increases the rates at which supportive paediatric disclosure can be given.<sup>13</sup> In the sub-Saharan African context, Brada<sup>14</sup> argues that a culturally dictated indirect speech for disclosing sensitive matters relating to sex, disease, death or disease present challenges for healthcare providers and all those involved in disclosing to children. The foregoing suggests that disclosure of HIV status to children could be affected by different cultural dynamics across countries.

### Cartoons, story books and videos

While scholars and clinicians have tried to convert the general principles for disclosure to practicable and context-sensitive or cultural-specific frameworks,<sup>15</sup> the literature demonstrates that it is mainly caregivers, with

or without any support from HCW, who eventually disclose to the CDWHIV in their care. Many important resources such as cartoon books and videos useful in the disclosure process have been identified.<sup>16</sup> A number of them were specifically designed not only to aid the process of disclosure, but also to have some interactive formats that would guide the conversation between the CDWHIV and their parents or healthcare providers. An example is 'Lukia's story',<sup>19</sup> an illustrated book popular in Uganda, which portrays the stigma faced by a young girl and other challenges before she learnt about her HIV status. The story addressed issues of adherence to therapy routines, while working out the best strategies for coping with stigma.

Brandt et al<sup>16</sup> found that caregivers and healthcare workers in Namibia observed a decline in disclosure barriers, and this was attributed to disclosure book's guided story. A common feature of the book is its repeated use of metaphor to illustrate the advantages of taking medicine without necessarily mentioning the virus. The focus on the adherence instead of the virus itself is an approach consistent with effective adherence communication strategies.<sup>16</sup> Metaphor has a persuasive power and can serve as the aftermath of cognitive and affective responses. As Harvey & Koteyko<sup>17</sup> have argued, metaphor is commonly used in medical fields to simplify intricate scientific and medical phenomena because it smoothes information processing, thereby making issues more understandable.

The cartoon book enables this interaction by strengthening communication between the affected child and the healthcare staff or caregivers.<sup>16</sup> This cartoon book was designed to stimulate feelings of self-efficacy and empowerment among children, with illustrations that encourage the children to take their medications in order to fortify their 'body soldiers' and neutralise the 'bad guys' in their body.<sup>18</sup> This enables the children to cope better with the aftermath of the disclosure.

Another example is illustrated in the video, 'Now You Know, Now What'.<sup>5</sup> This video features children who live with the virus shrugging off the fear while speaking to the newly diagnosed children. The books and videos help to address the barriers and issues affecting the disclosure by making light of the situation. The models are unique in their respective contexts, and they epitomise ongoing efforts by various stakeholders, policy-makers, caregivers and clinicians aimed at developing a functional model for disclosing the sensitive news of HIV diagnoses to children. Although these models appear to have been developed in recognition of the different cultural contexts within which they were developed, implementers and policymakers can still refer to or adopt them by working out their usefulness in various African cultural and health settings.

## Conclusions

Many of the studies reviewed demonstrated that fewer CDWHIV in resource-limited locations know their status. Although caregivers/family members have identified some important factors influencing disclosure, empirical evidence suggests that disclosure has both positive and

negative effects on CDWHIV. The appropriate age for disclosure has also remained contentious due to socio-cultural differences, despite the WHO's recommendation of 6-12 years. Bearing this in mind, it is important that implementers put them in perspective without losing focus of the various cultural, religious and social dynamics that shape different societies on the basis of their applicability and inherent strengths.

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