

PERCEPTIONS OF ADOLESCENTS PERINATALLY INFECTED WITH HIV REGARDING THE SELF-DISCLOSURE OF THEIR STATUS

Caroline Mpfu, Issie Jacobs

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Most children born with perinatally acquired human immunodeficiency virus (HIV) are now maturing into adolescence. From an ecological systems perspective, this qualitative study aimed to explore and describe the perceptions of adolescents who were perinatally infected with HIV (ApHIV) regarding the self-disclosure of their status. Semi-structured interviews were conducted with 10 ApHIVs and interpreted using thematic analysis. The findings of the study link participants' perceptions to societal attitudes towards HIV and to adolescent developmental factors, which contribute to decisions either to self-disclose or not to self-disclose their status. Recommendations are suggested regarding support for ApHIVs.

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## **PERCEPTIONS OF ADOLESCENTS PERINATALLY INFECTED WITH HIV REGARDING THE SELF-DISCLOSURE OF THEIR STATUS**

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### **INTRODUCTION**

Children born from mothers with the human immunodeficiency virus (HIV) are progressing into adolescence and adulthood as a result of the accessibility of antiretroviral treatment which prolongs their life expectancy (Arrive, Amghar, Bouah, Dabis, Dicko, Ogbo & Traore, 2012:56; Butler, Campbell & Hogwood, 2012:46; Cook, Ferrier, Haberer, Kityo, Ngambi & Walker, 2011:2; Zanoni, 2013:13). As the children born with HIV reach adolescence, the issue of managing their illness becomes important to them, to their caregivers and to healthcare professionals. Managing HIV illness in adolescents living with perinatally acquired HIV (from here on they will be referred to as ApHIVs) also entails dealing with the disclosure of their status, which is usually facilitated by their caregivers with the help of healthcare professionals (Carter, 2010:28; WHO, 2011:16). ApHIVs not only have to deal with the knowledge of living with HIV and how to manage the illness, but also have to master general adolescent developmental tasks.

Upon knowing their status, ApHIVs also have to deal with the dilemma of whether to self-disclose their status to others or not (Butler *et al.*, 2012:49). Self-disclosure is defined as an act of revealing one's own HIV status to another person or persons (Hoe, McKeown, Sobota, Stolts & Trow, 2003:7). The self-disclosure of HIV status is important for ApHIVs as they are in a developmental stage where they start forming intimate relationships and concerns about transmission may arise (Armstrong, Pungula, Sobantu, Cheserem & Moshal, 2013:27).

Self-disclosure can be perceived as being positive or negative. Self-disclosure may lead to support for people living with HIV when friends and family react positively to the diagnosis, which influences psychological adjustment to the illness (Groves, Maman & Van Rooyen, 2013:1; Tshabalala, 2014:2068). Furthermore, self-disclosure of one's HIV status is also seen as beneficial for HIV-positive children and adolescents orphaned by HIV, as it may improve their resilience mechanisms as they may feel protected and supported by family members and the community who understand their situation (WHO, 2013:19). Randeria (2013:35) highlights how disclosure can contribute towards reducing risky sexual behaviour, adherence to treatment and access to clinical and psychosocial services such as treatment of sexually transmitted infection and support groups. Support groups in school settings also provide a safe space for the ApHIVs, especially when support is received from teachers and peers (Birungi, Katahoire & Obare, 2010:12).

Self-disclosure more often, however, seems to be determined by a fear of being subjected to stigmatisation and rejection not only by the community in general, but also by family and friends. A study in a school setting in Uganda on the perceptions of

ApHIVs and the self-disclosure of their HIV status concluded that stigma and discrimination are specific hindering factors to the self-disclosure of their HIV status (Birungi *et al.*, 2010:12). Woollett (2013:23) states in the same regard that ApHIVs may fear that the self-disclosure of their status to others may expose them not only to stigmatisation but also to shame regarding their condition.

A study conducted in Zambia on barriers, attitudes and outcomes of HIV disclosure by ApHIVs confirmed that the majority of adolescents do not self-disclose their status to their sexual partners because of a fear of rejection (Cataldo, Haamujompa, Hodgson, Kalibala, Lowenthal, Mburu & Ross, 2014:1).

Parents also seem to play a role in whether or not ApHIVs will self-disclose their status or not out of fear of subjecting their child to stigmatisation and discrimination. A study by Butler *et al.* (2012:46), for instance, notes that the majority of ApHIVs express the desire to self-disclose their status, but feel constrained by their parents' views. Butler *et al.* (2012:45), Cataldo *et al.* (2014:94) and Mahloko and Madiba (2012:6) specifically note in this regard that biological parents of ApHIVs often prohibit their children from self-disclosing their status to people outside of the family because of fear of social rejection, or that the child will be teased, mocked or isolated by peers and the community. HIV infection therefore remains a household secret.

Several studies have confirmed that HIV-related stigma is rife in most South African communities (Arrive *et al.*, 2012:56; Campbell, Foulis, Maimane & Sibiyi, 2005:808; Deacon & Stephney, 2007:25; Greeff, 2007:21; Haberer *et al.*, 2011:3; Harper, Hosek, Lemons & Martinez, 2008:192; Kehler, Mtambo, Mthembu & Zungu, 2012:6; Mahloko & Madiba, 2012:6; Woollett, 2013:23). The high prevalence of HIV in South Africa and a lack of knowledge about HIV have led communities to maintain biased myths and fears regarding HIV (Campbell *et al.*, 2005:808; Deacon & Stephney, 2007:25; Kehler *et al.*, 2012:6).

Communities thus stigmatise people of all ages living with HIV, subjecting the affected person to discrimination, abuse and violence, hence hindering the self-disclosure of their status (Campbell *et al.*, 2005:808; Deacon & Stephney, 2007:25; Greeff, 2007:21; Kehler *et al.*, 2012:6; Woollett, 2013:23). For ApHIVs, the inability to self-disclose their status because of fears of stigmatisation and discrimination may have a huge influence on their development, especially the formation of interpersonal relationships, self-esteem and the practice of safe sex (Woollett, 2013:23).

This study was premised on the basis of ecological systems theory. Ecological systems theory, also known as human ecology theory, is defined by Bronfenbrenner (1979 in Johnson, 2008:2) as "human development within the context of systems of relationships" that form part of a person's environment. Furthermore, Bronfenbrenner (1979 in Härkönen, 2007:7) views the environment in which a person is functioning, as comprised of five layers of systems: the microsystem, mesosystem, exosystem, macrosystem and chronosystem.

Wakefield (1996:7) posits that people are interlinked to each other as well as their environment, which encompasses social institutions, cultural forces and physical space,

thus showing all possibilities of connections and interactions that individuals have with others and the environment. For ApHIVs, interconnections and interactions within various systems in their environment influence their development and growth (Johnson, 2008:2). The way in which the systems interact with the ApHIVs influences how they perceive themselves and their decision to self-disclose their status. The more encouraging and nurturing the various systems (family, school, peers, society) are towards the ApHIV, the better the ApHIV makes informed decisions about self-disclosing their status or not. It was against this backdrop that the researcher intended to explore and describe the perceptions of ApHIVs on self-disclosing their HIV status.

## **RESEARCH METHODOLOGY**

The major aim of the study was to explore and describe the perceptions of ApHIVs regarding the self-disclosure of their status, which may further create awareness of what ApHIVs perceive regarding the phenomenon of self-disclosure of their status. Additionally, the findings of the study may lead to dialogue and discourse amongst social workers and healthcare professionals working in programmes aimed at supporting adolescents living with HIV.

A qualitative interpretive naturalistic paradigm was followed to provide a contextual understanding of the subjective perceptions of ApHIV regarding self-disclosure of their status. According to Delport, Fouché and Schurink (2011:297), Krieger and McKenzie (2006:192) and Lincoln and Guba (1985:107), a paradigm is an interpretative framework that not only guides a set of beliefs and feelings about the world, but also how it should be understood and studied. The study explored the phenomenon of self-disclosure to gain insight into the perceptions of participants through utilising a multiple case study design. Using a multiple case study design (Fouché & De Vos, 2011:96) not only helped to collect rich data on the phenomenon under study, but also helped to elicit valuable information about the phenomenon as participants see it.

The population of the study was comprised of all ApHIVs who were registered in the database of a specific clinic in Port Elizabeth. For the purpose of this study, adolescents included in the study were aged between 13 and 18 years.

The sample was obtained by means of non-probability purposive sampling. In non-probability sampling all the elements in the population have an unknown chance of being included in the sample (Burns & Grove, 2009:353). According to Babbie (2007:183), a non-probability sampling approach tends to rely on the availability and accessibility of participants. Thus the limitation of the study is that the sample is not representative of the population and findings cannot be generalised.

The researcher decided on the inclusion criterion of the sample based on the knowledge of the population and purpose of the study (Babbie, 2007:183). Adolescents who had acquired HIV perinatally, whose status had been disclosed to them and were receiving psychosocial support at a clinic in Port Elizabeth, were purposively sampled for their availability and willingness to participate in the study. The status of most of the ApHIVs who formed part of the sample was disclosed to them at an average age of 10; they were

orphaned and some of them were living with grandparents and few of them with their biological mothers. Since the ApHIVs forming the sample of the study were receiving psychosocial support at the clinic, they were either in a support group at the time of the study or had been before the study was conducted.

Thirty-five ApHIVs were identified from the clinic register and received invitation letters to participate in the study from nurses during their monthly clinical consultations. Out of the thirty-five invitations handed out, the final sample was ten adolescents living with perinatally acquired HIV. Three of the participants were males and seven of them were females. Consent to undertake the study was provided by the head of the clinic as well as by the adolescents' primary caregivers. Assent to participate in the study was also obtained from the participants. The numerical value of the sample did not define the study, but the sample was sufficient to allow exploration of the phenomenon and yield rich descriptions of perceptions of ApHIVs.

**TABLE 1**  
**PARTICIPANT INFORMATION**

<b>Participant</b>	<b>Age</b>	<b>Gender</b>	<b>Age disclosed to</b>	<b>Grade in school</b>
Participant 1	13	Female	9	7
Participant 2	16	Male	10	10
Participant 3	14	Female	10	7
Participant 4	14	Male	13	6
Participant 5	16	Female	6	12
Participant 6	15	Male	Not sure	9
Participant 7	15	Male	13	7
Participant 8	17	Female	14	7
Participant 9	17	Female	15	Post-matric
Participant 10	15	Female	Not sure	9

Reflective journals kept by the participants and semi-structured interviews were used to collect data. According to Hatch (2010:141), journals “provide a direct path into the insights of participants.” Participants kept the reflective journals for a period of two weeks, writing down their perceptions regarding the phenomenon of self-disclosure, after which two semi-structured interviews were conducted with each participant in a private room. Semi-structured interviews contain open-ended questions, which gave the researcher some latitude to ask additional questions in response to significant views. The interviews lasted an average of 45 minutes per session and they were voice-recorded with participants' consent in order to avoid any loss of information. It took one month to meet all participants, from introducing the study to conducting the semi-structured interviews.

Upon transcribing the interviews and translating them from Xhosa into English, data from the interviews as well as the reflective journals were analysed inductively using thematic analysis. According to Braun and Clarke (2013:120-122), thematic analysis entails inductively generating codes from the data gathered, searching for themes

amongst codes, and reviewing and naming the themes. Thematic analysis informed the way the qualitative data from the participants were managed in order to describe the outcome.

### **Trustworthiness**

The researcher heightened trustworthiness through adhering to guidelines for trustworthiness, namely credibility, transferability, dependability, confirmability and authenticity (Bryman, 2004:274-276; Lincoln & Guba, 1985:301-327; Schurink, Fouché & De Vos, 2011:419).

Credibility was ensured through voice recording the interviews and transcribing them word for word as well as through prolonged engagement with participants. Transferability was ensured through collecting data from multiple sources as well as utilising different sources of data collection, allowing crystallisation of the themes emerging. Dependability was ensured by keeping an audit trail of all phases of the research process. Confirmability was ensured through establishing consistency from the different data sources. Evidence from different data sources and findings were audited through finding a link between the sources, interpretations and recommendations. An audit was done to ensure that there was coherence of themes and that the results of the findings were reflective of the subjective perceptions of participants, not of the researcher.

### **Ethical considerations**

Permission to undertake the study was obtained from the university as well as from the clinic in Port Elizabeth where participants were receiving psychosocial support. Since the topic was sensitive, the researcher also adhered to the following ethical principles highlighted by Babbie (2010:65-86), Brinkman and Kvale (2008:213-228) and Creswell (2009:88-92).

- **Informed and written consent:** This was obtained from the clinic where the study was conducted as well as from the pool of participants and their primary caregivers clearly explaining the purpose of the study and clarifying questions and concerns.
- **Voluntary participation:** This was obtained through asking participants to voluntarily participate in the study as well as making them aware of the right to withdraw from the study at any stage without fear of being persecuted.
- **Avoidance of harm:** This was obtained through ensuring that participants were aware of the possible effects of harm. Participants who displayed emotional discomfort and needed support were referred to their counsellors at the clinic for support. Participants were also informed of their right to withdraw from the study at any given time.
- **Confidentiality and anonymity:** This was obtained through conducting interviews in a private counselling room at the clinic. The privacy of participants was maintained and their identity protected by giving each participant a pseudonym.

- Respect of human dignity: This was ensured through explaining the nature of the research to the participants as well as what was expected from them.
- Actions, adequate skills and competence of the researcher: The researcher considered herself to be competent as she had attended a training course in research and also worked in the field of HIV with children and adolescents for six years. Additionally, the researcher was under supervision throughout the study. Self-reflexivity was utilised through conscious introspection and by taking field notes, allowing participants to subjectively construct their own truth regarding their perceptions.

## RESULTS AND DISCUSSION

A discussion of themes and sub-themes that emerged when the data were analysed follows below.

### CERTAIN CONDITIONS CONTRIBUTE TO THE CHOICE TO SELF-DISCLOSE

The first theme that emerged was that participants perceived certain conditions to be contributing factors to whether they would self-disclose their HIV status to others. These conditions involve trusting relationships and the need for support. It seems that both these conditions would contribute favourably to the participants' choice to disclose their HIV status.

#### Trusting relationships

Most participants described trusting relationships as essential for them to self-disclose their HIV status. A trusting relationship, according to Shang-Min (2008:7), "is more concerned about the welfare of others, capable of strong empathy, affection and intimacy and understanding of give and take in human relationships." In the context of this study, trusting relationships would mean relationships where there is an empathetic and affectionate understanding of the ApHIV. Trusting relationships were perceived to involve peers (Participants #2, #3, #5), family (Participants #3, #4, #5) and teachers (Participants #1, #3, #7), who either through personal experience understand what it is to live with HIV or who form part of the microsystem of the participants: "*... I will only tell people I trust and love, like my mother's family ... because they understand me.*" (Participant #3)

A trusting relationship for the participants also seems to involve people whom they perceive would not tell other people about their status: "*my old school teacher knows, I trusted her ... she knew everything about me and she never told anyone*" as well as "*the support group kids ... I can speak openly with them and they will not tell anyone outside the support group.*" (Participant #10)

The study also revealed that participants were willing to self-disclose to people with whom they share similar experiences. According to Greene, Gust, Petronio, Valerian and Yep (2003:54), similar experiences refers to others who share a similar background or who have similar health problems as alluded to by Participant #3: "*When I think about telling people my status, I feel I can only tell one friend from school, not my other four*

*friends, because that friend is also living with HIV and she understands me” and “The only other people who understand me are kids in the support group ... we talk about our treatment, how it is affecting us, side effects and how we can try living a healthy lifestyle” (Participant #5). Participant #9 shared a similar perception in her journal: “The ‘besties’ I have are my support group sisters ... they were open to tell me about their status ... we trust each other.”*

Paiva, Segurado and Filipe (2011:1699) highlight that persons tend to self-disclose their status easily to people with whom they have regular contact and are in steady intimate relationships with, which in itself leads to the strengthening of affectionate relationships. On this point McConville (1995:2) is of the opinion that relationships with peers shape the adolescent’s sense of feeling comfortable, sense of worthiness and attractiveness, allowing them to talk about themselves. In this regard participants mention that they would self-disclose to “trusted” people close to them such as support group peers who understand them, thus allowing the strengthening of affectionate relationships: *“I trust the other kids in the support group. They also trust me and we do not talk bad about each other or feel sorry for each other ...” (Participant #6).*

Trusting relationships were perceived to be a platform where private information could be shared without worrying that the information will be shared with others or gossiped about. Self-disclosure, therefore, is perceived to take place within the boundaries of trusting relationships where the confidant understands ApHIVs and would not reveal their status with anyone. Study results by Steel (1991:1319) suggest that a trusting relationship is necessary for self-disclosure to occur and that self-disclosure in part is a product of trust.

### **To gain support**

To give support, according to Seeman (2008), refers to things that people do to make others feel loved and cared for, and which boost one’s self-esteem. From the literature it seems that ApHIVs are in need of emotional, medical, educational and psychosocial support because of the complex and sometimes undetected cognitive, social and physical problems they encounter (Zanoni, 2013:16). The support that they need could, therefore, involve support in the form of clinical support in dealing with side effects of their medication, or support to manage their monthly clinic visits (Woollett, 2013:23), and educational support as a result of delayed cognitive abilities (Beyers & Hay, 2011:99). Participants, therefore, perceived that they would self-disclose to family, teachers and healthcare professionals when in need of support as indicated in the comments below.

(Participant #5): *“I think the only people that should know are professionals who are able to help me, for example, doctors, nurses and teachers, because they understand my situation and are always ready to listen and not judge me” and “My teacher knows and she helps me when I need to be absent from class.”* Participant #6 also shared the same perception: *“Doctors, nurses and social workers ... they will not judge or feel sorry for you but support you.”*

In fact some of the participants who have found themselves in situations where they needed support have already disclosed their status to specific role players. Participant



#3, who was in need of knowledge regarding HIV, shared the following: “... *tell Ubuntu counsellors ... because they support me to learn more about HIV.*” Participant #2, for instance, was in need of support from his mesosystem, which involved interactions between the school and his family: “*look here in my journal, there is my teacher ... drawn, I have disclosed to her ... my teacher will support me and call my mum when I am not feeling well.*”

Beyers and Hay (2011:101) quite rightly mention that learners living with HIV can only receive the support they need when they self-disclose their status to teachers. Not to self-disclose, according to Butler *et al.* (2012:44), therefore does not seem to be an option, as they are of the opinion that ApHIVs who have not self-disclosed their HIV status to teachers are likely to face difficulties in situations where they, for instance, need to explain their school absenteeism. To be in need of (psychosocial) support thus seems to be perceived by the participants as a contributing factor towards self-disclosing their HIV status. It also seems to be the one aspect where they realise the value of self-disclosing their status – to receive the support they need in order to function within their different ecological systems.

### **CERTAIN CONDITIONS ARE NOT CONDUCTIVE TO SELF-DISCLOSE**

The second theme that emerged was that participants perceived certain conditions not to be conducive to self-disclosing one’s HIV status. These conditions included a fear of being stigmatised and discriminated against as well as a fear of general societal attitudes. Butler *et al.* (2012:51) and Tshabalala (2014:2071) indicate that fears of stigmatisation and discrimination inhibit disclosure. Furthermore, Harper *et al.* (2008:210) state that ApHIVs have to confront innumerable fears, as they not only have to battle with normal adolescent developmental issues, but also have to carry the burden of living with a highly stigmatised and life-threatening illness.

#### **Fear of stigmatisation and discrimination**

Stigma is defined differently by different authors. Scambler (2009:441) relates stigma to a social process characterised by rejection, devaluation or social judgement of a person or group. The researcher, however, adopted Goffman’s (1968:4) definition of stigma as most suitable for the current study, which relates stigma to “a characteristic that is considerably discrediting” and the stigmatised individual is viewed as a person who possesses “an undesirable difference” that leads to “a spoiled identity.” In the context of this study the undesirable difference is the HIV-positive status of the adolescent.

To self-disclose their HIV status is perceived by the participants as allowing an opportunity for others to gossip about them or laugh at them. Participants, for instance, fear that after self-disclosure their peers would tell other people in their community and school about their HIV status.

*“... they will start laughing at me and they will say things like ... she is slim, she is sick now when I lose weight or she is fat, the ARVs (Anti-Retroviral Therapy) make her fat ... they will start telling others and gossiping about me.”*  
(Participant #3)

Furthermore, participants also indicated that they were scared of being excluded by other children and given nicknames, as alluded to by Participant #2: “... *they do not have what I have so if I tell them, they will not want to be my friends*” or by Participant #9: “... *they say she has BMW, she has the 3 alphabets, which is a three-letter word meaning HIV.*” Seeing that peers, social networks and socialisation in general are associated with adolescence, and provide adolescents with comfort, support and guidance (Geldard & Geldard, 2005:13; Van Dyk, 2008:188), ApHIVs thus perceive not self-disclosing their status as being safe, as they would then not be excluded from socialising with their peers.

It seems that ApHIVs mostly fear stigmatisation from those who form part of their microsystem, namely neighbours, relatives, peers and other school children as indicated below.

*“I am scared that if I tell the other family and my cousins, they will laugh at me.”* (Participant #2)

*“I do not want to tell friends at school because they also stay in the same area with me, they will laugh at me ... they will point fingers and say he is living with HIV.”* (Participant #4)

Stigmatisation also results in discrimination, which is defined by Liamputtong (2013:9) as unfair and unjust treatment of an individual on the assumption that he or she is deviant from others. People living with HIV are thus socially constructed as the “other” who are different from, and threatening to, the general public (Liamputtong, 2013:3).

For ApHIVs, discrimination has different facets, including the perception of being felt sorry for and alienated from peers. This perception has specifically been highlighted by Participant #3, who stated, “*It is not nice, Sisi, it makes you feel like you do not look like other kids ... I do not want to be felt sorry for because each person has their own issues, if someone has high blood pressure I do not feel sorry for them*” and Participant #2 “*I do not want my teacher to start feeling sorry for me and treating me differently.*”

Discrimination was also seen in the form of being isolated from play by other peers if their HIV status is known, as mentioned by Participants #2 and #4: “*They will stop playing with me because they will think that I will give them HIV*” (Participant #2) and “*They will tell their mothers and their mothers will say they must stop playing with me.*” (Participant #4)

The above results are supported by evidence from studies by Arrive *et al.* (2012:56), Butler *et al.* (2012:48), Greeff (2007:21), Haberer *et al.* (2011:3), Harper *et al.* (2008:192), Tshabalala (2014:2071) and Woollett (2013:23) on how the prevalence of HIV-related stigma and discrimination is a hindrance factor to the self-disclosure of one’s HIV status. According to Greeff’s (2007:21) study, people living with HIV specifically prefer keeping their status a secret because of fears of being rejected or humiliated.

The findings of the current study also support findings by Butler *et al.* (2012:55) and a report by UNICEF (2011:28) that ApHIVs prefer not to self-disclose their status because

of their perceptions and fears of stigmatisation and discrimination, which can negatively affect the forming of interpersonal relationships with peers. Within their microsystem, relationships with sexual partners or peers could also be compromised as a result of fears of being felt sorry for, or of being isolated if they self-disclose their status. It is almost as if ApHIVs find themselves in a Catch-22 situation, seeing that, on the one hand, they are in need of support and therefore need to self-disclose; on the other hand, however, they will not self-disclose out of fear for being stigmatised, discriminated against and being rejected by their peers.

### **General societal attitudes**

Linked to the above is the general community attitude which forms part of the macrosystem. Participants also perceive general community attitudes including ignorance about HIV as a contributing factor to inhibit their self-disclosure. A study by Butler *et al.* (2012:54) has found that societal myths and assumptions about HIV present a huge dilemma for the adolescent to self-disclose. According to the current study, the majority of the adolescents perceive the self-disclosure of their status as beneficial to their wellbeing, but at the same time are fearful of the consequences and do not want to risk alienation from the community and peers, as reflected by Participant #5: *“It is just how I think because of how people react to people living with HIV in the community, where when one has HIV, everything they do especially bad things will be linked to HIV”* and *“I will not tell friends ... they will start pointing fingers at me for all the mistakes I made and link them to HIV.”* (Participant #5)

Participants’ experiences of observing community members’ negative reactions to people living with HIV were also perceived as a condition that is not conducive to self-disclosure, as shown by Participant #2: *“I have seen it in the community at funerals. They group in corners and say it loud, things like ‘did you hear, so and so died of AIDS or HIV”* and Participant #4 *“... they stopped playing with him because they thought he will give them HIV.”*

Participants also expressed how society attaches HIV to promiscuity: *“... they may think I have a boyfriend who infected me or that I am being promiscuous”* (Participant #3). The participants perceived the community’s association of HIV with promiscuity as a reflection of the community’s lack knowledge on how HIV is spread. For ApHIVs who are not sexually active, being identified as promiscuous may present feelings of being judged (Butler *et al.*, 2012:55), thereby affecting their relationships with peers.

The participants, furthermore, seem to perceive that the general societal attitudes towards HIV/AIDS might also expose their parents’ status when they self-disclose their status: *“... they may also attach it to my mother and say bad things about my mother”* (Participant #2) and *“The mothers always say my mother died of AIDS because she was being promiscuous. I do not like it.”* (Participant #3)

In addition to stigma and discrimination, the particular theme shows how society still lacks knowledge regarding HIV transmission. This aspect is supported in studies by Campbell *et al.* (2005:808), Deacon and Stephney (2007:25) and Kehler *et al.* (2012:6) on how communities in South Africa have persistent myths and fears regarding HIV

because of a lack of knowledge on how HIV is transmitted. Societal attitudes form part of the macrosystem, where the community believes that HIV is transmitted because of promiscuity. The participants, therefore, seem to perceive that it is better not to self-disclose their status to avoid being labelled or judged by the community.

### **ADULTHOOD WILL BE A NEUTRALISER AND WILL “HELP” TO SELF-DISCLOSE**

The third theme that emerged was that the participants perceived adulthood to be a neutraliser which will help the participant to self-disclose. Participants indicated that they will self-disclose their HIV status in the future when they reached adulthood and are mature. Adulthood as perceived by participants meant different things to different people. In the context of this study, to be circumcised is perceived as having reached adulthood. According to Xhosa tradition, circumcision is a rite of passage into manhood (Anike, Govender, Ndimande & Tumbo, 2013:1).

*“Maybe one day when I am 19 years old after circumcision, when I am a man and mature I will be able to tell more people ... then I will be having a lot of knowledge about HIV.”*(Participant #4)

Participants preferred keeping their status a secret to avoid dealing with effects of discrimination and stigmatisation at a younger age, with a perception that when they are older they will cope better: *“... I will keep it a secret for now until I am mature, I do not want to be miserable* (Participant #8) and Participant #3: *“It is hard, Sisi, maybe when I am older one day they will be able to listen to me and stop talking about my mother.”*

Butler *et al.* (2012:50) note that adolescents are aware of the fact that self-disclosure is unavoidable in the future. The future in this context is associated with the transition from adolescence to adulthood, characterised by the forming of romantic or sexual relationships, getting married (Papalia, Feldman & Olds, 2009:144) or having children as well as getting future jobs. Participants further seem to perceive being older as gaining maturity and expecting a growing understanding amongst sexual partners and peers, as referred to by Participant #9: *“In future maybe I will tell my husband (smiles)”* and *“... I have one best friend I trust, maybe when I am 21 and I am mature I will disclose to her ... the rest I do not know.”* (Participant #8)

From the responses of the participants it almost seems, on the one hand, as if the participants associate adulthood with being emotionally strong. On the other hand, it might be that it is a mere postponing of a reality that they realise they will have to confront at some point.

### **EDUCATING THE BROADER SOCIETY IS PERCEIVED AS MEASURE TO ASSIST IN SELF-DISCLOSURE**

The fourth theme that emerged was that educating the broader society about the importance of supporting those living with HIV was perceived by the participants as a measure that would assist the self-disclosure of one's status. Participants perceived that HIV/AIDS awareness education has put more focus on how people can avoid

contracting HIV rather than on how people living with HIV must be supported. Participants thus not only came up with ways that such education can be undertaken, but also who can do this, as indicated by Participant #8: *“The community can make use of pamphlets or dialogues talking about how to support people living with HIV”*, and Participant #9: *“There must be community volunteers who can tell people in the community meetings and focus on people who have HIV and how they want to be supported and treated rather than focus on prevention all the time ...”* Participant #5 made the point that *“... people should be educated maybe on how we can be supported, not on how people with HIV look like. Whenever they talk about how a person with HIV looks like, I feel shy and will start feeling like everyone is looking at me.”* Therefore, putting the focus on how ApHIVs need to be supported may make it significantly easier for ApHIVs to self-disclose their status, knowing that they will be supported, and thereby reducing the effects of stigma and discrimination.

Healthcare professionals are perceived as important individuals who can educate the school community on how to support ApHIVs: *“Maybe nurses or social workers must go to schools and educate other kids about supporting people living with HIV, especially children”* (Participant #10). Butler *et al.* (2012:55) cite similar views, namely that more education on HIV in schools would help raise awareness and reduce stigma when focusing on the psychological and social needs of youths living with HIV. A study by Beyers and Hay (2011:104), however, has found that education and training regarding support for learners living with HIV should especially be focused on teachers, possibly because teachers could be seen as the gatekeepers for those adolescents in their class perinatally affected by HIV.

Participants thus perceived a shift in the focus from HIV-prevention awareness to education on how to support people living with HIV as an important point of departure in supporting ApHIVs to make a calculated decision regarding self-disclosing their HIV status.

## **CONCLUSIONS AND RECOMMENDATIONS**

From the findings it almost seems as if ApHIVs find themselves in a Catch-22 situation with regards to the choice to self-disclose their status or not. The dilemma is accompanied by the realisation of the benefits of self-disclosing one's HIV status, which includes support from peers, teachers and family regarding the management of their illness as opposed to not self-disclosing their HIV status and then not receiving any support. It seems that ApHIVs perceive the self-disclosure of their status as an opportunity to receive the support they need. However, despite the opportunity to receive support, there is also the chance that if they self-disclose, their status might not be treated as confidential, which may in turn lead to moral judgement from the community. They are, therefore, not only confronted with the decision to self-disclose or not, but also with the fear of whether they are going to be stigmatised or be discriminated against, or even being alienated by their peers.

It also seems that the quest for self-disclosure of one's status is driven by the availability of trusting relationships; yet, on the other hand, fears of being stigmatised and

discriminated against hamper self-disclosure. The perception is that if one is part of a trusting relationship with people who understand the situation, then self-disclosure is possible. From the findings the outcome of such a relationship seems to involve aspects such as a nurturing environment and receiving support regarding their wellbeing whenever it is needed. A trusting relationship also seems to be perceived as one where the participants will feel safe and protected, where they can just be themselves without any fear of being “exposed” for being HIV positive. Such trusting relationships also seem to be easily found amongst other peers living with HIV as well as healthcare professionals directly involved with medical and psychosocial support for ApHIVs. It would thus be important for healthcare professionals such as nurses, doctors and social workers to continue being available for ApHIVs and also to assist them in forming such trusting relationships with other peers.

On the other hand, to be stigmatised and discriminated against possibly stems directly from a lack of a trusting relationship. The fear of being stigmatised or discriminated against that hinder self-disclosure seems to be exacerbated by negative attitudes presented by school teachers, caregivers and other community members towards other people living with HIV. Through observing how other people living with HIV are negatively treated, it seems ApHIVs are faced with fears of whom to trust with the self-disclosure of their status. Negative treatment such as isolation or being mocked by peers may lead to feelings of shame, low self-esteem and inferiority. ApHIVs thus perceived keeping their status a secret as a coping mechanism and a way of curbing the effects of being rejected, morally judged or isolated by peers and the community.

The solution for the ApHIVs with regards to being confronted with stigmatisation and discrimination is perceived to lie in educating the ecological system in which the ApHIV is functioning. In order for this to happen, ApHIVs perceived that much more focus is needed regarding informing the community on the consequences of stigmatisation and discrimination against ApHIVs. When communities are aware of the consequences of stigmatisation and discrimination, they may have a positive approach towards ApHIVs, thus making it easy for ApHIVs to consider self-disclosing their status.

Therefore this study offers the following recommendations.

- Healthcare professionals need to continue providing a platform for support groups for ApHIVs in different settings, including schools, clinics and hospitals, which provide a platform for the self-disclosure of their HIV status and for support.
- Healthcare professionals need to target school settings, where ApHIVs spend most of their time with peers, and educate pupils and teachers on how to support learners living with HIV.
- Communities need to be educated more on the effects of stigmatising of, and discrimination against, people living with HIV, thus shifting the focus from an HIV-transmission awareness approach, to an approach where support programmes are being developed for people (also adolescents) living with HIV.

- More research needs to be done not only on how to support adolescents perinatally affected with HIV, but also how to empower them to deal with the self-disclosure of their status in their different ecological systems. These research projects should involve ApHIVs, not only to give them a voice, but also because they are the experts with regard to their specific needs.
- Institutions such as schools and healthcare centres need to develop policies, regulations and rules geared at mitigating stigma and discrimination in order to make it easy for ApHIVs who want to self-disclose their status to do so.

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