

Perceptions of adolescents perinatally infected with HIV regarding the self-disclosure of their status

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DECLARATION BY STUDENT

I, Caroline Mpofu, declare that the dissertation, “**Perceptions of adolescents perinatally infected with HIV regarding the self-disclosure of their status**”, reflects the work I conducted and all the references that were used or quoted were acknowledged.

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DECLARATION BY LANGUAGE PRACTITIONER

Hereby I declare that I have language edited and proofread the thesis **Perceptions of adolescents perinatally infected with HIV regarding the self-disclosure of their status** by Caroline Mpofu for the degree MSW in Child Protection. I am a freelance language practitioner after a career as editor-in-chief at a leading publishing house.

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SUMMARY

Most children born with HIV are maturing into adolescence due to the accessibility of medical support, specifically the availability of antiretroviral drugs. During adolescence, children are faced with critical adolescent developmental tasks in that they develop physically, cognitively and psychosocially, including assuming independence. As the adolescents living with perinatally acquired HIV mature, their care-givers start disclosing the adolescents' HIV status to them. Attaining the knowledge of living with HIV is encompassed with worries of how to manage the illness as well as other social ills such as taking care of sick loved ones and dealing with losses of loved ones. It is also during this stage of development that adolescents living with HIV begin to form intimate relationships, thus issues of self-disclosing their status become a concern.

The aim of this study was to explore and describe the perceptions of adolescents perinatally infected with HIV regarding the self-disclosure of their status to others. Following this, it was hoped that the study would come to conclusions and make recommendations regarding the wellness of and support for adolescents living with perinatally acquired HIV. A qualitative descriptive research approach with an interpretive paradigm was used to explore and describe the perceptions of the adolescents. A multiple case study design was suitable to explore and describe the perceptions of participants as they see it. Ethical approval for the study was obtained from the relevant body. A sample of 10 adolescents perinatally infected with HIV, whose status had been disclosed to them and were receiving clinical care and psychosocial support at a local clinic in Port Elizabeth, were selected through purposive sampling. Consent to undertake the study was provided by the head of the clinic in Port Elizabeth as well as by the adolescents' caregivers. Assent to partake in the study was also provided by the participants. A deeper understanding of participants perceptions was explored through utilising multiple sources of data collection methods which included reflective journals and semi-structured interviews. Multiple data collection methods were used in order to collect rich data and for crystallisation of the data to take place. After the data was analysed themes were identified and described leading to the findings of the study.

The findings of the study confirmed the perceptions of adolescents living with perinatally acquired HIV regarding the self-disclosure of their status. Adolescents perinatally infected with HIV perceive certain conditions as conducive to self-disclose their status against other conditions that were perceived to be unfavourable for the self-disclosure of their HIV status.

Conditions permitting self-disclosure included the availability of trusting relationships with people who understand them as well as the need for support which subsequently highlights the benefits of self-disclosure. Benefits included and are not limited to clinical support from healthcare professionals and an understanding from teachers when they are absent from school during their monthly clinical visits. Although adolescents see the benefits of self-disclosing their status they are however aware of the possible negative effects to self-disclose their status such as stigmatisation and discrimination manifested through isolation from peers and through moral judgement and rejection from the community. Peers living with HIV are perceived to be the closest people providing them with trusting and open relationships that foster self-disclosure. Adolescents also perceived adulthood as a phase where self-disclosing their HIV status could be possible with the belief that they would be more mature when they are adults.

Recommendations are made for healthcare professionals and policy makers to formulate and implement guidelines on supporting adolescents living with perinatally acquired HIV regarding the self-disclosure of their status. Providing measures of support for adolescents living with perinatally acquired HIV in their different ecological systems could widen the choice of to whom and when to self-disclose their HIV status.

KEYWORDS: *Adolescents, Self-disclosure, Perinatally infected, HIV status, Perceptions*

OPSOMMING

Die meeste kinders wat met MIV gebore word, groei op tot in adolessensie vanweë die toeganklikheid van mediese ondersteuning, veral die beskikbaarheid van antiretrovirale middels. Gedurende adolessensie word kinders gekonfronteer met kritieke ontwikkelingsake van dié fase, aangesien hulle fisies, kognitief en psigosiaal ontwikkel en onafhanklikheid ervaar. Soos wat die adolessente wat perinataal MIV gekry het ontwikkel, begin die versorgers die adolessente se MIV-status aan hulle bekendmaak. Hierdie verkryging van die kennis dat hulle met MIV saamleef, gaan gepaard met bekommernisse oor hoe om die siekte te bestuur sowel as ander sosiale eise soos om vir siek geliefdes te sorg en die verlies van geliefdes te hanteer. Dit is ook gedurende hierdie ontwikkelingsfase dat die adolessente wat met MIV saamleef begin om intieme verhoudings te smee, sodat kwessies rondom die self-bekendmaking van hulle status 'n probleem begin word.

Die doel van hierdie studie was om die persepsies van adolessente wat perinataal met MIV geïnfekteer is rakende die selfbekendmaking van hulle status aan ander te ontgin en te beskryf. In hierdie proses is gehoop dat die studie sou kom tot gevolgtrekkings en aanbevelings sou maak aangaande die welwese van en ondersteuning aan adolessente wat perinataal MIV opgedoen het. 'n Kwalitatiewe beskrywende navorsingsbenadering met 'n interpretatiewe paradigma is gebruik om die persepsies van die adolessente te ontgin en te beskryf. 'n Veelvuldige gevallestudie-ontwerp was geskik om die persepsies van deelnemers te ontgin en te beskryf soos hulle dit beskou. Etiese goedkeuring vir die studie is van die toepaslike liggaam verkry. 'n Steekproef van tien adolessente wat perinataal met MIV geïnfekteer is, wie se status aan hulle bekendgemaak is en wat kliniese sorg en psigososiale ondersteuning by 'n plaaslike kliniek in Port Elizabeth ontvang, is uitgekies deur doelgerigte steekproeftrekking. Toestemming om die studie te onderneem is toegestaan deur die hoof van die kliniek in Port Elizabeth, sowel as deur die adolessente se versorgers. 'n Dieper verstaan van deelnemers se persepsies is verkry deur veelvuldige bronne van data-insamelingsmetodes te benut, wat reflektiewe joernaalhouding en semigestruktureerde onderhoude insluit. Veelvuldige data-insamelingsmetodes is gebruik ten einde ryk data in te samel en sodat kristallisasie van die data kan plaasvind. Nadat die data geanaliseer is, is temas geïdentifiseer en beskryf wat tot die bevindings van die studie gelei het.

Die bevindings van die studie het die persepsies bevestig van adolessente wat met perinataal geïnfekteerde MIV saamleef rakende die selfbekendmaking van hulle status. Adolessente wat

perinataal met MIV geïnfekteer is, het sekere toestand geïdentifiseer wat bevorderlik is vir selfbekendmaking teenoor ander toestand wat ongunstig is vir die selfbekendmaking van hulle MIV-status. Toestand wat gunstig is vir selfbekendmaking sluit in die beskikbaarheid van vertrouensverhoudings met mense wat hulle verstaan sowel as die behoefte aan ondersteuning wat die voordele van selfbekendmaking uitlig. Voordele sluit in en is nie beperk nie tot kliniese ondersteuning van professionele gesondheidsorgbeamptes en 'n begrip by onderwysers wanneer hulle afwesig is by die skool vanweë hulle maandelikse kliniekbesoek. Alhoewel adolessente die voordele van die selfbekendmaking van hulle status insien, is hulle ook bewus van die moontlike negatiewe gevolge van die bekendmaking van hulle status, soos stigmatisering en diskriminasie wat uitkom in isolering deur hulle portuurgroep en deur morele veroordeling en verwerping deur die gemeenskap. Portuurlede wat leef met MIV word beleef as die naaste mense wat vir hulle vertrouende en oop verhoudings bied wat selfbekendmaking bevorder. Adolessente beskou ook volwassenheid as 'n fase waartydens selfbekendmaking van hulle MIV-status moontlik kan wees, met die geloof dat hulle meer volwasse sal wees wanneer hulle dié fase bereik.

Aanbevelings word gemaak vir gesondheidsorgbeamptes en beleidmakers om riglyne te formuleer en te implementeer om adolessente te ondersteun wat perinataal MIV opgedoen het met betrekking tot die selfbekendmaking van hulle status. Die skep van ondersteuningsmaatreëls vir adolessente wat perinataal met MIV geïnfekteer is binne hulle ekologiese sisteme kan die opsies verbreed van teenoor wie en wanneer om hulle MIV-status bekend te maak.

KERNWOORDE: *Adolessente, selfbekendmaking, perinataal geïnfekteer, MIV-status, persepsies*

PREFACE

This dissertation is presented in article format as specified in rule A5.4.2.7 of the North-West University Potchefstroom Campus. The article presented in Section B is intended for submission to and possible publication in the *Journal of Social Work/Tydskrif vir Maatskaplike Werk*. Please take note that references provided in the article are according to the guidelines for authors as stipulated in the *Journal of Social Work/Tydskrif vir Maatskaplike Werk* (Appendix F) and involve the Harvard referencing style. Section A, (Parts 1 and 2) is referenced by using the Harvard referencing style as indicated by the North-West University referencing manual of 2012.

The researcher has found it difficult to decide how to refer to the construct of HIV/AIDS as she has noticed that AIDS is mainly spoken about relating to issues of stigma and discrimination, but disclosure or self-disclosure mainly focuses on HIV. Seeing that the focus of the study was on the self-disclosure of adolescents perinatally infected with HIV and discrimination and stigmatisation also form part of the day to day challenges of these adolescents, the researcher therefore has decided to only refer to HIV even when referring to concepts such as discrimination and stigmatisation.

Due to the fact that most of the participants were orphaned and lived with their grandparents (and with only some living with their biological mother) it was decided to refer to the grandparents and the biological mothers as caregivers.

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SECTION A

PART 1: PROBLEM STATEMENT, RESEARCH QUESTION, RESEARCH AIM AND METHODOLOGICAL CONSIDERATIONS

1.1 INTRODUCTION AND RATIONALE OF THE STUDY

Disclosure of the status of children born with Human Immunodeficiency Virus (HIV) is a central issue for health care professionals and their caregivers, as well as the children concerned (United Nations Children's Fund (UNICEF), 2011:29). The majority of infants born from mothers with HIV automatically receive Highly Active Antiretroviral Therapy (HAART) from birth, while other children diagnosed with HIV have access to treatment after diagnosis depending on their CD4 count (World Health Organisation (WHO), 2013:29). The use of HAART has resulted in prolonging the average life expectancy of children born with HIV with many reaching adolescence and adulthood (Arrive, Amghar, Bouah, Dabis, Dicko, Ogbo & Traore, 2012:56; Butler, Campbell & Hogwood, 2012:46; Haberer, Cook, Ferrier, Kityo, Ngambi & Walker, 2011:2; Zandoni, 2013:14). Adolescents that have been perinatally infected with HIV (from here on these adolescents will be referred to as ApHIV) have to deal with both, the usual (or common) adolescent developmental tasks and the knowledge of their illness accompanied with the responsibilities of managing their health. Perinatally acquired HIV refers to, HIV transmitted from a mother to her child, either during pregnancy, labour or delivery, or through breastfeeding (Wood, Rutstein & Steenhoff, 2009:3). It is against this background that the current study was undertaken, namely to explore and describe the perceptions of adolescents (ranging from age 13-18 years) perinatally infected with HIV regarding the self-disclosure of their status.

How and when to disclose children's HIV status to them seems to have conflicting reactions with caregivers. Mahloko and Madiba (2012:4), for instance, have found that in South Africa (SA) the caregiver, generally with the support of healthcare professionals and relevant family members, disclose the illness to children at the age of ten (Carter, 2010:28; WHO, 2011:16). This is in accordance with the WHO guidelines which recommend that disclosure should take place when children are of school going age in order for them to understand that they are HIV positive. The disclosure, however, should take place while always considering the child's cognitive and developmental abilities (Cataldo, Haamujompa, Hodgson, Kalibala, Lowenthal, Mburu & Ross, 2014:93).

Studies on how caregivers deal with the process of disclosure, however, have shown that there are caregivers who delay the disclosure process (Madiba, 2012:326; Mahloko & Madiba, 2012:4; Woollet, 2013:23; Wu, Slocum, Comulada, Lester, Semaan & Rotheram-

Borus, 2008:35). A study on disclosing to children their HIV status in SA revealed that biological mothers seem to delay disclosure due to fears of being blamed for the infection as compared to non-biological parents (Madiba, 2012:326). On the other hand, non-biological parents (mainly grandparents) seem to lack the knowledge of when and how to disclose children's HIV status to them (Madiba, 2012:326). Delayed disclosure is seen as common in cultures that have no open communication with children on subjects such as HIV, sex and drugs (Santamaria, Dolezal, Marhefka, Hoffman, Ahmed, Elkington & Mellins, 2011:262; WHO, 2011:41). In addition, other reasons given for delaying the disclosure to children are due to feeling guilty and having a fear that the child may be too young to understand and may tell others in the community which could lead to stigmatisation and social rejection (Cataldo *et al.*, 2014:91; Haberer *et al.*, 2011:2; Woollett, 2013:23).

To place this study in context, it is important to understand the transition from childhood to adulthood, a developmental stage known as adolescence. Adlem (2011:28) defines adolescence, a stage known as puberty, as a developmental stage marked with changes in height and body composition. Adolescent development entails major physical, cognitive and psychosocial changes (Papalia, Feldman & Olds, 2009:144). Adolescence is a phase where adolescents are interested in talking in-depth about themselves. They also want to know what others think and feel about them, and they begin to form intimate relationships and initiate sexual activities as they approach adulthood (Papalia *et al.*, 2009:144). In this stage, adolescents seek to be independent and they search for a unique identity or separateness, with the end goal of pursuing knowledge of their uniqueness as well as developing the ability to be responsible individuals (Adlem, 2011:22). During this phase, adolescents assume their own independence and drift away from family influences to peers (Van Dyk, 2008:188).

In light of the marked physical, cognitive and psychosocial changes it is understandable that adolescents will react and cope differently when their HIV status is disclosed to them. (Santamaria *et al.*, 2011:262). Reactions may be negative or positive. Carter (2010:32) highlights how adolescents may react with sadness, anger and anxiety regarding how they were infected. On the other hand, ApHIVs may react positively through showing willingness to participate in managing their health and wellbeing which subsequently lead to signs of increased self-esteem and reduced risky sexual behaviour (Carter, 2010:29; Cataldo *et al.*, 2014:96; Mahloko & Madiba, 2012:4).

Despite the different reactions to the news of their diagnosis, ApHIVs who are aware of their HIV status or have participated in the disclosure process, seem to accept and adhere to medical care and treatment (Butler *et al.*, 2012:45; Chopra, Kadiyala & Norman, 2005:1). On the other hand, research conducted on ApHIVs receiving HAART who are unaware of or have not been told the reasons for taking medication, has found that these ApHIVs indulge in behaviour such as rebelling against the caregiver, which results in non-adherence and non-compliance to treatment. These ApHIVs, furthermore, often exhibit signs of high levels of anxiety, depression and are excluded from social support (Butler *et al.*, 2012:47).

While reference has been made to the disclosure of an adolescent's HIV status by a caregiver, reference of self-disclosure by ApHIVs should be considered as equally important. Hoe, Mckeown, Sobota, Stolts and Trow (2003:7) define self-disclosure of HIV status as an act of revealing one's own HIV status to another person or persons. Groves, Maman and Van Rooyen (2013:226) note that self-disclosure may lead to support for people living with HIV when their family and friends react positively to the news of their diagnosis. Furthermore, self-disclosure of HIV status is also seen as beneficial for HIV positive children and adolescents orphaned by HIV as it may improve their resilience mechanisms when they feel protected and supported by family members and the community who understand their situation (WHO, 2013:19). In settings where there are existing clubs and support groups within the school institutions, ApHIVs may experience a positive response from teachers and peers upon self-disclosing their status (Birungi, Katahoire & Obare, 2010:12).

Despite the positive experiences of self-disclosure, Butler *et al.* (2012:46) in a study in the United Kingdom (UK), regarding dilemmas of ApHIVs around self-disclosure, revealed that the majority of ApHIVs express the desire to self-disclose their status but feel constrained by their parents' views. Biological parents of ApHIVs often do not want their children to self-disclose their status to people outside of the family as self-disclosure presents concerns for social rejection, fears that the child will be teased, mocked and isolated by friends at school and in the community (Butler *et al.*, 2012:45; Cataldo *et al.*, 2014:94; Mahloko & Madiba, 2012:6). HIV infection thus remains a household secret. Additionally, other ApHIVs choose not to self-disclose their status. Yet, they are likely to face difficulties pertaining to decisions and conversations such as explaining their school absences to peers and teachers, taking medication, coping with physical changes while at the same time having to deal with parental bereavement (Butler *et al.*, 2012:46).

The inability to explain school absences to peers and teachers may be due to fears of stigma and discrimination as concluded by a study in Uganda on the perceptions of ApHIVs regarding the self-disclosure of their HIV status in the school setting (Birungi *et al.*, 2010:12). A study conducted in Zambia on barriers, attitudes and outcomes of HIV disclosure by ApHIVs also confirmed that fear of rejection was a predominant reason for the majority of ApHIVs not to self-disclose their status to their sexual partners (Cataldo *et al.*, 2014:91). The fear of stigmatisation thus may have an enormous influence on interpersonal relationships, self-esteem and the practice of safe sex where openhearted discussions about sexual transmission and protection are crucial (Woollett, 2013:23).

The literature search on adolescents that have been perinatally infected by HIV, focused on topics such as the need for self-disclosure to romantic partners and prevention of further HIV transmission. The researcher could not find any studies that have been published on what are the perceptions of SA adolescents perinatally infected with HIV regarding the self-disclosure of their HIV status. However, in countries such as Zambia (Cataldo *et al.*, 2014:91), Uganda (Birungi *et al.*, 2010:12) and the UK (Butler *et al.*, 2012:45) studies on the perceptions of ApHIVs regarding self-disclosure were published. Thus not much is known about the perceptions of ApHIVs in SA regarding the self-disclosure of their status and consequently social workers, other professionals and community members supporting this vulnerable group of individuals might miss the opportunity to contribute to the wellbeing, treatment and support of the ApHIVs and their family members. Therefore, the primary research question that was formulated for this study was: What are the perceptions of adolescents perinatally infected with HIV regarding the self-disclosure of their HIV status?

1.2 RESEARCH AIM AND OBJECTIVES

The aim of this study was to qualitatively explore and describe the perceptions of adolescents perinatally infected with HIV regarding the self-disclosure of their HIV status. This research may contribute to creating a general awareness of what the perceptions of ApHIVs are regarding the phenomenon of self-disclosing their status to others. The research findings may further lead to dialogue and discourse amongst social workers and healthcare professionals working in programmes aimed at supporting adolescents living with HIV.

In order to achieve the aim the following objectives were formulated:

- To collect and analyse data in order to explore and describe the perceptions of adolescents perinatally infected with HIV regarding the self-disclosure of their status.
- To come to conclusions and make recommendations in order to contribute to knowledge regarding wellness of and support for ApHIVs.

1.3 THE PARADIGMATIC CONSIDERATIONS UNDERPINNING THIS STUDY

In this study, the researcher sought to gain an in-depth understanding into the perceptions of perinatally HIV infected adolescents regarding self-disclosing their HIV status to others and the meaning attributed to those perceptions regarding self-disclosure. The nature of the phenomenon investigated, called for a qualitative interpretive naturalistic paradigm (Fouché & Schurink, 2011:309). A paradigm is an overarching framework that consists of the researcher's world view, assumptions, beliefs and values that shape and guide what is observed and understood (Delpont, Fouché & Schurink, 2011:297; Knipe & Mckenzie, 2006:192; Lincoln & Guba, 1985:107). The researcher's philosophical assumptions which include her view on ontology, epistemology and methodology (Creswell, 2013:23; Fouché & Schurink, 2011:309; Lincoln & Guba, 1985:108), not only directed the research process and knowledge development (Chinn & Kramer, 2011:253) but also the researcher's actions (Creswell, 2013:15).

The ontology (the nature of reality or the way of being in the world) assumes that multiple subjective realities exist (Johnson & Onwuegbuezie, 2004:14) and that reality is local in nature illustrating that reality is specific and varies between individuals or groups (Fouché & Schurink, 2011:309; Lincoln & Guba, 1985:111). Influenced by the ontology, the epistemological assumptions address two aspects, namely, how reality is known and how this knowledge is constructed (Creswell, 2013:20; Fouché & Schurink, 2011:309), and the kind of relationship that exists between the researcher and participant (knower and the known) (Lincoln & Guba, 1985:108). In qualitative research, the researcher cannot be separated from the participant, but is interrelated (Kirkham, O'Flynn-Magee & Thorne, 2004:5) and thus, persons subjectively co-construct their reality (Knipe & Mckenzie, 2006:13). Bronfenbrenner's ecological systems theory, however, assumes that persons are not only

connected to others but also to social institutions, cultural forces and physical space that make up their environment, indicating all potential connections and levels of interactions that individuals have with others and the environment (Wakefield, 1996:7).

Pertaining to this study, the participants' truth and the meaning attributed to the phenomenon being investigated, were negotiated through dialogue and the interaction with the researcher. Bronfenbrenner's (1979) ecological systems theory provided the basis for the analytical framework that assisted the researcher in making sense (interpreting) of the perceptions of ApHIVs on self-disclosing their status to others.

1.4 DEFINING KEY CONCEPTS

1.4.1 Disclosure vs self-disclosure

The notion of the disclosure of a person's HIV status is an act of telling the infected person, another person or an external party, for example doctor, family members or teacher about the infected person's HIV status (Hoe *et al.*, 2003:7). In the context of this study, disclosure of HIV status is the process of informing ApHIVs about their HIV status which is mainly done by the caregiver with the help of healthcare professionals. Subsequently, the self-disclosure of HIV status is an act of revealing one's own HIV status to another person or persons (Hoe *et al.*, 2003:7). Self-disclosure in this study thus entails the process where ApHIVs reveal their own HIV status to other people.

1.4.2 Adolescent

An adolescent is a young person going through adolescence. Adolescence, being a period of development, is defined by many authors as a transition period from childhood to adulthood (McConville & Wheeler, 2001:38; Moultrie, 2013:4; Papalia *et al.*, 2009:144; UNICEF, 2006:1; WHO, 2010:4) encompassing major physical, cognitive and psychosocial changes. Although UNICEF (2006:2) differentiate between early (age 10 to 13), middle (age 14 to 16) and late adolescence (age 17 to 19), this study focused on adolescents aged 13 to 18 years. Furthermore, the study focused on adolescents that were born with HIV or acquired HIV through birth or breastfeeding from their biological mothers.

1.5 THE RESEARCH METHODOLOGY

The methodology is concerned with how reality can be investigated and the process for acquiring that knowledge (Creswell, 2013:21).

1.5.1 Literature study

A literature study was done using academic search engines such as NEXUS, Pro-Quest, Sage Publications, Ebsco-Host and Google Scholar. Initially, the researcher explored national and international literature on the phenomenon of adolescents perinatally infected with HIV, looking for peer reviewed articles and publications on Sage Publications, NEXUS, Ebsco-Host and Google Scholar. The nature of positive and negative impacts and effects of disclosure and self-disclosure of adolescents' HIV status were explored through articles from the search engines. Further literature on adolescent development was explored from books and Google Scholar. This assisted in understanding the link between ApHIVs and the adolescent developmental stage.

1.5.2 Research design

The type of research question and the paradigmatic assumptions in this study called for a basic qualitative descriptive approach (Fouché & De Vos, 2011:95; Merriam, 2009:2). Therefore, a multiple case study design seemed most suited to collect rich data and the design was exploratory and descriptive in nature (Fouché & De Vos, 2011:96). The researcher aimed to explore the phenomenon of self-disclosure using multiple sources of data collection (participants' reflective journals and semi-structured interviews) and describe the phenomenon as participants perceive it in their natural environments (in its real life context). There are different views and multiple definitions of what encompasses a "case study" and a "case" (Yin, 2014:24). Some authors suggest a case study is a "choice of what is to be studied" (Creswell, 2013:97; Fouché & Schurink, 2011:320; Stake, 2005:443), while others view a case as a bounded system (bounded by time, context and/or setting) (Creswell, 2007:73). A case is the unit of analysis and is a single unit in a study (for example a person or setting), and different (multiple) cases can be explored intensively using multiple methods (Bowling, 1997:359). Since the study employed a multiple case study design, cases of ApHIVs were chosen in Port Elizabeth, enabling the researcher to describe the perceptions of each case. As a result it yielded a thick description and contextual understanding and

interpretation (Bryman, 2004:281) of subjectively constructed perceptions of participants, organised into themes and which may be applicable to other contexts.

1.5.3 The participants

The population is the total number of study units that are relevant to the study (Bryman, 2004:87) and is the pool from which the sample was drawn for actual inclusion of the study (Strydom, 2011b:223). Based on considerations such as accessibility, availability and time and cost constraints, the study population was narrowed down to all ApHIVs that were registered in the data base of a specific clinic in Port Elizabeth. The majority of the population under study were orphaned and vulnerable and living with grandparents and few of them were living with one biological parent, specifically the mother. Their status was disclosed to them at an average age of 10 and they were all school going. Due to the fact that the population was receiving psychosocial support at the clinic, most of the ApHIVs were part of a support group at some point, thus would have self-disclosed their status to other peers living with HIV.

Sampling is “the process of selecting a portion of the population to represent the entire population so that inferences can be drawn” (Polit & Beck, 2008:338). The sampling strategy that suited the explorative and descriptive nature of this study was non-probability purposive sampling (Babbie, 2010:193). In non-probability sampling, “not every element of the population has an opportunity to be included in the sample” (Burns & Grove, 2009:353). Non-probability sampling approach tends to rely on the availability and accessibility of participants (Babbie, 2007:183).

In order to obtain rich information a purposive sampling technique was used based on the knowledge of the population and purpose of the study (Babbie, 2007:118). Purposive sampling, according to Hartas (2010:69), is therefore considered a sampling technique with a purpose.

The inclusion criteria used for identifying the sample were adolescents:

- that had acquired HIV perinatally;
- aged between 13 and 18 years;

- who have been told (disclosed to) about their HIV status by their caregivers;
- that were willing to discuss the phenomenon of self-disclosure;
- who were adhering to antiretroviral therapy and managing their illness, thus whose HIV had not developed into acquired immunodeficiency syndrome (AIDS); and
- who received medical treatment and psychosocial support at a clinic in Port Elizabeth.

In qualitative research, it is difficult to predict accurately what the sample size will be like. Qualitative studies tend to involve a small number of informants to collect in-depth and contextualised information about the social phenomena (Hartas, 2010:71). The focus, therefore, is on “the quality of information obtained from the person, situation, event or documents sampled versus the size of the sample” (Burns & Grove, 2009:361). In this study, the sample of the study was not representative numerically, but was sufficient to allow exploration of the phenomenon under study and yielded rich in-depth descriptions of the perceptions of a group of ten ApHIVs regarding self-disclosing their HIV status.

1.5.4 Research procedure

Upon finalising the research question and title, a proposal was developed and once approved by AUTHeR (Africa Unit for Transdisciplinary Health Research at the North-West University), the research process began. Literature on the phenomenon of adolescents living with perinatally acquired HIV and the concept of disclosure of their status was explored so as to gain background knowledge about the study.

According to Burns and Grove (2009:363), effective recruitment of subjects is crucial to the success of a study. The participants were recruited with the help of the clinic nurses who are the custodians of the clinic database of ApHIVs. The nurses acted as gatekeepers to access ApHIVs. Gatekeepers are people who have a say over who is to be let in and who is not to access the study participants (Terre Blanche, Durrheim & Painter, 2006:312). This purposive sampling process commenced with the researcher:

- Identifying thirty five ApHIV participants from the clinic register. Thirty five invitation letters were handed out by nurses to ApHIVs during their monthly consultation clinical visits. The invitation letters (Appendix A) were written in English and Xhosa (population of study’s mother tongue) explaining the purpose and

procedure of study in detail so that participants could make an informed decision to participate in the study or not. Out of the thirty five letters handed out, fifteen adolescents responded to the invitation through sending a call back to the researcher and informing their assigned counsellors about their interest in the study.

- Contacting prospective participants telephonically setting up a meeting with them to explain the research and to seek their assent to participate in the study. Of the fifteen participants, twelve agreed to meet with the researcher upon telephonic contact. Two meetings were held:
 - The first meeting was with each individual prospective participant in a private counselling room due to the private nature of the topic under study. The researcher had to first meet with prospective participants before the caregivers because the participants were the first recipients of the invitation letters and a verbal clarification of the invitation followed through informing participants to inform their caregivers about their interest in the study.
 - Upon informing their caregivers about their interest in the study, prospective participants then met with the researcher and their caregiver at which point the researcher specifically sought consent (Appendix B) from the caregivers for the participation of the ApHIV in the study.

In these meetings questions and concerns about the research were clarified. Two caregivers did not consent to have their ApHIV participate in the study and their views were respected. From the twelve candidates, the study was left with ten participants who showed interest to participate in the study thus limiting the actual number of possible participants.

A semi-structured interview guide (Appendix C) was developed which was used in conducting the interviews with the participants. After the pilot interview was conducted, the researcher restructured the questions to allow participants' perceptions to unfold as per participants' views, not the researcher's views (Greeff, 2011:348).

1.5.5 Data collection

The data collection process included the crystallisation of multiple sources of data collection methods which included: semi-structured interviews and reflective journals. Hatch (2010:141) contends that reflective journals "provide a direct path into the insights of

participants”. Participants kept the reflective journals for a period of between two and three weeks after which a meeting was scheduled with the researcher. On the day of meeting with the researcher, participants brought back the journal whereupon the researcher read the journal first and then met one-on-one with the participant for the semi-structured interview (Babbie, 2007:291) in a private counselling room. Reference was also made to the contents of the journal during the semi-structured interview. Additionally, the semi-structured interviews gave the researcher some latitude to ask additional questions in response to significant views (Bryman, 2004:543) on their subjectively constructed thoughts, and perceptions on self-disclosing their status.

A pilot study was conducted with one participant using the interview guide upon which the researcher restructured the semi-structured interview questions to include questions that would allow perceptions of participants to unfold. Gall, Gall and Borg (2003:56) posit that although the general interview guide approach is more structured than the informal conversational interview, there still is quite a bit of flexibility in its composition. The strength of the general interview guide approach for McNamara (2009:22) lies in the ability of the researcher “to ensure that the same general areas of information are collected from each interviewee; this provides more focus than the conversational approach, but still allows a degree of freedom and adaptability in getting information from the interviewee.”

The semi-structured interviews contained open ended questions (Greeff, 2011:343), giving the participants the opportunity to describe contents of their reflective journal regarding their perceptions on self-disclosing their status. All the interviews were transcribed and translated into English by the researcher. Field notes (Denscombe, 2010:187) were kept in written format to capture observations made during the interviews and were kept in a password protected laptop.

The researcher read through each participant’s journal again and the transcript of the first semi-structured interview whereupon the researcher realised more information was needed to clarify information from the two sources. A second semi-structured interview was thus held with each participant to clarify contents of the journal and further clarify misconceptions from the first interview.

All interviews were recorded using a voice recorder with consent from the caregivers of the participants and the participants in order to avoid any loss of information. Permission was

granted by the participants to make copies of the reflective journals for the purpose of data analysis and these copies were stored in a locked cabinet at the researcher's home.

1.5.6 Data analysis

After the data from the semi-structured interviews were transcribed and translated into English, the researcher through a process of thematic analysis, inductively generated codes from the transcribed data and the reflective journals of the participants. The researcher then searched for themes amongst these codes and finally reviewed and named the themes (Braun & Clarke, 2006:78-79).

All this was achieved by utilising Tesch's proposed eight steps of data analysis (Creswell, 1994:154-155) and whereby the researcher:

- Familiarised herself with data gathered from the different sources by carefully reading the interview transcripts and participants' reflective journals several times and searching for participants' descriptions of their perceptions on self-disclosing their HIV status to others.
- Selected one interview transcript and by reading through it, extracted meaning from the information and writing down thoughts that came to mind.
- Repeated the process with all the transcripts and explored the data through writing memos in the margins of the transcripts (Appendix D) and displayed key concepts of the coding process (Schurink, Fouché & De Vos, 2011:409).
- Coded the data through highlighting keywords and phrases in the transcripts with coloured dots so as to refer back to the important sections.
- Found the most descriptive wording from the identified concepts that seemed to relate to the same perceptions from the transcripts and the reflective journals, grouped them into categories and interpreted the categories in line with the ecological systems theory.
- Defined each category and made a final decision about the categories to be used.
- Utilised concept maps to put together data belonging to each category thereby identifying, naming and presenting emerging themes.
- Discussed and described the findings subsequently with reference to literature (Braun & Clarke, 2006:90). Forthcoming themes were summarised and in turn reported on in

article format. The analysis of the data was stored in CD format provided as Appendix E.

1.6 TRUSTWORTHINESS OF THE STUDY

Trustworthiness and rigour of the research was enhanced through paying attention to the guidelines of trustworthiness for qualitative research namely; credibility, transferability, dependability, confirmability and authenticity (Bryman, 2004:274-276; Lincoln & Guba, 1985:301-327; Schurink *et al.*, 2011:419). These guidelines are explained below:

- Credibility

Credibility of the study is viewed as a substitute to internal validity whereby the researcher aims to show that the participants of the study and their views were accurately presented (Schurink *et al.*, 2011:419). The researcher ensured credibility by tape recording the interviews and transcribing them verbatim. Prolonged engagement (Lincoln & Guba, 1985:180; Schurink *et al.*, 2011:420) with participants took place which also added to the credibility of the findings. Prolonged engagement was achieved through meeting with the participants twice before the semi-structured interviews in order to seek their assent and consent to participate in the study and whereby a trusting relationship was built with the participants. Two semi-structured interviews were further conducted with each participant at different times, with the second interview aiming at getting more information from the participants after the researcher had read their reflective journals and first interview transcript. The second interview, therefore, could be seen as member checking (Lincoln & Guba, 1990:134), but was more done to get to a deeper understanding of the participants' perceptions regarding self-disclosing their HIV status. The researcher anticipated that the participants might share more personal perceptions in their journals and therefore planned for the second semi-structured interview to take place. Rich and in-depth descriptions (Tracey, 2010:843) of participants' subjectively constructed perceptions regarding the phenomenon under observation were provided in an article format.

- Transferability

Transferability relates to the ability of the research findings to be generalised to other settings or populations which can be problematic in qualitative research (Schurink *et al.*, 2011:419). Nonetheless, a study in which multiple sources or informants are used can increase the probability of the study to be generalised to other settings. The researcher ensured transferability through collecting data from multiple cases as well as utilising different sources of data collection (participants' reflective journals and semi-structured interviews) allowing crystallisation by different methods. Ellingson (2009:3) contends that crystallisation validates results of the study through utilising and analysing multiple sources of data into a series of texts or coherent texts thereby yielding rich descriptions of the phenomena under study. In addition, thick descriptions of the findings were provided through using direct quotations from the interviews. Records of data analysis (Appendix E) were kept and will be available upon request.

- Dependability

Dependability relates to how the “research process is logical, well documented and audited” (Schurink *et al.*, 2011:419) and could show that the findings are consistent and can be repeated. Dependability was ensured by keeping an audit trail of all phases of the research process. A record of the invitation letter to partake in the study, all consent forms, copies of participants' reflective journals, and the researcher's field notes during data collection, interview transcripts and data analysis records were kept.

- Confirmability

Confirmability represents how the findings can be confirmed by another person (Schurink *et al.*, 2011:421) and the extent to which findings of the research are shaped by participants and not the researcher's bias. In this study confirmability was ensured through establishing consistency from the different data sources. The researcher kept all copies of raw and processed data, which included the audio discs of the interviews, transcribed data, reflective journals, field notes, data analysis copies and findings of the study. Records were kept for auditing, to ensure that there was coherence of themes so that the results of the findings are reflective of the subjective perceptions of participants and not that of the researcher.

- Authenticity

The criteria of authenticity focuses on how the research represents the viewpoints of participants and members of a social setting fairly (Bryman, 2004:276). The researcher

allowed participants to subjectively construct their own truth regarding their perceptions on self-disclosing their status. The researcher was guided by ethics on research highlighted below to ensure that as far as possible participants were respected and allowed to express themselves.

1.7 ETHICS

The researcher had ethical approval (Appendix G) from the relevant body to undertake the study. The researcher also adhered to the following ethical implications highlighted by Babbie (2010:65-86); Brinkman and Kvale (2008:213-228) as well as Creswell (2009:88-92):

- Informed and written consent

For Brinkman and Kvale (2008:216), informed consent entails a process of ensuring that participants understand the overall purpose and procedure of the study as well as any possible risks so that they can decide in a conscious, deliberate way whether they want to participate or not. Seeing that “seeking permission is an essential part of any research project” (Henning, Van Rensburg & Smit, 2006:66), the researcher therefore sought permission to conduct the study from the head of the clinic in Port Elizabeth as well as to gain access to its clients (participants) before the study was conducted. Once permission was granted, the goal and procedure of the study as well as possible risks were explained to potential participants (Babbie 2010:66) and their caregivers, where-upon those that were interested to participate in the study gave assent and their caregivers gave written consent. Questions and concerns about the study were addressed before consent was given.

- Voluntary participation

Babbie (2010:64) highlights that, being a research participant interferes with the person’s daily routine of living, hence no one should be forced to participate in a study. The Social Service Profession Act (No. 10 of 1978: 5.1.1(e) further highlights that

those involved in evaluation and research should obtain voluntary and informed consent from participants without any implied or actual deprivation or penalty for refusal to participate; without undue inducement to participate; and with the due regard for participants’ wellbeing, privacy and dignity.

In as much as the researcher is employed by the clinic, participants were not forced or coerced to participate in the study. The researcher is not directly involved in the adolescents' health and psychosocial support programs. Participants were asked to voluntarily participate in the study and were made aware of their right to withdraw from the study at any stage, (Brinkman & Kvale, 2008:216) without fear of victimisation or penalty.

- Avoidance of harm

According to Babbie (2010: 65), participants in social research should never be injured regardless of whether they volunteer to participate in the study or not. Strydom (2011a:115) further highlights that, avoidance of harm is not only about minimising harm to participants or protecting them from harm, but informing participants about the possible effects of harm. The researcher explained potential risks of the study which included exposure to disclosure issues participants may not have dealt with. However, any potential physical, emotional or cognitive harm of participants were minimised by applying the principle of beneficence. As a trained and registered social worker, the researcher referred participants who showed signs of emotional discomfort to their assigned counsellors at the clinic. For example, one participant was reminded of a bad experience at school (which she battled to cope with), when peers teased and likened the participant to a dead dog. The participant decided to continue with the interview and the researcher referred the participant to a counsellor for support after the interview. Participants were further informed of their right to withdraw from the study should they feel uncomfortable in any situation during the research process.

- Confidentiality and anonymity

Babbie (2010:67) distinguishes between anonymity and confidentiality, where anonymity entails that neither the researchers nor the readers of the findings can identify a given response with a given participant and confidentiality is when a researcher identifies a person's response but promises not to do so in public. Strydom (2011a:119) views the above terms synonymously since they complement each other. The researcher maintained both the privacy and identity of participants through anonymising the data and identities of the participants by giving each participant a pseudo name. Confidentiality was further ensured by conducting the interviews in a private counselling room at the clinic. Furthermore, all transcripts were done using codes, were stored in a password protected laptop, which was accessible to the researcher and were made available to the supervisor through email and only upon request (for the purpose of study guidance).

- Actions, adequate skills and competence of the researcher

The researcher saw herself as being competent to do the research as she not only has been working in the field of HIV for six years, or attended a research training course, but also because she was under supervision throughout the whole research process. The researcher was further guided by the professional code of ethics, as stipulated by the South African Council of Social Service Profession (SACSSP) guidelines (Children's Act 38 of 2005) on research and the North-West University code of ethics on research in the Health Science Faculty.

1.8 SUMMARY

This part of the study, being section A part 1, outlined the problem statement as well as research methodology of the study. Section A Part 2, will examine the literature providing background pertaining to the study. Section B is presented in article format and mainly refers to a discussion on the results and conclusion of the findings. The final part of this dissertation concludes with section C with an overview and reflection on the process and a discussion of the strengths and limitations of the research. Recommendations and contributions of the findings to knowledge regarding the wellbeing and support for ApHIV's and the self-disclosure of their status are also given in section C.

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PART 2: LITERATURE REVIEW

2.1 INTRODUCTION

A literature review as a fundamental part of the research process involves a review of relevant research studies and documents and offers a critical analysis and synthesis of previous research (Hartas, 2010:96). For the purpose of this study the literature reviewed therefore included literature on the ecological systems theory, adolescent development and the disclosure and self-disclosure of one's Human Immunodeficiency Virus (HIV) status. A literature review was further done to understand the link between adolescents perinatally infected with HIV (ApHIVs) and the nature of ecological systems that influence their perceptions regarding self-disclosing their HIV status.

2.2 ECOLOGICAL SYSTEMS THEORY

The ecological systems theory, also known as human ecology theory, was developed by Bronfenbrenner (1979:33-47) to define "human development within the context of systems of relationships" that form part of a person's environment (Johnson, 2008:2). According to Bronfenbrenner (1979:33-47), the environment in which a person is functioning, is comprised of different layers of systems which include the microsystem, mesosystem, exosystem, macrosystem and chronosystem (Härkönen, 2007:7; Johnson, 2008:2). These systems interact in complex ways and all have an impact on a person's development. Persons are viewed as being connected to other persons, as well as to social institutions, cultural forces and physical space that make up their environment, indicating all potential connections and levels of interactions that individuals have with others and the environment (Wakefield, 1996:7). An illustration of the systems in relation to an individual is illustrated in diagram 2.1:

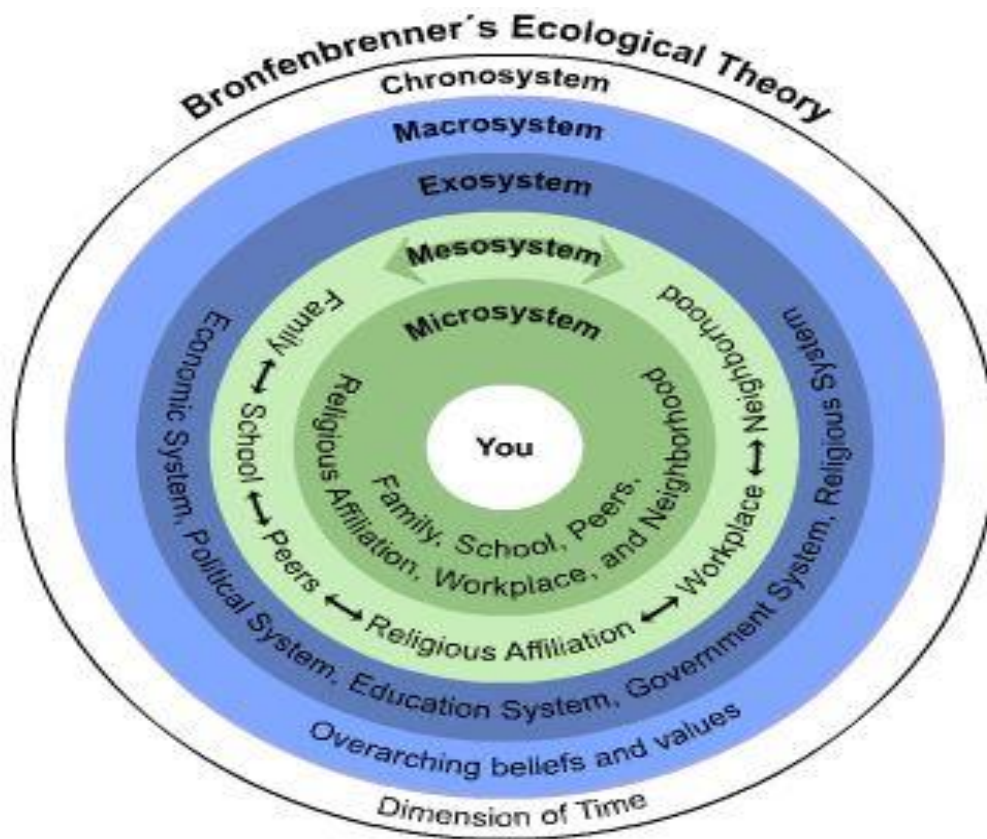


Diagram 2.1: Ecological systems in relation to an individual. Adapted online: <http://faculty.weber.edu/tlday/human.development/ecological.htm> (08.11.2014).

The microsystem is the closest environment for an individual and includes structures with which the individual (the adolescent) maintains direct contact (Harkonen, 2007:7; Johnson, 2008:2), for example the family, peer group, neighbourhood and school life. Bronfenbrenner (1979:35) describes the meso-system as the relationship and interconnections between the microsystems, being interactions between two or more settings linked to the developing person (Härkönen, 2007:10).

These could include interactions that are taking place between adolescents living with HIV and their caregivers and could for instance involve a lack of support that the adolescents living with HIV experience from their caregivers. This lack of support can have a negative impact on how the adolescents view themselves at school and amongst their peers. It may further lead to the adolescents isolating themselves from their peers out of fear that their

peers may not want to interact with them if the peers are to know that the specific adolescent is living with HIV.

The exosystem represents the larger social system and encompasses aspects such as events, contingencies, decisions and policies that an individual does not actively participate in, but which indirectly influences the individual (Härkönen, 2007:11; Johnson, 2008:3). For example, a decision by all medical institutions which stipulates that all children and adolescents living with HIV have to attend monthly health check-up visits during school hours could place these adolescents in a predicament. These adolescents have no direct influence on the decision, but may now be faced with anxiety of not knowing whether to self-disclose (or not) their status to their teacher and peers in order to explain their absence from school.

Macrosystems are those formulated by ideologies in society or the culture of the society as well as the overarching patterns of values, belief systems, lifestyles, opportunities, customs, and resources embedded therein (Johnson, 2008:3). The macrosystem is considered to exert unidirectional influences in the micro, meso and exosystems (Härkönen, 2007:12). For example, an ApHIV may have biological parents who died due to HIV related illnesses in a community where HIV is stigmatised and this may influence the adolescent's decision to self-disclose his or her status or not.

The last system added is the chronosystem, being a system developed as a result of experiences in a person's life and which may influence the operation of all levels of ecological systems (Harkonen, 2007:13; Johnson, 2008:3). For example, an adolescent perinatally infected with HIV may have a family history where most family members died of HIV related illnesses. The loss of the family members due to HIV related illnesses may affect the adolescent in different systems including lack of financial support or support from the community or broader family support. The question arises how this could influence an ApHIV's perception to self-disclose.

2.3 ADOLESCENCE: A CRITICAL STAGE OF DEVELOPMENT

According to the World Health Organisation (WHO) (2010:4), adolescence is seen as a "period in human growth and development that occurs after childhood and before adulthood, from ages 10 to 19". Whilst some authors differentiate between early, late and middle

adolescence and the different age groups, this study focused on adolescents aged 13 to 18 years. Moultrie (2013:4) defines adolescence as a stage in which children transcend into adulthood through progressively developing their autonomy and taking responsibility of their own lives including their health.

McConville and Wheeler (2001:38) define adolescence as the de-structuring of the childhood unity, as the expansion and differentiation of life space and as the transformation of the boundaries which leads to growth and forming of identities. The adolescent developmental phase is characterised by major transitions between childhood and adulthood, which according to Papalia, Feldman and Olds (2009:144), entail major physical, cognitive and psychosocial changes.

Healthy development during adolescence involves successful alignment with inner life and outer opportunities which represent the ability of the adolescent to self-regulate in their environmental field (McConville, 1995:6). McNeely and Blanchard (2009:3) concurs and mentions that healthy adolescence development entails self control and acquiring of core assets such as competence, confidence, connection, character and caring within their environments. For ApHIVs healthy development is often hampered by the effects of the virus (Zanoni, 2013:16).

2.3.1 Adolescents living with perinatally acquired HIV

Perinatally acquired HIV, also known as vertically transmitted HIV, describes HIV transmitted from mother to child, which may transpire during pregnancy, labour, delivery and during breastfeeding (Wood, Rutstein & Steenhoff, 2009:3). The World Health Organisation (WHO) guidelines on initiating antiretroviral therapy (ART) to infants born with HIV state that these babies must be initiated as soon as they are diagnosed (WHO, 2013a:108). The use of ART has resulted in prolonging average life expectancy for children born with HIV, thus many are maturing into adolescents (Arrive, Amghar, Bouah, Dabis, Dicko, Ogbo, & Traore, 2012:56; Butler, Campbell & Hogwood, 2012:46; Haberer, Cook, Ferrier, Kityo, Ngambi & Walker, 2011:2; Zanoni, 2013:14).

However, Moultrie (2013:4) posits that ApHIVs in South Africa (SA) are likely to have been commenced on ART after they were five years of age due to late diagnosis in the past years. As ApHIVs are maturing, having knowledge of their illness becomes an important part of HIV prevention and wellness (Madiba, 2012:319). ApHIVs who have been disclosed to their

status, start dealing with the knowledge of the illness and responsibilities of managing the illness in the midst of dealing with adolescent developmental tasks, encompassing physical, cognitive and psychosocial changes.

2.3.2 Healthy adolescent development versus the development of an ApHIV

2.3.2.1 Physical changes

Physical changes during adolescent development encompass changes in height and body composition, a stage known as puberty (Adlem, 2011:25). According to McNeely and Blanchard (2009:7), physical transformations of puberty affect every aspect of the lives of adolescents. McConville (1995:5) further highlights that the body comes alive in somewhat confusing, exciting or frightening ways. Physical changes during adolescence are also marked by sexual exploration, taking sexual risks and developing intimate relationships (McConville, 1995:5; Moultrie, 2013:4; Santamaria, Dolezal, Marhefka, Hoffman, Ahmed, Elkington & Mellins, 2011:257). Adolescents become self-conscious and agonise about their appearance (McNeely and Blanchard, 2009:7). McConville (1995:5) concurs that, awareness of body consciousness is raised including concerns over attractiveness, physical strength and strange sensations such as loneliness and the need to be cared for.

For some ApHIVs, physical developmental tasks are marked by signs of stunted growth due to the effects of the virus (WHO, 2013b:5). Stunted growth is common with children that were diagnosed and initiated on treatment as they approached adolescence (WHO, 2013b:5). For ApHIVs, knowing that they are living with a highly stigmatised infectious illness may lead to concerns about infecting others, of having children of their own and having to disclose to partners (Armstrong, Pungula, Sobantu, Cheserem & Moshal, 2013:27).

4.3.2.2 Cognitive changes

Cognitive changes are dominated by concrete thinking, egocentrism and impulsive behaviour (Adlem, 2011:27). Adolescents' cognitive development also includes advanced cognitive skills giving adolescents the ability to organise information in their minds, as well as an expanded capacity to commit things to memory (Papalia *et al.*, 2009:144). The cognitive abilities of ApHIVs are often delayed due to the effects of the virus on the central nervous

system that cause neuronal death leading to high degrees of cognitive and learning problems (WHO, 2013:5; Zandoni, 2013:15).

4.3.2.3 Psychosocial changes

Psychosocial changes in adolescence involve moving away from being interdependent of parents and culture to the heightened sense of difference, searching a unique identity or separateness and independence (Adler, 2011:22; McConville & Wheeler, 2001:38). McNeely and Blanchard (2009:) highlight that psychosocial changes encompass the search for self-concept and self-esteem through seeking independence, experiencing intimacy and establishing social status. The adolescent begins to stand apart from adult influence and turns to peers creating a differentiating boundary within the field (McConville & Wheeler, 2001:38), hence peers become an important source of information providing adolescents with opportunities for socialisation (Van Dyk, 2008:188). Peers' social networks provide the comfort, support, and guidance that were once provided by their family. McConville (1995:2) concurs that peers become self-mate with friendships, romances and rivalries shaping the adolescent's experience of self, sense of worthiness, attractiveness and conformability.

Adolescents begin to seek knowledge of who they are in relation to others. They also have a willingness to take responsibility for who they are becoming, and to develop a realised commitment to live with others in community (Adler, 2011:22). During the adolescent phase, worries of what their parents and peers think of them and whether their new emerging self is accepted become eminent (McConville, 1995:3; Papalia *et al.*, 2009:144). Expectations of society, family and peers coupled with physical, psychological and cognitive changes foster adolescents to evaluate and change their social behaviour (Geldard & Geldard, 2005:12). Adolescents furthermore become interested in talking in-depth about themselves (Adler, 2011:28), and as has been referred to they begin to form intimate relationships and initiate sexual activities as they approach adulthood (Papalia *et al.*, 2009:144). McNeely and Blanchard (2009:46), posits that, adolescents may engage in risky and adventurous behaviours while trying on new identities and ways of thinking. Erikson (in Papalia *et al.*, 2009:146) views this stage as a stage of identity versus role confusion, where adolescents work to achieve a sense of who they are, how they see society, the community and the country.

Adolescence is further characterised by the exploration of ideological and occupational options available in society and the experimentation with a wide range of social roles with the

aim of consolidating their beliefs into representing who they are (McAdams, 2001:102). According to McNeely and Blanchard (2009:72), an adolescent may start to broadly explore world views and ideologies thus finding a link amongst religious, spiritual and societal values. A positive sense of self develops in societies where there are consistent values and expectations whereas in societies where family, school and community fail to offer consistent values and positive goals, adolescents tend to be confused and portray a dispersed sense of self (Geldard & Geldard, 2005:49). McNeely and Blanchard (2009:72) concurs that a positive sense of self is seen with identification with a particular group for example, female, black, Jewish, amongst others. Identification with consistent values and morals assist the adolescent in gaining autonomy (Geldard & Geldard, 2005:13). Russel and Bakken (2002:1) posit that autonomy is important in allowing the adolescents to think, feel and make decisions as well as act on their own.

ApHIVs may face considerable challenges in achieving autonomy due to both psychosocial and physical manifestations of HIV. Achieving autonomy may be affected by high rates of developmental delays such as stunting and sexual maturation; orphaning; recurrent bereavement, and increased vulnerability to violence and abuse which can result in stigma and discrimination (Moultrie, 2013:5). Feelings of depression, loneliness and anger (Santamaria *et al.*, 2011:257) become common in this stage for ApHIVs with some of them translating into psychological problems such as conduct disorder, social phobia, oppositional defiant disorder and attention deficit hyperactivity disorder (Butler *et al.*, 2012:47; Woollet, 2013:23; Zaroni, 2013:16). ApHIVs often suffer from undiagnosed behavioural, cognitive and mental health problems manifesting as learning problems, substance abuse or adherence to treatment problems (Zaroni, 2013:16; United Nations Children's Fund (UNICEF), 2011:28). In the African context these symptoms may be exacerbated by lack of knowledge of their illness, orphanhood and bereavement, increased poverty and lack of food security (Woollett, 2013:23). Knowledge of their HIV status may thus be important for these adolescents in order for them to be able to participate in their own medical treatment and tackle issues of their wellbeing (Santamaria *et al.*, 2011:257).

2.4 DISCLOSURE OF HIV STATUS TO CHILDREN AND ADOLESCENTS LIVING WITH HIV

As children perinatally infected with HIV mature, the issue of disclosing their HIV status to them becomes a central issue for health care professionals, their parents and/ or care givers, as well as the children concerned (UNICEF 2011:29). Disclosure to children perinatally infected with HIV is seen as an on-going process over a period of time. As children mature cognitively, emotionally, and sexually numerous discussions take place whereby information regarding the aetiology, course and the psychosocial and physical effects of the illness are being provided (WHO, 2011:7). In addition, disclosure to children is a requisite in order to gain access to treatment programmes, to receive social grants and psychosocial support (Chopra, Kadiyala & Norman, 2005:5). Although there is no recommended age for disclosing their HIV status to children, WHO (2011:15) and Mahloko and Madiba (2012:4) have found in their research that in SA the caregiver, generally with the support of healthcare professionals and relevant family members, will disclose the illness to children infected perinatally with HIV at the age of 10 (Carter, 2010:28; WHO, 2011:16). However, some children develop into adolescence without knowing their status and learn about their status through questioning the reasons for taking medication and attending clinic visits without a particular reason (Mahloko & Madiba, 2012:2).

Studies in SA by Madiba (2012:6), Mahloko and Madiba (2012:4) and the WHO (2011:15) on disclosing a child's or an adolescent's HIV status, contend that the process is usually facilitated by healthcare professionals through preparing the caregivers of ApHIVs:

- on how to disclose the adolescent's status,
- on the effects of disclosure and
- on being there to support the actual process.

Studies on how caregivers deal with the process have also shown that some caregivers delay the disclosure process due to lack of knowledge on how to disclose out of fear that the child may be too young to understand and may tell others leading to social rejection (Haberer *et al.*, 2011:2; Madiba, 2012:326; Mahloko & Madiba, 2012:4; Wu, Slocum, Comulada, Lester, Semaan & Rotheram-Borus, 2008:35).

2.4.1 Impacts of disclosing HIV status to ApHIVs

Disclosure to children perinatally infected with HIV is seen as supportive, assisting them to deal with practical issues such as coping with having to live with HIV; managing with a sick or dying primary caregiver (usually the mother); obtaining financial and social support and

dealing with psychological concerns such as what will happen to them if their mother dies (WHO, 2011:14). Disclosure of HIV status to children and adolescents on the other hand also gives caregivers an opportunity to talk about preventative measures of transmission of the virus to their sexual partners (Madiba, 2012:322).

Some of the studies have proved that adolescents who are aware of their HIV status, who have some knowledge about their illness and/or have participated in the disclosure process, seem to accept and adhere to medical care and treatment (Butler *et al.*, 2012:45; Chopra *et al.*, 2005:1). These adolescents are more willing to positively participate in managing their health and wellbeing, show signs of increased self-esteem and demonstrate reduced risky sexual behaviour (Carter, 2010:29; Mahloko & Madiba, 2012:4). All of these signs highlight the benefits and necessity of disclosure (Butler *et al.*, 2012:45; Mahloko & Madiba, 2012:6). Studies (Butler *et al.*, 2012:47; Vreeman, Gramelspacher, Gisore, Scanlon & Nyandiko, 2013:1) have found that adolescents receiving ART and attending clinic visits yet have not been told the reasons for taking medication are susceptible to rebellious behaviour against their caregivers, high viral load and non-adherence to ART as well as show signs of anxiety, depression and low self-esteem.

While the issue of disclosing the status of children and adolescents perinatally infected with HIV has received widespread attention in the recent years (Moultrie, 2013:5), less attention has been put on the self-disclosure of one's status to peers and significant others and its possible impacts.

2.4.2 Self-disclosure of HIV status

Self-disclosure is defined as a form of communication whereby one reveals something unique about oneself (Greene, Derlega & Matthew, 2006:441). In the context of HIV, self-disclosure of one's HIV status would thus refer to whereby an individual tells others about his/her HIV status. Self-disclosure of one's HIV status can both negatively and positively impact on the individual's wellbeing.

2.4.2.1 Impact of self-disclosing one's HIV status

Communities in SA, due to lack of knowledge on HIV by community members and long-standing myths and fears, have a vicious stigmatisation of people living with HIV of all ages, subjecting the affected to discrimination, abuse and violence and making it difficult for them to self-disclose their status (Campbell, Foulis, Maimane & Sibiyi, 2005:808; Deacon &

Stephney, 2007:25; Kehler, Mtambo, Mthembu & Zungu, 2012:6; Mahloko & Madiba, 2012:6; Woollett, 2013:23).

A recent research conducted in various local townships, on the self-disclosure of one's HIV status and its relation to gender based violence in SA, for instance concluded that women living with HIV presented with fears of disclosing their HIV status due to potential risks of rejection, abuse and violence upon disclosure (Kehler *et al.*, 2012:6). The socio political status of a community (with reference to interactions of social and political systems such as poverty, human rights and education status) furthermore seems to have an impact on the way people perceive those living with HIV, possibly explaining why stigmatisation manifests itself in different ways across countries, communities, religious groups and individuals (Butler *et al.*, 2012:55).

The prevalence of stigma in SA communities (Arrive *et al.*, 2012:56; Haberer *et al.*, 2011:3; Harper, Hosek, Lemons & Martinez, 2008:192; Woollett, 2013:23), may lead to the fact that some ApHIVs might internalise the fears of stigmatisation and discrimination that their parents have regarding the disclosure of their status. These fears of being stigmatised may therefore create barriers to open and honest disclosure of an adolescent's illness. Groves, Maman and Van Rooyen (2013:1), however, have in their study on self-disclosure of HIV status found that, self-disclosure may rather result in support for people living with HIV when family and friends react positively to the news of the diagnosis.

A study conducted in Zambia (Menon, Ngoma, Campaign & Glazebrook, 2007:349) on mental health and disclosure of HIV status in Zambian adolescents living with HIV, highlighted the benefits of self-disclosure such as social support from friends and family which subsequently lead to improved self-esteem and health promoting behaviour. On the other hand, Armstrong, Pungula, Sobantu, Cheserem and Moshal (2013:27) in their study in SA found that adolescents living with HIV have the same reproductive and sexual needs as other adolescents but face difficulties with self-disclosing their status to their sexual partners, yet they are often concerned about infecting others.

Difficulties on self-disclosing HIV status seem to be due to fears of being abandoned; isolated; and self-imposed isolation due to shame; as well as exposure to stigma and discrimination (Cataldo, Haamujompa, Hodgson, Kalibala, Lowenthal, Mburu & Ross, 2014:91; Randeria, 2013:35).

2.4.2.2 Self-disclosure of HIV and the adolescent's ecological system

The self-disclosure of adolescents' HIV status is embedded within an ecological systems perspective, where the adolescent is viewed as an individual in interaction with the systems in his or her environment and where the systems influence how the adolescent acts and behaves in the various systems. For ApHIVs, their wellbeing is always embedded within the family context (within this study the African family), being mainly the nuclear family and representing the microsystem (Brennan, Calabrese, Martin, Toledo-Tamula, Wolters & Wood, 2012:1092).

Rejection by school or community represents the mesosystem where different systems are in interaction. Labelling the virus as a secret that cannot be discussed may inadvertently increase the stigma starting within the family (Woollett, 2013:23). Adolescents may, for instance, observe the way their parents discuss the diagnosis in their presence, which may lead to low self-esteem and identity issues. ApHIVs who know their status may devalue themselves, end up feeling depressed or engage in denial of their status and may avoid disclosing their status to others out of fear of being excluded from social settings (Butler *et al.*, 2012:55; UNICEF, 2011:28).

Literature on disclosure, and on discrimination, provides the most compelling evidence that HIV/AIDS related stigma due to the beliefs that people have (and which represents the macrosystem) is a critical problem for people affected by HIV/AIDS in stigmatised societies (Deacon & Stephney, 2007:25; Harper *et al.*, 2008:192; Woollett, 2013:23). The fear that ApHIVs have of stigmatisation may result in feeling shameful regarding their condition which may affect their interpersonal relationships, their self-esteem and the practice of safe sex where openhearted discussions about sexual transmission and protection are crucial (UNICEF, 2011:28; Woollett, 2013:23). Some ApHIVs may experience rejection from the community (or the macrosystem) leading to pain and embarrassment.

In 2013, the WHO (2013b:1-100) released guidelines on the use of antiretroviral medication, HIV prevention and support including recommendations on the importance of supporting adolescents regarding the disclosure of their HIV status. The guidelines focus on the adolescents' ecological systems which encompass mainly their family, school and the community they live in (WHO, 2013b:1-100). Emphasis is put on the importance of counselling adolescents on aspects such as health benefits of disclosure with such as treatment adherence due to support from disclosure of status. On the other hand, the

guidelines highlight the risks of disclosing one's HIV status to others and the importance of empowering and supporting adolescents on making informed decisions regarding self-disclosing their HIV status (WHO, 2013b:24).

As highlighted above there seems to be a lot of risks surrounding self-disclosing one's HIV status, such as stigmatisation and discrimination. The stigmatisation and discrimination of people living with HIV may pose as a threat for self-disclosing HIV status for ApHIVs. ApHIVs seem to function in an ecological system that lacks an understanding of HIV, thus the researcher is of the opinion that ApHIVs may find it difficult to self-disclose their status within their various ecological systems where there are myths and misconceptions associated with HIV and its transmission. Society may thus need to gain more knowledge regarding HIV so as to curb stigma and discrimination towards people living with HIV.

2.5 SUMMARY

Most adolescents living with HIV in Africa struggle for recognition, protection and rights (UNICEF, 2011:28). The struggle for recognition stems from a lack of knowledge of HIV by the community, representing the macrosystem (attitudes and ideologies of society), that is consequently concerned about the transmission of the virus as well as associating it with socially unacceptable activities such as prostitution, thus stigmatising people and adolescents living with HIV (Butler *et al.*, 2012:55). Yet adolescence is seen as “a pivotal time to build on their development in the first decade of life”, hence it is important to support them in navigating risks and vulnerabilities and set them on a path of fulfilling their potentials (UNICEF, 2011:2). It is therefore important to understand the perceptions of ApHIVs regarding the self-disclosure of their HIV status.

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SECTION B: ARTICLE

Perceptions of adolescents perinatally infected with HIV regarding the self-disclosure of their status

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ABSTRACT

Most children born with perinatally acquired Human Immunodeficiency Virus (HIV) are maturing into adolescence due to the accessibility of antiretroviral treatment. During adolescence they experience developmental changes including formation of intimate relationships, thus making issues of the self-disclosure of their HIV status unavoidable. This study aimed to explore and describe the perceptions of adolescents perinatally infected with HIV (ApHIV) regarding the self-disclosure of their status. Findings of the study reveal link participants' perceptions directly to that of societal attitudes towards HIV and to adolescent developmental factors posing conditions to either self-disclose or not self-disclose their status. Recommendations are suggested regarding support for ApHIVs.

INTRODUCTION

Children born from mothers with Human Immunodeficiency Virus (HIV) are progressing into adolescence and adulthood due to the accessibility of antiretroviral treatment which prolongs their life expectancy (Arrive, Amghar, Bouah, Dabis, Dicko, Ogbo & Traore, 2012:56; Butler, Campbell & Hogwood, 2012:46; Haberer, Cook, Ferrier, Kityo, Ngambi & Walker, 2011:2; Zandoni, 2013:13). As the children born with HIV reach adolescence, the issue of managing their illness becomes important to them, to their caregivers as well as to healthcare professionals. Managing HIV illness for 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 do not only have to deal with the knowledge of living with HIV and how to manage the illness, but also have to master the 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 by Hoe, Mckeown, Sobota, Stolts and Trow (2003:7) as an act of revealing one's own HIV status to another person or persons. 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 of 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 to reduce risky sexual behaviour, adherence to treatment and access to clinical and psychosocial services such as treatment of sexually transmitted infection and support groups consecutively. 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) in the same regard states 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 due to fear of rejection (Cataldo, Haamujompa, Hodgson, Kalibala, Lowenthal, Mburu & Ross, 2014:1).

Out of fear to subject their child to stigmatisation and discrimination parents also seem to play a role in whether or not ApHIVs will self-disclose their status or not. 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) in this regard specifically note that biological parents of ApHIVs often prohibit their children from self-disclosing their status to people outside of the family due to fears 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 (SA) communities (Arrive *et al.*, 2012:56; Campbell, Foulis, Maimane & Sibiya, 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 SA and a lack of knowledge on HIV have led communities to have 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 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 due to 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 framework of the ecological systems theory. The 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 four layers

of systems which include 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 the 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 towards 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 the 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 thick descriptions of ApHIVs regarding their perceptions of self-disclosing their status. According to Delpont, Fouché and Schurink, (2011:297), Kriple 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 of the phenomenon under study but also helped to elicit thick descriptions of the phenomenon as participants see it.

The population of the study comprised of all ApHIVs that were registered in the data base 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 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 that formed part of the sample was disclosed to them at an average age of 10 and they were orphaned with some of them living with grandparents and few of them living 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 before.

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. The numerical value of the sample did not define the study but the sample was sufficient to allow exploration of the phenomena and yield rich descriptions of perceptions of ApHIVs.

Table 1: Participant information

Participant	Age	Gender	Age disclosed to	Grade in school
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 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 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 were voice recorded with participant consent in order to avoid any loss of information.

Upon transcribing the interviews and translating them from Xhosa to 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 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 themes emerging. Thick descriptions of the findings were provided through using direct quotations from the interviews. 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 so that the results of the findings were reflective of the subjective perceptions of participants, not that 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) as well as 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 upon 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 possible effects of harm. Participants that 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 pseudo name.
- **Respect of human dignity:** This was ensured through explaining the nature of the research to the participants as well as what was expected from the participants.

- Actions, adequate skills and competence of the researcher: The researcher considered herself to be competent as she has 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.

RESULTS AND DISCUSSION

Below is a discussion of themes and subthemes that emerged when the data was analysed.

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 the self-disclosure of one's HIV status to others. These conditions involve trusting relationships and the need for support. It seems that both these conditions would favourably contribute 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 whom they share similar experiences with. According to Greene, Gust, Petronio, Valerian and Yep (2003:54), similar experiences refer 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 in her journal shared a similar perception, *“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 they have regular contact with and within steady intimate relationships, which in itself leads to the strengthening of affectionate relationships. McConville (1995:2) on this point is of the opinion that relationships with peers shape the adolescent’s sense of comfortability, 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 like 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 a trusting relationship where the confidant understands ApHIVs and would not share 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 literature it seems that ApHIVs are in need of emotional, medical, educational and psychosocial support due to 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 due to 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 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 actual 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 due 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 to self-disclose their HIV status. It also seems to be the one aspect where they realise the value to self-disclose 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-disclose one's HIV status. These conditions included a fear of being stigmatised and discriminated against as well as a fear for 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 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 various 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" which 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 an opportunity for others to gossip about them or laugh at them. Participants, for instance, fear that after self-disclosure, 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 ARV's (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 to be secluded by other children and be 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"* and *"... or they say she has BMW, she has the 3 alphabets, which is a three letter word meaning HIV"* (Participant #9). Seeing that peers, social networks and socialisation in general are associated with adolescence, and provide them with comfort, support and guidance (Geldard & Geldard, 2005:13; Van Dyk, 2008:188), ApHIVs thus perceive not to self-disclose 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 narrated 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 an unfair and unjust treatment of an individual with the assumption that one is deviant from others. People living with HIV are thus socially constructed as the “others” who are different 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 by other peers from play 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).

Results above are supported by evidence from studies by Arrive *et al.* (2012:56), Butler *et al.* (2009:48), 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 due to 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 due to 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 due to 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 twenty two situation, seeing that they on the one hand 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 such as ignorance about HIV as a contributing factor to inhibit 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 well-being 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, were 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 for 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 attachment of HIV to promiscuity as a reflection of how the community lacks 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 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 SA have on-going myths and fears regarding HIV due to lack of knowledge on how HIV is transmitted. Societal attitudes form part of the macrosystem where the community believes that HIV is transmitted due to promiscuity. The participants, therefore, seem to perceive that by not self-disclosing their status is better 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 the 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 as 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 with the forming of romantic or sexual relationships, getting married (Papalia, Feldman & Olds, 2009:144) or having children as well as 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 on the one hand almost seems 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 AN ASSISTING MEASURE TO SELF-DISCLOSURE

The fourth theme that emerged was that educating the broader society about the importance of supporting the ones living with HIV was perceived by the participants as an assisting measure to 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 of how education can be done, but also by whom 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 alluded 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 focus on how ApHIVs need to be supported may auspiciously make it easy for ApHIVs to self-disclose their status knowing that they will be supported, thereby reducing the effects of stigma and discrimination.

Healthcare professionals are perceived as important individuals to 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 psychological and social needs of youth 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 towards 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 twenty two situation with regards to the choice to self-disclose their status or not to. 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 managing their illness as opposed to not self-disclosing their HIV status and then not receiving any support. It seems 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 lead to moral judgement from the community. They are, therefore, not only confronted with the decision to self-disclose or not, but also with whether they are going to be stigmatised, or being 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 them, 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 assist them with 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 fears of being stigmatised or discriminated against that hinder self-disclosure seem 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 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 of 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 recommendations from this study are:

- 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 stigma to and discrimination against people living with HIV, thus shifting the focus from an HIV transmission awareness approach, to an approach where support programs are being developed for those people (also adolescents) living with HIV.
- More research needs to be done on not only 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 regards to their specific needs.

- Institutions such as schools and healthcare centres need to develop policies, regulations and laws 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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SECTION C

REFLECTIONS ON THE STUDY, LIMITATIONS AND FINAL COMMENT

1. INTRODUCTION

The aim of this document was to give a detailed discussion of the study that was conducted and it is believed that the results of the study will contribute to the vast knowledge base on HIV/AIDS, but more specifically on the discourse of self-disclosure by adolescents perinatally infected by HIV. The purpose of this section is to reflect on the study, to identify the limitations of the study and give a final thought on the study.

2. REFLECTIONS OF THE RESEARCHER ON THE STUDY

The study answered the research question, namely: What are the perceptions of adolescents perinatally infected with HIV regarding the self-disclosure of their HIV status? To answer the question, the scope of the study was properly demarcated as the researcher clearly outlined the background of the research and the orientation of the study. The study's aim and objectives were clearly defined. The design and approach of the study suited the qualitative nature of the study allowing participants to give their subjective perceptions, thus answering the research question. The literature review gives a concise description of the different key concepts, namely: HIV status, self-disclosure, perceptions, adolescents and being perinatally infected. Data were collected, specifically focusing on the core of what the research question asked, thus answering the question.

Collected data were then analysed through outlining common themes and the research was reported in article format. The researcher succinctly concluded the study and gave recommendations based on the findings. The researcher was under supervision and guidance throughout the study which helped the researcher to stay focused on the research question.

3. LIMITATIONS OF THE STUDY

Limitations of the study were as follows:

- Participant's pool was not diverse as it only consisted of black adolescents living with perinatally acquired HIV. Findings are thus only limited to that part of the population and cannot be likened to all adolescents living with perinatally acquired HIV.

- The sample of study was relatively small and cannot be generalised to a wider population.
- The perceptions of these adolescents are confined to the community where the participants live (Port Elizabeth), thus findings may not be likened to other areas in South Africa or globally.
- It was difficult to recruit male participants as few of the male persons showed interest in participating in the study as compared to female participants. Findings may not reflect a balance between perceptions of both males and females.
- The majority of participants were receiving psychosocial support and were or had been members of a support group for HIV positive youth, meaning they had self-disclosed their status to other peers. Their involvement in psychosocial support and support groups may have contributed to them being open and more willing to participate in the study and talk about HIV and their perceptions surrounding self-disclosure. Findings may thus not reflect perceptions of adolescents perinatally infected with HIV who are not receiving any form of psychosocial support and are not open to talk about their status.

4. FINAL COMMENT

The South African constitution as well as the Children's Act 38 of 2005 clearly state that information regarding children and adolescents must be kept private and confidential. This is applicable to adolescents' HIV status as well, thus adolescents perinatally infected with HIV must not be coerced to self-disclose their status. However, one way or another ApHIVs are faced with a dilemma to self-disclose their status either to their families, peers or school teachers amongst others due to demanding developmental tasks. On the other hand, it is not easy for the adolescent to just self-disclose their status as they have to weigh the advantages versus disadvantages of self-disclosing their status depending on whom they want to self-disclose to. It is in such dilemmas that people within the ecological systems of ApHIVs need to be knowledgeable on how to support them. In reality, society does not have much knowledge regarding HIV and is still subjecting those affected to stigma and discrimination, despite ongoing HIV/AIDS education through various media since the prevalence of the

pandemic. Is enough education being done to change the mindset of people who have myths and misconceptions regarding HIV or is society just being ignorant? Healthcare professionals who possess knowledge of HIV/AIDS and how the affected must be supported, remain an important pitch for ApHIVs to receive the support they need regarding self-disclosing their HIV status so as to traverse through adolescence and its demanding tasks.

SECTION D APPENDICES

APPENDIX A: INVITATION LETTER TO PARTICIPATE IN THE STUDY



Centre for Child, Youth and Family Studies

Corner of East and College Street

Wellington

7655

Tel: 021 864 3593

Fax: 021 864 2654

6 January 2014

INVITATION TO PARTICIPATE IN A STUDY

A research study of the North-West University

My name is Caroline Mpofu and I am a Masters Social Work student at North-West University. I am currently working on a research study which seeks to understand the perceptions of a group of adolescents regarding self-disclosure of their HIV status which was perinatally contracted. The reason for this is to ensure the voices of perinatally infected adolescents are heard regarding self-disclosure of their HIV status which could be valuable in developing new or changing existing support programs for adolescents and their families.

I would like to invite you to participate and assist me in completing my studies, if you are:

- Aged between 13 and 18 years and perinatally infected by HIV.
- Receiving medical treatment or support or counselling at a clinic in Port Elizabeth.
- Have been told about (disclosed to) your status by your caregiver.
- Are willing to discuss the topic of self-disclosure with me.

If you decide to participate in the study, you will be asked to do the following:

- Get consent from your primary caregiver.
- Give consent to participate.
- Meet me at the clinic for an information session. There I will explain the details of the study, tell what you are expected to do in the study, answer any concerns and questions you may have. For example, you will be asked to keep a private journal about your perceptions regarding self-disclosing your status for a period of two weeks during February before we meet again for the actual interview at the centre.
- Meet me at the clinic for the interview session, where you will have the opportunity to share what you put into your journal. In addition I will also be asking you some questions regarding your perceptions surrounding self-disclosing your status. With your permission the interviews will be tape/video recorded and kept private and confidential. In addition pseudo (fake) names will be used throughout the process so that no one can identify you or your responses.
- Support will be available from your designated counselor at the centre if you need any help.

If you are interested in participating in the study and fulfill the study participation criteria please contact me or your clinic counselor so that I can meet you at the center from the 13th of January to the 31st of January 2014.

Thank you for taking time to read this letter. For further clarifications on the project please contact the researcher on the number provided below.

Yours sincerely

Caroline Mpofu

Contact: XXX

APPENDIX B: PARENTAL CONSENT (ENGLISH AND XHOSA)



Centre for Child, Youth and Family Studies

Corner of East and College Street

Wellington

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Tel: 021 864 3593

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13 January 2014

Perceptions of adolescents perinatally infected with HIV regarding the self-disclosure of their status.

PARENT / GUARDIAN INFORMED CONSENT FOR PARTICIPATION OF A MINOR IN THE RESEARCH PROJECT

(To be explained in mother tongue, Xhosa, where parent does not understand English language)

I am Caroline Mpofu from the North-West University. I am working on a research study to explore and describe the perceptions of adolescents regarding self-disclosure of their HIV status after being perinatally infected. I would like to seek your consent for your child to participate in the study, as your child has indicated an interest and voluntarily agreed to participate with your permission.

The information about the study is listed below, enabling you to make an informed decision.

PURPOSE OF THE STUDY

The purpose of this study is to explore and describe the perceptions of adolescents who are perinatally infected with HIV. Its focus is on the self-disclosure of their HIV status, as this is

a developmental phase where for many adolescents talking about herself/himself becomes an important matter. In order to understand how adolescents perceive self-disclosure of their HIV status, this study intends to collect data from a sample of voluntary participating adolescents who have been perinatally infected with HIV and are between the ages of 13 and 18 years. In addition, these adolescents have been told their status by their caregivers and are currently registered for and receiving medical treatment and psychosocial support or counselling at a clinic in Port Elizabeth.

Your child has been invited to participate in this study as she/he fulfills the inclusion criteria. I am interested in your adolescent's perception regarding talking about her/his HIV status to others and believe this may add to the understanding of adolescents and families in the same situation.

1. PROCEDURE

If you agree that your child can participate in this study, she/he will be expected to do one/all of the following:

She/he will be briefed individually about the study and what she/ he is expected to do in a language that she/he understands. This will include activities such as keeping a journal for two weeks during February, where she/he will be asked to write down or draw anything regarding her/his thoughts surrounding self-disclosing her/his status. This journal will be discussed during a follow-up individual interview session with me during the last two weeks of February. The interview will be conducted in a private counselling room at the clinic. During this time she/he will be asked to describe the contents of her/his journal, as well as some questions regarding his/her perceptions on self-disclosure on his/her status to others. A second interview may be conducted to get more information regarding their perceptions from your child. With your and your adolescent's permission, the interviews will be video/audio tape recorded. The identity of the participant will not be revealed and all information obtained will be kept private and confidential.

2. RISKS / DISCOMFORTS

Pseudo (fake) names will be used throughout the research process so that no one can identify your child's responses. All sensitive information will be protected by storing it on a password protected computer.

In case of any emotional discomfort as a possible risk, support will be available from your child's designated social worker at the clinic if she/he needs any help.

3. BENEFITS

Including your child's perceptions regarding self-disclosure of her/his HIV status could assist in developing new or changing existing support programmes for adolescents and their families who have children in the same situation.

4. COSTS

There will be no cost to your child as a result of her/his participation in this study.

5. PAYMENT

Your child will receive no payment for participation, but will receive refreshments when she/he comes to meet the researcher at the clinic. Transport will be provided for your child to take her/him home after meeting with the researcher.

6. QUESTIONS

If you have any additional questions or concerns regarding the study, you are welcome to contact me directly at XXX.

7. FEEDBACK OF FINDINGS

The findings of the research will be shared with your child at her/his request when they become available.

Centre for Child, Youth and Family Studies

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13 January 2014

PARTICIPATION IN THIS RESEARCH IS VOLUNTARY

You are free to withdraw your child from this study, or to have your child withdraw at any point, even after you have signed the form to give consent, without any consequences.

Should you be willing that your child participates you are requested to sign below:

I _____ hereby voluntarily consent that my child participates in the above mentioned study. The information above was explained to me in a language I understand. The explanation was done by Caroline Mpofu. I am not coerced in any way to have my child participate and I understand that my child can withdraw at any time should she/he feel uncomfortable during the study. I also understand that my child's name will not be disclosed to anybody who is not part of the study and that the information will be kept confidential and not linked to my child's name at any stage. I also understand what my child might benefit from participation, as well as what might be the possible risks. Should I need further discussions, someone will be available to assist me. I was given an opportunity to ask questions and they were answered to my satisfaction.

Date

Signature of the parent

Date

Signature of the person obtaining consent

Centre for Child, Youth and Family Studies

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Tel: 021 864 3593

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13 January 2014

Iindlela abo bakwishumi elivisayo bavakalelwa ngayo ngokuphathelele ukuxelela abanye ngokwesuleleka kwabo ngoxa babezalwa yiHIV

IMVUME YOMZALI YOKUBA UMNTWANA WAKHE MAKATHABATHE INXAXHEBA KUPHANDO

((Mayicaciswe ngolwimi lwabo, isiXhosa apho umthathi nxaxheba angaluqondiyo ulwimi lwesiNgesi))

Ndingu Caroline Mpofu ofunda kwiYunivesithi yaseNorth West. Ndenza isifundo esiphicotha yaye sichaze iindlela abantwana abakwishumi elivisayo abavakalelwa ngayo ngokuchaza/ukwazisa ekuhlени malunga nokosuleleka kwabo yintsholongwane iHIV ngelaxesha babezalwa. Uyacelwa ukuba uthabathe inxaxheba kwesisifundo. Nceda unikele ingqalelo kulenkcazelo ilandelayo ukuze wenze izigqibo esisengqiqweni nesobulumko Ngokuphathelele ukuba uzakubaninxaxheba okanye kusini na.

INJONGO YESISIFUNDO

Injongo yesisifundo kukuphicothat nokuchaza iindlela abantwana abakwishumi elivisayo abavakalelwa ngayo kuba baye bafumana intsholongwane yeHIV ngoxa babezalwa. Sijoliswe kwisigqibo sabo sokuxelela abanye ngokwesuleleka kwabo, njengoko oku kuyinxalenye yokukhula kwabo ukuba bathethe ngabo. Ukuze kuqondwe indlela olulutsha olukuqonda

ngayo ukuzichaza okanye ukuxelela abanye ngokwesulelelka kwabo, oluphando luqokelela inkcazelo kubantu abakulungeleyo ukuthatbatha inxaxheba ngokuzithandela, abaye basuleleka yiHIV ngoxa babezalwa. Kufuneka aba bathathi nxxheba babephakathi kweminyeka eli-13 ukuya kweli-18 ubudala. Ukongezelela, koku aba bakwishumi elivisayo kufuneka babe baye bachazelwa ngabo babanyamekelayo kwaye bafumana uncedo lezonyango nokwelulekwa kwasengqondweni e-clinic.

Umntwana wakho/ omnyamekelayo uyamenywa ukuba athabathe inxaxheba koluphando ukuba uyazifanelekela ezizibakala zikhankanyiweyo. Ndinomdla wokwazi indlela avakalelwa ngayo ngokuphathelele ukuthetha nabanye ngokwesuleleka kwakhe yiHIV. Ndikholelwa ukuba oku kuyakunceda ekuqondeni aba bakwishumi elivisayo neentsapho zabo ezikulemeko.

7. UMGAQO

Ukuba uyavuma ukuba umntwana wakho/omnyamekelayo abeninxaxheba kwesisifundo/uphando, ulindeleke ukuba wenze oku/ konke oku kulandelayo:

Uzakucaciselwa ngoluphando ngolwimi aluqondayo, isiXhosa. Emva koko uzakucelwa ukuba abhale ijournal kangangeeveki ezimbini ngoFebruary. Uzakucelwa futhi ukuba abhale phantsi iingcinga okanye iimvakakleleo zakhe ngokuphathelele ukuxelela abanye ngokwesuleleka kwakhe. Le journal yakhe uzakuyiphatha xa sisenza I interview ekupheleni kuka February. Le interview iyakuthatha ihour, yaye iyakwenzelwa kwi ngumbi lecounselling lalapha e-clinic. Kule-interview, uzakucelwa ukuba athethe ngejournal yakhe, abuzwe nemibuzo ngokuphathelele iimvakalelelo zakhe ngokuxelela abanye /omnye umntu ngokwesulelelka kwakhe. Ngemvume yakhe, le interview izakushicilelwa ngevideo okanye ngetape. Yena mntu uzakube ebuzwa imibuzo igama lakhe alizukubhengezwa kule video yaye inkcazelo oyinikezileyo iyakugcinwa iyimfihlo.

8. UMNGCIPHEKO

Akukho mngcipheko azakube ezifaka kuwo xa athe wangenelela oluphando. Siyakusebenzisa amagama angengawo ukukhusela ukuba ungaziwa. Yonke inkcazelo yakhe ebuthathaka okanye efihlakeleyo iyakugcinwa nge password kwicomputer, akukho mntu ungomnye uyaziyo lepassword. Uyakufumana incedo kwinonthlalthle yakho nanini na uyifuna.

9. IINGENELO

Indlela avakalelwa ngayo ngokuphathelele ukuxelela banye abantu ngokwesulelelka kwakhe ingaluncedo kwabanye abantu. Oku kunganceda indlela ekuncedwa ngayo abo bakwishumi leivisayo abakwimeko efanayo neyakhoe.

10. IINDLEKO

Akukho zindleko ayakuhlangabezana nazo ngokuthatha kwakhe inxaxheba koluphando.

11. INTLAWULO

Akazukuhlawulwa ngokuthaththa kwakhe inxaxheba koluphando. Kodwa uyakuthi aphiwe izimuncumuncu xa ezoku bonana nomqhubi woluphando. Uzakulungiselelwa netransport xa egoduka emva kokuba udibene XXX.

12. UKWAZISWA NGEZIPHUMO ZOPHANDO

Iziphumo zophando uyakuzaziswa nanini na uzicela, emva kokuba uphando lugqityiwe.

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13 January 2014

IFOMU EGUNYAZISA IMVUME YOMTHATHI NXAXHEBA

UKUBANENXAXHEBA KOLUPHANDO AKUSOSINYANZELO. Ukhululekile ukuba ungarhoxa kulo nanin na ufuna ukwenjenjalo, nasemva kokuba uye wasayina le form kwaye oko akunakukufaka nakwencinci ingxaki,

Ukuba uyavuma ukuba nenxaxheba, ucelwa ukuba utyobele apha ngezantsi:

Mna _____ ndiyavuma ngokuzithandela ukuba umntwana wam/ endimnyamekelayo athabathe inxaxheba kwesisifundo sikhankanywe apha ngentla. Le nkcazeleo ingentla iye yacaciswa kum ngolwimi endiluqondayo. Loo ngcaciso iye yenziwa nguCaroline Mpofu. Andinyanzelwanga ukuba ndivumele umntwana wam/endimnyamekelayo athabathe inxaxheba kwesisifundo., yaye ndingamorphomxisa nanini na ndifuna ukwenjenjalo. Ndiyazi futhi ukuba igama lakhe alisayi kuze libhengezwe kuye nabani na ongeyonxalenye yesisifundo, kwakhona inkcazelo ayidlulisileyo iyakugcinwa iyimfihlo. Ndiyazi futhi ukuba angafumana iingenelo ezithile ngokuthatha kwakhe inxaxheba, kwaye akusikho nomngcipheko othile. Ukuba umntwana wam/endimnyamekelayo udinga inkcazelo ethe vetshe, ukhona Umntu oyakuzenza afumaneke aze amncede. Ndiye ndanikwa ithuba lokuba ndibuze imibuzo yaye loo mibuzo iye yaphendulwa ngendlela eye yandonelisa.

Umhla

Utyobelo

Umhla

Utyobelo (umamkeli wale form)

APPENDIX C: SEMI-STRUCTURED INTERVIEW GUIDE

Please tell me

- What are your perceptions about self-disclosing your status to others? (such as friends, teachers, relatives etc)
- When would you feel comfortable to self-disclose your HIV status to others?
- What are your perceptions regarding not self-disclosing your status?
- What are your perceptions on what would happen if you self-disclose your status to others?
- What are your opinions on what would happen if you do not self-disclose your status to others?
- If you are to self-disclose your status, what would influence your choices on who to self-disclose to and whom not to self-disclose to?

APPENDIX D: TRANSCRIPT

Participant age	14
Sex	Female
Grade	7
Date	12/02/14
Time	15:45
Duration of interview	52 minutes

Perceptions:

Self-disclose to people who understand and who can be trusted

Fear of self-disclosure

Need for support

Educate people about supporting people living with HIV

	NWU:Caroline Mpofu	Research topic: Perceptions of adolescents regarding self-disclosure of their HIV status when perinatally infected.	Question: What are the perceptions of adolescents perinatally infected with HIV regarding self-disclosure of their HIV status? Aim: The purpose of this study will be to explore and describe the perceptions of adolescents perinatally infected with HIV regarding self-disclosure of their HIV status.
1	R	How are you, P3?	
	P3	Am good, Sisi.	
2	R	Great, make yourself comfortable. When you were having your lunch, I managed to go through your journal and made copies of pages you wrote something on as agreed. Thank you for taking your time to write and for making time to share your thoughts with me. Would you like to share with me what your thoughts are about self-disclosing your status? I	

		will also make reference to your journal, take notes and ask some questions as you share your thoughts with me. (pauses)	
	P3	Sisi, when I think about telling people my status, I feel I can only tell one friend from school, not my other 4 friends, because that friend is also living with HIV and she understands me.	T. 6.2.2 Self disclose to other peers living with HIV – microsystem.
3	R	Where is the friend from?	
	P3	She is from school.	
4	R	How did you know she is living with HIV?	
	P3	Her name is Chipso (<i>pseudo name</i>). We are in the same class, our teacher had left documents that asked pupils about their health on her desk open with Siphosethu's document on top which shows she has HIV and the whole class knew about it. One boy started teasing her and she was crying. I went to the girl to comfort her and then I told her I also lived with HIV, she must not worry about what people say , so we became friends.- T: 2.10	
5	R	I see in journal you mentioned her on your first page and put stars and a heart and a flower. Is there a reason why you put the stars?	
	P3	Yes, I think she is a star, because she stayed strong even though the whole class knows about her situation. I even advised her to come and register at this clinic and she came.	
6	R	Earlier on you mentioned that you do not think you will tell your other 4 friends. Is there a reason why you would not tell them?	
	P3	They may start asking me a lot of questions and tell the whole school.	Talked about (gossiping)-interaction of microsystem: T. 5.5.19; t.5.9.43; T.6.2.4;

			T.4.2.3; T.9.3.12; T.9.4.19; T.8.3.15; T.8.4.19; T.10.3.17.
7	R	What questions do you think they will ask you?	
	P3	Like how I got HIV and they may think I have a boyfriend who infected me, or that I am being promiscuous.	Macrosystem – ideologies of society on HIV – think HIV is due to promiscuous behaviour
8	R	How will that make you feel?	
	P3	I will feel bad, Sisi, because it pains, I did not choose to have HIV, they may also attach it to my mother and say bad things about my mother.	Attitudes about HIV- Macrosystem.
9	R	What kind of bad things?	
	P3	Some of them are staying close to my area and their mothers were friends with my mother. The mothers always say my mother died of AIDS because she was drinking alcohol and being promiscuous. I do not like it, it pains me. (sighs heavily)	Macrosystems, attitudes and beliefs about HIV.
10	R	What do you do if they say such kind of information about your mother?	
	P3	The other time, they were saying it to my granny and I told them they were wrong, but they said I was not there, I do not know anything. It makes me feel bad, It is not my fault or my mother's fault that I have HIV, they should not talk about it badly.	Experience of participant does not blame mother for perinatal infection
11	R	You mention that it pains you and makes you feel bad. How do you cope with that?	
	P3	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 in a bad way.	Wishes of participant

12	R	Tell me more about what you wrote in your journal.	
	P3	I think at school it is important to tell only 1 teacher, so that if anything happens, the teacher can call my granny, especially when I am not feeling well. She will be able to understand when I do not attend school because of clinic visits, but sometimes I worry if she would tell other teachers or pupils. What if the whole school knows?	Mesosystem in action – interaction of the school and the family. Talked about-fear
13	R	What do you think would happen if the other teachers know?	
	P3	I will not trust my teacher anymore. The other teachers will start treating me like an egg because they will be feeling sorry for me and the other kids at the school will know that I am HIV. I just want to be treated like any other child. I want to be happy.	
14	R	What do you think would happen if other kids at school know?	
	P3	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 make her fat”. They will start telling others and gossiping about me. I do not like that, it is embarrassing.	Laughing: T.1.2.3; T.4.3.10; T.4.4.13; T.5.3.9; T.6.3.14; T.7.3.6; T.8.5.28; T.9.3.14, T.10.2.9 Macrosystem – ideologies of society – HIV linked to losing weight and sick
15	R	Has that ever happened to you?	
	P3	No, Sisi, but to this boy who had TB at school, they laughed at him and teased him when he lost weight. He ended up dropping out of school.	Experience of others
16	R	I see on the 4 th page you mention that you do not think you will tell your other family. Which other family is this?	
	P3	My father’s family, they do not care	

		about me, If I ask something from them, they do not give me.	
17	R	What do you think would happen if you self-disclose to them?	
	P3	They will tell their children and their children will never want to talk to me, they will think I will also give them HIV. They will just say “hai shame P3.” and not do anything. My father’s family is not understanding like my mother’s family.	Rejection – T.1.4.13; T.4.2.4-5 not want to play with me; T. T.6.3.11; T.10.3.10;
18	R	Has this ever happened to you?	
	P3	No, Sisi, but I see it in books about HIV at school, were they put pictures and stories of family and friends not wanting to talk to people living with HIV.	Macrosystems – ideologies, how society think and acts towards people living with HIV.
19	R	What do you mean when you say your mother’s family is understanding?	
	P3	Look at my granny and aunt, Sisi, she loves and supports me. I also love them and trust them. They make me happy and treat me like any normal child.	Support – within microsystem
20	R	What would influence your choice on whom to self-disclose to and whom not to self-disclose to?	
	P3	I will only tell people I trust and love, like my mother’s family, my teacher, my close friends, Ubuntu counsellors and the support group kids because they understand me. With the support group kids, we are like a close family, we feel the same way and we trust each other, we do not laugh at each other but we laugh together. (smiles)	Self disclose to people one trusts – mesosystem Microsystem – peers living with HIV.
21	R	You also mention Ubuntu counsellors, why do you trust them?	
	P3	Because they have helped me and	Counsellors – mesosystem

		they always ask me what my needs are, they do not feel sorry for me but they support me to learn more about HIV and how to look after myself to be healthy and live longer.	Experience with counsellors
22	R	I see the last page in your journal you wrote that you want more support from Ubuntu. What kind of support is this?	
	P3	I want to have more knowledge about HIV through the support groups, so that as I grow older, I can be more confident to even tell other people about HIV and how I want to be treated.	Support groups- source of support Macrosystem – belief
23	R	Is there anything else you would like to share with me?	
	P3	Sisi, I just feel happy if I do not tell people for now. I feel normal; the people who do not know treat me normal.	Feel happy – for not self-disclosing
24	R	What about the people who know?	
	P3	Those that are not my mother's family or Ubuntu people, feel sorry for me when they look at me especially people who knew my mother in the area we live and I do not like it. (PAUSES)	
25	R	Thank you for sharing all the information you shared with me. You can keep your journal if you want. Will it be Ok if I contact you again to understand more about what you think regarding self-disclosing your status?	
	P3	Yes, Sisi, you can call me on my granny's number.	
		Participant observation: P3's interview was set for 14:30 but she arrived at 15:25pm. She was carrying a heavy bag of books looking exhausted before she had her lunch.	

		She ate her lunch and then I took her to the counselling room where she looked energetic. First she took off her bag and sat on the couch. I asked for her journal whilst she was having lunch for 15 minutes. I went through it and photocopied were she had written. Participant spoke slowly but had a lot to share hence the interview was very long. I could tell she was tired at the end as she sat skewed on the couch leaning with one hand on the cushion and the fist on her forehead. Self-reflective notes: I was prepared for P3 to come at 14:30, but when she was late, I got a bit nervous that she would not come. I was happy when she arrived even though later. During the interview, I felt participant was saying a lot of incoherent information which made it difficult for me to formulate follow-up questions. I tried my best to stay with the question. I realised from the previous interview it helps to ask to read the participant's journal and make a copy whilst participant is eating, rather than ask to make a copy later. It helps to read at the same time with the participant. When participant says a lot without pausing, it made it difficult for me to clarify all the information she says because clarifying about one issue will lead to more issues that makes it difficult to go back to other issues I would have thought needed clarity.	
		Themes identified: - Being laughed at by other peers if HIV status is known. Same as P1, P2 - Does not want to be felt sorry for – same as P2 - Need to disclose to people	

		who will understand - same as P1 - Need to disclose to other children living with HIV – same as P1, P2 - Need for support group – P1, P2, P3 - not to self-disclose to paternal family – P2 and P3. (both raised by maternal family and their biological mothers are deceased) - Self-disclose to teacher for support – same as P1	
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2nd Interview lasted 20 minutes

26	R	Thank you, P3, for agreeing to meet with me again. How are you today? (P3 sits opposite me in the counselling room and she is leaning on the couch, relaxed.)	
	P3	I am fine, Sisi.	
27	R	Today, like I mentioned on the phone, I just want to verify a few more questions from our previous interview. You mentioned in the previous interview that you will only disclose your status when you are older but you will not disclose to any of your peers because they will laugh at you. What do you think makes people laugh?	
	P3	Bahleka ngamehlo (they laugh with their eyes) bathi ubani bani uphila ngalento (so and so is living with HIV).	Type
28	R	What do you think can make them stop laughing?	
	P3	You can sit down with them and tell them that you are not the only one living with HIV. We can sit down as peers and talk about it. At school we are taught about HIV, but mainly on how it is spread.	Solution to negative perceptions on self-disclosure within the microsystem
29	R	If other kids are educated at school, how does it help?	
	P3	They do not stop laughing, Sisi, because they are only taught about how HIV is spread, so when they see someone with HIV they laugh thinking the person was naughty and was sleeping around. They do not know that there are some people who were born with HIV.	Beliefs of society on HIV – macrosystem

30	R	How will knowing that some children were born with HIV help?	
	P3	They may stop laughing knowing that it is not my fault that I have HIV.	Does not blame herself, is fully aware of perinatal infection and thinks it is not her fault – T.5.9.40.
31	R	You mentioned that people will never stop laughing. How do you think the person being laughed at feels?	
	P3	Njani sisi (How sisi)	
32	R	If people were laughing at you, how would you react?	
	P3	I may feel bad at first and will tell them to stop, but if they do not stop, I will ignore them until they are tired of laughing at me.	Resilience mechanism
33	R	Ok, how does your granny feel about you self-disclosing or not self-disclosing your status?	
	P3	She told me it is my choice, I can choose to tell my father's family or not, or friends or not.	
34	R	You also mentioned you do not want people to feel sorry for you if you self-disclose? What makes you feel like that?	
	P3	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, maybe someone has high blood pressure, I do not feel sorry for them.	Type of perception on self-image as an adolescent
35	R	Has it ever happened to you?	
	P3	No, Sisi, but if it happens I will tell the people not to feel sorry for me.	Coping mechanism
36	R	You also mentioned you will disclose to someone who understands you. What does it mean to be understood?	
	P3	Someone knowing what type of food I should eat, when I must take my medication and how many times and someone I can talk to about my clinic visits, like my support group friends.	Support needed – within the microsystem
37	R	Ok, is there anything else you would like to share with me?	
	P3	Other kids must be taught about HIV and get tested, otherwise akukonto (there is nothing else).	
38	R	Thanks, P3, for sharing all this information with me. Is it Ok if I contact you to share results of the study when I get them?	
	P3	It is fine, Sisi.	
	R	Participant observation: P3 was very comfortable and full of energy. She sat on the opposite couch and was leaning forward showing interest in the interview. Self-reflective notes: I was hoping to elicit more information from participant. Participant shared the same information, she had shared previously and the interview was short. I feel like the second interview is more like a confirmation of what participant had said. I wanted the participant to do an eco-map, but realised I	

		would be leading the participant hence I did not do eco-maps with all participants. Themes identified: Same as in the previous interview. It is just interesting to know that participant is fully aware that she was perinatally infected and feels it is better that way. Same with P5, P4.	
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APPENDIX E: DATA IN CD FORMAT

APPENDIX F: AUTHOR GUIDELINES (SOCIAL WORK/ MAATSKAPLIKE WERK)

The Journal publishes articles, book reviews and commentary on articles already published from any field of social work.

1. Contributions may be written in English or Afrikaans.
2. All articles should include an abstract in English of not more than 100 words.
3. All contributions will be critically reviewed by at least two referees on whose advice contributions will be accepted or rejected by the editorial committee.
4. All refereeing is strictly confidential (double blind peer-review).
5. Manuscripts may be returned to the authors if extensive revision is required or if the style or presentation does not conform to the Journal practice.
6. Articles of fewer than 2 000 words or more than 10 000 words are normally not considered for publication.
7. Manuscripts should be typed in 12 pt Times Roman double-spaced on A4 paper size.
8. Use the Harvard system for references.
9. Short references in the text: When word-for-word quotations, facts or arguments from other sources are cited, the surname(s) of the author(s), year of publication and page number(s) must appear in parenthesis in the text, e.g. "... (Berger, 1967:12).
10. More details about sources referred to in the text should appear at the end of the manuscript under the caption "References".
11. The sources must be arranged alphabetically according to the surnames of the authors.
12. Note the use of capitals and punctuation marks in the following examples.

TWO AUTHORS: SHEAFOR, B.W. & JENKINS, L.E. 1982. Quality field instruction in social work. Program Development and Maintenance. New York: Longman.

COLLECTION: MIDDLEMAN, R.R. & RHODES, G.B. (eds) 1985. **Competent supervision, making imaginative judgements**. New Jersey: Prentice-Hall.

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APPENDIX G: ETHICAL APPROVAL LETTER