FACING THE TRUTH: THE CHALLENGES OF HIV DISCLOSURE AMONG ADOLESCENTS WITH PERINATAL HIV IN BULAWAYO, ZIMBABWE

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ABSTRACT
The purpose of the study was to explore the process of 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 was collected through in-depth interviews. The data collected revealed that HIV status disclosure to children was difficult for caregivers which caused the disclosure to be done late than recommended by Ministry of Health and Child Care Zimbabwe. This had a significant negative impact on the psychological wellbeing of the children who also struggle to disclose their status to others. The study revealed that the HIV counsellors lacked skills to counsel on psychological issues. The study recommended that Psychologists be integrated in formulation of HIV manual and be employed at OI clinics to counsel children and caregivers.

Keywords: *perinatal HIV; children; psychosocial; OI clinic*

INTRODUCTION
Human Immunodeficiency Virus (HIV) has been one of the most devastating diseases in the world, and perinatal or transmission from mother to child HIV is the most common way children below the age of 5 years contract HIV. Transmission of perinatal HIV can happen in the uterus, during labour or after delivery from breastfeeding (McGowan & Shah, 2000). World over, there are approximately 1.4 million HIV positive women who become pregnant (UNAIDS, 2014). With the use of ART, transmission of HIV from the mother to child has decreased according to reports by the World Health Organization (2015). In 2009, there were an estimated 400,000 children born with HIV and by 2013, there were 240,000 (UNAIDS, 2014). Countries in Southern Africa are worst affected by the HIV and AIDS pandemic. In 2010, 30% of all pregnancies in the region were affected by HIV. In 2011, HIV was responsible for 50% of the deaths for children below the age of 5 (WHO, 2015). A major factor that distinguishes HIV/AIDS from another chronic or terminal illness is the stigma, many HIV infected children, and their families live in a 'conspiracy of silence' and shame associated with AIDS (Vranda & Mothi, 2013). This means the Illness is often kept as a secret.

In Zimbabwe during 2015, mother-to-child transmission was estimated to account for 6.39% of all new HIV infections in children aged 0-14 years. The number of new infections in this age group has itself fallen from 12,000 in 2010 to 4,900 in 2015 (Zimbabwe Ministry of Health, 2016). In 2015, HIV prevalence among this age group was 1.8%. When broken down more specifically by age, prevalence among 0 - 4-year old was 1.1% and 2.7% among 10-14 years (Zimbabwe Statistics agency, 2016). In 2015, 80% of children (0-14 years) living with HIV had access to ART (UN, 2016). 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 whilst playing, caregivers while reprimanding the child or from listening to the conversation of family members.

The issue of disclosure is very challenging to both the caregiver and the adolescent. 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 adolescents have to deal with the reality of being HIV positive. Besides the challenges of physical illnesses related to HIV, 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 this 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 has an impact on family attachment, social growth, dating, peer relations and self-identity on adolescents (Vranda & Moththi, 2013)

Objectives

The specific objectives of the study were to:

i. Explore the process of HIV status disclosure to children.
ii. Identify the challenges of HIV disclosure to children living with perinatal HIV

METHOD

Population

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

Sample and sampling techniques

The samples for the study were 8 adolescents living with perinatal HIV and receiving therapy at the clinic of study, 3 of the caregivers of these children, and 2 counsellors working with these children at the clinic. A **homogeneous** purposive sample was used to select participants having a shared characteristic or 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 was used to include participants with similar characteristics which include age category, HIV status and facility where therapy is being received. Altogether, there were 13 participants, which comprised 8 adolescents living with perinatal HIV, 3 Caregivers and 2 counsellors.

Data gathering Instrument

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

Procedure

Permission to collect data was obtained from the Medical Research Council of Zimbabwe since the study is among adolescents who are also categorized as children, and studies a medical condition which is HIV. Another permission to collect data was obtained from the Mpilo Hospital Clinical Director. The Clinic superintendent helped the researchers to identify the children living with perinatal HIV and their caregivers who would have 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 instrument used to collect data which was in-depth interview 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 researchers. The consent and assent forms were also translated to Ndebele language to allow the participants to fully understand the research they were participating in.

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).

Data Analysis

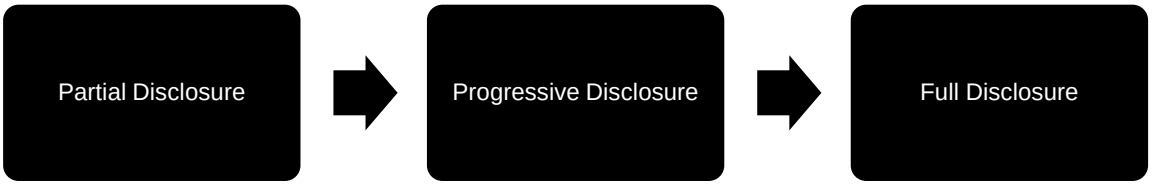
Phenomenological data analysis was used for this research. Phenomenological data analysis includes epochal approach, which involves laying out one's assumptions about the phenomenon under research, bracketing, imaginative variation, synthesis of texture and structure to come up with codes to generate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

RESULTS AND DISCUSION

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.

Process of HIV status disclosure to children living with perinatal HIV

Disclosure of HIV status on children was described as a process rather than an event, which starts from young age. If the process is not followed, 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 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.



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 which starts when the child is 5 years until they fully understand that they are living with HIV. This method was recommended by 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 then full disclosure. Children who go through the process grow up with understanding of their status and are attached to their caregivers

HIV status disclosure by counsellor

Counsellors stated that the steps of disclosure of HIV status starts by building rapport with the child and caregiver. Counsellor A stated that it is best to disclose 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 explained,
"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 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 children of the little conversations they used to have when the child was young, 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 emphasized that it was important to check the knowledge the child has concerning HIV and how it can be transmitted. The counsellor stated

> *"the maturity of the child and knowledge of the disease is important in determining how to disclose the HIV status to the child……"*

Point of awareness of HIV status by Adolescents

The study unveiled that the means that the child gets awareness about his/her HIV status matters and influence who they become. The children had experienced different point of awareness of their HIV status which had great impact on the way they have psychologically developed. The children who got to know about their HIV status at younger age had developed acceptance and coping strategies of living with HIV against those who got to know their HIV status later.

Clinic Corridors

Two participants stated that they got to know of their HIV status through the health talks that were done at the clinic corridors whilst clients were 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 was when I knew that the pills I have been taking were for HIV, at the age of 10"*

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 the grandmother who got her tested for HIV and immediately told her. She stated *"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 in grade 6."*

Testing after sickness

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

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 explained:

> *"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."*

Disclosure by caregiver

Two participants interviewed stated that their caregivers disclosed to them that they were HIV positive. Participant F stated *"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."*

Disclosure by counsellor

Counsellor B stated that most children get to know of their HIV status after defaulting taking the ARV and their viral load has gone high. When the child has done 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 high viral load in the blood sample. Referral to HIV counsellor at clinic usually follows the discovery that the child has high viral load.

Counsellor B explained

"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.

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 did a study in Uganda and found out that children living with perinatal HIV have risky sexual behaviours characterized by being sexually active, inconsistent condom use, and having partners of unknown status. This is also supported by Koenig, Pals, Chandwani, Hodge, Abramowitz and Barnes (2010) who revealed that irrespective of how HIV was acquired, adolescents have high-risk behaviour characterized by having unprotected sex and multiple sexual partners. This places them at high risk of pregnancy, HIV reinfection and STIs.

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."*

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 elaborated *"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 realizes that her relationship is solid. She elaborated *"I hate the process of having to explain myself to another person how I got the HIV and then get dumped afterwards".* The counsellors explained 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 stated *"the adolescents should date within the support group to avoid rejection"*

The relationship of adolescents living with perinatal HIV with their friends

All of the adolescent's 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 explained 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'*

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 questioning the sexual life of a parent. They also feared emotionally hurting their parents. The children living with perinatal HIV get to question themselves about their identity, that is; who they are, why they have HIV and why it had to happen to them. Erikson termed it an identity crisis which is a time of inner conflict during which children

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. Participant B, D, E and F all claimed they feel their parents should sit down with them and explain how they got to have HIV. Participant E explained *"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."*

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 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 adolescents. These are escalated by the circumstance that the adolescents are already going through challenges that come with the adolescence stage where by 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 disclosure their HIV status for fear of rejection. This is very risk to 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 specialized intervention will not be available. The gap in capturing the statistics of adolescents living with perinatal HIV means that
they are also few interventions for them.

Recommendations

Based on the findings of this study, it is recommended that:

i. the National Guideline Committee for ART in Zimbabwe should include Psychologists who can further research and come up with better counselling therapies for adolescents living with perinatal HIV.
ii. 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 have HIV counsellors who are mostly skilled in counselling on matters of HIV adherence and not psychological problems that come with living with HIV.
iii. HIV support groups should partner with registered psychologists so as to come up with well researched information to help adolescents living with perinatal HIV.
iv. 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 stigmatization, and promote health sexual behaviour among adolescents.

v. There is 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 guide the counsellors on counselling adolescents living with perinatal HIV.

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