

Facing the truth: The challenges of HIV disclosure among children with perinatal HIV in Bulawayo, Zimbabwe

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Abstract

The purpose of the study was to explore the process of human immunodeficiency virus (HIV) disclosure to children living with perinatal HIV at Mpilo Opportunistic Clinic (OI) in Bulawayo Metropolitan Province. The qualitative approach was used to study the topic and a phenomenological research design was used to describe the process of disclosure to children living with perinatal HIV. Data were collected through in-depth interviews. The data collected revealed that the HIV status disclosure to adolescents was difficult for caregivers, which caused the disclosure to be done later than recommended by the Ministry of Health and Child Care Zimbabwe. This had a significant negative impact on the psychological well-being of children who also struggled to disclose their status to others. The study revealed that the HIV counsellors lacked skills to counsel on psychological issues. The researcher recommended that psychologist be integrated in the formulation of an HIV manual and be employed at OI clinics to counsel children and caregivers.

Keywords: Perinatal HIV, children, psychosocial, OI clinic.

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1. Introduction

Human immunodeficiency virus (HIV) has been one of the most devastating diseases in the world. By the end of 2018, there was an estimated 37.9 million people living with HIV (UNAIDS, 2019). Mother-to-child transmission, which is also known as 'vertical transmission', accounts for the vast majority of infections in children aged between 0 and 14 years. Vertical transmission can happen during pregnancy, childbirth and breastfeeding (Avert, 2018). An estimated 1.7 million children aged 0–14 years were living with HIV at the end of the year 2018, and 160,000 children were newly infected. An estimated 100,000 children died of AIDS-related illnesses in 2018 (WHO, 2020). With the use of ART, the transmission of HIV from the mother to child can be reduced to 5% according to reports by the World Health Organisation (2018). The 160,000 new infections were a major decrease from 240,000 in 2010 (UNAIDS, 2019). Eastern and Southern Africa are home to more than 60% of children and adolescents living with HIV. In 2017, an estimated 120,000 adolescents aged 10–19 years and 94,000 children aged 0–9 years were newly infected with HIV (UNICEF, 2018). They are now part of the estimated 1.9 million children and adolescents living with HIV in the region. Despite ongoing progress, 65,000 of the region's children and adolescents died of an AIDS-related cause in 2017 (UNICEF, 2018).

Zimbabwe has one of the highest HIV prevalence in sub-Saharan Africa at 12.7%, with 1.3 million people living with HIV in the year 2018 (Avert, 2020). The number of people acquiring HIV each year is falling in Zimbabwe, although levels are still relatively high. Avert (2018) states that there were 38,000 new infections (33,000 among adults and 4,800 among children) in comparison to 62,000 (47,000 adults and 15,000 children) in the year 2010. In 2017, mother-to-child transmission was estimated to account for 6.74% of all new HIV infections in children aged 0–14 years and it still appears to be on track to achieve the global elimination target of less than 5% by 2020. As a result of this success, new infections among 0–14-year-olds have fallen by two-thirds since 2010, from 15,000 to 4,800 (Ministry of Health and Child Care Zimbabwe, 2018). However, despite the expansion of PMTCT services, only 63% of infants born to HIV-positive mothers received an HIV test within the first 2 months of life (Ministry of Health and Child Care Zimbabwe, 2018).

Previous research by Dahourou, Raynaud and Leroy (2018) showed that HIV disclosure remains challenging in sub-Saharan Africa as it occurs at a late age (median 13 years). The main barriers to disclosure were caregivers' lack of knowledge regarding the disclosure process and when to disclose, the fear of child's reaction and fear of stigmatisation and associated negative social consequences (Hayfron-Benjamin, Obiri-Yeboah, Ayisi-Addo, Siakwa & Mupepa, 2018).

Children infected with HIV at birth grow up not knowing their status until their caregivers, nurse at a clinic, family members and neighbours disclose it to them. Disclosure can potentially happen through other children while playing and caregivers while reprimanding the child or from hearing the conversation of family members.

The issue of disclosure is very challenging to both the caregiver and the children. The consequences of disclosure can be devastating as the child is left with so many questions and stress. The challenge comes when the caregivers or counsellors disclose the status and the children have to deal with the reality of being HIV-positive. Besides the challenges of physical illnesses related to HIV, the death of a parent and stigma attached to the disease, they have to deal with the psychological and social issues of having HIV at a crucial stage of human development. Most of the children grow up not knowing their status and parents tend to avoid disclosing their statuses until they reach teenage hood. Most caregivers feel that it is the right time to open up to the children about their status. The question arises as to who is supposed to disclose the child's status, at what age, how this is to be done and the counselling for these children. The effects of living with HIV transmitted from a parent have an impact on family attachment, social growth, dating, peer relations and self-identity on adolescents.

1.1. Objectives

The specific objectives of the study were to:

- i. Explore the process of HIV status disclosure to children.
- ii. Appreciate the challenges of HIV disclosure to children living with perinatal HIV
- iii. To determine the support system needed by adolescents living with HIV.

2. Methodology

2.1. Population

The target population of this study was children living with perinatal HIV and who receive their ART therapy at Mpilo OI clinic in Mzilikazi District, clinic counsellors and caregivers of the children.

2.2. Sample and sampling techniques

Purposive sampling was used to sample the population. A homogeneous purposive sample was used to select participants having a shared characteristic or a set of characteristics (Crossman, 2017). The size used was determined by data saturation, which is defined by Smith (2003), as the point in data collection and analysis when new information produces little or no change to the research. A homogeneous purposive sampling method was used to include participants with similar characteristics, which include age category, HIV status and receiving therapy at the OI clinic of study. The sample size had 13 participants, which comprised the following:

- Eight children living with perinatal HIV
- Three caregivers
- Two counsellors

2.3. Data gathering instrument

The researchers used in-depth interviews to collect data. In-depth interviews are suited for understanding the process of HIV status to children living with perinatal HIV because the topic is complex and requires the researcher an opportunity to formulate questions and probes in a way which was sensitive and comfortable to the participant so as to get detailed data.

2.4. Procedure

Permission to collect data was acquired from the Medical Research Council of Zimbabwe since the study is on children and also studies a medical condition, which is HIV. Another permission to collect data was acquired from Mpilo Hospital's Clinical Director. The clinic's superintendent helped the researcher to identify the adolescents living with perinatal HIV and their caregivers who would come to the clinic for collection of their anti-retroviral medication and counselling. This was based on the availability and willingness of both caregivers and adolescents. The researcher adhered to the following ethics: voluntary participation and right to withdraw by participants, avoidance of harm, informed consent and assent, respect confidentiality and privacy of participants.

The instrument used to collect data which was in-depth interviews, which were translated from English to a vernacular language of Ndebele which is mostly used in Bulawayo Metropolitan Province so as to allow the participants to understand the questions and freely express themselves in their own language. The findings were then translated back to English by the researcher. The consent and assent forms were also translated to Ndebele language to allow the participants to fully understand the research they were participating in.

2.5. Design

A phenomenology research design was used for this study. Phenomenology is a strategy of inquiry in which the researcher identifies the essence of human experiences about a phenomenon as described by the participants (Patton, 2015).

2.6. Data analysis

Phenomenological data analysis was used for this research. Phenomenological data analysis includes epochal approach, which involves laying out one's assumptions about the phenomenon under research, bracketing, imaginative variation, synthesis of texture and structure to come up with codes to generate themes from the meaning of data (Kawulich, 2004).

3. Results and discussion

The results of this study show that most of the children living with perinatal HIV have psychosocial challenges that emanate from how their HIV status was disclosed to them, their relationship with their parents or caregiver and counselling received after awareness of being HIV positive.

3.1. Process of HIV status disclosure to children living with perinatal HIV

Disclosure of HIV status to children was described as a process rather than an event, which starts from a young age. If the process is not followed, then the disclosure could come as a shock to the child, which could even lead to suicide. The counsellors mentioned that the process involves part disclosure, continual gradual disclosure and complete or full disclosure. They stated that the disclosure of HIV status has to start by the parent disclosing their own status to the child then explaining that it is unfortunate that the disease was also transmitted to the child.



Figure 1. Adapted from Zimbabwe 2016 ART Guidelines (Ministry of Health and Child Care)

The counsellor B stated that, 'the best time to start disclosure process to a child is from 5 years without stating the word HIV or AIDS and the best person to disclose the HIV status of a child is a parent or caregiver, however if the parent cannot do this the HIV counsellors are also skilled to disclose'.

Counsellor A stated, 'As the child develops the caregiver should check the child's maturity and continue talking about why she or he is taking ARV tablets. This is done to avoid shock and prepare the child psychologically on full disclosure'.

The counsellors all stated that HIV disclosure to children was not an event but a process starting when the child is 5 years until they fully understand that they are living with HIV. This method was recommended by the Ministry of Health and Child Care (2016), who stated that disclosure to children is a process which starts by partial disclosure, followed by progressive disclosure and then full disclosure. Children who go through the process grow up with an understanding of their status and

are attached to their caregivers. This is supported by Bowlby (1969), who states that health attachment between caregiver and the child has a great influence on the child's trust for caregivers and others. The attachment is formed when the caregiver is responsive to the physical, emotional and communication needs of the child. This allows the child to trust and have unconditional love for the caregiver.

3.2. HIV status disclosure by counsellor

Counsellors stated that the steps of the disclosure of HIV status start by building a rapport with the child and caregiver. Counsellor A stated that it is best to disclose the status when the child comes with the caregiver who resides with the adolescent, as this enable them to empower both the child and caregiver. Counsellor A said,

'the best person to disclose the status of the child still remains the caregiver even when the caregiver comes with the child for the counselling'.

Counsellor A further elaborated the process of disclosure by saying that the child is kindly asked to leave the room and the caregiver is asked to look at the empty chair and imagine the child seated and then try to disclose. The counsellor's role is to assist the caregiver to structure their words, tone and how to reach out to the child without offending them.

Counsellor B said the best way to disclose is for the caregiver to remind the adolescent of the small talks they used to have about when the child was younger, and then explain that all along they have been trying to explain what they are about to reveal. This is followed by acceptance counselling by the counsellor.

Counsellor C also emphasised that it was important to check the knowledge the child has concerning HIV and how it can be transmitted. The counsellor said,

'the maturity of the child and knowledge of the disease is important in determining how to disclose the HIV status to the child.....'.

3.3. Point of awareness of HIV status by adolescents

The study unveiled that the means through which the child get awareness about their HIV status matter and influence who they become. The children had experienced different points of awareness of their HIV status which had a great impact on the way they have psychologically developed. The children who got to know about their HIV status at a younger age had developed acceptance and coping strategies of living with HIV against those who got to know their HIV status later. The participants got to know their HIV status at various ages ranging from 5 years to 15 years.

3.3.1. Clinic corridors

Two participants stated that they got to know of their HIV status through the health talks that are carried out at the clinic's corridors while clients are waiting to receive their ARV pills.

Participant A stated,

'one day whilst seated at the clinic corridors with my mother, a health worker talked about the correct way of taking HIV pills. This is when I knew that the pills I have been taking were for HIV, at the age of 10'.

3.3.2. Death of a parent

One participant got to know that she was living with HIV at the age of 5 years. After the death of the mother, participant C moved in with her grandmother who got her tested for HIV and immediately told her. She said, *'I have always known that I was HIV positive although I did not understand what*

really the disease was because I was never sick. My grandmother told me that my mother died of HIV and had transmitted it to me. I fully got to know about the disease from school when I was grade 6'.

3.3.3. Testing after sickness

Participant D stated that he grew up being a weak child who was always sick. He said, *'I was always a sick child from young age, I suffered from tuberculosis at the age of five and prior was sick from diarrhoea'.*

3.3.4. Support group

Counsellor A stated that most adolescents get to know about their HIV status when they join the adolescent support groups at the clinic at the age of 11. She said,

'most children will be knowing that they are taking tablets because they are sick but they do not fully understand what the sickness is about or how they got it, until they join the support group'.

3.3.5. Disclosure by caregiver

Two participants interviewed stated that their caregivers disclosed to them that they were HIV positive. Participant F said, *'my mother told me I was HIV positive after I kept asking her why I have to keep taking the pills everyday even if I'm not sick at the age of 10'.*

3.3.6. Disclosure by counsellor

Counsellor B stated that most adolescents get to know of their HIV status after defaulting in taking the ARV and when their viral load goes high. When the child does a regular blood test for viral load and CD4 count that is when it is noted that the child is defaulting to take pills. This is noted through the high viral load in the blood sample. When the child has a high viral load, that is when they are referred to a HIV counsellor at a clinic.

Counsellor B said *'when you ask the adolescent during counselling why they have been defaulting, they say they are tired of taking the pills every day and yet they are not sick. We ask the child to bring their caregiver and do disclosure counselling'.*

3.4. Disclosure to others

Disclosure to others came up as a difficult process to children living with perinatal HIV. Children living with perinatal HIV who participated in this research had not disclosed their HIV status to their friends outside the support group. 63% (5 out of 8) of the children who participated in this research and were dating had not disclosed their HIV to people they were dating or having sex with. These findings resonate with Mbalimba, Kiwanuka, Eriksson, Wanyenze and Kaye (2015), who carried out a study in Uganda and found out that children living with perinatal HIV have risky sexual behaviours characterised by being sexually active, inconsistent condom use and have partners of unknown status. This is also supported by Koeniget al. (2010) who revealed that irrespective of how HIV was acquired, adolescents display high-risk behaviours characterised by having unprotected sex and multiple sexual partners. This places them at a high risk of pregnancy, HIV reinfection and STIs.

3.4.1. Disclosure to friends

The participants mentioned that disclosure to friends was strenuous as they could never know how the friends would react after.

Participant H stated that, *'It is hard to disclose my status to friends at school as teenagers tend to isolate people living with HIV. They will not say anything to your face but I know they would be gossiping about me'.*

3.4.2. Disclosure to partners

All of the adolescent participants stated that disclosure of HIV status to partners was very difficult as they fear being stereotyped as promiscuous.

Participant H said, *'it is hard to meet someone and immediately disclose that you are HIV positive. The person would assume that you are a promiscuous person who has sex with several people'*.

Participant F stated that, *'if I go around disclosing my status I will die without dating because this disease immediately chases away the person'*.

Participant F mentioned that she only discloses when she realises that her relationship is solid. She said, *'I hate the process of having to explain myself to another person how I got the HIV and then get dumped afterwards'*.

The counsellors stated that they encourage the adolescents living with perinatal HIV to join support groups and date within the group as it makes their dating easier as they do not have to continue explaining themselves to partners. Counsellor B said *'the adolescents should date within the support group to avoid rejection'*.

3.5. The relationship of adolescents living with perinatal HIV with their friends

All of the adolescent participants mentioned that their best friends are people from the adolescent support group. This was because the friends understand what they are going through and they could open up to them about anything.

Participant B stated that, *'my best friend and I met here at the clinic whilst waiting to get our pills, we both attend the clinic adolescent support group'*.

Participant C said, *'I try not to become too close to friends at school because they would end up knowing my HIV status. I always fear rejection so I will rather keep a distance than get close to a friend then one day she would start ignoring me'*.

3.6. Unanswered questions

Due to African culture norm of respecting the elders and not questioning their behaviour, most participants had not asked their caregivers about how they got HIV. From this study, it came out that the children had many unanswered questions concerning their HIV status and openly questioned the sexual life of a parent. They also feared emotionally hurting their parents. The children living with perinatal HIV got to question themselves about their identity, i.e., who they are, why they have HIV and why them. Erikson termed it an identity crisis which is a time of inner conflict during which adolescence worry intensely about their identities (Gross, 2010). Their failure to resolve this causes them to feel as outsiders and suffer in silence thereby becoming isolated, develop depression, anger and bitterness.

Participant A mentioned that she had a lot of questions to ask concerning her HIV status but unfortunately her parents died.

Participants B, D, E and F all said they feel their parents should sit down with them and explain how they got to have HIV.

Participant E said, *'I want to know who brought the HIV between my mother and father, why they did not prevent it from infecting me, am I the reason they separated, why they never disclosed to me my status and why is it everyone acts as if I am the one who brought the disease'*.

4. Conclusion

The study revealed that adolescents living with perinatal HIV do not get the opportunity of going through the disclosure process which is recommended by HIV counsellors but instead they get full disclosure from others that they are HIV-positive without psychological preparedness. This emanates from lack of knowledge on how to disclose to children by parents and caregivers. Parents fear to disclose the HIV status to their children because of guilt as they feel they are to blame for transmitting the disease to the child. Parents also fear resentment from their children and having to explain who came with the disease to the family and why they could not prevent it.

The way the disease is disclosed to the children also causes the stressors in the lives of the adolescents. These are escalated by the circumstance that the adolescents are already going through challenges that come with the adolescence stage, whereby the adolescents are trying to gain self-identity and have a lot of questions about who they are, exploring the world and develop independence. Adolescents have to deal with the issue of culture where in traditional African culture they cannot summon their elders or parents and ask for answers on the questions they have concerning their disease. Adolescents also fear to evoke pain to their parents if they are to question about what might have caused the parent to have HIV and they end up relying on support groups to gain better understanding of the disease.

Interpersonal relationships play a pivotal role in the lives of adolescents living with perinatal HIV as they need close support to manage HIV viral load in their blood through adherence to ART. Attachment of children to their caregiver from childhood determines the relationship they will continue to have with them after they have knowledge that they are HIV-positive. Close attachment and open communication relationship lead to healthy relationship and strong bond between the adolescent living with perinatal HIV and the caregiver or parent. Disclosure of HIV to partners is a challenge for adolescents living with perinatal HIV. They do not disclose their HIV status for fear of rejection. This is very risky for other adolescents who assume unprotected sex with another virgin adolescent is safe as they would not have sex before.

The lack of differentiation in the health sector between children living with perinatal HIV and those with behavioural infection makes it difficult to track this subgroup as they transcend to adulthood. Their number will remain unknown as adults and specialised intervention will not be available. The gap in capturing the statistics of adolescents living with perinatal HIV means that there are also few interventions for them.

5. Recommendations

The researcher recommends that:

- i. The National Guideline Committee for ART in Zimbabwe should include psychologists who can carry out further research and come up with better counselling therapies for adolescents living with perinatal HIV.

The Ministry of Health and Child Welfare should employ a permanent registered psychologist at OI clinics so that they can come up with healthy ways to disclose HIV status to children and counsel caregivers and adolescents living with perinatal HIV, as the institution only has HIV counsellors who are mostly skilled in counselling on matters of HIV adherence and not psychological problems that come with living with HIV.

HIV support groups should partner with registered psychologist so as to come up with well-researched information to help adolescents living with perinatal HIV.

More public awareness needs to be done in communities and schools on perinatal HIV by the Ministry of Health and child welfare so as to create awareness on HIV status disclosure by

caregivers on children living with perinatal HIV, remove stigmatisation and promote health sexual behaviour among adolescents.

- ii There is a need for further research involving various OI clinics to study the psychosocial experiences of adolescents living with perinatal HIV so as to come up with a psychological theory and manual that can guide the counsellors on counselling adolescents living with perinatal HIV.

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