AN EXPLORATION OF THE PSYCHOLOGICAL EFFECTS OF DISCLOSURE OF AN HIV POSITIVE STATUS TO CHILDREN ON ANTIRETROVIRAL TREATMENT AT DR GEORGE MUKHARI ACADEMIC HOSPITAL

by

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DECLARATION

I, Lizzy Mmathapelo Makua, student number (201117273) hereby declare that the
dissertation hereby submitted to the Sefako Makgatho Health Sciences University, for the
degree of Master of Science in Clinical Psychology has not been submitted by me for a
degree at this or any other university, that it is my work in design and execution, and that all
material contained herein has been duly acknowledged.

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ABSTRACT

The purpose of this study was to explore the psychological effects of disclosure of a positive Human Immunodeficiency Virus (HIV) status to children who are on antiretroviral therapy (ART). The study was qualitative in approach and used a transcendental phenomenological method. Due to the topic of the research study, purposive sampling was used. A semi-structured interview guideline developed by the researcher was used to collect data from the participants. In total, nineteen participants (19), nine males (9) and ten females (10) were interviewed for the study. The participants age ranged between 10 years to 16 years. Content analysis of the responses of the participants was done through Interpretative Phenomenological Analysis (IPA). Trustworthiness and dependability were achieved through triangulation of the results. The results of this study indicate that parents and caregivers find it difficult to tell the children that they (the children) were infected with HIV at birth and that they are currently HIV positive. Fear of stigma, judgement and rejection were cited as reasons for not disclosing. Furthermore, the findings revealed that disclosure does not have overall negative psychological effects on the infected children.

KEY WORDS: antiretroviral therapy, caregivers, child development, disclosure, HIV, phenomenology, South Africa
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CHAPTER 1: INTRODUCTION

1.1. Background

In today’s society, both children and parents experience diverse challenges on a daily basis. Society expects parents to be responsible for their children in all respects and to take into account their physical, emotional and mental well-being. In South Africa, one of the greater challenges currently faced by parents or caregivers is that of dealing with the issue of disclosing a positive Human Immunodeficiency Virus (HIV) status to children who were infected by their mothers at birth. There are various factors for the parents to consider before disclosing, such as the age of a child, socio-economic status, culture, fear of stigma and the impact of disclosure of an HIV positive status on the child. According to Family Health International [FHI] (2007), disclosure may have various implications for the child, such as his or her adherence to medication, behavioural and emotional difficulties.

This research aimed to focus specifically on the psychological effects of disclosure of a positive HIV status on children who are HIV positive. Children are especially vulnerable to the impact of HIV infection both physically and psychologically.

It is imperative to explore the challenges that these children face, their coping mechanisms, their behavioural and emotional experiences (FHI, 2007). Parents are expected to have integrity and practice ethical parenting (Baumrind & Thomson, 2002). These latter researchers further state: “ethical parenting above all is responsible caregiving, requiring of parents enduring investment and commitment throughout their children’s long period of dependency” (p.3).
Paediatric HIV disclosure is a multi-layered challenge that requires consideration and sensitivity. Some children inadvertently discover their HIV status, which usually leads to adverse impact (American Academy of Paediatrics, 1999). HIV positive children are surviving past adolescence age, and participate in activities that any other pubescent youth may, such as dating and engaging in sex. It becomes vital that these children be aware of their HIV status as withholding this information could potentially bear detrimental consequences, especially in relation to risky sexual behavioural practices (American Academy of Paediatrics, 1999). The significance of this research is therefore to be able to understand the psychological impact of disclosure on the children, from their own perspectives, and to disseminate the findings of the study to assist parents and caregivers to deal with disclosure to children holistically.

1.2. Motivation for the study

Paediatric HIV disclosure is complex and numerous reasons can perpetuate its complexity. According to International Centre for AIDS Care and Treatment Programs (ICAP, 1999), some of the issues can include but are not limited to the following:

- children having several different caregivers at a time that care for them
- stigma and taboos associated with the illness
- parents’ belief that children would not understand prejudice
- parents’ fear of rejection by their children
- guilt about the transmission
- parents’ perceptions that pertain to their child’s ability to comprehend their illness

Disclosure can be empowering as it can assist the child to not only become autonomous and be responsible for his or her own health but to understand the severity of his or her illness and to aid
their mental well-being. Effective communication is required when disclosing a child’s status to them in order to convey the gravity of their illness to them and to minimise the risk of misunderstandings (Kekesi, 2009).

1.3. Aim of the study

The aim of the study is to explore the psychological effects of disclosure of an HIV positive status on children who are on Antiretroviral (ARVs) treatment at Dr George Mukhari Academic hospital in Ga-Rankuwa Township.

1.4. Objectives of the study

The study objectives are firstly, to investigate the psychological effects (i.e. coping styles, emotional reactions, benefits of disclosure or lack thereof) of an HIV positive status disclosure by parents or caregivers to children who are on ARV treatment at Dr George Mukhari Academic hospital in Pretoria. Secondly, to investigate retrospectively the thoughts and feelings of the children at the time when their HIV status was disclosed to them. Thirdly, to investigate in which contexts (e.g. school, home, church) do they (children) experience unpleasant emotions and thoughts and the reasons thereof. Finally, to explore challenges that these children face since they were diagnosed with HIV.

1.5. Research Question

What are the psychological effects of disclosure on children who are HIV positive and are on ARV treatment at Dr George Mukhari Academic hospital in Ga-Rankuwa Township, Pretoria?
1.6. Dissertation outline

Chapter 1, provides a contextual background to the study.

Chapter 2 explores the literature on child development theories, including Piaget’s cognitive developmental theory, Bowlby’s attachment theory, behavioural and emotional problems in children with HIV, disclosure and the impact of HIV and stigma.

Chapter 3, discusses the research method that was followed in this study. The basic tenets of the interpretive qualitative approach are also presented including Smith’s Interpretative Phenomenological Analysis (IPA), data collection, analysis, ethical considerations and training of research assistants.

The results of this study are presented in Chapter 4.

Chapter 5 provides a discussion of the results of the study. A linkage is found between themes, the participants’ narratives and literature on HIV and disclosure or lack thereof. The strengths and limitations, recommendations and the implications these have for the study are also discussed.
CHAPTER TWO: LITERATURE REVIEW

2.1. Introduction

In this chapter, child development theories are discussed with the emphasis on Piaget’s cognitive developmental theory, Erickson’s psychosocial developmental theory, and Bowlby’s attachment theory. The literature pertaining to paediatric HIV is explored particularly, the overall impact of the illness on infected children across various social contexts such as the school and the community. The effects of the retroviral disease on the physical, psychosocial and neurological development of children are also discussed. Emphasis is placed on the psychological effects of the HIV disclosure on children. The thoughts and feelings of infected children about their illness, coping strategies that they employ and the challenges they encounter. Furthermore, disclosure to children as well as issues that may hinder disclosure to them will be reviewed. The psychological impact of the stigma arising from disclosure will also be discussed. The chapter will conclude with the impact of HIV on the brain and language development.

2.2. Paediatric HIV

In 2010, the World Health Organisation (WHO) published a bulletin in which it stated that the leading cause of death in the Southern African region was HIV-related. According to WHO (2010), the prevalence rate of HIV in Sub Saharan Africa (SSA) is the highest in the world with almost 80% of all HIV-1 positive children in the world living in this region (UNAIDS, 2006).
African countries are usually classified as the third world, which means that much needed services related to the needs of those infected with HIV are likely to be scarce and/or poor. There also exists a great possibility of mother-to-child (MTCT) transmission if there is no intervention available or if the intervention is defective or of poor quality (WHO, 2010). Children infected by their mothers have special needs in terms of health care, but it can be difficult for them to receive the required services in this region (WHO, 2010). Perinatal infection is the most common cause or route of transmission among children. Although the rates of mother to child infections have decreased, the infections that still occur do so in utero, at birth or during breast-feeding (UNAIDS, 2006). HIV positive mothers who mix-feed their babies- that is to feed them formula milk as well as breast milk-instead of only using a single method during the first six months of a child’s life place a higher risk of infection on their neonates through this practice (Abubakar, Van Baar, Van de Vijver, Holding, & Newton, 2008).

2.3. Theories of development

Slater and Bremner (2003), define human development as “the discipline that attempts to describe and explain the changes that occur over time in the thought, behaviour, reasoning and functioning of a person due to biological, individual and environmental influences” (p. 4). Taking this definition into cognisance, various viewpoints are elaborated on as an attempt to explicate human development, as well as the implications thereof in relation to each viewpoint. There is a broad spectrum of theories aimed at explaining the phenomenon of human development and thus some theories may contradict each other, as human development is a complex phenomenon.
2.3.1. Early human development theories

There are various theories that are used to explicate the different stages that children go through, in relation to development and maturity. Craig (1996) referred to three principal domains of development namely the physical, cognitive and psychosocial domain. The physical domain refers to features such as height, weight, sensory skills, motor skills as well as brain structure. The cognitive domain refers to mental capabilities, thought organisation and mental activities. The psychosocial domain refers to personality characteristics as well as social skills (Craig, 1996).

Various theoretical frameworks and principles in developmental psychology are imperative to understanding human development. These are briefly discussed below:

2.3.1.1. Stability versus change

Earlier psychologists such as Freud, Jung and Piaget (Cavanaugh & Blanchard-Fields, 2011) believed that personality is formed during the formative childhood years and that it remained unchanged for the remainder of an individual’s life. Modern psychology differs from this argument and states that children do not merely absorb and turn out to be products of their environments, but that they also contribute to what happens to them (Hook, Watts & Cockcroft2002).

2.3.1.2. Life-span perspective

This perspective not only focuses on the first few years of a person’s life, but also rather examines their development throughout their whole life, from birth to death. The thinking behind this perspective is that people do not only develop during their formative years but that development is a life-long process. This aspect also alludes to the fact that development is multidimensional and thus other various factors such as context-are taken into account. This approach refutes the argument
that behaviour is fixed and thus cannot be altered. There are seven basic characteristics within this approach that should be considered concerning human development. Hook et al., (2002, p. 16-18) lists them as follows:

- Development is lifelong: growth and development occur across the full lifespan
- Development is multidimensional: biological, socio-emotional and cognitive aspects may overlap
- Development is multidirectional: some facets of development may continue to thrive while others may decline, for example, mental agility
- Development is plastic: development may be influenced by a person’s context and by certain conditions which either aid or hinder any further development
- Development is embedded in history: historical contexts of people impacts on their development
- Development is multidisciplinary: different professionals study a phenomenon but from different perspectives, for example, sociologists, psychologists, neurologists could all study human development, but from varying viewpoints.
- Development is contextual: the individual’s environment can affect the extent to which he or she can develop.
2.3.1.3. Nature versus nurture

Another important aspect in human developmental psychology is the question of nature versus nurture, which plays a major role in terms of what will affect a person in various ways. Nature refers to the biological factors such as genetics, neurological and hormonal aspects, while nurture refers to social factors such as parental support and environmental factors, for example, socio-economic status (Hook et al., 2002). The two factors are constantly in interaction and they affect individuals differently. It is thus not possible to predict how different individuals may react in particular situations or environments. The concepts are not equally applicable or important in terms of some stages of human development. Notwithstanding, some universal behaviours are guided by genetics, for example, when a child learns to walk, he or she has reached a certain point of maturity pertinent to that milestone. Other universal behaviours are perceived as instinctive, for example, a new-born baby gasping for air while others may transcend these categories, for example, babies imitating adult facial expressions. This phenomenon alludes to the fact that there are number of factors that influence human development and some that cannot be quantified or oversimplified (Hook et al., 2002).
2.3.1.4. Continuity versus discontinuity

There is no consensus about the course that human development follows. Hook et al., (2002) state that some human developmental theories see development as a slow and gradual process in which humans accrue knowledge and understanding in order to progress.

Others accept as true that development is a process that has genetic basis as evidenced by particular qualitative stages that are applicable at certain ages (Hook et al., 2002). In light of these disagreements relating to development, development can be either incessant or intermittent. This also brings to the fore the issue of whether development is qualitative (kind or structure unique to the individual) or quantitative (changes in degree or amount). Hook et al., (2002) state that there is a difference in viewpoints between how a continuity theorist and discontinuity theorist view development.

2.3.1.5. Ontogeny versus phylogeny

Hook et al., (2002), define ontogeny as “application of developmental psychology to the understanding of the individual development of the specific child or person” (p. 21). Phylogeny is defined as “application of developmental psychology to the understanding of a wider group of people, or ‘species’ development” (Hook et al., 2002, p. 21). In terms of human development, it is essential when looking at behaviour to do so on these two levels to be able to generalise behaviour and appreciate individual uniqueness.
2.3.1.6. Critical periods

This refers to “a specific time during development when a given event has its greatest impact” (Hook et al., 2002, p.21). This links well with the term readiness which is defined by Hook et al., (2002) as “the point at which an individual can be said to have matured sufficiently to benefit from a particular learning experience” (p.22). This therefore implies that children may be able to learn and understand certain things at various ages. This does not mean that all children move through developmental milestones at the same time in that particular age.

2.3.1.7. Normative and non-normative influences

A normative event is one that generally occurs at a particular human developmental stage within that particular group of people. Normative events include age-graded influences that occur to most people of a particular age, for example, puberty and history-graded influences that occur to most people in a specific culture and at which they experience it at the same time, for example, epidemics and changing attitudes towards sexuality. Conversely, non-normative influences are random or uncommon events that can result in substantial impact on the individual (Hook et al., 2002). Non-normative events can be favourable such as winning a lottery or gaining promotion or unfavourable, for example, being diagnosed with cancer or involvement in an accident (Cavanaugh & Blanchard-Fields, 2011).
2.3.2. Organismic and mechanistic views

Lerner (1986, in Slater & Bremner, 2003) mentions two dominating discourses in developmental psychology, namely organismic and mechanistic views. Briefly, the organismic worldview postulates that a person is a biological being that is not passive in his or her existence, but rather shapes his or her own development through interacting with the environment (Lerner, 1986, in Slater & Bremner, 2003). Through experience, the organism matures and develops novel ways through which to process environmental information. This may be in the form of internal psychological structures (Slater & Bremner, 2003). Through this process, the model alludes to the idea that an organism moves through various stages of development. These stages are unique to an organism, are qualitative in nature, and are distinct at various stages of that particular organism. These structures become integrated and are what makes that organism unique. The stages are progressive and should become more advanced through the successive completion of each. Piaget would be one theorist in this category as he also used stages in describing and explaining development (Slater & Bremner, 2003). The mechanistic worldview likens human functioning to that of machines in that humans are passive until they are influenced or stimulated by their environment.

Theorists who employ this view are of the opinion that humans develop certain behaviours that would have been brought about or shaped by their environment. Developmental theorists utilising this approach study direct link between the increase or decrease of behaviour and the environment. Slater and Bremner (2003) refer to two methods of studying age-related changes of human development namely; cross sectional designs and longitudinal designs. The former is a method whereby people of different ages are assessed simultaneously.
The latter entails a process whereby people are assessed on more than one occasion in order to observe changes within them, to be able to make comparisons of the person in relation to others, within the same study. There are however, limitations and strengths for both methods. A major advantage of the cross sectional design is that it saves time. The disadvantage of the design is that there may be confounding variables that may influence the results of the study. In order to collect meaningful data over a certain period, a longitudinal design should be used. The disadvantage is that it may be costly and individuals may drop out of the study and that could influence the outcome of the study (Slater & Bremner, 2003). Considering the wealth and complexity of human development, the next section briefly explores a few newer theories pertinent to child development specifically for this study. The areas of development to be explored are motor development, cognitive development and social development.

2.3.3. Motor development

Children transition from milestone to milestone according this view. With each milestone that is successfully accomplished, a child is expected to have mastered certain tasks like crawling, standing and walking, without parental assistance, in order to progress towards independence (Slater & Bremner, 2003). There are two types of motor developmental skills that could be used to assess infants’ development and these are gross and fine motor skills. It is during the period after birth that infants begin to exhibit the vital signs of these abilities in support of normal development. The developmental milestones should follow a particular sequence and are tools that an infant requires in order to survive. These include crying, lifting of the head, rolling, grasping, crawling, and breathing (Slater & Bremner, 2003).
Although an infant may undergo rapid changes, these changes are measurable against normalcy, in other words, they can be utilised as markers and make it possible to recognise challenges within an infant’s growth, should there be any deviation from their peers. The phenomenon that is applicable here is known as **maturation**. It is possible that some infants can master certain skills earlier than their peers, or could lag behind their peers. Gessel (1940, in Slater and Bremner, 2003) theorised that motor development occurred from the general to specific in two ways, namely cephalocaudal trend and the proxidistal trend. Concerning the former, he postulated that an infant gains control of their movements sequentially from the head, followed by the trunk, arm and lastly, the legs. In the latter trend, he postulated that motor control occurred from the centre of the body- the head, trunk, and pelvis fully controlled before the elbows, arms, wrist, knees and ankles. McGraw (1945, in Slater & Bremner, 2003) questioned this view as she discovered that provided with training, infants were able to achieve milestones at an accelerated rate.

She hypothesised that maturation on its own could not be singled out as the only determinant of motor development (Slater & Bremner, 2003). This contradiction sparked the emergence of a theory known as the dynamic systems theory, which emphasised learning as an important factor in children developing their own skills. It is therefore just to review the maturation theory as it suggests that a child is passive in relation to their environment. The dynamic systems theory accommodates for children learning to acquire novel skills from the time they first attempt that skill to the point of successful execution without much toil (Slater & Bremner, 2003).
2.3.4. **Cognitive development**

Craig (1996) referred to three principal domains of development namely the physical, cognitive and psychosocial domain. The cognitive domain refers to mental capabilities, thought organisation and mental activities. Hook et al., (2002) define cognitive development as “the acquisition, development, and refinement of our mental abilities” (p.175). The definition also encompasses how information is organised, manipulated and used by the individual. These processes change during the course of different stages of human development through learning and maturation. The ability of an individual to receive, organise, process and change information age-appropriately, indicates maturation. Piaget’s cognitive developmental theory will be briefly discussed below to ascertain how cognition shapes development.

2.3.5. **Piaget’s cognitive developmental theory**

Described as an articulate student, Piaget received honorary degrees from various universities for his contribution to various fields such as biology, philosophy but most importantly, psychology (Wadsworth, 1989). Piaget, a developmental psychologist and constructivist theorist, worked tirelessly researching various aspects that were related to cognitive development of children. He became increasingly interested in analysing and examining processes related to children when he worked in Binet’s grade school in 1919 (Wadsworth, 1989). Piaget’s theory postulates that development shows children’s efforts to comprehend the world through information processing. The theory consists of four developmental stages that children go through.
The stages are as follows:

**Stage 1: Sensory motor**

The first stage occurs from birth to two years and is called sensorimotor stage. During this stage, children’s thought is primarily based on action. This means that their actions are not planned or deliberate but serve an automatic function (Bukatko & Daehler, 2001). This means that during this stage, infants and toddlers acquire knowledge through sensory experiences and by manipulating objects (Slater & Bremner, 2003).

**Stage 2: Preoperational**

The second stage is the preoperational stage and occurs from two years to seven years. When the child is at this stage, their thought processes become symbolic and a child can attach meaning to a word or object (Bukatko & Daehler, 2001). During this stage, kids learn through pretend play but still struggle with logic and taking the point of view of other people (Slater & Bremner, 2003).

**Stage 3: Concrete operational**

The third stage is the concrete operational stage and takes place approximately from age seven to eleven years. During this stage, children are able to reason and understand others around them, as their thought processes become more logical (Bukatko & Daehler, 2001). Children at this point begin to think more logically, but their thinking can also be very rigid. They tend to struggle with abstract and hypothetical concepts (Slater & Bremner, 2003).
Stage 4: Formal Operational

The final stage is the formal operational stage and takes place from age eleven and beyond. During this stage, children can think more abstractly and logically. Piaget’s theory explains that children learn new information and store it for future use through processes called accommodation and assimilation (Bukatko & Daehler, 2001). This stage involves an increase in logical thinking, the ability to use deductive reasoning, and an understanding of abstract ideas (Slater & Bremner, 2003). According to the final stage, children incorporate new and existing information in order for them to make sense of their environment. This suggests that Piaget did not view these changes or stages in a quantitative manner but in a qualitative way.

This means that there is a qualitative change in how children think as they gradually proceed through these four stages. For example, when a child is seven years of age, he or she does not simply have more information about the world than he or she did at an earlier age; but that there is a fundamental change in how he or she thinks about the world. There are four concepts that Piaget refers to in order to elaborate on cognitive development namely schema, assimilation, accommodation and equilibration.

They will be briefly discussed below:

- Schema

These are hypothetical or unobservable structures that Piaget believed every human being possessed. Schemas are used to explain the stable responses to stimuli, which are widely exhibited by human beings. The structures can be compared to bodily organs that have various functions within the body, such as the heart, lungs, eyes and so forth.
These structures can also be likened to book catalogues, which organise or categorise incoming sensory information in a particular manner and stored for later usage. This also enables the individual to differentiate information or stimuli. The older they grow, the more refined their schemata will be, thus an increase in the capacity to differentiate and generalise information or stimulus. This process is continuous (Wadsworth, 1989). According to Wadsworth (1989) schema or schemata are defined as “intellectual structures that organise events as they are perceived by the organism and classified into groups according to common characteristics. They are repeatable psychological events, in a sense that a child will repeatedly classify stimuli in a consistent manner” (p. 11).

• Assimilation

Wadsworth (1989), defines assimilation as “the cognitive process by which a person integrates new perceptual, motor or conceptual matter into existing schemata or patterns of behaviour (p. 13)”. Assimilation is a process, which assists an individual to organise information from their environment so that it is more meaningful to them. This process is thus subjective in that experiences are incorporated and modified in line with individuals’ existing beliefs (Wadsworth, 1989).

• Accommodation

Wadsworth (1989), defined this concept as “the creation of new schemata or the modification of old schemata. Both actions result in a change in; or development of cognitive structures or schemata” (p. 14). This means that with new incoming information, an individual “makes space” for that new information and forms new experiences (Wadsworth, 1989).
• Equilibration

The balance between the process of assimilation and accommodation is known as equilibration. In order for an individual to recognise equally the similarities and differences in stimuli, equilibration is essential (Wadsworth, 1989). This translates to the fact that in order to adapt behaviour accordingly, there must be a balance between accommodation and assimilation, which translates to balancing how pre-existing knowledge will be used effectively to effect behavioural changes (Wadsworth, 1989).

2.3.6. Moral development and emotions

According to van Dyk (2012), children between the ages of five and ten are developmentally at the moral realism stage and are believed to become strict about abiding to rules. According to them (children), rules are to be obeyed but if they are broken, they believe that justice will applied in order to correct the wrongdoing. Children at this stage believe that what authority figures such as parents or caregivers say and do is the absolute truth and that they should not question this. From age 10 upwards, children reach the moral relativism phase where they realise that rules are not absolute and that they can be pliable. From 12 years, children can differentiate whether an action was fuelled by intent or by consequence (van Dyk, 2012). Children from this age are able to comprehensively express their feelings, for example fear.

Children in middle childhood become curious about their bodies as well their gender identity (van Dyk, 2012). These children can engage in some form of sexual play and it is important for parents and caregivers to handle this matter with sufficient sensitivity. If parents or caregivers react extremely negatively or harshly when it comes to children experimenting with sexual play, it could have long lasting negative effects on the children’s development (van Dyk, 2012). This can be in the
form of inner conflict where the developing child may think that sex is an abhorrent and unnatural behaviour.

2.3.7. Social development

This refers to “a process to attain maturity in a social relationship. It is a learning process to conform to group standards, morals and tradition. It is a process where new types of behaviours are learnt, change in interest occurs, and new friendships are developed” (http://www.studyleturenotes.com/).

2.3.7.1. Vygotsky’s contextual theory

Vygotsky’s contextual theory states that an individual’s immediate and distant environments influence each other and could have an influence on their development, stressing the fundamental role of social interaction in the development of cognition. Contrary to Piaget’s view that children’s development must pave the way for their learning, Vygotsky argued that social learning occurred prior to development. Vygotsky (1978) emphasized the role that parents play in transferring culture and developing skills for problem solving, to their children. He focused on culture shaping the child’s development rather than using universal stages of development and thus allowed for variance in terms of development. Vygotsky also emphasised that thought developed separately and prior to language, and that it is internalised and incorporated when a child is approximately at the age of three, to produce verbal thought (Louw & Louw, 2007).

He also stated that there are four elementary mental functions possessed by people, namely attention, perception, sensation and memory. He stated that through culture, children developed different strategies to function and to enhance these mental functions. Tools of intellectual adaptation used in this case are culture specific (Louw & Louw, 2007). In relation to HIV, this can affect many factors
surrounding the child’s illness, such as disclosure, stigma, communication styles, coping styles as well as scholastic performance. Vygotsky also argued that cognitive development stemmed from social interactions from guided learning within the zone of proximal development as children and their parents and or caregivers co-construct knowledge (Louw & Louw, 2007).

The term scaffolding refers to temporary assistance provided by a skilled individual to encourage, support and help another less skilled individual to complete a task. In essence, this is the expectation on parental figures to do for children. A child learns through the process of modelling (Louw & Louw, 2007). Vygotsky refers to the zone of proximal development, which is a concept that relates to the difference between what a child can achieve independently and what a child can achieve with guidance and encouragement from a skilled party, be it a caregiver or parent (Slater & Bremner, 2003). This theory fits well with children diagnosed with HIV in terms of how to become independent in caring for themselves and in adhering to their medication.

2.3.7.2. Vygotsky and language development

According to Vygotsky (1978), language plays two critical roles in cognitive development. Firstly, it is the main route through which adults convey information or communication to children and secondly, it is a powerful adaptation tool. There are three forms of language he discussed, namely, private, social and silent inner speech.

The first type of speech refers to self-directed speech, the second type refers to communication with others and the third one refers to self-directed speech which is not audible and thus self-regulating
Kozulin (1986) points out that Vygotsky, theorized that language and thought are interrelated. In his view, language and speech formed part of higher mental functions and thus they are seen as psychological tools. As much as language and thought are psychological tools that help in the development of higher mental functions, they too are higher mental functions.

Vygotsky’s research led him to believe that although speech and thought develop simultaneously under reciprocal influence, they are rooted in different areas. Vygotsky (in Kozulin, 1986), states “studying the development of thought and speech in childhood, we found that the process of their development depends not so much on the changes within these two functions, but rather on changes in the primary relations between them. Their relations and connections do not remain constant.” (p. xxxi). Vygotsky reviewed studies about primates and how they communicate. He discovered that they possess human-like intelligence and that their language was similar to that of humans, for example, phonetically. He realised that the difference between humans and these primates was the close reciprocity in the functioning of higher mental abilities, that is, speech and thought.

Kozulin (1986) states, “a child’s development knows preintellectual speech as well as non-verbal thought; only with the establishment of interfunctional systemic unity does thought become verbal, and speech become intellectual. (p. xxxii). The idea is that thought and speech become more developed over time but this depends on the reciprocity between other mental functions. Vygotsky also conducted experiments which tested concept formation in children. He discovered pseudoconceptual thinking, which Kozulin (1986) state is “a form of child reasoning that phenotypically coincides with reasoning in the adult and yet has a different, preconceptual nature.” (p. xxxiii). Vygotsky proposed that pairing children’s different life experiences with their developmental stages can help in determining their level of concept formation. He also referred to
two concepts, namely *scientific* (these occur in formal educational systems such as school) and *spontaneous* (the child’s reflections regarding his or her daily experiences (Kozulin, 1986).

Vygotsky explained that children process information based on their level of development and understanding and this has an influence on the level of assimilation they will achieve. In Kozulin (1986), Vygotsky states, “spontaneous concepts, in working their way “upward,” toward greater abstractness, clear a path for scientific concepts in their “downward” development toward greater concreteness.” (p. xxxiv). This led to Vygotsky’s idea that a child’s intellectual abilities can be evaluated by adults who assist them in various settings. The zone of proximal development alludes to this in that it suggests that a child’s “disorganised spontaneous concepts” align with the more adult ‘scientific’ reasoning, and thus balancing both concepts in development (Kozulin, 1986, p. xxxv). Internalization of the child-adult cooperation can enable a child to reason logically.

2.3.8. **Psychosocial development**

Erikson’s psychosocial theory indicates that there are eight developmental stages that human beings must complete (Louw & Louw, 2007). According to this theory, the child must successfully master each stage to become a well-adjusted adult. Focus will be on the first five stages, as only they are pertinent to this study.
Stage 1: Trust versus Mistrust (birth-18 months)

During this stage, children’s development of trust in the world is dependent on the quality of the relationship with their primary caregiver. Failure to complete this stage successfully may see children experiencing difficulty developing basic trust later in life. Conversely, successful completion of this stage means that children will be able to develop trust and hope in the future.

Stage 2: Autonomy versus shame and doubt (18 months- 3 years)

Upon successful completion of the previous stage, children should learn to become independent and be able to make their own decisions as they exercise their will. The extent to which parents or caregivers exert control, for example, rigidity plays a role in this period of development. Successful completion of this stage assists children to become autonomous, whereas failure to master this stage may result in shame and doubt for children.

Stage 3: Initiative versus guilt (3-5 years)

Children at this stage learn self-regulation, self-observation and self-punishment through the development of the superego. Failure to complete this stage successfully may lead to conflict between initiative and guilt. Successful completion of this stage assists children to develop a sense of purpose (Louw & Louw, 2007).

Stage 4: Industry versus inferiority (5-13 years)

When children reach this stage, they are expected to develop a sense of industry by generating new skills and to develop socially through working with others. When this stage is not successfully completed, children may develop a sense of inadequacy and inferiority. Successful completion assists children to achieve competence in terms of becoming independent and paving their own way.
through the subsequent life stages. They are supposed to be able to manoeuvre their environments and make decisions that pertain to their well-being (Louw & Louw, 2007).

*Stage 5: Identity versus identity confusion*

This stage occurs when children reach age 12 to 18 years. Puberty takes place and children start to experiment with their sexuality, question ideologies of others and their own as they are on a path of self-discovery. When this stage is successfully completed, identity is the resulting strength. If this stage is not successfully completed, the result is identity confusion. If this stage is not fulfilled developmental regression may occur and this may be exhibited through an individual who does not have stability at work, with sexual partners and an individual who lacks age-appropriate progress. Success in mastering this stage can be seen in the form of individuals becoming independent and relying on their own ideologies, and being able to trust others who offer them valuable guidance in life (Feist & Feist, 2006).

2.3.9. *Bronfenbrenner’s ecological systems theory*

Bronfenbrenner’s theory postulates that children’s development may be influenced by the multiple systems in which they operate, for example, school, home and church (Louw & Louw, 2007). The first system he referred to is *microsystem*, which is the closest to the child and this can be the child’s immediate family or caregivers and relatives. The relationships within this system provide interaction towards the child and away from the child- bi-directional influences or communication. This system has the strongest impact on the child (Paquette & Ryan, 2001). The second system
described is the *mesosystem* and this structure connects the child’s microsystem such as teachers and preachers and has an impact on the child as well as on the parents.

The third system is the *exosystem*, which is for example the parents’ place of employment, which does not have a direct impact on the child but on the parents’ and this may in turn produce consequences negative or positive for the child (Paquette & Ryan, 2001). The fourth system, is known as the *macrosystem*, is larger and consists of laws, values, beliefs, to mention but a few, and are the furthest away system from the child. This system can however influence the parents in terms of how they believe their children should be raised specifically with regard to HIV and impacts on disclosure. Some parents may be influenced by cultural beliefs not to disclose to their children that they have perinatal HIV (Paquette & Ryan, 2001). The last system is referred to as the *chronosystem*, and relates to time in relation to a child’s environment and can be internal or external. The example here can be timing of disclosing a child’s seropositive status to them (external) or developmental changes that that a child may be going through (internal) (Paquette & Ryan, 2001). This bioecological systems approach views a child’s biology as the main factor contributing towards their level of maturity. That is because Bronfenbrenner viewed the body as part of the microsystem.

The body is the life support system, the mobility system, and that with which we perceive and interact with the environment (Paquette & Ryan, 2001). This means that the child’s biological development and interactions with other contexts may influence their maturity. Several bodily characteristics can influence development in different ways. The first and broadest is the general health of the body. A person’s health is determined by how effectively the various subsystems in the body function and the influences of environmental factors. In addition, children can be of the same chronological age but be on different maturity levels physically, mentally, and biologically, due to
other factors from any one of the systems, for example, socioeconomic contexts affecting the ability to provide adequate sustenance, thus nutrition being affected (Paquette & Ryan, 2001). These theories discussed above explain child development from various points of departure and no one theory is preferred over others as they all provide imperative information in understanding how children make sense of their world (Louw & Louw, 2007).

It is consequently important to understand the children’s subjective emotional journeys in order to appreciate their contexts and strategies they use to cope with their daily challenges (ICAP, 1999).

2.4. Attachment theory

Holmes (1993) state “attachment is an overall term which refers to the state and quality of an individual’s attachments and these are divided into secure and insecure attachment” (p. 67). Bowlby’s (1969) attachment theory was influenced by Freud’s (1926) psychoanalytic drive theory, which linked the bond between a mother and child directly to libido, which is physical energy. Freud (1926) explained that the child’s need to suck on the mother’s breast could be viewed as an expression of sexual infantility. He further states that the infant experiences inner tension due to unsatisfied needs and that in order for the child to experience relief from this tension, the mother was of utter importance. According to Freud, when the mother meets the infant’s needs for nutrition, the infant in turn learns to love the mother as she has satisfied the nutritional needs and by so doing, also reduced the infant’s internal tension and anxiety caused by hunger.

Freud also allude to the fact that when the mother is absent (object loss), the infant may experience anxiety (Holmes, 1993). This theory led to further developments of attachment theories through
Kleinian *Objects relations theory*. This theory attributes both physiological and psychological linkage of an infant to his or her mother. This theory suggests that an infant attributes nourishment and satisfaction of needs to his or her mother, to a “good object.” The discomfort of the infant’s needs as well as the absence of his or her mother is prototyped as a “bad object.” This bad object also applies to the infant’s reactions to his or her needs not being met (Holmes, 1993). Bowlby (1969) states that attachment between a mother and an infant is a psychological bond. “Attachment is a primary motivational system with its own workings and interface with other motivational systems” (in Holmes, 1993, p. 63).

He drew from Neo-Darwinism concerning attachment, emphasising the importance of physical protection that a mother needs to provide for her infant in order to eliminate external threats (Holmes, 1993). Furthermore, he states that children from different contexts will form different attachments that are unique to their environments and parental dynamics. Thus, individuals can obtain psychological protection and functionality by developing secure attachment (Holmes, 1993).

### 2.4.1. Attachment and grief

Grief is the process that people go through when they have lost someone or something that was emotionally close to them (Cavanaugh & Blanchard-Fields, 2011). This can be loss of a loved one or an animal that a person was attached to. When people experience grief, they may experience intense emotions that may be overwhelming to deal with at first. Bowlby (1998) states that infants and children can and do experience grief when they lose their mothers or primary caregivers. He further explains that an infant may show signs of grief such as restlessness and continuous crying, which can indicate the child’s distress in seeking his or her mother. The child may experience a sense of
longing for his or her mother and may become apathetic and withdrawn should the mother continue being absent (Bowlby, 1969).

This can apply to children as young as 12 months old to 3 years old. Bowlby (1969) also states that children come out of these states of despair and that they seek new attachments with other caregivers that become responsible for them. The nature of the attachment will depend on the context and environment in which the child and caregiver find themselves (Bowlby, 1969). Bowlby (1969) draws from studies by Kliman, 1968; Becker and Margolin, 1967. to shed light on child mourning, although he referred to the limitations of those studies. One such limitation was that the sample size of the studies was small and thus results could not be generalised. Children from various contexts were selected for these studies.

The contexts or backgrounds from which the children came, were varied in relation to culture, race, religion and socio-economic status. Bowlby’s (1969) analysis of these studies revealed that when children were informed sufficiently and truthfully about the death of a parent, they were able to deal with their loss more effectively. Bowlby was of the opinion that if a child is made aware that all living creatures such as insects, birds and animals including human beings do come to pass at some point, they could be able to deal with death. Bowlby (1968) adds that if a child is made to understand the permanence of death and is allowed to partake in culturally appropriate funeral rites, it is likely that the child may be better equipped to deal with the death of a parent.

Parents and caregivers who are unable to deal with the intensity of their children’s feelings may be more inclined to discourage children from enquiring about the parent’s death. This may hinder the child’s ability to effectively deal with his or her loss. Bowlby (1998), states that because of the child’s continued yearning for his or her dead parent, some distressing situations may intensify this
yearning when the child realises that he or she can no longer enjoy to be comforted by his or her parent. Anger, anxiety, resentment, self-reproach, depression and a sense of guilt may be likely to surface when the child comes to this realisation.

2.5. The caregiver and the child

Becoming a parent comes with many challenges and one should be ready and mature enough to cope with these challenges. Punctuating from a systemic point of view, Minuchin (in Vorster, 2003) states, “families are rule-governed systems that could be best understood in their context and that a presenting complaint serves a function within the family” (p. 35). In terms of children who are HIV positive, this phenomenon becomes especially important as children may experience additional difficulties as compared to children who are not infected or whose parents are not infected with HIV. Caregivers are tasked with the mammoth responsibility of meeting basic needs of children. A caregiver refers to any person who assumes responsibility of a child. The caregiver can be the child’s biological or adoptive parents, legal guardian, grandparents, relative or any other person who is tasked with accountability pertaining to gratification of a child’s needs (Delport, 2009). Children may not be able to live with their parents for various reasons such as being orphaned, due to illness, abuse or neglect and parents’ employment, which may require the parent to migrate, and thus relatives or other members of the community may become liable for the child’s wellbeing. This is very much likely in the case of HIV/AIDS where children live with relatives after their parents succumb to death due to illness. Children may experience trauma after losing a parent and this may create a need for them to live with relatives, which may become comforting to be supported by other members of their family (Billing, Ehrle, Kortenkamp, 2002). This may create a sense of stability for
the children and help them to adapt to the major loss they are required to deal with. However, moving in with relatives can also prove to be difficult in that it poses hardships financially (Ehrle, Green & Clark, 2001).

Various studies (Ehrle et. al, 2001; Lee & George, 1999 cited in Billing et. al., 2002) show that children’s well-being can thus be affected by living with relatives. Studies based on the National Survey of America’s Families (NSAF) (1997 &1999) suggested that children from low income families and live with their relatives scored worse on some measures as compared to their counterparts who lived with their parents (Billing et. al, 2002). The survey took into account various factors that affect the child, such as household income and health factors. There has been evidence to support the notion that children who did not reside with their parents may exhibit behavioural and emotional problems. The study undertaken by Raina, O’Donnell, Schwellnus, Rosenbaum, King, Brehaut, Rusell, Swinton, King, Wong, Walter & Wood (2004) was based on children with Cerebral Palsy (CP), which is a central nervous system disorder. This disorder is chronic in nature as is the case with HIV/AIDS and thus children require continuous care and support.

Children with HIV can function within various contexts such as school, home and church like any other children, provided that they adhere to their treatment and undergo regular- usually monthly- check-ups with their health practitioners. Persons who assume the role of caregiver, especially in the case of orphaned children, must re-inspect and realign their priorities in order to cater for the child’s needs as part of their own adaptation. The role of caregiver may be strenuous at first, as the caregiver was most likely not prepared to assume this role (Raina et al., 2004). In terms of garnering support and distributing the caregiving responsibilities, family units may have become smaller, and members who are willing and available to care for children may be fewer than ideally required. This burden of
care and support is most prevalent among children whose parents have succumbed to the illness (Maman, et al., 2009). The demands placed on these family members may overwhelm the children’s relatives and at times may even lead to stigmatisation (Maman et al., 2009).

2.5.1. Behavioural problems in children with HIV

There has been evidence to support the notion that children who did not reside with their parents may exhibit behavioural and emotional problems. According to these studies, it is more likely for teenagers than younger children to exhibit these problems, especially within the school context (Vranda & Mothi, 2013). These behaviours may vary from absconding from school, being suspended due to delinquencies, to expulsion (Billing et al., 2002). Of course, numerous other variables may contribute to a child exhibiting behavioural problems. These are, but not limited to child abuse, discrimination, bullying, child neglect and even learning difficulties. Although it appears that the study has highlighted negative impacts on children that lived with relatives, benefits of children living with relatives have also been established.

Unlike living with non-relatives, the children who lived with relatives maintained familial and community bonds, which could enable them to maintain relationships with siblings and other significant persons (Billing et al., 2002).

2.5.2. Emotional problems in children with HIV

Bowlby’s (1969), theory of attachment postulates that all infants have an innate drive to form attachment with their caregiver or parent and that this is the primary drive. He focused his research mainly on maternal deprivation that was consequent to maternal separation or being orphaned.
Ainsworth (1963), highlighted the various patterns of attachment namely Type A that is insecure avoidant, Type B known as securely attached and Type C, which is Insecure resistant. There was a fourth type of attachment introduced by Main and Solomon called insecure-organised. These are related to four codes or behaviours displayed by infants towards their caregivers or parents. These behaviours are categorised in the following manner (Slater & Bremner, 2003, p. 157):

- Proximity-seeking
- Contact maintenance
- Resistance
- Avoidance

In addition to the attachment styles, other developmental factors may be of value in terms of infants’ recognition and expression of emotions. According to Slater and Bremner (2003), Darwin proposed, “expressing emotions through facial expressions is an innate ability that humans possess” (p. 143). Researchers have investigated this by questioning whether “different emotional expressions could be universally understood and observed infants to determine whether they spontaneously produced recognizable facial expressions” (Slater & Bremner, 2003, p.143). Halfon, Mendoca and Berkowitz (1995, cited in Billing et al., 2002) stated that children who are in ill-health are more likely to be separated from their parents- more likely as necessary for the children to be hospitalised. Another finding in the NSAF (1997 & 1999) was that children who were being cared for by relatives from low SES households were more likely to have an immobilising or restrictive illness than those also from low SES households but lived with parents. The children that lived with relatives were also more likely to have learning difficulties and mental health disorders (Billing et al., 2002).
In terms of mental health and well-being, an HIV positive parent with an HIV positive child or children, may experience strong feelings of loss or chronic sorrow (Antle, Wells, Goldie, De Matteo & King, 2001). This concept applies to the constant and recurrent feelings of sadness, which vary in intensity and are present throughout the parents’ and children’s or child’s life. This phenomenon may be coupled with grief, anxiety, depression, self-blame and usually remains unchanged. Researchers attributed the lack of change to the fact that by being aware of their own statuses as well as that of their children, parents bear this heavy emotional burden and they can be consumed by feelings of guilt (Antle et al., 2001). This in return may affect the quality of caregiving by parents or caregivers, as the focus for them will be how to deal with their own illness. This may hamper the desire for the parent or caregiver to disclose the child’s positive status to them.

2.5.3. Poverty and HIV in children

According to NSAF (1997 & 1999), children from a low socio economic status (SES) who resided with relatives were perceived to engage less in extracurricular activities than those who resided with their parents. There may be various reasons for these results, two hypotheses being that the child may not be able to dedicate time to extra activities as they are still possibly adapting to the living arrangements, or that due to other demands on the caregivers, resources such as time and money may be scarce (NSAF, 1997 & 1999). The study by NSAF (1997 & 1999) showed that relatives of children who are from homes with a low SES were less likely to provide a stimulating environments that children raised by parents in from a low SES. Furthermore, children who had physical or medical conditions showed to be difficult to care for (Billing et al., 2002).
2.6. Disclosure and the impact of HIV

The AIDS Consortium (2009, in van Dyk, 2012), states that the HIV and AIDS charter advocates to maintain basic rights of people living with HIV and AIDS (PLWHA). The charter (cited in van Dyk, 2012) further states, “Children have the right to information and education concerning their human rights in the context of being HIV infected or affected.” (p. 443). Informing significant others of one’s HIV status is a difficult choice for many living with the disease. Various factors- such as fear of stigma and denial- influence the decision to disclose. This is especially true in paediatric disclosure as it is intricate in nature. Disclosing to children about their HIV status may bear with it complexities such as explicating the routes of infection- especially if sexually transmitted- and the stigma attached to it (WHO, 2010).

Furthermore, paediatric disclosure is different to adult disclosure because other important dynamics that need be observed depend largely on the environments in which children exist. In investigating the dynamics that play a pivotal role in considering disclosure to children, the International Centres for AIDS Care and Treatment Programs (ICAP, 1999) took heed and stated, “The needs, feelings, beliefs of the child, as well as the needs, feelings, beliefs of the parent(s)/caretaker(s) are to be considered” (p. 6). Children are in constant flux developmentally as well as cognitively and this affects disclosure immensely in terms of their ability to deal with the revelation. This necessitated the paediatric health care workers to act in some ways as custodians for children’s needs whereas multidisciplinary teams avail themselves to assist families with their needs. The state of the families’ systems and the types of communication that the families have adopted should not be disregarded (ICAP, 1999).
Disclosure may be partial, where the child is informed only of the other HIV related illnesses that they are being treated for, or it may be non-existent (Antle et al., 2001). Parents may wish to protect their children from being discriminated against especially in the school context (Vranda & Mothi, 2013). This is a complex matter as children lead relatively normal lives with the use of ART, and do live into and past their teen years. This becomes a challenge in that children may begin to experiment within certain avenues, which are in line with their developmental milestones. They may begin to explore in their pre teenage and teenage years with drugs, alcohol and even sexual encounters. If a child is not aware of their HIV status when they begin exploring certain activities, especially sexual, it poses a risk in terms of sexual health and this may perpetuate the spread of HIV if condom use is not practiced (Antle et al., 2001).

2.7. The psychosocial and psychological impact of stigma

Stigma is a complex phenomenon and is defined and described differently by various researchers. The term stigma according to Herek, 1999; Mak, Cheung, Law, Woo, Li and Chung, 2007 refers to ‘prejudice, discounting, discrediting and discrimination directed at people (p. 1106). While stigma may lead to discrimination, it does not necessarily result in discrimination. There is a distinction between stigma and discrimination in that discrimination is relation to acts that place others at a disadvantage, while stigma is like a stain or a mark that a member of a subgroup bears and can lead to discrimination (Maman, 2009). In addition to Herek’s (1999) definition, Goffman (1963, cited in Maman et al., 2009) states, “people experience stigma by others because they are different, and the deviance results in spoiled identity.” (pp. 2271). Weiss, Ramakrishna and Somma (2006) cited in Gernberg, et al., (2009), define stigma as ‘a social process, experienced or anticipated, characterised
by exclusion, rejection, blame or devaluation that results from experience, perception, or reasonable anticipation of an adverse social judgement about a person or group’ (p. 2279).

Research by Castro & Farmer, (2005); Link & Phelan, (2001); Yang et al., (2007), cited in Maman et al., (2009) has also been conducted, focusing on the role power structures- such as politics and the economic system- play in perpetuating stigma in the social contexts. Stigma impacts on the treatment and prevention of HIV as PLWHA experience psychosocial and psychological challenges such as depression, anxiety, stress, low quality of life, poverty, loss of income and loss of support among others. Concerning people living with HIV/AIDS (PLWHA), stigma is usually directed toward them due to certain aspects that indicate that they may be living with the illness such as physical appearance in the later stages of HIV.

A vast body of literature on HIV stigma (Herek, 1999; UNAIDS, 2006) shows that PLWHA have been stigmatised since the illness was reported in the early 1980’s. Stigma may have a profound impact on a person’s psychological well-being (Mak, et al.,2007). It may affect PLWHA adversely in that they may become ostracised by their communities, health care facilities, places of employment, places of worship, schools and even from their families (Mak et al., 2007).

In a study conducted in China by Lau and Wong (2001), to assess the level of stigma in the workplace, it was revealed that twenty percent (20%) of the companies in the study sample responded that they would dismiss their employees who were HIV positive (Mak et al., 2007). The way in which people perceive their illness may affect them in different ways and how a PLWHA internalises stigma is vital in terms of how they will experience the illness. The definition of self-stigma is ‘when a member of a devalued group, being aware of the prejudice, stereotype and discrimination in society endorse and internalise these beliefs, feelings and behaviours’ (Mak et al.,
According to Mak et al., (2007), studies have shown that because of how some PLWHA internalise stigma, certain emotions may be experienced. These common emotions can be shame, guilt, unworthiness, perceptions of being discredited, and behavioural intentions to conceal seropositive status (Mak et al., 2007). Studies by Lesserman et al., (2002); Lee, Kochman, & Sikkema, (2002) cited in Mak et al., (2007) have shown that high levels of stigma experienced by PLWHA is linked to faster disease progression as well as a significantly higher degree of psychological distress (Mak et al., 2007). Using the attribution theory to understand stigma, Weiner (1993, cited in Mak et al., 2007) explains that when an individual becomes aware of the cause of his or her illness, it can have an effect on his or her emotional state as well as how they behave within their context. Controllability of disease also has an impact on how individuals handle stigma.

According to the study by Corrigan, Markowitz, Watson, Ronan and Kubiak (2003 cited in Mak et al., 2007), there is a correlation between contraction of illness and inferences of responsibility when contagion or contraction of a disease is controllable. Feelings of self-pity and or blame have also been reported (Mak et al., 2007). Two studies (one qualitative and the other quantitative in nature) were conducted in five different sites namely, two South African sites, Thailand, Tanzania and Zimbabwe showed that stigma is rife across cultures. There were some variances and similarities that were identified concerning stigma perpetuation and protective factors (Maman et al., 2009).

Results of the two studies showed some contradictions with regards to stigma perception in Tanzania. The qualitative study consisted of 655 participants and semi-structured interviews were conducted. The quantitative study was conducted on 14 203 participants where interviewers administered questionnaires. The quantitative study results showed that more than half the respondents in Tanzania scored in the 75 percentile of the negative attitudes towards PLWHA scale.
However, in the qualitative study, a high number of participants blamed PLWHA for being infected, but others perceived infection as a matter of chance and that anybody remained at risk (Maman et al., 2009). This alludes to the fact that stigma does exist and can be perpetuated by how much information is available about HIV and what people understand it to be.

### 2.7.1. Expression of stigma

Some participants in the qualitative study expressed that they felt pity and sympathy towards PLWHA, whilst others expressed blame, disgust, othering and neutrality (Maman et al., 2009). Blame and othering were established to be related to how someone was infected, especially concerning sexual practices and availability of protection in the form of condoms.

The PLWHA were labelled as ‘immoral, reckless and even irresponsible’ in term of being infected, labels which were highly judgemental and could elicit self-stigmatisation for PLWHA (Maman et al., 2009). Behaviours of PLWHA contributed to the degree of stigmatisation they experienced, especially those pertaining to sexual health and practices post HIV positive status discovery (Maman et al., 2009). Social isolation is usually a phenomenon that occurs at the progressive stages of HIV, where a PLWHA is very ill and signs and symptoms of the illness are visible. Either the individual alone or the family as a whole can experience this isolation (Maman et al., 2009). In countries such as Thailand and South Africa, social grants are also mitigating factors from stigmatisation, although this too, can have converse outcomes- those of perpetuating stigma (Maman et al., 2009). Gossip and public shaming have also been reported as a way of stigmatisation. This can be due to the visible signs of illness or by way of suspicion by the community or family.

The rifeness of stigmatisation can be due to various reasons such as fear of contagion usually due to lack of knowledge about HIV transmission. Another contributing factor can be fear of death and
suffering, although there are other illnesses that may cause suffering and death other than HIV e.g. cancer, tuberculosis, heart disease, renal failure etc. (Maman et al., 2009). Although the situation may seem dire, there are factors that mitigate against discrimination and stigmatisation. These include support from family members, who can employ measures to limit contact between the PLWHA and the outside world to try to minimise gossip and disgust, among other stigmatising behaviours (Maman et al., 2009). Access to ARTs also assist in minimising stigma in that PLWHA can live longer without exhibiting signs of being ill. It is also noted however, that access to ARTs may lead to further stigmatisation, although not to a much greater extent than it being a protective factor (Maman et al., 2009).

In countries such as Thailand and South Africa, social grants can also be a mitigating factor from stigmatisation, although this too, can have converse outcomes- those of perpetuating stigma (Maman et al., 2009). Findings in studies should be understood within their contexts and thus further research is required in order to understand the extent of stigma within the context of children, as most studies were conducted with adults.

2.8. Impact of HIV on the brain

According to Vranda and Mothi (2013), the earliest and most devastating indicators of HIV infection in children are neurological, neuropsychological and developmental in nature. They state that forty to ninety percent (40%-90%) of infected children assessed for central nervous system markers showed some neurological deficits (Vranda & Mothi, 2013). They further indicated that eight to thirteen percent (8%-13%) of the HIV positive children assessed presented with signs of neurological delays, while an even higher percentage of children with AIDS- nineteen to thirty one percent (19%-31%)- exhibited significant neurodevelopmental delays (Vranda & Mothi, 2013). Two
common neurodevelopmental deficits found in children with HIV are Progressive encephalopathy (PE) and Static encephalopathy (SE), with HIV related PE occurring in 50% of children diagnosed with AIDS. Along with these deficits, HIV can directly affect a child’s developmental milestones, expressive and receptive language development, as well as motor development skills.

Research by Martin et al., (2006); Smith et al., (2006); Wood, Shah, Steenhoff & Rutstein, (2009 cited in American Psychological Association (APA, 2013) shows that children who are diagnosed with AIDS earlier in their lives showed lower cognitive performance later regardless of being on ART. If children receive ART from birth, it is likely that their cognitive abilities or development may be normalised. This may present a challenge in some regions as access to ARTs may be difficult, especially in developing countries (APA, 2013).

Nath, Tardieu, Ma and Johnson (2003), suggested that due to the variable nature of the consequences of CNS infection by HIV, clinical manifestations should be considered holistically and in congruence with the child’s health context. This means that neurologic symptoms should be considered in relation to factors such as immunity and viral load (Nath et al., 2003). Furthermore, neurologic deficits may co-morbid with other conditions i.e. premature birth defects, low birth weight etc. (Nath et al., 2003). Furthermore, they also explained that calcific vasculaopathy of the basal ganglia is the most characteristic and most consistent neuropathologic finding in infants and children with HIV, and that neurological damage starts from an early age and progresses as the child grows older.
2.9. **Impact on language development**

Cognitive abilities, behavioural and emotional well-being form a vital part of quality of life. Cognitive abilities involve memory, attention, language, processing or thinking speed, problem solving as well as decision-making (APA, 2013). Children with perinatal HIV or those infected when young through blood products may experience deficits in these cognitive domains. These deficits may be a hindrance as children progress scholastically, socially as they make transitions into puberty and adulthood, and when they transition into employment as young adults. Moreover, it is likely that these children may exhibit behavioural, psychiatric and/or emotional difficulties—such as depression and anxiety (APA, 2013). Transmission of HIV perinatally has dropped substantially, however, children who are living with HIV still face challenges on a daily basis and further research needs to be conducted concerning interventions aimed specifically at children with HIV.

2.10. **Conclusion**

The chapter reviewed the literature pertaining to factors that influence parents or caregivers to disclose or not to disclose to their children that they are HIV positive. The literature also mentions the impact of HIV on persons living with the virus, their challenges, and the negative impact that the virus may have on their biological structures and psychological well-being. In the next chapter the research methods of the study will be presented.
CHAPTER 3

RESEARCH METHOD

3.1. Introduction

The previous chapter presented the literature on Human Immuno Deficiency Virus (HIV), child development, caregivers and the psychological effects of disclosure on children. This chapter deals with the research methods of the study with emphasis on qualitative research. Furthermore, the Interpretative Phenomenological Analysis (IPA), phenomenology, sampling, procedure and data analysis will also be discussed.

3.2. Qualitative research

There is no one definition to what qualitative research is. Different authors have produced definitions based on the focus of their research, for example Merriam, (2009) states that “Qualitative researchers are interested in understanding the meaning people have constructed, that is, how people make sense of their world and the experiences they have in the world” (p. 13). Parkinson and Drislane (2011), observe an epistemological position on research and state that using methods like participant observation or case studies result in a narrative, descriptive account of a setting or practice and that these methods generally discard positivism and take on interpretative forms. According to Denzin and Lincoln (2005), qualitative research can focus on the process and data collection in that materials can include tape recorders, photographs, interviews, conversations and field notes.
These materials become a vessel in enabling the researcher to explore the subject matter in its natural state and form interpretative material that makes the participant’s world more accessible, more natural. According to Terre Blanche, Durrheim and Painter (2006), naturalism is one characteristic of qualitative research and it postulate that, data is collected in a natural setting instead of ‘conducting’ laboratory observations and experiments. Qualitative research employs various methods to seek out certain truths of people’s realities and the way they experience their world. The authors further state that the beauty of qualitative research lies in the bottom-up and ‘choreographic’ nature in that participants are allowed to share and construct their life worlds without adhering to strict rules and they become choreographers of their stories. The qualitative field is often riddled with differences concerning philosophical assumptions. These philosophical assumptions are concerned with how psychological knowledge should be produced.

These philosophical assumptions serve as guidelines as to what type of knowledge can be produced and are influenced by relationships between language, cognition and reality (Lyons & Coyle, 2007). These assumptions are based on a domain of philosophy of science referred to as epistemology. Qualitative research is often employed to answer the “hows’ and ‘whys’ in human behavioural sciences. Qualitative data consists of nonnumerical data such as descriptions obtained from interviews, conversations and video recordings with participants (Whitley, 2002). According to Biggerstaff and Thompson (2008), qualitative research methods allow the researcher to understand the participants’ realities from the participants’ own perspectives. This means that the researcher is able to understand the participants ideographically, in that the researcher extracts the meaning of the participants’ realities on a deeper level. Babbie and Mouton (2001); Lyons and Coyle (2007); Fischer (1994), emphasise the importance of a researcher as an instrument. This means that the researcher draws from his or her own resources during the collection and analysis of the data.
Individual instances of a phenomenon are analysed and interpreted to reveal explicit and implicit meanings, resulting in a narrative descriptive account. By using a qualitative method, the researcher can explore social processes, participants’ relationships and interactions, lived subjective experiences and the meaning thereof. This method allows context to be considered and gives depth and richness to the research. In psychology, this method employs the postmodern way of conducting research (Mason, 2002).

Another major concept in qualitative research is reflexivity. This entails how a researcher positions herself or himself in the process and the acknowledgement of the role she or he plays. Willig (2008) mentions two levels of reflexivity, personal reflexivity and epistemological reflexivity. The latter interrogates how the research process was structured, from formulation of a research question, data collection, how the design of the study influenced data analysis and findings. The former touches on the impossibility of entering the field as ‘pure’ in a sense that it acknowledges that researchers have their own values, personal belief systems, and importantly, the academy is riddled with many theories and epistemologies. Coyle (in Lyons & Coyle, 2007) is of the opinion that devoting too much time reflecting should be avoided because it gives an impression that the research process is much about the researcher than it is about participants. Qualitative research was preferred in this study as it enables the researcher to understand the phenomena in question through the understandings of the participants.

Another reason that the qualitative research was embarked upon was that the findings are not hypothesised or produced in advance, and thus there is flexibility in utilising this form of research method. The method employed here answers the “how” and “what” of phenomena, and this may be done in an exploratory manner.
3.2.1. **Epistemology**

Lyons and Coyle (2007) state that “epistemology refers to a branch of philosophy that that is concerned with the theory of knowledge and that tries to answer the questions about *how* we can know and *what* we can know. The epistemological position adopted by the study specifies what kinds of things that the study can find out,” (p. 11). Thus, the approach one takes to investigate phenomena will determine what kind of information will emerge or which questions will be answered. Epistemology thus refers to knowledge production. This leads the researcher to briefly discuss what phenomenology is and what it entails.

3.2.2. **Phenomenology**

According to Wertz, Charmaz, McMullen, Josselson, Anderson and McSpadden (2011) “pure phenomenology involves describing the essence of phenomena (by “*eidetic analysis*” which involves conceptualising what is invariant through all imaginable examples of phenomenon)” (p. 91). Eidetic analysis and description in other words produces knowledge that is reflective of lived experience. Qualitative analyses stemming from phenomenology can use a process called *reflection*, which examines previously lived experience in order to explain the “*noeses*” (the “how”) of experience and the meanings or “*noemata*” (the “what”) of experience (Wertz et al., 2011). Creswell (1998) states:

> A phenomenological study describes the meaning of the lived experiences for several individuals about a concept or the phenomenon. The researcher needs to understand the philosophical perspectives behind the approach, especially the concept of studying how people experience a phenomenon. The investigator writes research questions that explore the meaning of that experience for individuals and asks individuals to describe their everyday
lived experiences. The investigator then collects data from individuals who have experienced the phenomenon under investigation (p. 51).

The researcher tries to understand the psychological world of the participant. This means that the meaning or essence of human phenomena is explored. This is done through the process of identifying emergent themes in the data, as well as attaching meanings to them as the participants experienced them. The methodology that will specifically be used in this research is the *Interpretative Phenomenological Analysis Approach (IPA)*. This method provides the framework for conducting research and is derived from philosophy. This method has a dual focus on the unique characteristics of individual participants (ideographic focus) as well as the patterning of meaning across participants (Smith, Flowers & Larkin, 2009).

For purposes of this inquiry, Smith’s Interpretative Phenomenological Analysis (IPA) was used because it allowed the researcher to interpret the participants’ perceptions and experiences because of the impossibility of gaining direct access to their world. Three pillars of IPA are discussed by Smith and Eatough, (2007); Biggerstaff and Thompson, (2008). These are *hermeneutics, phenomenology and idiography*. 
Below is a graphic presentation of these pillars:

![Diagram showing Phenomenology, Hermeneutics, and Idiography]

**Figure 1:** Three pillars of IPA

Willig (2008) identifies two distinct schools of thoughts within phenomenology which are *descriptive phenomenology* and *interpretative phenomenology*. Descriptive phenomenology by its nature is rooted in transcendental phenomenology and the basic premise is that a researcher should be able to transcend their biases and presuppositions in trying to understand a phenomenon or their participants (Husserl, 1936, in Willig, 2008). In other words, the focus for researchers should be on descriptions rather than trying to interpret participants’ experiences. There are two specific approaches that can be followed when it comes to reflexivity; these are *bracketing* and *reduction*, which will be explained in Section 3.2.4.
3.2.3. Bracketing and reduction

According to Husserl (1936, 1954, in Willig, 2008), there are two fundamental approaches that are aimed at studying experience. He identified two epoches (abstentions) namely the natural sciences and the natural attitude. He argues that in the former epoche, researchers should abstain from utilising natural scientific knowledge such as hypotheses, prior research and measuring tools when dealing with a particular phenomenon. This is known as bracketing and Husserl argued that this enables the researcher to study the phenomenon in its “pure” form or as it appears (Wertz et al., 2011). The second epoche refers to putting aside the natural attitude of a researcher to focus on the participant and experience independently. The researcher does not actively take a position to actively acknowledge their own experience and this is known as psychological phenomenological reduction (Wertz et al., 2011). Phenomenology is reflective and thus researchers contribute their experiences.

There are two other procedures that Husserl developed, namely intentional analysis and eidetic analysis. The former refers to the process of reflecting in order to know the how and what of experience. The latter refers to the fact that consciousness is transcendental and goes beyond itself for example being able to tangibly have the experience of seeing an object visually, or visualising it in the mind (Wertz et al., 2011). There is an awareness of the role played by interpretation, particularly during the analysis of participants’ perceptions but this interpretation must be kept to its minimal. Interpretative phenomenology, which is rooted in the hermeneutic thought, is of the opinion that lived experiences cannot be easily divorced from interpretation because they are already organised through language.
The argument they put forward is that since people begin making sense of their world from an early age, it is difficult to discount that history and its impact on them. Schooling, politics, history, values, church and media all have an effect on how one perceives the world and in this case a phenomenon.

3.2.4. Hermeneutics and Idiography

This process of interpretative analysis is employed when a researcher wants to understand meanings of phenomena by going back and forth between parts of a whole and the contexts of the whole. This can be in the form of making inferences, deductive and inductive reasoning (Wertz et al., 2011). Smith and Eatough (2007), have shown themselves to be proponents of the hermeneutic tradition. They elaborate more on three interrelated hermeneutic processes, and these are double hermeneutic, critical hermeneutic and emphatic hermeneutic.

According to Smith and Eatough (2007, hermeneutic phenomenology acknowledges that a researcher cannot ‘purely’ and objectively understand participants’ experiences without interpreting them and double hermeneutic allows the researcher to co-create meaning with her or his participants and taking it further by doing a meta-analysis and “second order sense-making of someone else’s experiences” (p.36).

Critical hermeneutic is important in the research process because it allows the researcher to ‘stand back’ and be objective with regard to participants narratives. The researcher engages in critical questioning of participants accounts. This should be practiced with utmost care because it may alienate participants. On the contrary, some researchers use emphatic hermeneutic whereby they put themselves in the shoes of participants. This allows them to be in tune to the same mental processes that their participants use (Smith & Eatough, 2007).
This again should be practiced with caution because the researcher could easily ‘get lost’ in the emotional roller-coaster of her or his participant. Finally, *idiography* as one of the pillars of IPA is well in synchrony with qualitative research philosophy in that both approaches dedicate energy to in-depth understanding of participants’ real experiences. There is value in making sense of stories because in most cases, these stories (experiences) are unique. In addition to three pillars of IPA, Wertz et al. (2011), cautions researchers to strive for essence, which will be discussed briefly.

### 3.2.5. Essence

Essence refers to the meaning “form” (Wertz et al., 2011, p. 127). This means that the researcher should understand that people live and experience some phenomena during their lifetime, and that they try to make meaning of their experiences in various ways. In other words, essence can be seen as the heart of the matter or of the phenomenon.

### 3.2.6. Theme

According to Braun and Clarke (2006), a theme refers to any significant information in the data that relates to the research question. This can be recurring or can occur once in the data. A theme captures a common, recurring pattern across a data set, clustered around a central organising concept. Themes describe the different facets of that singular idea and demonstrate that there is patterning in that data set. According to Smith et al., (2009), a sub-theme exists under the umbrella of a theme and it shares the same central organising concept as the theme. A subtheme however focuses on a single notable element (Smith et al., 2009).
3.2.7. Trustworthiness

When conducting quantitative research, there are variables known as reliability and validity, which determine whether results from a particular study reflect truthfulness. ” Trustworthiness in qualitative research is about how the researcher promotes rigour in their research. Rigour is applied in ensuring that the transcriptions are carefully captured and checking whether themes are coherent and congruent. The researcher immerses herself in the research data working through the themes that are emerging  (Braun & Clarke, 2006). Credibility refers to whether there is confidence in the “truth” of the findings (Lincoln & Guba, 1985).

Credibility in this research will be assessed by allowing the assistant researcher to go through the themes that have been found by the main researcher and these will be compared with those found by the assistant researcher. An agreement of 80% between both the main researcher and the assistant researcher will be acceptable thus indicating the credibility of the main themes and subthemes. Transferability is related to whether findings are applicable in other contexts. Dependability refers to whether the findings can be repeated or if they are consistent (Rolfe, 2004). A third person who is well conversant with qualitative research will compare the process followed by the main researcher including the findings and this will be checked against those of the research assistant by this independent person and agreement of 80% will be accepted as indicating dependability of the findings. The researcher intends to elaborate on the steps followed prior to embarking on the actual research and thereafter.
3.3. **Steps taken by the researcher before embarking on research**

3.3.1. **Seeking permission**

Permission was sought from the Clinical Director at Dr George Mukhari hospital which will serve as the setting of the study. The researcher explained the study as follows:

This study is part of my academic requirements for a Master’s degree in Clinical psychology at the Sefako Makgatho Health Sciences University. The focus of this study is to explore the psychological effects of disclosure on HIV positive children who are on ARV treatment at the paediatrics ART clinic at Dr George Mukhari academic hospital in Ga-Rankuwa Township.

It is anticipated that the results will assist in the effective rendering of treatment addressing emotional and other factors that may shed light on coping strategies.

Thereafter, permission was also sought from the Clinical Head of the HIV unit within the Paediatrics department at Dr George Mukhari academic hospital in Ga-Rankuwa Township. After granting of the authorization, permission to conduct the study was also be sought from prospective participants, including their parents or caregivers.
3.3.2. Ethical considerations

This protocol followed the requirements of the Sefako Makgatho Health Science University Research Ethics Committee. The researcher requested signed consent from the parent or caregiver, as well as ascent from the children to participate in the study. Both parties were informed about the research as stated under paragraph 3.3.1., and they were encouraged to ask questions for clarity if anything was unclear regarding the context and process of the research. They were informed that they could pull out of the study at any point during the research process and that this would in no way affect their treatment.

According to Smith, Jarman and Osborn (1999), when utilising the Interpretative method to analyse data, researchers are required to record their interactions with participants so as to capture all the nuances. The participants were made aware of the recording devices to be used and gave consent. (Refer to Appendix 3). Opting not to record the interviews may lead to important information to be omitted from the data. Confidentiality was maintained through participants using pseudo names or numbers. The interviews were conducted in the preferred language of the participants. The recordings of the sessions were transcribed. Any of the participants who showed uncontrollable emotional distress were referred to a psychologist for intervention. Due to budgetary restrictions, no compensation was given to participants.
3.3.2.1. **Informed Consent and Confidentiality**

The participants’ parents were required to give written consent in order for their children to participate in the study (Refer to Appendix 1). The researcher requested ascent from the children to partake in the study (Refer to Appendix 2). The children receive ARV treatment from the Antiretroviral Therapy (ART) paediatric clinic at Dr George Mukhari hospital. This provided access to the participants.

The participants’ confidentiality was maintained by not discussing any information with family members or staff members at the hospital unless the participants were aware of this. In the results of the study, the researcher refrained from making known any of the participants’ identities in any dissemination of the material.

3.3.3. **Sampling**

Purposive sampling was utilised for the purpose of the study, consisting of patients who were seeking HIV treatment at Dr George Mukhari academic hospital in Ga-Rankuwa Township. Purposive sampling was useful in the study as it was a select population who experienced what it means being HIV positive and some of them not understanding the health implications of being HIV positive due to their young age and level of maturity. Twenty participants were initially selected for focus groups and individual interviews. This was controlled by saturation of data. The four focus groups consisted of at least five participants per group depending on availability of the participants who are patients.
3.3.3.1. Selection criteria

Participants were selected according to following inclusion criteria:

- Children aged between 9 and 16 years, this was determined by the level of the participants’ maturity
- Both males and females were eligible
- They had to be HIV positive and were fully aware of their status, and are on ARV treatment
- They have to be without cognitive impairment (mental retardation or impairment from AIDS)
- Accompanied by a caregiver or parent
- Be able to communicate in English, Sepedi or Setswana

3.3.3.2. Exclusion criteria

Participants that could not take part in this study include:

- Children under the age of 9 and those above the age of 16 years
- Who were too ill to attend the ART clinic
- Who were unaccompanied by a caregiver or parent and
- Who were cognitively impaired
3.3.4. Sensitising the research assistant

It was essential to sensitise the research assistant with Smith, Jarman and Osborn’s (1999) IPA method. In this regard, both the main researcher and the assistant researcher read and revised Smith and Osborn’s phenomenology. This was later discussed by the main researcher and the assistant researcher to arrive at a common understanding of the IPA method. The assistant researcher is a qualified research psychologist. Although being quite conversed with research methods it was essential for the purpose of this research to operate from the same literary framework and the sequence to be followed in the analysis of the emerging themes. (Refer to paragraph 4.2.2).

3.3.5. Recruitment of participants

Prospective participants and their parents or caregivers were informed of the study, as a study exploring the psychological impact of HIV positive status disclosure on children on ARV’s at Dr George Mukhari academic hospital in Ga-Rankuwa Township. (Refer to appendix 3). The nursing sister in charge of the clinic informed the potential participants and caregivers/parents about the researcher’s interest in conducting a study about HIV as they arrived at the reception. The researcher approached the caregivers and the parents to enquire if they would be willing to let their children participate in the study. If the caregivers and parents agreed, the researcher continued with the recruitment process.

There were 19 participants in total, consisting of 9 males and 10 females.

The ages of the participants in the female group ranged from 10 years to 16 years. For the 10-year-old female group, there was 1 participant. For the 11-year-old female group, there were 2
participants. For the 12-year-old female group, there were 3 participants. For the 14-year-old female
group, there were 3 participants. For the 16-year-old female group, there was 1 participant.
The ages of the participants in the male group ranged from 9 years to 16 years. For the 9-year-old
male group, there was 1 participant. For the 9-year-old male group, there was 1 participant. For the
12-year-old male group, there were 2 participants. For the 13-year-old male group, there was 1
participant. For the 14-year-old male group, there were 4 participants. For the 16-year-old male
group, there was 1 participant.

With regard to the residential areas in which the participants lived or reside, 1 of the participants
resides in Ga-Rankuwa, 12 reside in Soshanguve, 3 reside in Mabopane, 1 participant is from the
North West, 1 from Hammanskraal and 1 participant was from an undisclosed area.
All the participants and their parents/caregivers had to sign a consent form prior to embarking on the
research. (Refer to item 3.3.2.1.)

3.3.6. Material

An interview guide consisting of eleven (11) open-ended questions was used for the focus groups to
gather information. This type of interviewing allows for flexibility for both the researcher and
participants in order not to limit the depth of the responses that the participants gave (Durrheim &
Wassenaar, 1999). A biographical data sheet was also used to obtain more information about
participants. (Refer to Appendix 4) An audio recorder was used during the focus groups.
3.4. Procedure

This section seeks to take the reader through the steps taken prior to undertaking the main research as well as the researcher’s experiences through the process.

3.4.1. Pretesting the interview guide

The questionnaire was initially tested on a sample of five (5) participants in a focus group. The aim of the pretesting was to gather information about difficulties regarding understanding the questions contained in the interview guide. The results indicated that it was not necessary to change any questions.

3.4.2. Data collection methods

The researcher conducted focus groups and one on one interviews to collect data from children who are HIV positive and who are receiving ARV treatment at Dr George Mukhari academic hospital in Ga-Rankuwa Township. Focus groups are group discussions centred on a particular topic organised for research purposes (Gill, Stewart, Treasure & Chadwick, 2008), whilst in-depth interviews are generally focused on obtaining data that is historically rich to the participant, and explores their personal experiences in relation to the phenomena. A moderator was to assist with the process, however due to space and time limitations she could not assist with the process. Some participants who were recruited dropped out before the interviews, thus leaving the researcher with only one participant at times. The researcher conducted one on one interviews. Biographical data was obtained from the participants and from their parents or caregivers before going to the interview room.
The focus groups were conducted in an interview room, which was based at the paediatric ART clinic at Dr George Mukhari hospital in Ga-Rankuwa Township. The information obtained from the biographical sheet assisted in ensuring that some of the participants’ information such as age could be confirmed.

The researcher used different icebreakers to create rapport and to allow the participants to settle down after welcoming them. For the icebreakers, the researcher expanded on what the participants were interested in talking about during the recruitment stage, such as school, their health or how they were feeling at that time. She also used an ice breaker called “guess my number”, where each participant was asked to pick a number between 1 and 20 and guess what their neighbours had chosen. The interview guide was followed however, some of the questions were not necessary to ask as some participants elaborated on their experiences in-depth thus touching on a successive question. (Q 1 & 2)

According to Smith et al., (1999), when conducting a semi-structured interview using an interview schedule, it is not necessary to follow the sequence on the schedule, nor for every question to be posed in the exact way as it appears on the schedule. The researcher used an audio recording device during the interview sessions. These interviews were timed, varying from 10 minutes to 35 minutes each and they were scheduled to suit the participants. Once the interview was through, the researcher thanked the participants, who proceeded to their doctor’s appointments.
3.4.2.1. Elimination of Bias

In qualitative research a method known as triangulation may be used to eliminate bias. The research may be subjective and trained assistants or fellow colleagues may assist in minimising that kind of subjectivity by coming through with a fresh look at the themes that emerge, whether related to the research or if they are the researcher’s bias. To eliminate bias in this study, a research assistant who is a qualified psychologist will also independently analyse the results of this study. (Refer to paragraphs 3.3.6 and 3.2.7).

After the research assistant has analysed the data, he sent through the themes that emerged from the transcripts. The researcher independently compared the themes that were extracted from her data to those that were extracted by the research assistant. This was done to check if there was an 80% agreement between the themes extracted by the researcher and the research assistant. This was in fact the case thus meaning that bias was eliminated.

3.4.3. Data analysis

Data analysis involves constructing and organizing the “product” of one’s research (Mason, 2002). For this research, data analysis involves searching for themes or patterns within the data as suggested by Braun and Clarke (2006). The data should be contextual and give meaning to the participants’ realities and experiences (Braun & Clarke, 2006). The Interpretative Phenomenological Analysis (IPA) approach was used to analyse the data. Using Smith et al., (1999) approach, through repeated engagement with the themes from each focus group, using transcripts from the various groups, the researcher compared emergent themes that were arranged according to responses to questions posed...
to the respondents. The common thread of ideas, perceptions, beliefs and concerns that emerge in response to the questions were highlighted. Smith and Eatough (2007), Willig (2008) and Shinebourne (2011) identify four stages of IPA:

**Stage 1: Initial reading of the transcript**

This is the most important step in the data analysis because the researcher gets an opportunity to refresh her memory of the interviews. The transcripts were read repeatedly in order to recognise recurrent themes. The reason for reading the transcripts repeatedly was to assist the researcher to find any significance from the statements made by the respondents (Smith & Eatough, 2007). According to Wertz et al., (2011) this step involves “reading for the sense of the whole, (p. 131)”. It is also during this stage when the researcher is encouraged to begin writing notes, her interpretation and reflections (Smith & Eatough, 2007).

**Stage 2: Identifying and labelling themes**

The researcher must immerse herself into the data by engaging carefully with what the respondents had said and try to pick up other nuances that were indicated in the scripts. The researcher made notes in order to make sense of the emotions and beliefs noted throughout the transcripts, and to gain a better understanding of the participants’ way of making sense and meaning of their world (Smith & Eatough, 2007). Wertz et al. (2011), consider this step as “differentiating the description into meaning units, (p. 131)”. During this stage, the researcher is encouraged to use her notes and transcripts to identify themes. Smith and Eatough (2007), caution that even though this stage allows for the introduction of psychological terms, themes must come from participants stories and be congruent with participants accounts.
Stage 3: Linking themes and identifying thematic clusters

Willig (2008), identifies this stage as critical because it introduces structure into the analysis. Themes are also narrowed and connections are identified between initial themes. Similarities and differences of themes were sought (Smith, et al., 1999). The interview guide was used to check if the themes correspond with what the study sought to explore. Themes were clustered into different categories. This was done for each group of participants or each participant within a group setting. The same was done for the individual interviews that took place. This is known as “reflecting on the psychological significance of each meaning unit” as stated by Wertz et al. (2011, p. 131).

Stage 4: Producing a summary table of themes with illustrative quotations

The final stage requires one to provide a summary of main themes, with their sub-themes in table form, accompanied by quotations, with line numbers. Certain quotes from the transcripts were used to make the necessary connection.

Based on the steps of Smith, Jarman and Osborn (1999), the researcher worked as follows:

Step 1

The researcher created and sent an electronic copy of all the interview transcripts to the assistant researcher so that he could carry out his own analysis independently, at the same time, listening to the recorded data to check if the transcripts of the main researcher are in agreement with the recording. Thereafter, the main researcher read the interview transcripts several times in order to immerse herself in the data and began writing notes on the left hand margin of the electronic document.
**Step 2**

The researcher made notes on the right side of the electronic document, in order to identify the emergent themes in the data. The main researcher copied all the interview transcripts from the various interviews and created one electronic document. The main researcher ensured that on this document, each sentence was allocated a number in order to make the coding process easier. She subsequently made use of a notebook to draft all the emergent themes in order to make sense of the emotions and beliefs of the participants. In a notebook, the main researcher noted down the initial emotions and beliefs of the participants and a brief explanation or reflection was made in light of the findings by the main researcher.

**Step 3**

All the emergent themes were noted in the notebook, a number was allocated as a code next to the theme to indicate the sentence or line number where that code (quotation) can be found on the interview transcript. Thereafter, the interview guide was used to check if the themes are in line with the themes that had emerged in the data. Themes that were found to be congruent by the researcher with the interview were then regarded as reliable themes.

**Step 4**

The main researcher sent the analysed data to the research assistant. Thereafter, the main researcher and the research assistant had a joint meeting where themes from both the main researcher and assistant researcher were compared and checked again. For those themes that there was an 80% agreement, these were accepted as valid. The researcher presented this information in a tabular form, which can be seen in the following chapter. These were sent to the independent analyst to check
including the transcribed raw data. Based on the 80% level of agreement from the independent analyst, these themes were then accepted as trustworthy and dependable.

3.5. Conclusion

Research is a journey, which becomes easier when one has a properly articulated research design. IPA as a paradigm perspective was suitable for undertaking this study as it is flexible and accommodates the researcher’s values, beliefs and opinions. It was often challenging for the researcher to be completely objective and to not be moved by the participants’ accounts of their context and experiences. The next chapter presents the results of this study in detail.
CHAPTER FOUR

RESULTS

4.1. Introduction

The aim of the study as stipulated in chapter 1 (paragraph 1.4.), was to investigate the psychological effects (i.e. coping styles, emotional reactions, benefits of disclosure or lack thereof) of an HIV positive status disclosure by parents or caregivers of children who are on ARV treatment at Dr George Mukhari academic hospital in Ga-Rankuwa Township. A qualitative approach was utilised for the purpose of the study. The phenomenological method of investigation was utilised, and Smith et al., (1999). Interpretative Phenomenological Analysis (IPA) was applied to analyse data. The following section presents the results of the study in tabular form, with the themes and subthemes identified from the participants’ responses which were captured on an audio tape recorder and typed interview transcripts. A number was allocated as a code next to the theme to indicate the sentence number where the information or code (quotation) can be found.

The themes and subthemes are in the first column, a code (sentence number) in the second column, and a quotation from the transcript in the third column. The questions that led to the emerging themes are indicated below. For more information regarding the analysed data, refer to the attached appendices. (Refer to Appendix 6).
4.2. Interview questions posed to participants

1. How do you understand your illness?

2. How did you discover that you were HIV positive? (Who told you?)

3. Can you remember how you reacted when you learnt that you were HIV positive?

4. How does it make you feel knowing that you are HIV positive?

5. What are your thoughts around being HIV positive?

6. How has your status impacted on/ changed your life- e.g. school, work, community, relationships with family and friends?

7. How do you cope with being HIV positive?

8. What challenges/ difficult things have you had to deal with so far, about knowing your status?

9. If you could change anything in your life, what would it be and why?

10. Is there anything else that I have not mentioned that you would like to add?
4.3. Results of individual participants

Table 1: Participant 1

<table>
<thead>
<tr>
<th>THEME &amp; SUB-THEMES</th>
<th>LINE NUMBERS</th>
<th>QUOTATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Knowledge (understanding) of HIV</td>
<td>10</td>
<td>They said that I fetch medication because I have an illness</td>
</tr>
<tr>
<td>Responses about the illness</td>
<td>18</td>
<td>It is a dark illness</td>
</tr>
<tr>
<td>Participant’s explanation</td>
<td>20</td>
<td>It is an illness where if you do not look after yourself it is possible that you can die</td>
</tr>
<tr>
<td>Discovery of HIV-who disclosed</td>
<td>26</td>
<td>This other nurse</td>
</tr>
<tr>
<td>Type of disclosure (full, partial, non-disclosure)</td>
<td>14</td>
<td>They said that I have HIV</td>
</tr>
<tr>
<td>2. Initial reactions</td>
<td>40, 47</td>
<td>I didn’t feel great; I didn’t feel okay</td>
</tr>
<tr>
<td>Feelings towards others</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Feelings towards self</td>
<td>59</td>
<td>I was okay, I did not stress anymore</td>
</tr>
<tr>
<td>3. Cognition/thoughts</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Towards self</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td><strong>Towards others</strong></td>
<td>91</td>
<td>Not okay</td>
</tr>
<tr>
<td>--------------------</td>
<td>----</td>
<td>----------</td>
</tr>
<tr>
<td><strong>Towards illness</strong></td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Impact of HIV + status</th>
<th>91, 152</th>
<th>Not okay; I have been ill and missed school</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>On participant</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Others</strong></td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td><strong>Systems (school, church etc.)</strong></td>
<td>n/a</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5. Coping mechanisms</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Withdrawal</strong></td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td><strong>Acceptance</strong></td>
<td>190</td>
<td>The fact that I am not too ill</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6. Difficulties/challenges experienced</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adherence</strong></td>
<td>101</td>
<td>Drinking pills everyday</td>
</tr>
<tr>
<td><strong>Illness</strong></td>
<td>152</td>
<td>I have been ill and missed school</td>
</tr>
<tr>
<td><strong>Fear of rejection</strong></td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td><strong>Fear of judgement</strong></td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td><strong>Burden of secrecy</strong></td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td><strong>Fear of stigmatisation</strong></td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td><strong>Loss</strong></td>
<td>61, 62</td>
<td>My mother passed away</td>
</tr>
</tbody>
</table>
They are okay, but they say that I should halve them; That I should not drink that many tablets.

7. Seeking explanation 93  That I have HIV and I don’t know how I was infected.

8. Changes to be effected n/a  n/a

Table 2: Participant 2

<table>
<thead>
<tr>
<th>THEME &amp; SUB-THEMES</th>
<th>LINE NUMBERS</th>
<th>QUOTATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Knowledge (understanding) of HIV</td>
<td>213</td>
<td>They said that I should come to the doctor so that he can check if I am still okay</td>
</tr>
<tr>
<td>Responses about the illness</td>
<td>222</td>
<td>Isn’t it if I do not drink this treatment I would get sick and die? As far as I know or I am concerned, I am not ill</td>
</tr>
<tr>
<td>Participant’s explanation</td>
<td>224</td>
<td>My aunt</td>
</tr>
<tr>
<td>Discovery of HIV-who disclosed</td>
<td>228</td>
<td>For my leg.</td>
</tr>
<tr>
<td>Type of disclosure  (full, partial, non-disclosure)</td>
<td></td>
<td>They say that I would get sick if I did not drink my treatment</td>
</tr>
</tbody>
</table>
Deception | 248, 249 | and that I will die if I did not drink it and that the treatment is very important

2. Initial reactions | n/a | n/a
   Feelings towards others | n/a | n/a
   Feelings towards self | n/a | n/a

3. Cognition/thoughts | n/a | n/a
   Towards self | n/a | n/a
   Towards others | n/a | n/a
   Towards illness | n/a | n/a

4. Impact of HIV + status | n/a | n/a
   On participant | n/a | n/a
   Others | n/a | n/a
   Systems (school, church etc.) | n/a | n/a

5. Coping mechanisms | n/a | n/a
   Withdrawal | n/a | n/a
   Acceptance | 349 | I don’t understand but I feel okay about it

6. Difficulties/challenges | n/a | n/a
<table>
<thead>
<tr>
<th>Experienced</th>
<th>n/a</th>
<th>n/a</th>
</tr>
</thead>
</table>

**Adherence**  

**Illness**  

358, 359  

Because doctors tell me that my leg will heal soon, but it has been long that I have been waiting for my leg to heal, even now, I am still waiting!

**Fear of rejection**  

n/a  

n/a

**Fear of judgement**  

n/a  

n/a

**Burden of secrecy**  

n/a  

n/a

**Fear of stigmatisation**  

n/a  

n/a

**Loss**  

275  

She passed away

**Misinformation**  

358  

Because doctors tell me that my leg will heal soon, but it has been long that I have been waiting for my leg to heal, even now, I am still waiting!

**7. Seeking explanation**  

349, 383  

I don’t understand but I feel okay about it; Why am I drinking pills endlessly, and when I miss taking them you say that I would die, why?
Table 3: Participant 3

<table>
<thead>
<tr>
<th>THEME &amp; SUB-THEMES</th>
<th>LINE NUMBERS</th>
<th>QUOTATION</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Knowledge (understanding) of HIV</strong></td>
<td>416</td>
<td>When someone has HIV, they have a blood illness</td>
</tr>
<tr>
<td><strong>Responses about the illness</strong></td>
<td>404</td>
<td>They say that I am HIV positive</td>
</tr>
<tr>
<td><strong>Participant’s explanation</strong></td>
<td>406</td>
<td>I am sick. I have blood that has HIV</td>
</tr>
<tr>
<td><strong>Discovery of HIV-who disclosed</strong></td>
<td>410</td>
<td>My mother</td>
</tr>
<tr>
<td><strong>Type of disclosure (full, partial, non-disclosure)</strong></td>
<td>404</td>
<td>They say that I am HIV positive</td>
</tr>
<tr>
<td><strong>Deception</strong></td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td><strong>2. Initial reactions</strong></td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td><strong>Feelings towards others</strong></td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td><strong>Feelings towards self</strong></td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>
3. Cognition/thoughts

<table>
<thead>
<tr>
<th></th>
<th>Towards self</th>
<th>Towards others</th>
<th>Towards illness</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n/a</td>
<td>n/a</td>
<td>416</td>
</tr>
</tbody>
</table>

- It’s like someone who has an illness that affects their legs, or head, or has eye ailments

4. Impact of HIV + status

<table>
<thead>
<tr>
<th></th>
<th>On participant</th>
<th>Others</th>
<th>Systems (school, church etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

5. Coping mechanisms

<table>
<thead>
<tr>
<th></th>
<th>Withdrawal</th>
<th>Acceptance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

6. Difficulties/challenges experienced

<table>
<thead>
<tr>
<th></th>
<th>Adherence</th>
<th>Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n/a</td>
<td>440, 450</td>
</tr>
</tbody>
</table>

- Sometimes I get sores; My eyes are easily affected by allergies
<table>
<thead>
<tr>
<th>Fear of rejection</th>
<th>n/a</th>
<th>n/a</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of judgement</td>
<td>511</td>
<td>Because they will pass it on (spread news about my HIV status)</td>
</tr>
<tr>
<td>Burden of secrecy</td>
<td>489, 511</td>
<td>No, nobody knows; because they will pass it on (spread news about HIV status)</td>
</tr>
<tr>
<td>Fear of stigmatisation</td>
<td>511</td>
<td>Because they will pass it on (spread news about HIV status)</td>
</tr>
<tr>
<td>Loss</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Misinformation</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

7. Seeking explanation | n/a | n/a |

8. Changes to be effected | n/a | n/a |

**Table 4: Participant 4**
<table>
<thead>
<tr>
<th>THEME &amp; SUB-THEMES</th>
<th>LINE NUMBERS</th>
<th>QUOTATION</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Knowledge (understanding) of HIV</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participants’ explanation</td>
<td>603,604</td>
<td>…if you have this kind of illness (HIV), you do not recover, and this illness does not go away…</td>
</tr>
<tr>
<td>Responses about the illness (other source)</td>
<td>717,718;730,731</td>
<td>you contract HIV when you sleep with someone (sexually) without using a condom; or you can be born with it</td>
</tr>
<tr>
<td>Discovery of HIV-who disclosed</td>
<td>572,573,574</td>
<td>The illness doesn’t go away, but you need to look after yourself when you have it</td>
</tr>
<tr>
<td>Type of disclosure (full, partial, non-disclosure)</td>
<td>573</td>
<td>My mother didn’t tell me my Grade 5 teacher explained what it means when you have HIV, the kind of pills you take, so I saw that my pills looked like the ones she had showed us or that she told us about, so I realised then that I have HIV</td>
</tr>
<tr>
<td>Deception</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td><strong>2. Initial reactions</strong></td>
<td>583</td>
<td>I felt okay. I was okay.</td>
</tr>
<tr>
<td>Feelings towards others</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Feelings towards self</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td><strong>3. Cognition/thoughts</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Towards self</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Towards others</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Towards illness</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

### 4. Impact of HIV + status

| On participant | 619 | I only miss school when I come to the hospital |
| Others | n/a | n/a |
| Systems (school, church etc.) | n/a | n/a |

### 5. Coping mechanisms

| Withdrawal | n/a | n/a |
| Acceptance | 607,608 | …when someone says something horrible just tell them that it’s fine and be happy and don’t let it play in your mind and bother you |

### 6. Difficulties/challenges experienced

| Adherence | 593 | But the thing that I struggle with …those pills |
| Illness | n/a | n/a |
| Fear of rejection | 623,624,625 | My mom said that when you have HIV you shouldn’t tell people about it because people will (judge) you based on that and you will feel sad and cry |
| Fear of judgement | 623,624,625 | |

77
<table>
<thead>
<tr>
<th>Subject</th>
<th>Code(s)</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burden of secrecy</td>
<td>623</td>
<td>and you will feel hurt No, only my mom, dad and I know about it, even my mom’s family doesn’t know about it</td>
</tr>
<tr>
<td>Fear of stigmatisation</td>
<td>623,624,625</td>
<td>My mom said that when you have HIV you shouldn’t tell people about it because people will gage (judge) you based on that and you will feel sad and cry and you will feel hurt</td>
</tr>
<tr>
<td>Loss</td>
<td>660</td>
<td>That I have HIV and that I am not like other children</td>
</tr>
<tr>
<td>Misinformation</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>7. Seeking explanation</td>
<td>579, 711</td>
<td>I asked her “mom when you have HIV, do you drink pills hey; I want to know, if you have HIV, do you end up being a granny still having HIV?</td>
</tr>
<tr>
<td>8. Changes to be effected</td>
<td>686,688</td>
<td>I would change my life; I would play with people who like me</td>
</tr>
</tbody>
</table>

Table 5: Group 1
<table>
<thead>
<tr>
<th>THEME &amp; SUB-THEMES</th>
<th>LINE NUMBERS</th>
<th>QUOTATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Knowledge (understanding) of HIV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Responses about the illness</td>
<td>794</td>
<td>She said that my blood is dirty, it has a virus</td>
</tr>
<tr>
<td>Participant's explanation</td>
<td>779, 787, 780</td>
<td>My grandmother told me; I was told by my mother</td>
</tr>
<tr>
<td>Discovery of HIV-who disclosed</td>
<td></td>
<td>I am drinking them because I have HIV</td>
</tr>
<tr>
<td>Type of disclosure (full, partial, non-disclosure)</td>
<td>780</td>
<td></td>
</tr>
<tr>
<td>Deception</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>2. Initial reactions</td>
<td>815</td>
<td>I was scared, because I always see something about people dying of HIV on television</td>
</tr>
<tr>
<td>Feelings towards others</td>
<td>839</td>
<td>I feel good; She’s also supportive</td>
</tr>
<tr>
<td>Feelings towards self</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>3. Cognition/thoughts</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Towards self</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td></td>
<td>824, 868, 870</td>
<td>I feel bad. I feel as if I am lonely; I felt bad… That my father kept this secret from me</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td><strong>Towards others</strong></td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td><strong>Towards illness</strong></td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td><strong>4. Impact of HIV + status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>On participant</em></td>
<td>868,870</td>
<td>I felt bad; …my father kept this secret from me</td>
</tr>
<tr>
<td><em>Others</em></td>
<td>858,859,860</td>
<td>When he was told to go get tested he said that he did not have HIV. Thereafter when he died, my mother told me that my father had HIV but that he did not want to tell me.</td>
</tr>
<tr>
<td><em>Systems (school, church etc.)</em></td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td><strong>5. Coping mechanisms</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Withdrawal</em></td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td><em>Acceptance</em></td>
<td>1004</td>
<td>So that I can go to school and carry on with life</td>
</tr>
<tr>
<td><strong>6. Difficulties/challenges experienced</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Adherence</em></td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Illness</td>
<td>Fear of rejection</td>
</tr>
<tr>
<td>-------------------------</td>
<td>---------</td>
<td>-------------------</td>
</tr>
<tr>
<td></td>
<td>n/a</td>
<td>If she or he would be supportive and not tell others I would be okay</td>
</tr>
<tr>
<td></td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n/a</td>
<td></td>
</tr>
</tbody>
</table>

81
7. Seeking explanation | n/a | n/a

8. Changes to be effected | 1020, 1022, 1030, 1032 | I wish I could change how I eat because I eat too much; I want to stop beating up girls; I would change that I drink my pills and be healed; I do, but I want to recover

Table 6: Group 2

<table>
<thead>
<tr>
<th>THEME &amp; SUB-THEMES</th>
<th>LINE NUMBERS</th>
<th>QUOTATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Knowledge (understanding) of HIV</td>
<td>1071, 1086</td>
<td>My mother told me that I have HIV</td>
</tr>
<tr>
<td></td>
<td>1073</td>
<td>Kidney stones</td>
</tr>
<tr>
<td></td>
<td>1080</td>
<td>They tell me it is for the pain</td>
</tr>
<tr>
<td></td>
<td>1071</td>
<td>My mother told me that I have HIV</td>
</tr>
<tr>
<td></td>
<td>1071, 1073</td>
<td>My mother told me that I have HIV; Kidney stones</td>
</tr>
<tr>
<td>Deception</td>
<td>Kidney stones</td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td>--------------</td>
<td></td>
</tr>
<tr>
<td>1073</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Initial reactions

<table>
<thead>
<tr>
<th>Feelings towards others</th>
<th>Feelings towards self</th>
<th>n/a</th>
<th>n/a</th>
<th>n/a</th>
</tr>
</thead>
</table>

3. Cognition/thoughts

<table>
<thead>
<tr>
<th>Towards self</th>
<th>Towards others</th>
<th>Towards illness</th>
<th>n/a</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>061,1069</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>1063,1064</td>
<td>n/a</td>
<td>n/a</td>
<td></td>
</tr>
</tbody>
</table>

So that we can be like other children and be okay; So that I can be like other children and be healed so that people don’t know what illness you have and that they don’t keep asking what is wrong with me or looking at me strangely

4. Impact of HIV + status

<table>
<thead>
<tr>
<th>On participant</th>
<th>Others</th>
<th>Systems (school, church etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1066</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

I say that I come to hospital so that I can be like other children

5. Coping mechanisms

<table>
<thead>
<tr>
<th>Withdrawal</th>
<th>n/a</th>
<th>n/a</th>
</tr>
</thead>
</table>

83
<table>
<thead>
<tr>
<th>Acceptance</th>
<th>n/a</th>
<th>n/a</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Difficulties/challenges experienced</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adherence</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Illness</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Fear of rejection</td>
<td>1086, 1087</td>
<td>there’s no way you can tell people that you have it, only your family</td>
</tr>
<tr>
<td>Fear of judgement</td>
<td>1086, 1087</td>
<td>there’s no way you can tell people that you have it, only your family;</td>
</tr>
<tr>
<td>Burden of secrecy</td>
<td>1086, 1087</td>
<td>there’s no way you can tell people that you have it, only your family</td>
</tr>
<tr>
<td>Fear of stigmatisation</td>
<td>1086, 1087</td>
<td>there’s no way you can tell people that you have it, only your family</td>
</tr>
<tr>
<td>Loss</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Misinformation</td>
<td>1073</td>
<td>Kidney stones</td>
</tr>
<tr>
<td>7. Seeking explanation</td>
<td>n/a</td>
<td>I don’t understand but I feel okay about it; Why am I drinking pills endlessly, and when I miss taking them, you say that I would die, why?</td>
</tr>
<tr>
<td>8. Changes to be effected</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

Table 7: Group 3
<table>
<thead>
<tr>
<th>THEME &amp; SUB-THEMES</th>
<th>LINE NUMBERS</th>
<th>QUOTATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Knowledge (understanding) of HIV</td>
<td>1129,1133</td>
<td>Because I have HIV; Because of HIV</td>
</tr>
<tr>
<td>Responses about the illness</td>
<td>1151</td>
<td>She said because I drink pills like my mom then I have HIV</td>
</tr>
<tr>
<td>Participant’s explanation</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Discovery of HIV-who disclosed</td>
<td>1147,1155,1169</td>
<td>My sister; My aunt; My grandmother</td>
</tr>
<tr>
<td>Type of disclosure (full, partial, non-disclosure)</td>
<td>1129,1133</td>
<td>Because I have HIV; Because of HIV</td>
</tr>
<tr>
<td>Deception</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>2. Initial reactions</td>
<td>1189,1203,1209</td>
<td>I was surprised; I got up and left; I wasn’t okay</td>
</tr>
<tr>
<td>Feelings towards others</td>
<td>1248</td>
<td>I don’t care anymore</td>
</tr>
<tr>
<td>Feelings towards self</td>
<td>1269</td>
<td>I feel like I am the same person</td>
</tr>
<tr>
<td>3. Cognition/thoughts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Towards self</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Towards others</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Towards illness</td>
<td>1249</td>
<td>It makes me angry</td>
</tr>
<tr>
<td>4. Impact of HIV + status</td>
<td>On participant</td>
<td>1249</td>
</tr>
<tr>
<td>--------------------------</td>
<td>---------------</td>
<td>------</td>
</tr>
<tr>
<td>Others</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Systems (school, church etc.)</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5. Coping mechanisms</th>
<th>Withdrawal</th>
<th>n/a</th>
<th>n/a</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6. Difficulties/challenges experienced</th>
<th>Adherence</th>
<th>1319,1320</th>
<th>Because sometimes when I am with my friends I would get called by my family to tell me that I need to go home and go take my medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness</td>
<td>n/a</td>
<td>n/a</td>
<td>I don’t tell them; I don’t tell them; I don’t tell them; I’d tell my friends that I have to be sent somewhere by an elder so then I had to leave.</td>
</tr>
<tr>
<td>Fear of rejection</td>
<td>1261,1263,1265</td>
<td>I don’t tell them; I don’t tell them; I don’t tell them; I’d tell my friends that I have to be sent somewhere by an elder so then I had to leave.</td>
<td></td>
</tr>
<tr>
<td>Fear of judgement</td>
<td>1261,1263,1265</td>
<td>I don’t tell them; I don’t tell them; I don’t tell them; I’d tell my friends that I have to be sent somewhere by an elder so then I had to leave.</td>
<td></td>
</tr>
<tr>
<td>Burden of secrecy</td>
<td>1307,1308,1309,1319,1320</td>
<td>I don’t tell them; I don’t tell them; I don’t tell them; I’d tell my friends that I have to be sent somewhere by an elder so then I had to leave.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Perception</th>
<th>Code Numbers</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of stigmatisation</td>
<td>1319,1320</td>
<td>when I am with my friends I would get called by my family to tell me that I need to go home and go take my medication</td>
</tr>
<tr>
<td></td>
<td>1166,1167</td>
<td>Because sometimes when I am with my friends I would get called by my family to tell me that I need to go home and go take my medication</td>
</tr>
<tr>
<td></td>
<td>n/a</td>
<td>your parents died before they could tell you?; Yes</td>
</tr>
<tr>
<td>Loss</td>
<td>1333,1334,1175,1189,1190</td>
<td>What I would like to know is that if you drink your medication well, can they tell you to stop drinking them at some point?; I wanted to know what was wrong with me; I asked my aunt how come my brother who is my mother’s child does not have it</td>
</tr>
<tr>
<td>Misinformation</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>7. Seeking explanation</td>
<td>1304,1317,1325</td>
<td>I’d ask that you’d remove the HIV; To change the HIV status; Mumbles about also changing status</td>
</tr>
</tbody>
</table>
4.4. Summary of the results

The researcher used Smith et al., (1999) IPA method to extrapolate themes and sub-themes from the interview transcriptions. From these themes, there were some commonalities among more than half of the participants and only a few unique findings. Out of 17 participants, 13 were fully aware of their HIV status. Of the 13 participants, some were able to explain their illness and how it is transmitted, while others had a vague idea about the illness. The other four participants were unaware of their HIV status. Instead, they had been deceived into believing that they collect medication to treat a mysterious illness, but they are not aware that their real illness is due to a positive HIV status.

Threats are used as a ploy to ensure that the participants adhere to their ART medication. Upon discovering their positive HIV status, participants’ initial reactions varied from shock, anger and sadness but as time passed, they accepted their positive HIV status. However, two of the 13 participants struggled with feelings of anger, and have not yet fully accepted their positive HIV status. Four (4) participants sought more information about HIV and its ramifications during the interview sessions. Also notable was the fact that participants who knew their HIV status stated that being HIV positive had not changed their lives much. However, the participants experienced the following challenges:

- Adherence to medication
- Illness
- Fear of rejection
- Fear of stigma
• Fear of judgement

• The burden of secrecy

• Loss

• Misinformation and deception

Of the 13 participants who knew their status, 4 stated that they wished they could remove their positive HIV status or be healed, while the other participants were concerned with developmentally aligned desired changes, such as maintaining a healthy weight or how to interact with the opposite sex. The discussion of the findings of this study is dealt with in Chapter 5.
CHAPTER FIVE
DISCUSSION AND CONCLUSION

5.1. Introduction

In this chapter, the researcher discusses the results of the study. Through the emerging themes, the researcher looked at the impact of a positive HIV status on participants and the coping mechanisms employed to cope with being HIV positive. Also to be discussed are the challenges that these participants are also discussed. In exploring how the participants understand the phenomena at hand namely, coping with being HIV positive, the researcher uses quotations from the interview transcripts in order to highlight and substantiate the themes. Thereafter, the limitations of the study are discussed and the conclusions are drawn from the findings. Recommendations concerning future research are given.

5.2. Brief background information

To put the reader into perspective, a brief background on the participants who took part in this study is given. The participants were all patients in the paediatric HIV unit at the Dr George Mukhari Academic hospital in the Ga-Rankuwa Township with ages ranging from 9 years to 16 years. The participants were at different developmental stages. All the participants were on antiretroviral medication, which they collect monthly from the aforementioned hospital.

This hospital is a referral hospital, which serves the North West province and other adjacent areas to Pretoria including far-flung areas such as Polokwane and its outlying districts. Therefore, the
referred patients come from within the Ga-Rankuwa and Soshanguve areas including other areas within the North West and Limpopo provinces. Regarding the residential areas in which the participants lived or reside, 1 of the participants resides in Ga-Rankuwa, 12 reside in Soshanguve, 3 reside in Mabopane, 1 participant is from the North West, 1 from Hammanskraal and 1 participant was from an undisclosed area. The participants all spoke and understood Sepedi or Setswana and expressed themselves in these languages. Analysis of the participants’ responses was done utilising Interpretative Phenomenological Analysis (IPA) as a method of choice. Emerging themes that were a common thread among the participant were analysed into clusters after verification by the assistant researcher therefore establishing the trustworthiness and dependability of the results. The common emergent themes, which link with the literature in chapter 2, are as follows:

- Knowledge of HIV
- Initial reactions regarding their HIV status
- Cognitions or thoughts
- Impact of HIV positive status
- Coping mechanisms utilised by the participants
- Difficulties or challenges experienced by participants
- Seeking of information
- Desired changes to be effected by participants
5.3. Discussion of the findings

Based on the findings of the study it appears that participants experienced some psychological distress arising from finding out that they are HIV positive. The researcher intends to discuss the findings based on the areas that her research focused on, including the participants’ responses to the interview guide.

5.3.1. Knowledge of HIV

This refers to what the participant understands about their illness and how much they know about HIV. This also ties in with whether the parents or caregivers of the child have disclosed the child’s HIV positive status fully, partially or not at all. Partial disclosure means that the child may be receiving treatment for HIV and/or a related illness, but the parents or caregivers deceive the child into believing that the HIV related illness is the main illness for which the child is receiving treatment. According to the findings of Antle et al., (2001) disclosure may be partial, where the child is informed only of the HIV related illnesses that he or she is being treated for, or it may be non-existent. When asked why they were collecting their medication, four participants’ responses were similar and this is highlighted by one participant’s response, “They said that I came so that the doctor can check if I am still okay. That I drink treatment. So that I do not die. As far as I know or I am concerned, I am not ill. For my leg.” As far as the participant knows, the treatment he is on is for his leg, which broke because of a car accident more than five years ago. He is unaware of the fact that he has HIV.
5.3.1.1. Responses related to illness (HIV)

This refers to what the participants were told concerning their illness, either by the parents, caregivers or by the medical staff. Depending on the participant’s age, he or she may not be able to internalise the meaning of what was said about their positive HIV diagnosis. Children may simply repeat what they have been told by an adult and not necessarily process the information in full. Looking at the participants’ varying ages, this is very likely to be the case when taking into account Piaget’s stages of development. He suggests that the concrete operational stage and takes place approximately from age seven to eleven years. During this stage, a child is able to reason and understand others around them, as their thought process becomes more logical (Bukatko & Daehler, 2001). The final stage is the formal operational stage, where children 11 years and beyond have a more developed ability to think more abstractly and logically (Bukatko & Daehler, 2001). Thus, children can understand the meaning of being diagnosed with HIV if they are given age appropriate information, shown by the similar responses of the participants who were aware of their positive HIV status.

According to van Dyk (2012), children between the ages 5 years and 10 years are developmentally at the moral realism stage and they become strict about abiding to rules. The children also tend to believe that what figures of authority tell them is the absolute truth. One participant demonstrates this when he said, “They said that I came (to hospital) so that the doctor can check if I am still okay. As far as I know or I am concerned, I am not ill. They say that I would get sick if I did not drink my treatment and that I would die if I did not drink it and that the treatment is very important.” This particular participant was 14 years old, which is well above the ages referred to by van Dyk (2012),
and should be in the operational stage according to Piaget. A possibility exists that the participant’s obedience may possibly be fuelled by lack of knowledge and the fear of dying.

5.3.1.2. **Participants’ understanding of HIV**

This refers to what the participant made of what their illness means to them. The participants were asked to explain according to their own understanding and the meaning attached by them to the disease. Craig (1996, in Hook et al., 2002) referred to three principal domains of development namely the physical, cognitive and psychosocial domain. The cognitive domain refers to the mental capabilities, thought organisation and even mental activities. This was precisely the reason that the participants were asked to explain what they understood their illness to be to the researcher.

Some participants expressed that someone else said that they have an illness, and thus they may not be internalising the concept of HIV at hand. “They say that I am HIV positive. She said that my blood is dirty, it has a virus.” As with the findings of this study, although the participants whose caregivers fully disclosed their illness to them were aware that HIV is a virus that is found in blood, some did not understand that it is incurable. The participants associated drinking medication to healing. “I feel okay. Since my mother told me that by drinking my medication, I will be okay if I drink it every day. I believe I will be healed”.

According to the APA (2013), children who were perinatally infected with HIV may experience hindrances in developing cognitively. It may be likely to be the case with some of the participants, based on their ages and their level of understanding. However, another reason could be that the participants were not equipped with age appropriate information concerning HIV, hence their limited understanding of the illness.
5.3.1.3. **Source of information regarding participants’ HIV status**

This refers to who informed the participant about their positive HIV status. The issue of disclosure of HIV in paediatrics is rather complex. The study revealed that of the 13 participants who were aware of their positive HIV status, a nursing sister disclosed to only one of them. The participant’s response to the question ‘who told you?’ was, “This other nurse.” A family member informed the remaining 12 participants. Various factors- such as fear of stigma and denial- influence the decision to disclose. This is especially true in paediatric disclosure as it is an intricate in nature. Some other factors such as the systems in which the parents or caregivers and children exist in, may not enable disclosure to children.

5.3.1.4. **Disclosure**

The communication that exists between parents or caregivers and children, is a factor that can be based on the type of parental relationship that exists between parents and children. This is also true for HIV disclosure. There are three categories of disclosure, namely *full disclosure, partial disclosure* and *non-disclosure*. Full disclosure means that the child is given full information about HIV. Thirteen of the participants in this study said that their caregivers fully disclosed the illness to them. Partial disclosure means that the child is informed only of the other HIV related illnesses that they are being treated for. Only one participant in this study was partially disclosed to. Three participants did not know that they had HIV. This is clearly highlighted by one respondent who said, “As far as I know or I am concerned, I am not ill.” Non-disclosure means that nothing related to the illness is discussed with the child (Antle et al., 2001). Partial disclosure and non-disclosure may be due to lack of knowledge, denial, shame, fear and/or cultural beliefs of the family. Participants who were aware of their HIV status similarly responded that nobody else knows that they have HIV.
One participant said, “Only my mom, dad and I know about it, even my mom’s family doesn’t know about it. My mom said that when you have HIV you shouldn’t tell people about it because people will “gage” (judge) you based on that….” It may be the parents’ wish to protect their child against judgements and stigma. This finding is supported by Vranda and Mothi (2013) who said that parents may wish to protect their children from being discriminated against, especially in the scholastic context. A finding in this study was that after some of the participants’ biological parents had died, the burden of disclosing the participants’ positive HIV status was upon those who were left to care for them.

5.3.1.5. **Deception by significant others**

Deception refers to when the participants are told that they have a different illness other that HIV. It may be possible that the participants have a secondary illness that they suffer from due to being HIV positive, but the real nature of their main illness remains concealed. Parents or caregivers may partially disclose, and this involves this deception for various reasons. Parents may wish to protect their children from being discriminated against. Four participants did not know that they had HIV but were informed that they need to drink their medication diligently. One participant responded by saying, “Isn’t it if I do not drink this treatment I would get sick and die… For my leg… A car knocked me down… A long time ago. They say that I would get sick if I did not drink my treatment and that I would die if I did not drink it and that the treatment is very important.”
5.3.2. Initial reactions and feelings

The participants’ initial reaction reactions varied. They varied from anger, shock, fear and indifference perhaps due to the various developmental stages of the participants. It was expected that the older participants (11 years and above) would be able to provide more comprehensive explanations concerning their past emotional experiences in relation to their positive HIV diagnosis. This was not the case with some of the participants. According to Paquette and Ryan (2001), maturity of a child may be related to their chronosystem, which relates to time in relation to a child’s environment. There exists a possibility that the participants were not mature enough at the time of disclosure, hence their inability to fully express their thoughts and feelings about that experience. Hook et al., (2002), also referred to a child’s readiness which is defined as “the point at which an individual can be said to have matured sufficiently to benefit from a particular learning experience” (p.22). It is likely that some of the participants in the study may not fully understand the complexities and seriousness of their illness, as they have not been able to internalise what their parents or caregivers have revealed about their HIV status.

The responses of these participants were similar concerning how they felt when they were initially told about their illness, three participants stated, “I didn’t feel okay. I was okay. I wasn’t okay”. One issue to be mindful of regarding how participants expressed their emotions is the hindrance of language. There are fundamental differences between the English and Sepedi languages, where one word may be used to describe various emotions in Sepedi, whereas various words can be used to express related words in English. For example, one participant communicated, through what he did after being disclosed to, that he was angry.
When asked a follow up question about feelings, “…what did you do when she told you that you had HIV…? Did you get angry?” the participant responded, “I got up and left. I went to my friends. I wasn’t okay”. This indicates that the participant was possibly angry, overwhelmed or in shock. On the other hand, another participant was able to elaborate and said, “I was scared, because I always see something about people dying of HIV on television, but then my mother said that I should not be scared... and that as long as I drink my treatment I will be okay”. Most of the participants stated that they were “fine” after the disclosure, indicating that there were no long lasting negative psychological effects.

5.3.2.1. Feelings of anger and shame

Although most of the participants stated that they had accepted their positive HIV status, one participant expressed feelings of shame and anger regarding HIV diagnosis. When he was asked how he felt when he saw advertisements on television talking about HIV, he said, “I don’t feel proud, it makes me angry.” This response may suggest that the participant has not yet completely accepted his positive HIV status, as he alludes to the fact that he did not want to be constantly reminded of his status through television advertisements. He said, “Why do they keep advertising it?”

5.3.2.2. Cognitions based on comparison with others

Some of the participants made social comparisons between themselves and other people. This may suggest that they think differently of themselves, as they are HIV positive. These are some of their excerpts, “So that we can be like other children and be okay”; “I say that I come to the hospital so that I can be like other children”; “So that I can be like other children and be healed.”
Some of the participants compared themselves socially to other children, implying that there is something wrong with them. This finding appears to endorse the finding of Mak et al., (2007) who alludes that HIV and AIDS may be a form of social stigma, where as a member of a “devalued group, being aware of the prejudice, stereotype and discrimination in society, they endorse and internalise these beliefs, feelings and behaviours’ (pp. 1550).

5.3.3. Impact of HIV positive status

HIV is not without any effects on the participants, family members and other systems like school. The impact can be psychological, psychosocial, financial and even spiritual in nature.

5.3.3.1. Participants and family

Children react in different ways upon discovering their positive HIV status. This may be because children are in a state of constant flux developmentally as well as cognitively and this influences disclosure immensely in terms of their ability to deal with the revelation. Children with HIV function within various contexts such as school, home and church like any other children, if they adhere to their treatment and undergo regular usually monthly check-ups with their health practitioners. This has implications for the participants. The participants had to miss school for the day on which they collected their medication. This could result in the decline of their scholastic performance. The participants’ family members assumed the responsibility of taking them to the hospital on those particular days. A family member accompanied all the participants in this study. This has financial implications for the family members as they make use public transport.
It is a challenge for family members to care for children who constantly need medical care, as they may have to invest both their own time and funds. Billing et al., (2002) alluded to the fact that children who have physical or medical conditions showed to be difficult to care for. Caregivers have to adapt to caring for an additional member of the family with limited resources, such as time, money and physical health. This is illustrated by the following: “I usually come with my aunt but she’s ill, so I am here with my grandmother”. The primary caregivers have to ensure that another family member assumes responsibility of the child in the case that they are unable to meet the child’s needs. Relatives who are willing and are available to care for children may be fewer than required. This burden of care and support, based on the findings of this study, is most prevalent among children whose parents have succumbed to the illness. This finding is in agreement with the findings by Maman, et al., (2009).

5.3.3.2. Systems (e.g. schools)

Most of the participants in this study stated that they came to the hospital at least once a month to collect their medication and to undergo regular check-ups. This process may take a whole day, especially if the participant is required to see other health practitioners such as dieticians. This means that the participant will miss a day of school monthly. This may mean that the learner relies on the teacher or friends for assistance with catching up with schoolwork. Some participants seemed to be struggling at school; they mentioned that they wanted to impress their parents by passing this year. This is illustrated by the following quote: “So that I can pass at school. So that I can please my parents because they said that they would like to see me pass this year so that is what forces me. I want to make them happy.” Teachers may have to do additional work in assisting participants as they are regularly absent from school. Other authors did not previously discover this finding.
5.3.4. **Coping mechanisms**

How children make sense of situations is dependent on various factors. These factors include but are not limited to the child’s age, level of understanding and developmental level. According to *nature versus nurture* perspective, Hook et al. (2002), suggest that the two factors are constantly in interaction and they affect individuals differently. This means that people react to different situations in various ways, where emotional intelligence and self-regulation skills serve an important purpose. It is thus not possible to predict how different individuals may react in particular situations or environments; this was also another finding of this study. The participants did not react the same nor did they deal with the disclosure in the same way.

5.3.4.1. **Acceptance**

Taking into consideration the various ages of the participants and their developmental stages, some of the participants may not have fully yet grasped the severity of their illness due to not grasping the concept of HIV fully. They were unaware that HIV is an incurable disease. Another possibility could be that the information they received from their parents or caregivers insinuated that if they adhered to their medication, they would recover fully. Five participants who associated drinking their medication with the notion of full recovery from the illness gave evidence to this factor. They said, “*I would change that I drink my pills and be healed. So that I can be like other children and be healed.... can take care of me and take me to the hospital so that I can be healed.*” Almost all of the participants who are fully aware of their HIV positive status said that they were dealing and coping with their illness. They also reflected on the fact that they are living a normal life. Not one of the participants alluded to being withdrawn from their various contexts namely, from friends and family.
Of the 13 participants, only one was still struggling with coming to terms with having HIV. “It makes me angry. Why do they keep advertising it?”

Weiner (1993, cited in Mak et al., 2007) explains that when an individual becomes aware of the cause of his or her illness, it can have an effect on his or her emotional state and on how he or she behaves within his or her context. It is suggested that children develop various strategies for coping and adapting. Vygotsky’s contextual theory suggests that children use tools of intellectual adaptation to develop different strategies to function adequately. Vorster (2003) states that, “families are rule-governed systems” (p. 35). Considering this from a systemic viewpoint, a possibility exists that the rules of the system from which the participant comes are rigid, thus the system is not open to feedback.

5.3.5. Difficulties and challenges experienced by HIV positive participants

The participants may have said that they are leading relatively normal lives in light of being diagnosed with HIV however; this does not mean that there are no challenges that they have to deal with.

5.3.5.1. Adherence

Some participants explained that being mindful of time in relation to their location at any point was imperative. They reported that they were mindful that they are home at the time their medication was to be administered to them. The participants understood the importance of taking their ARV medication on time, the same time every day. The participants even adapted their lives in terms of having reminders set on their phones or being aware of time by wearing a watch. According to Vygotsky’s of zone of proximal development, with guidance from adults, children learn to master
tasks and therefore become more independent (Louw & Louw, 2007). This however, does not mean that there were no challenges. Some participants said that they usually had to exit social situations not because they wanted to, but because it was time to drink their medication.

One said, “…because you find that at times I am playing with friends and I have to keep looking at my watch to ensure that I can leave on time and don’t miss my dosage. I’d tell my friends that I have to be sent somewhere by an elder so then I had to leave”.

5.3.5.2. Illness

Three participants reported that they get ill frequently and they may have to come to the hospital more often than others do. Some of the participants had been suffering from HIV related illness that they were being treated for. When asked what illnesses they suffered from, three participants said “Kidney stones. I don’t know but I was told that my ears have a problem and that they have something inside and the doctor said that they need to take those (things) out before they (ears) get blocked. My eyes are easily affected by allergies.”

5.3.5.3. Fear of rejection

Of the 13 participants who were fully aware of their HIV status, one said that people other than his family members were aware of his HIV positive status. The rest of the participants said that they would not want to expose their statuses, some not even to their extended families such as grandmother, aunt or uncle. When asked if they would disclose to their teachers about their positive
HIV status, the participants said that there would be provisional conditions about disclosure agreed to by the teacher.

One participant said, “If she or he would be supportive and not tell others I would be okay.” Another participant said, “Isn’t it that some people see HIV as a huge illness, they say that-others- they don’t want to be your friend because you would infect them, they would do that. I have a lot of friends in class, so then they would not want to be my friends anymore”.

My mother said that this should be our secret and if I want to I can talk about it, but if I do then people will treat me like I am not a human being”. Clearly, this fear can also be linked to stigma and judgement, as stigma is characterised by exclusion, rejection, blame or devaluation, confirming the findings of Weiss, Ramakrishna and Somma (2006), cited in Gernberg et al., (2009).

One participant experienced bullying, although this was not brought on by her positive HIV status. This could be an isolated incident. This particular participant mentioned that she had trouble with vision at school. She explained that she suffered from eye allergies. She said, “My eyes are easily affected by allergies. The medication helps but I cannot see properly at times at school. The boys say that my eyes are brown, chocolate-like and I feel hurt about that”.

Another participant however, instigated the bullying behaviour. According to Billing et al. (2002), there are variables that may contribute to a child exhibiting behavioural problems, such as child abuse, discrimination, bullying, child neglect and even learning difficulties. I want to stop beating up girls (smiles) because they like to bother me a lot. They say that I have a big nose and when I run after them they run away” he said. This participant was bullied and also bullying, which simply perpetuates the cycle of aggression.
5.3.5.4. Fear of judgement

Disclosure is a difficult issue in paediatrics. Parents may often than not feel ashamed of disclosing their HIV positive status to their HIV positive child or children. Disclosing to children about their HIV status may bear with it complexities such as explicating the routes of infection—especially if sexually transmitted—and the stigma attached to it (WHO, 2010).

Children may not be mature enough to understand the complex issues related to sexual matters and love, thus parents may feel ashamed to explain the child or children’s HIV positive status to them. This does not mean that children are not afraid of being judged. Participants who were aware of their positive HIV status were told by their parents or caregivers not to disclose to anybody else. The same principle is applicable here concerning the fear of being judged, as judgement is closely related to stigma. Some of the participants said, “so that people don’t know what illness I have and that they don’t keep asking what is wrong with me or looking at me strangely. No, only my mom, dad and I know about it, even my mom’s family doesn’t know about it. My mom said that when you have HIV you shouldn’t tell people about it because people will “gage” (judge) you based on that....”

5.3.5.5. Burden of secrecy

In investigating the dynamics that play a pivotal role in considering disclosure to children, the International Centres for AIDS Care and Treatment Programs (ICAP, 1999) took heed and stated “the needs, feelings, beliefs of the child, as well as the needs, feelings, beliefs of the parent(s)/caretaker(s) are to be considered” (p. 6). Either this may lead to the parents and caregivers
deceiving the child about his or her status, or partially informing the child what they think is appropriate.

The participants who were fully aware of their HIV status were warned against disclosing their status to outsiders for fear of stigmatisation and judgements. “No, only my mom, dad and I know about it, even my mom’s family doesn’t know about it. My mom said that when you have HIV you shouldn’t tell people about it. Only my parents and I know.” Not only is this burdensome to the children, but also on the parents. Antle et al. (2001), state that by being aware of their own status as well as that of their children, parents bear this heavy emotional burden and they can be consumed by feelings of guilt.

5.3.5.6. Fear of stigma

Literature pointed out important factors about stigma. It was established that blame and othering are related to how someone was infected, especially concerning sexual practices and availability of protection in the form of condoms. The PLWHA were labelled as ‘immoral, reckless and even irresponsible’ in term of being infected, labels which were highly judgemental and could elicit self-stigmatisation for PLWHA (Maman et al., 2009). One participant explained that his father did not disclose his HIV to the family. On further investigation by the researcher, it was evident that parent-child boundaries were diffused. The participant stated, “When he was told to go get tested he said that he did not have HIV. Thereafter when he died, my mother told me that my father had HIV but that he did not want to tell me. That my father kept this secret from me. He used to come home late at night, coming from his other girlfriends”. The manner in which the participant’s mother disclosed to him was through judging and blaming his father. It is likely that because of his implied infidelity, the
participant’s father he was harshly judged and blamed. Behaviours of PLWHA contributed to the degree of stigmatisation they experienced, especially those pertaining to sexual health and practices post HIV positive status discover (Maman et al., 2009).

Stigma has also been related to gossip. One participant stated, “I don’t know. I heard someone last year. There’s someone who has HIV and then said they do not want to be friends with that person anymore because they would get infected. When I asked how then I was told that when the other person coughs they do not close their mouth so then the virus would “leave” through the cough and they would get it.” It seems that the participants are aware that talking about their HIV status would potentially expose them to discrimination and being labelled or othered, as was found in this study. Gossip and public shaming have also been reported as a way of stigmatisation (Maman et al., 2009).

5.3.5.7. Loss

Some of the participants had been orphaned because of HIV. Loss was a difficult issue to deal with for some of the participants as some did become emotional when they spoke about their deceased parents. The participants had since been living with relatives, but they still found it difficult to talk about the loss of their parents. This is very much likely in the case of HIV/AIDS where children live with relatives after their parents succumb to death due to illness. Children may experience trauma after losing a parent and this may create a need for them to live with relatives, which may become comforting to be supported by other members of their family (Billing et al., 2002). Four participants had lost their parents to HIV and were living with relatives, thus confirming the findings of Billing et al., (2002). Bowlby’s (1969) analysis revealed that when children were informed sufficiently and truthfully about the death of a parent, they were able to deal with their loss more effectively.
Children deal with grief in various ways, and it is a unique experience for those who go through it, especially if the loss is of a parent.

One participant who became overwhelmed during the interview said, “My mother died, she is not here. I don’t even know her. They just explained to me that my mother died when I was young”. The participants said that they had some support from their family members, but for some of the participants, it clearly did not suffice. Bowlby (1998), states that because of the child’s continued yearning for his or her dead parent, some distressing situations may intensify this yearning when the child realises that he or she can no longer enjoy being comforted by his or her parent. Some participants whose positive HIV status was not disclosed to them were not told the truth about what killed their parents. One participant said, “I think she was killed. They say that she was killed. The people she was with. They poisoned her”. This misinformation or non-disclosure may not be beneficial for the child’s understanding of death and emotional well-being.

Parents and caregivers who are unable to deal with the intensity of their children’s feelings may be more inclined to discourage children from enquiring about the parent’s death (Bowlby, 1998). Unlike the participants who did not know their HIV status, those who were fully aware of their HIV positive status knew what happened to their deceased parents. They stated that they had lost a parent and knew that it was HIV related. “She said because I drink pills like my mom then I have HIV. I was staying with my mom and dad but they hadn’t told me by the time they died. So even my aunt when she found me here in hospital she had to tell me.”
5.3.5.8. Misinformation

One participant reported that his family members informed him to reduce the number of pills he was ingesting as he was taking too much medication. “They are okay, but they say that I should halve them.” Misleading children can be easy, especially if a relative who is an adult trying to help the child does this.

This may be due to the relative showing empathy due to the large quantity of medication the child may be ingesting, or simply due to lack of sufficient information and knowledge concerning how the child’s medication functions. Misinformation can also be in the form of deliberate deceit, which has been discussed under disclosure. (Refer to Paragraph 5.3.5.). There was however, no evidence in the literature to support this finding.

5.3.6. Seeking information

Although some participants were aware of their HIV status, they still asked for further information concerning their illness. They sought to understand why this illness did not go away and what it means to be HIV positive. “I want to know, if you have HIV, do you end up being a granny still having HIV?” This participant wanted to fully grasp what it meant to live with HIV as evidenced by the question. She showed genuine interest in wanting to know more about the illness. Another participant asked, “What I would like to know is that if you drink your medication well, can they tell you to stop drinking them at some point?” This shows that the participants have a need to know more about HIV, and the long lasting impact it will have on their lives. This information needs to be readily available to those who need it. The AIDS Consortium (2009, in van Dyk, 2012), states that
the HIV & AIDS charter advocates to maintain basic rights of people living with HIV and AIDS. The charter (cited in van Dyk, 2012) further states, “Children have the right to information and education concerning their human rights in the context of being HIV infected or affected” (p. 443).

5.3.7. Desired changes to be effected

The participants engaged in this ideally fantastical talk about changes that they wished they could make in their lives. Even so, most of the participants’ responses were in line with their developmental levels. Some participants wished that they could change certain aspects of their lives, such as being healthy, eating healthy and engaging in sports activities. Three participants wished that they did not have HIV as evidenced by their responses. “I’d ask that you’d remove the HIV. To change the HIV status. About HIV”. Some participants were under the impression that HIV is a curable illness. They understand HIV to be curable because they are on medication. “I would change that I drink my pills and be healed. I do, but I want to recover. I do, but I want to recover.” Some participants however, said that there is not much that they would want to change about their lives. There is no literature available to substantiate the findings about children with HIV engaging in fantasy talk.

5.4. Integration of results

In light of the results, HIV does affect the lives of children in various ways namely, psychologically, socially and educationally. The developmental level of a child is important when it comes to information processing and internalising that information. Thus, it is imperative to take into account that children reach maturity at various times. The child’s maturity level and living context can also influence how children cope with being HIV positive. The study sought to investigate the psychological effects (that is coping styles, emotional journeys, benefits of disclosure or lack
thereof) of an HIV positive status disclosure by parents or caregivers to children who are on ARV’s. As seen in the themes, most participants were able to somewhat express their feelings and views about HIV in this study. Some participants experienced fear, shock, anger and others were indifferent about discovering their positive HIV status. Participants were able to move past those emotions and adjust to their illness. They said that they were able to continue with life as normally as possible and that being HIV positive has not changed much how they live their daily lives. The study also sought to investigate the thoughts and feelings of the children at the time that their HIV status was disclosed to them. The general theme was that the participants expressed that they had adjusted to living with HIV, as they were reassured by their families that they would be healthy provided that they strictly adhered to their medication. Participants who lost their parents lived with their relatives, and this provided them with some comfort. The study was also, to investigate in which contexts (for example, school, home, church) they experience unpleasant emotions and thoughts and the reasons thereof. The general theme was that the participants had not disclosed their HIV status to other people. Although this was the case, they faced challenges in social situations, where there had to leave the company of friends early so that they can take their medication on time.

They had to miss one day of school per month, as they would spend it at the hospital to collect their medication. Others had to go to the hospital or stay home often that others did, as they were susceptible to illness. In addition to these challenges, some participants experienced bullying at school. Lastly, the study sought to explore challenges that the children face since being diagnosed with HIV. Themes that emerged were related to loss of one or both parents to HIV, fear of stigma, judgement, and rejection. In addition, children bore the burden of keeping their illness a secret. Some participants cited that having to drink their medication at the same time daily was challenging but
this was not in any way a serious challenge. Some participants also expressed that they suffer from other illnesses from time to time.

5.5. **Strengths and limitations of the study**

The findings from this study can help with future HIV research on children. Through this study, the researcher was able to obtain information regarding the feelings of participants in relation to disclosure as being HIV positive. The feelings varied from anger, sadness, fear, shock and indifference. The study also shows that although children may be informed about being HIV positive, it does not necessarily cause much upheaval in their daily lives. This also may be due to the ability of the child to understand what they are told by their parents or caregivers. The limitations of the study include the small sample size which may not fully represent the HIV positive population of children, and the results are not generalisable.

5.6. **Recommendations and future research**

In light of the findings, interventions such as family therapy may be considered for implementation to assist parents, caregivers and children. Firstly, parents and caregivers need to be prepared on how to disclose children’s positive HIV status to them, counselling and psychotherapy can be included as part of clinic visits where children collect their HART medication. Secondly, to help children adapt to their newly disclosed HIV positive status, counselling and psychotherapy should be applied as a principle to their routine check-ups as and when needed. The sessions may encompass issues like behavioural problems, such as bullying and being bullied, residual emotions such as anger and
resentment. Also, for children who have suffered loss of a significant family member to HIV/AIDS, grief counselling should be accessible to assist the children to deal with the loss.

Exploring the experiences of the caregivers as well as those of the child may bring to light the dynamics of the family system. Research on the need for support groups for children and parents could be undertaken, especially for those participants that have lost one or both parents to HIV/AIDS.

5.7. Conclusion

The researcher hopes that this study will prompt others in the field of psychology to conduct further studies related to HIV and children, particularly in townships. The researcher hopes that in light of the findings of the study, interventions can be developed, particularly in relation to imparting skills to parents to disclose their children’s positive HIV status. A model on how parents and caregivers can disclose to their children can be developed specifically to the context of this catchment area. In addition, a model on how to minimise stigma and judgement in this community can be developed to help community members to learn about HIV in general.
REFERENCES


APPENDICES

APPENDIX A: CONSENT FORM

SEFAKO MAKGATHO HEALTH SCIENCES UNIVERSITY ENGLISH CONSENT FORM

Name of Study

An exploration of the psychological effects of disclosure of an HIV positive status to children on ARVs at Dr George Mukhari Academic Hospital

I have heard the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressured to participate in any way.

I understand that participation in this Study is voluntary and that I may withdraw from it at any time and without supplying reasons. This will have no influence on the regular treatment that holds for my condition neither will it influence the care that I receive from my regular doctor.

I know that this Study has been approved by the Medunsa Campus Research and Ethics (MCREC), Sefako Makgatho Health Sciences University / Dr George Mukhari Hospital. I am fully aware that the interview will be audio taped and that the results of this Study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participate in this Study.

.................................................................................................................................
Name of volunteer                      Signature of volunteer or guardian.
.................................................................................................................................

Place.        Date            Witness

___________________________________________________________________________

Statement by the Researcher

I provided verbal information regarding this Study. I agree to answer any future questions concerning the Study as best as I am able will adhere to the approved protocol.

.................................................................................................................................

Name of Researcher  Signature  Date  Place
APPENDIX B: ASCENT FORM

SEFAKO MAKGATHO HEALTH SCIENCES ENGLISH CONSENT FORM

Statement concerning participation in a Research Project

Name of Study

An exploration of the psychological effects of disclosure of an HIV positive status to children on ARV's at Dr George Mukhari Hospital, Pretoria

I have heard what the study is about; I was given an opportunity to ask questions and enough time to decide if I want to do it. I have not been pressurized to participate in any way.

I understand that being in this Study is completely up to me and that I may stop it at any time and without supplying reasons. This will not stop me from getting my medication or treatment as I usually do.

I have been told what will happen with the information I give and that my name will not be included in the printed research document. I agree to this study, as long as my personal information is not included in the academic document that will be published.

.....................................  ..................................   ................................

Name    Date     Place

.....................................

Researcher
Statement concerning participation in a Research Project

Name of Study

An exploration of the psychological effects of disclosure of an HIV positive status to children on ARV’s at Dr George Mukhari Academic Hospital, Pretoria

My name is Lizzy and I am currently conducting a study for my degree in Clinical psychology. I would like you to participate in the above-mentioned study because I am interested to know more about how your illness has affected you.

The aims of this study:

- To explore psychological effects of HIV on children
- To explore the thoughts and feelings of children at the time of HIV disclosure
- To explore the contexts in which the experiences occur
- To explore the challenges that children face due to being HIV positive

What we will be doing is basically just talking about how your illness has impacted on you and how you deal with everything. I am going to record the conversation so that I don’t have to write notes, so that I can focus on what you are telling me. Remember you can pull out of the interview at any time if you would like to, without explaining why. This will have no influence on the regular treatment you receive from your doctor.

If you feel that you need to talk to someone else when you feel uncomfortable or when you experience overwhelming emotional distress, I can refer you to a clinical psychologist who can assist you in dealing with whatever emotional distress you experience. Please also note that there is no reward that will be offered to you for doing the interview with me.

Do you understand what I have just discussed with you? Do you have any questions for me?

Would you be interested in taking part? If yes, continue with consent. If no, thank the patient and keep looking.
APPENDIX D: BIOGRAPHICAL INFORMATION

PARENTS/GUARDIAN

Age____________________

Ethnicity_____________________

Gender_________________________

Home language______________________

Marital status________________________________________

Employment status______________________________________

Educational level (highest level completed) __________________________

CHILDREN

Place of residence (area)_____________________________________________

Child’s age and gender_____________________________________________

Child’s grade_________________________________________________

Number of children in the family___________________________________
APPENDIX E: INTERVIEW TRANSCRIPTS

R: We can start. So when you come to the hospital, how often do you come here?

P: A lot

R: How often-per month, year, week?

P: I come monthly

R: Okay, and who accompanies you?

P: I usually come with my aunt but she’s ill, so I am here with my grandmother

R: Okay, and did they explain to you how come you come to the hospital?

P: Yes

R: What did they say?

P: They said that I fetch medication because I have an illness

R: Mh, okay, did they explain to you what the illness is?

P: Yes

R: What did they say?

P: They said that I have HIV

R: Okay, and do you understand what HIV is or what do you understand it to be? (Repeats question)

P: Yes

R: What do you understand it to be?

P: It is a dark illness

R: Hm?

P: It is an illness where if you do not look after yourself it is possible that you can die

R: Okay, so they have told you how it is contracted?
R: No

R: Okay, and when were you told that you have HIV? Do you remember?

P: I don’t remember but it was the time that I was admitted here at the hospital

R: Who told you?

P: This other nurse

R: And what did she say about your illness?

P: She asked me why I drank those pills and I told her that I did not know. Then she said that I had HIV and that I should take care of myself

R: Mm, is that all that she mentioned to you that day?

P: Pardon?

R: Was that all that she said, did she explain anything else about HIV?

P: She said that I got HIV from my mother

R: Did she explain how or what she meant by that?

P: She said that it was the breast, so through my mom’s breast feeding

R: From your mom’s breast? So she explained to you that you contracted HIV through breast milk hey?

P: Yes

R: After this was explained to you, how did you feel on that day?

P: I didn’t feel great, but when I got home I asked my mother about this

R: And what did your mother say?

P: She also told me (confirmed) that I contracted HIV from her

R: Mm, okay, and when she explained to you about you contracting the illness from her, what did she say?

P: She didn’t say anything
R: How did you feel when you your mom confirmed the HIV status to you?

P: I didn’t feel okay

R: What was it that made you not to feel okay?

P: Because my mom was ill

R: Okay, so because your mom was ill. Did you feel like she was the one that made you ill?

P: Yes

R: Did you tell her that?

P: Hey?

R: Did you tell her that?

P: Yes

R: What did she say about that?

P: She said that I shouldn’t worry because I was going to live

R: Okay, and when she told you so, how did you feel? Did you believe her?

P: I was okay, I did not stress anymore

R: Mh, but I can see now that you are not okay, something seems to be hurting you right now, what is the matter? (Participant is crying). (R: repeats, what is going through your mind?)

P: My mother passed away

R: When did she pass away?

P: Last year (2013)

R: Was she ill?

P: Yes

R: Was she ill for a short or a long while?
P: A long while

R: And you miss your mom at times?

P: Yes

R: What’s making you cry now? What do you remember most about your mom?

P: She used to take care of me

R: Do you feel like she has left you and that nobody can care for you like she did?

P: Yes

R: And it hurts!

P: Yes

R: And what about your gran?

P: Yes?

R: Does she look after you?

P: Yes

R: I guess it still hurts though because your mom’s no longer here, you still feel as though your mom left you?

P: Yes

R: Do you ever tell your gran about how you feel?

P: Hey?

R: (Repeat)

P: She what?

R: (Repeat, what does she say?)

P: Shakes head
R: How do you feel about this today?

P: Not okay

R: What is it that is not making you feel okay?

P: That I have HIV and that I don’t know why

R: So it is that you do not understand why you have HIV and why someone else doesn’t (may not) have it?

P: No (Yes)

R: So what do you want to say? Do you wish that you didn’t have it and that you wish that someone else had it instead of you?

P: Yes

R: What are your challenges with regards to living with HIV?

P: Drinking pills everyday

R: Okay, mh, and what else do you find as a challenge?

P: And that I do not want to drink too many pills

R: Okay, so they give you too many pills? How many pills?

P: Four (4)

R: How frequent?

P: Four per go

R: So it is 8 pills per day? (4 twice a day?)

P: Yes

R: Okay, so they are too many for you? (Silence), repeats question.

P: They are okay, but they say that I should halve them

R: At home? Your family? How should you halve them?
P: That I should not drink that many anymore

R: Your family says that you should not drink that many but the doctor said that you should drink them all?

P: Yes

R: Who said that you should halve them (reduce them)?

P: My aunt

R: Okay, so is your aunt aware of you have HIV? (Repeats question)

P: I don’t know

R: So perhaps she is not aware or does not understand how come you drink that many pills?

P: Yes

R: Who do you live with at home?

P: With my aunt and my grandmother

R: Okay, does your aunt know that you are ill?

P: She knows

R: Okay, so when she said that you should reduce the pills you drink, what did she mean by that? Does she force you to reduce them (make you) or was she just commenting?

P: She was just commenting

R: Mm, and what does your grandmother say?

P: They say (nurse/doctor) that should drink them (medication) every day and that I should not skip a day

R: Okay, so you drink them before school and in the evening?

P: Yes, when I come back from school, in the evening

R: Only in the evening?

P: Both, morning and evenings
R: Okay, and how do they affect you?

P: They are okay

R: Okay, they don’t make you sick?

P: No

R: Okay, so when you are at school, do you think about your status and does it get to you?

P: No

R: Okay, do you learn about HIV at school?

P: Yes

R: What kind of things do they teach you?

P: That people with HIV have problems with their lungs. So you should not fight with them, or hit them. You should treat them well

R: So everybody who ill should be treated equally or fairly?

P: Yes

R: Okay, what are your challenges in life in light of having HIV? (E.g. having HIV, missing school, church etc. Because you were ill?)

P: I have been ill and missed school where I had a headache and I was throwing up

R: How long did that last?

P: It was three or four days

R: Thereafter you went back to school and you were okay? Not all week?

P: Yes

R: Okay, and you said earlier that your ears hurt, what causes that? What happened?

P: They were always excreting puss

R: Okay, what causes that? Did you ask the doctor or your grandmother?
P: I don’t know but I was told that my ears have a problem and that they have something inside and the doctor said that they need to take those (things) out before they (ears) get blocked

R: So they didn’t explain what it is?

P: They told me it is a black thing or substance

R: Okay, but not what it is?

P: No

R: And is it painful or is it just blocked (your ear?)

P: Painful

R: Okay, does that affect your hearing?

P: Yes

R: Okay, as they said that they would extract the substance or things, perhaps that would help with getting your hearing back?

P: Yes

R: When did this pain start?

P: Long ago

R: Was it last year or before that?

P: Before

R: Okay, so it has been a while?

P: Yes

R: So when you go to the doctor do you think your ears are getting better or worse?

P: They are getting worse

R: What do the doctors say?

P: They give me medication to irrigate my ears at night and during the day
R: And does that help with the pain? (Interjected by participant)

P: But it takes all the dirt out of the ears

R: And the pain?

P: No, it is not that painful anymore

R: So it is improving (medication) everything and keeping the pain low? And when you are t home, how do you cope? (Nurse interrupts, participant is next to see the doctor)

R: How do you cope with having HIV? What do you do to make yourself feel better?

P: The fact that I am not too ill

R: Okay, and taking your medication?

P: Yes

R: Okay, you know what? Because I see how much you are still hurting after losing your mom, how would you feel if I referred you to a psychologist? A psychologist is someone that you can talk to, like me, but he or she will be able to be it you longer than I currently can here. You can speak to this person about how losing your mom has left you feeling really das and hurt. Can I send you to them? I can see that you are still struggling with your mom’s loss and maybe you could express what is in your heart. Can I send you there so that you can speak to someone about the fact that your mom is no longer here?

P: Yes

R: Okay, I am going to tell your grandmother that, when you are with the doctor, she should ask him or her to write a referral letter for you to go and see the psychologist alright?

P: Yes, okay

R: Okay, let us go so that I can talk to your grandmother about arranging this for you

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Lizzy Individual interview with Ko

R: Alright, I have explained who I am and that we’re going to talk. So as I asked earlier, how often do you come to the hospital?

P: I am not sure
R: Okay, and when it was explained to you that you were ill, what were you told?

P: (Interrupted by a nursing sister looking for keys etc…)

R: So did they explain to you about your illness and what you are coming to do here at the hospital?

P: They said that I came so that the doctor can check if I am still okay

R: You’re still okay? How so?

P: That I drink treatment

R: That you take treatment? Okay, did they explain to you why you drink treatment? What do you know that you are taking treatment for?

P: Hey?

R: Why are you on treatment?

P: So that I do not die

R: Die? What would cause you to die?

P: Isn’t it if I do not drink this treatment I would get sick and die

R: So when you drink treatment, what do you know about the illness that you are being treated for?

P: As far as I know or I am concerned, I am not ill

R: You know that you are not ill but yet you are on treatment?

P: Yes

R: Okay, and then who told you that you have to take this treatment?

P: My aunt

R: Okay, so at the time when she told you that you need to drink this treatment, when you agreed to do so, did you ask her what it was for?

P: I did not ask her

R: So you know that you are not sick as far as you are concerned, but yet you take this treatment?

P: Yes

R: Okay, so when you think about it, what do you think the treatment could be for?

P: For my leg

R: Your leg? Okay, how come?
P: I was knocked down by a car
R: Okay, when was that?
P: A long time ago
R: Okay, and then what happened to your leg?
P: It was broken
R: Okay, so after they had brought you to the hospital you started with this treatment then?
P: Yes
R: Okay, so you are only aware that you are on this treatment only because of your leg?
P: Yes
R: Okay, but you told me that if you don’t drink your treatment you would die? What would cause you to die?
P: They say that I would get sick if I did not drink my treatment and that I would die if I did not drink it and that the treatment is very important
R: Oh okay, who said that?
P: My aunt
R: Okay, so she stressed that it is important that you drink your treatment because you would die if you did not?
P: Yes
R: Oh okay. When she said that to you, what did you make of it?
P: I think that they (medication) protect my life
R: From what? (Long silence) Hm?
P: I don’t know
R: But you said that they (medication) protect your life though, from what?
P: (Smiles and chuckles)
R: How come you are smiling? (Respondent still chuckling), are you feeling shy?
P: No
R: Why are you smiling? (Interrupted by nursing staff gain)
R: Sorry, let us get back to what you were still telling me. So what do these pills protect you from?
P: My body
R: How so? (Long silence) Hm? Hawu K?
P: That I won’t die
R: That’s all you know about your medication?
P: Yes
R: Okay, who do you live with at home?
P: With my aunt
R: Who else?
P: Her children
R: Oh okay, where is your mom?
P: She passed away
R: I am sorry to hear that
P: It has been a long time now (long time ago) about 2008 or 2007
R: Oh, I am sorry to hear that
P: Yes
R: And when did you start living with your aunt? Since your mom died?
P: Yes
R: Okay, so your mom died in 2006 or 2007?
P: In 2007 or 2008
R: What happened?
P: I don’t know
R: You don’t know what happened to her? Was she ill or what killed her?
P: She was ill, then she said that she was going to sleep
R: And then?
P: When I woke up the (family) told me that she was not around
R: Mh?
P: That she had died
R: Mh? And then?
P: I didn’t know that people died at the time
R: You didn’t know? And when you asked what killed her, what were you told?
P: I did not ask
R: Wow, so you heard that she had died, and then? How did you feel or how did that affect you?
P: What?
R: The fact that your mom was no longer alive?
P: It didn’t feel good
R: what was it about your mom’s death that affected you?
P: That I didn’t (don’t) know how she died, and where she died
R: When she was ill, where was she?
P: She was at home
R: At home?
P: Yes
R: And did you see her at the time that she was ill?
P: I saw her, then it was night time and I went to bed and my family stayed behind, but they never told me that she had died
R: Where did this happen?
P: At home
R: Where is that? Where you lived with your mom?
P: Yes
R: Where did you live?
P: Phase 3
R: Okay, and who did you live with?
P: With my grandmother

R: Mh, where is your grandmother now?

P: She is still around

R: And do you still get to see her?

P: Yes

R: And were you ever told what happened or what killed your mom?

P: No

R: Oh okay, when you think of it, what do you think killed your mom?

P: I think she was killed. They say that she was killed

R: By?

P: The people she was with. They poisoned her

R: They poisoned her? Who did she stay with?

P: I don’t know. Where she comes from

R: Where is or was she from?

P: I don’t know

R: Was she there to work or visit?

P: She was there to work

R: So when she came back from work they poisoned her?

P: Yes

R: So what made you think that he was poisoned?

P: They said that when she left she was fine

R: Okay, and how long was she gone for?

P: A Day

R: And when she returned she was not okay?

P: Yes

R:
After she died you didn’t discuss what happened to her?

P: No (Interrupted again…)

R: So you think that it was poisoning?

P: Yes

R: When your aunt told you that you need to drink your treatment, how did you feel?

P: I am and was okay

R: You are okay? You don’t feel like you drink treatment although you don’t understand why?

P: I don’t understand but I feel okay about it

R: You don’t understand why you drink it yet your leg is not healed or is it healing?

P: It does not heal! But it is not the same size as the other leg either, it can’t walk properly (I can’t walk properly)

R: So you understand it as that your treatment will help your leg?

P: Yes

R: Okay, I also hope that your treatment will help your leg to heal

P: I don’t know

R: What don’t you know?

P: Because doctors tell me that my leg will heal soon, but it has been long that I have been waiting for my leg to heal, even now, I am still waiting!

R: When did the accident happen?

P: Long ago, in 2005

R: Mh, and when did you start taking the treatment?

P: After the accident when I was hospitalised

R: Meaning from 2005?

P: Yes

R: Did you ever stop taking the treatment at any point?

P: No

R: When did your aunt explain that you shouldn’t stop your treatment?
P: Long ago
R: Round about when?
P: 2008
R: Okay, so you have never stopped drinking it right?
P: Yes
R: Even now you’re still on it?
P: Yes
R: Okay, alright. When you ask your aunt how come she said you would die what did (does) she say?
P: I have not asked her
R: What do you think she would say? (Silence). You are smiling I see, how come??
P: I am not in her head
R: So you do not know what she would say?
P: Yes
R: Okay, no problem, if you decide to ask her what would you say?
P: “Why am I drinking pills endlessly, and when I miss taking them you say that I would die, why?”
R: Okay, that is what you would ask her?
P: Yes
R: Okay, alright. I hope that you can come and tell me what she says, one day. We are done here, I just wanted to check with you, how your treatment is affecting you and how anything had changed in your life
P: Okay
R: Is there anything you did not understand or anything that you would like to ask me before we go?
P: No
R: Okay, that’s it for us. Thank you for your time. Bye

Lizzy Individual interview with Sa
R: So, today we are going to talk about you coming to the hospital and what your mom may have told you about why you come to the hospital okay?

P: Mm (Yes)

R: Okay, what I would like to know is how often you come to the hospital?

P: A lot

R: Okay, when did you start coming to the hospital?

P: Long ago

R: Okay, it has been a while. What do you understand regarding the illness you have?

P: They say that I am HIV positive

R: Did they explain to you what being HIV positive means?

P: I am sick. I have blood that has HIV

R: Okay, HIV blood? When did they disclose your status to you?

P: They told me now (Not sure if participant meant recently or that day)
R: Who told you?

P: My mother

R: Okay, so when she told you how did you feel about that?

P: Sorry? (Pardon?)

R: How did you feel?

P: I don’t know

R: Okay, in your understanding, what is HIV and what does it mean?

P: When someone has HIV, they have a blood illness

R: Okay (Disturbed by nursing sister). How do you feel that you have HIV?

P: I feel okay
R: So it doesn’t make you feel any different?

P: No

R: So you are okay?

P: Yes

R: So when you think of HIV, what comes to mind?

P: I think that if you have it you can only get it once

R: Can you explain to me what you mean?

P: It’s like someone who has an illness that affects their legs, or head, or has eye ailments

R: Mm, okay, so that’s how you understand HIV?

P: Yes

R: Okay, alright, since you discovered that you have HIV, how did this change your life?

P: Nothing’s changed

R: Nothing has changed and nothing bothers you?

P: No

R: Alright, and then when you go to school, how do you cope when it comes to drinking your medication (pills)?

P: I drink them in the morning and at night

R: Mm okay, and what are the effects, like do they make you feel sleepy for example when you are at school?

P: No, nothing like that

R: Okay, I wanted to hear about effects

P: Sometimes I get sores

R: You get sores?
P: Yes

R: What kind of sores?

P: On my face/eyes

R: Oh, okay, and when you do, how do you deal with that?

P: They squeeze them

R: Okay, and thereafter?

P: Then my mom puts medicine on them

R: Okay, and did they tell you if HIV causes them?

P: My eyes are easily affected by allergies

R: Did they explain to you what that is?

P: Yes

R: Okay, and how do you feel about the fact that your medication may be affecting your eyes?

P: The medication helps but I cannot see properly at times at school

R: Did you get spectacles?

P: No

R: What did the doctor say about your vision being affected?

P: I didn’t tell him/her

R: Okay, but have they ever examined your eyes?

P: Yes, they said that I have allergies

R: Okay, when you are unable to see properly at school, how do you deal with that?

P: I tell my mom to buy me spectacles

R: And your teacher? What does she/he say?
P: She says that I must sleep a little bit

R: What do you do when you are in class and you cannot see properly?

P: My eyes get teary

R: And then what do you do?

P: Because my eyes become teary and I cannot see properly then it looks like ma’am didn’t write properly on the board

R: Then what do you do? Do you let her know that you are unable to see properly and what does she say if you do?

P: She says I should leave the books alone

R: Okay, and when you leave them what must you do?

P: I would write tomorrow (the next day)

R: Okay, so you leave them and write the next day?

P: Yes

R: What happens the next day if you get more work to do then how do you deal with that?

P: I cannot write

R: Okay, so if you cannot write then how do you deal with that in class?

P: In class?

R: Yes

P: I tell ma’am that I can’t write too many things

R: So how come you cannot write? In your own understanding?

P: When I can see properly, then I can write a lot of things but when I cannot see properly I can’t write much

R: Oh okay, and does the teacher scold you for not writing or not doing your work in class?
P: No, she does not

R: Ok, does the teacher know about your HIV status?

P: No, nobody knows

R: Okay, and what about where you live, do you have friends there? Do you play with other children?

P: Yes

R: Do you enjoy that?

P: Yes

R: Do they ever… (Interjected by participant)

P: They are boys

R: Oh okay, how are they when you play with them?

P: Girls?

R: No, those boys

P: Boys like bullying me at school. I don’t play with them

R: They bully you? How so?

P: They bully me by saying that I have a big head (ya sgumbagumba)

R: They say that you have a big head (ya sgumbagumba)? Are they aware of your status?

P: No

R: And the girls?

P: The girls hit

R: So nobody at your school is aware of your status?

P: No

R: Okay, so would you want to tell them?
P: No

R: Okay, how come?

P: Because they will pass it on (spread news about HIV status)

R: How so?

P: They will spread the news to other people about my status

R: Okay, I understand now. Is there anything that you would like to ask me at this point?

P: What I want to tell you is this thing with my eyes. The boys say that my eyes are brown, chocolate-like and I feel hurt about that

R: Of course it hurts when they say that, and so when they do say that, what do you do or say?

P: I tell them that they hurt my feelings

R: Yes, it would be hurtful, and do you report them to your teacher?

P: Yes

R: What does she do or say about it?

P: That she would give them a hiding

R: Okay, but do they continue teasing or bullying you thereafter?

P: Yes

R: Okay, so if they come back to you to say the same things, what would you do or say to them?

P: I don’t want to talk to them

R: Okay, what happens when or if they return and do the same things, how would you deal with that?

P: I would tell the teacher

R: Okay, you would tell her so that she could help you/

P: Yes
R: Okay, so is there anything you want to ask me?

P: There are other ones (Not sure who) who wanted to hit me and I wanted to hit them too

R: They hit you? How come?

P: I don’t know. They like bullying me after school, they said that I swore at one of them and I never did. After that they told on me and ma’am gave me (alone) a hiding that day

R: So when you told the teacher, what did she say?

P: When I said “ma’am, it wasn’t me that hit another child, nor was it me who swore” she gave me a hiding and the boys laughed at me.

R: They laughed?

P: Yes

R: Did you tell her what really happened?

P: Yes

R: And what did she say or what happened?

P: She said “don’t do that anymore”

R: Mm, okay, so since they hurt your feelings like this, what will you do next time?

P: I don’t know

R: Okay, but you had said that the last time the boys teased or bullied you told the teacher?

P: Yes

R: So when they do that again then as you said, you could tell the teacher or your mom about it right?

P: Yes

R: Okay, I am done with asking questions, is there anything else that you want to ask me?
P: There are other boys who also bully me, and at assembly we were told that nobody should steal from another, nobody should bully a child, nobody should steal other’s pencils or pens, but they steal our crayons

R: Why do they do that?

P: I don’t know, they say that they belong to them after that. They lie

R: What do you do when they steal your crayons?

P: I tell ma’am that they stole my crayons, and I tell them that early next morning I want my crayons.

R: Oh okay. (Interview ended abruptly as participant had to go see the doctor)

Individual Interview with Sp

(After icebreaker talking about her school experience and ensuring that her ascent form is signed)

R: So as you’re here now, they’re going to give you medication then after that you will know if your results are okay?

P: No, if now the doctor says I should have my blood analysed I am going t and then we collect my medication thereafter. Then I will be issued with a date like they can tell me to return on the 21st of February, I will only know then what my blood results show, if they are okay then we can request a transfer from the doctor so that I go to Kopanong.

R: Oh so they would check in January and then a month later you come back for the results?

P: Yes

R: Okay. How do you understand your illness?

P: My mother didn’t tell me, so my teacher in my Grade 5 class explained what it means when you have HIV and what kind of pills you take, so I saw that my pills looked like the ones she had showed us or that she told us about, so I realised then that I have HIV

R: Oh so your teacher was the one who explained to you that you have HIV?

P: No, ma’am was explaining to the whole class and then I realised for myself that I have HIV

R: So when you understood that ma’am was explaining that you have HIV, when you got home did you ask your mom if you had HIV or how did you deal with it? What did you do?

P: I asked her “mom when you have HIV, do you drink pills hey?” Then she asked me why. I told her that ma’am told us all. Then she said “Yes”
R: Okay, and then after your mom confirmed that you have HIV, how did you feel? What did you do after that?

P: I didn’t do anything, I felt okay. I was okay.

R: Mm, and then at that time how were you feeling? Like when ma’am was talking in class how did you feel when she explained?

P: I didn’t think that I had it so I heard ma’am explaining so when I got home I saw that they (pills) were the same

R: Mh, mh, okay, and how did you feel at that time after you realised that you have HIV?

P: I felt okay

R: How about now, how do you feel knowing that you have HIV?

P: I feel okay

R: Mh

P: But the thing that I struggle with …those pills…they are huge and I am afraid of choking on them, so my mom showed me how to drink them so that I don’t choke on them

R: Mh, okay, so how do you deal with that, so that you don’t choke?

P: My mom told me to throw them far back and then drink water

R: So after your mom explained everything you were okay?

P: Mh

R: Okay, that is good. Then when you think about HIV, the illness in general, what do you think about it?

P: Uhm, I don’t know how I can explain it. Uhm, when I thought about it before I knew what HIV was, I used to think it was something like a cough or lung issues and then that you recovered completely. So when I got to Grade 4, ma’am also told us that if you have this kind of illness (HIV), you do not recover, that this illness does not go away, until you grow up and you have your own place and do everything like that. The illness doesn’t go away, but you need to look after yourself when you have it and just be happy. After that I found out that there is also another learner in class who also has it (HIV), and told ma’am. So ma’am said that not to worry when someone says something horrible just tell them that it’s fine and be happy and don’t let it play in your mind and bother you. She said not to think about that only, just that you must concentrate in class and on your books, and not to entertain or think about it. As long as you take your medication accordingly, don’t worry about what people say. So ma’am asked us who else has HIV so I didn’t know at the time so I didn’t put my hand up.

R: Mh, mh. Then when you realised or understood that you have HIV, did you tell ma’am that you have it?
P: Hm m (no), my mom said that she would let ma’am know and explain to her accordingly as to what is happening, but ma’am does get the letters from us that I was at the hospital, so my mom said that the day she gets off she would come to school and explain that I have this problem and the reason why I don’t attend school sometimes.

R: And are there other days where you are unable to go to school?

P: Hm m (no). I only miss school when I come to the hospital.

R: Okay. So far are your meds treating you okay?

P: My meds are treating me fine (mmm).

R: Do other children at school know about your status?

P: No, only my mom, dad and I know about it, even my mom’s family doesn’t know about it. My mom said that when you have HIV you shouldn’t tell people about it because people will gage (judge) you based on that and you will feel sad and cry and you will feel hurt when other children are happy.

R: How do you feel about not telling people about your status?

P: It is right because you will be feeling or thinking about it whilst the teachers are teaching and other children are concentrating, and when you ask the teacher what was happening in class you will be shouted at for not listening and things like that.

R: Mm and then so far have you sat in class and felt sad or something like that?

P: Hm m (No).

R: Okay, nothing like that? Okay. You found out about your illness at school, what would you say has changed in your life since finding out?

P: I was fine and back then I didn’t know anything much.

R: So it has changed nothing in your life?

P: Hm m (no).

R: So you are still okay and happy?

P: MM (yes).

R: How do you cope with having HIV?

P: I live okay because my mom does everything I want, like now she has bought me a phone because I requested her to buy me one and I also do what she says I should do. She told me not to think about this illness, but to be happy and to play well with other children. Some children, this other one in particular that I was playing well with, uttered the words “don’t be forward or flighty, you have HIV” but I don’t think that she was aware of my status. I told my father, who said that I should just leave her alone.
R: how did you feel when she said that?
P: I cried
R: How come you cried, what made you feel like that?
P: I was hurt (cries)
R: Of course, it hurts
P: Mm (Yes)
R: and how did he know that you have HIV?
P: She just said that
R: What was it that hurt you about what happened?
P: When I thought about the fact that she just unwittingly said that I have HIV and I really do have it
R: Mm, so when she spoke, she spoke without thinking, but she didn’t know that you have it. That really hurt you. I see that you’re crying now, it still hurts you
P: When I talk about it
R: Mm, what hurts so much?
P: That I have HIV and that I am not like other children
R: Mm, and when you cry it still hurts, do you understand why?
P: I don’t understand
R: I mean like now, you are feeling hurt, what about having HIV gets to you or hurst you?
P: I do not know
R: Mm, just that you feel hurt that you have HIV?
P: Yes
R: Okay, and if this girl approaches you again, how would you deal with her?
P: I would be okay because I know that I have HIV
R: Mm, and if she said the same thing as the last time to you, how would you react?
P: I would not do anything, I will not play with her anymore
R: And where does she live??
P: She lives in the next line (street)
R: So she’s someone who stays close by?
P: Yes
R: What about the other people who live close to you or around your neighbourhood, did they ever ask about your status?
P: No
R: When you think of this issue (the girl saying you have HIV), how do you think she came up with it?
P: I don’t know
R: Okay. What are the challenges that you face since discovering that you are HIV positive?
P: Nothing
R: Mhm, okay. So only that people talk like that about you? (The girl)
P: Yes
R: What would you change about your life?
P: I would change my life
R: How so?
P: I would play with people who like me, not people who hate me and who tell me such things (that I have HIV), and there are friends who love me very much, they are my best friends. I would play with them. When that one girl comes I would go home and play with my sibling
R: Mm, so what else would you change?
P: I would tell my mother to take me to things like Spur, like that and just go to places like the swimming pool with my friends and have fun.
R: Mm, so when you talk about those things, do you not currently do them?
P: at the pool close to my home there is a snake there so my mother refuses that I go there, so there is no other one that she can take me to
R: Oh okay, so what about Spur, do you ever go out with your parents or your mom?
P: We go to Spur when my mother has money
R: So it’s not like you do not ever go at all, it’s still nice and you’re still enjoying your life?
P: Yes
R: Okay, so is there something that we have not spoken about that you would like to talk about?

P: No

R: Are you sure?

P: Yes

R: Okay. So you said that if that girl came back and said what she had said to you would not play with her but with the friends that you like and love right?

P: Yes

R: Okay, so if there is nothing that you would like to ask me then… (She interrupts)

P: I want to…

R: Mmhm?

P: I want to know, if you have HIV, do you end up being a granny still having HIV?

R: Isn’t it as they (teacher/doctors) have explained to you before, HIV is an illness that cannot be cured, so as people, nobody knows how life will end for us. So HIV will always be in your blood. As people, we do not know how we are going to die, do you understand what I am telling you?

P: Yes

R: What do you understand about HIV?

P: Ma’am told us that you contract HIV when you sleep with someone (sexually) without using a condom, and that if the person that you slept with without using a condom has HIV, then they could have infected you

R: Mm

P: So you also have or get it

R: Is that the only way you understand it?

P: Yes

R: Okay, and then did they explain to you how you contracted HIV?

P: No, they did not explain it to me

R: Okay, so let’s say when you are at school, you could ask your teacher also, or your mom about other ways that one can be infected. I think that they can explain it to you so that you understand the other ways that you can be infected with HIV, except through unprotected sex with someone who is already infected
P: Okay. But my friend told me that some people, like if your mom falls pregnant, then you can be born with it

R: Mm, okay. Yes, that is another one of the ways you can get HIV. Not because you did something, but because your mom was pregnant and she was HIV positive and had it in her blood, the you can be born with it, yes. So do you understand what I mean??

P: Yes (Mm)

R: Alright, so...we are done for today. Are you satisfied with the questions and answers that we discussed?

P: Yes

R: Okay, by the way, when did you say your teacher explained HIV to you?

P: I was in Grade 5

R: Oh okay, so you already understood what HIV was?

P: Yes

R: Okay. We are done. If you have any questions for me you can still ask me, other than that I do not have any more questions

P: No

R: Thank you. And good luck with the doctor's appointment and your transfer okay?

P: Okay

Group Lizzy Interviews

R: Alright guys let's talk. So when you come to get your treatment, how many times do you come here (hospital)? Or how does it work? Do you come here once a week, once a month?

P1: I fetch it once a month

P2: I also fetch it once a month

P3: I fetch it once a month

P4: I fetch it once a month

R: Okay so all of you fetch treatment once a month? And when you come collect your medication, what about school, do you miss a whole day of school or not?
P1: I don’t go

P2: I also do not go

P3: Me too

P4: I do go to school

R: Okay, and how do you get your treatment if you go to school?

P4: I have not fetched my treatment myself for a few months now

R: Okay and who fetched your treatment for you?

P4: My mother fetches it

R: Oh so she can fetch your treatment on your behalf so that you don’t miss school?

P4: Yes

R: Okay, so you come only when you must see a doctor for a check-up or when they have to get some blood sample from you?

P5: Yes

R: So it is not compulsory then to come for monthly check-ups? How often do you come for check-ups?

P3: We come when they need to get blood drawn and for check-ups

R: So how often do you come for a check-up?

P2: Only once a year

R: Oh okay, so not monthly? Okay, that’s good. So when they explained to you what illness you have, what did you understand about HIV? What did they tell you and who told you about your illness?

P2: My grandmother told me. She asked me if I knew why I was drinking medication, and I told her that I did not know. Then she said to me that I am drinking them because I have HIV and so that I could gain weight. She told me that I shouldn’t stress because I am on treatment

R: Oh okay, and how old were you when she told you?

P2: I was seven or eight, somewhere there, but I am not sure.

R: And did you stay with your grandmother at the time?

P2: Yes

R: Okay, and you?
P5: I was told by my mother too. At the time she told me, it was the year I started taking treatment in 2012. She said that I should not be scared and that I should not skip taking my medication accordingly because it’s not okay. She said those that are very ill with HIV are those people who do not drink their medication properly or every day, so she told me not to skip a day.

R: Okay, so she explained how they work and what they are for, and that was in 2012?

P5: Yes

R: Oh okay, and you S?

P4: My mom told me not to get scared. She said that my blood is dirty, it has a virus.

R: Oh okay, and that was all she explained to you?

P4: Yes

R: And you?

P3: I was told in 2013, and she said that I can tell people that I have HIV if I want to, but if I didn’t want to I didn’t have to tell them.

R: So it was last year when your mom told you, and how old were you?

P3: I was thirteen years old

R: Okay, and then when your parents or caregivers told you that you were HIV positive, can you remember how you felt? Were you scared, were you okay or what went through your minds at the time?

P3: I was okay

R: Okay and you?

P4: I was scared

R: What was it that made you feel scared?

P4: I didn’t know what it was

R: Okay, and what made you feel okay after that?

P4: I was okay because my mother told me to take my pills so that I can become well again, then I was okay.

R: Okay so when your mom told you to drink pills it reassured you and you felt better? I hear you. And how did you feel?
P5: I was scared, because I always see something about people dying of HIV on television, but then my mother said that I should not be scared because the ones that look obviously ill are the ones who do not take their treatment, and that as long as I drink my treatment I will be okay

R: So you were afraid for a while until your mother explained that you should be okay as long as you take your pills?

P5: Yes

R: Okay, and what about you?

P2: I was okay because I know that my family supports me all the time

R: Okay. Now, when you think that you are HIV positive, how does it make you feel?

P2: I feel bad. I feel as if I am lonely

R: What is it that makes you feel lonely?

P2: I don’t know, when I think about it, it makes me want to cry

R: Mm, and what is it that makes you want to cry?

P2: I don’t know

R: Is it because being HIV hurts you, or is there something that’s worrying you? What is it that you’re feeling right now?

P2: My mother died, she is not here. (Crying, and tries to speak but her speech is inaudible)

R: When did your mom pass away?

P2: I was one year and six months old

R: Mh

P2: I don’t even know her. They just explained to me that my mother died when I was young

R: So it hurts you that you don’t know your mother and that she died when you were very young hey?

P2: Yes

R: And then when you think of the support that your grandmother gives you?

P2: I feel good

R: And then the person that brought you here today, who is she?

P2: She’s my aunt
R: And when you think of how she is towards you, support wise?

P2: She’s fine. She’s also supportive

R: Okay, so she’s also supportive like your grandmother?

P2: Yes

R: Okay, you see that sometimes there are things that hurt you, but you find that there are people who can help you feel better and who are there for you hey, so that you don’t feel that feeling hey?

P2: Mh

R: Okay, and others, how do you feel about this (HIV) as you can see, N is still hurting. How do you feel?

P5: I feel okay. Since my mother told me that by drinking my medication I will be okay if I drink them every day. I believe I will be healed

R: Okay, and you S?

P4: I am okay

R: Oh so you’re okay and all is well for you?

P4: Yes

R: Okay so you’re okay now and all is well with you. And you?

P3: I am okay because I saw with my dad. When he was told to go get tested he said that he did not have HIV. Thereafter when he died, my mother told me that my father had HIV but that he did not want to tell me.

R: How did you feel about that?

P3: I did not feel okay about it

R: When did your dad pass away?

P3: He died in 2010

R: Okay so he didn’t tell you himself that he had HIV?

P3: No, he didn’t tell me

R: When your mom told you this information, how did you feel about it?

P3: I felt bad

R: What is it that made you feel bad?
P3: That my father kept this secret from me
R: And how come you think he did that?
P3: He used to come home late at night, coming from his other girlfriends
R: So you think that’s how come he kept the secret from you?
P3: Yes
R: And how did you feel? When you saw him did you suspect that he was keeping a secret from you?
P3: No, I did not
R: So you only found out after your father’s death about HIV?
P3: Yes
R: Okay, and when you think of HIV, how has it changed your life?
P3: It hasn’t changed anything in my life
R: So your life is the same as it has always been?
P3: Yes
R: Okay, and you N? How has HIV changed your life?
P2: Eish (exclaims). It changed it, okay…
R: Okay, you mentioned earlier that your mom died when you were young, so that’s also a change in your life right?
P2: Mh
R: Yes, so what else has it changed in your life?
P2: Nothing has changed
R: So everything is the way it used to be like when you were young?
P2: Yes
R; Okay. What has changed for you?
P5: It has not changed anything. I am okay, I am still the way I used to be
R: Okay so nothing much has changed for you. And you?
P3: I am okay, it’s still the same
R: Oh okay. So at school, is anybody like your friends or teachers, aware of your status or illness?
P4: Nobody knows
R: Your extended family?
P4: Only my parents and I know
Okay, and you?
P5: Only my family knows
Okay, and you?
P2: Only my family knows
R: Mhm. And you?
P3: My family knows. The teachers and some of my friends know
R: Okay, so you do have some friends that you trust and those who do not know?
P3: Yes
R: Okay, so what if one day you find out that one of your friends has told others about your illness, how would you feel?
P3: I would feel bad about it
R: What would make you feel bad that other people know?
P3: Because others would be telling others, I would not be the one telling them myself
R: What is it that scares you that other people know?
P3: They did not hear from me
R: So if someone comes to you and tells you that they know, how would you feel?
P3: I don’t know, it’s okay, I don’t know what I would say
R: Okay so there are people you trust, how many friends did you tell?
P3: I told two
R: And teachers?
P3: My class teacher
R: Okay, so why do you think your mom told the teacher?
P3: So that they know that if I am not at school I am at the hospital

R: Okay, and then others, are your teachers aware?

Ps: No they don’t

R: If your teachers were to find out, how would you feel?

P5: If she or he would be supportive and not tell others I would be okay. My mother said that this should be our secret and if I want to I can talk about it, but if I do then people will treat me like I am not a human being

R: When you say not like a human being, what do you mean?

P5: Isn’t it that some people see HIV as a huge illness, they say that-others- they don’t want to be your friend because you would infect them, they would do that. I have a lot of friends in class, so then they would not want to be my friends anymore

R: When they say infect them, how do they mean?

P5: I don’t know. I heard someone last year. There’s someone who has HIV and then said they do not want to be friends with that person anymore because they would get infected. When I asked how then I was told that when the other person coughs they do not close their mouth so then the virus would “leave” through the cough and they would get it.

R: Mm, and do you all know how HIV is transmitted?

Ps: No

R: Okay, have you ever asked how it is transmitted? (N was fetched from interview room to go see the doctor)

R: Sorry hey, okay, where were we?

Ps: We were discussing how it is transmitted

R: Oh yes, so how do you think it is transmitted?

P3: I know through sex

R: Okay, how so?

P3: Mumbles

R: Okay, but they did tell you about it at school, so what did they tell you?

P3: Through sex without using a condom

R: Okay, and what about others, what do you know
P4: I don’t know

R: Did they teach you at school how HIV is transmitted?

P5: Yes they did tell us, the way he just explained it

R: Mm, okay, and you?

P4: Yes I also know that it is through unprotected sex

R: Okay, so you only know that it is transmitted through unprotected sexual intercourse. So as you mentioned with these friends that talked about contracting it through coughing, do you think that it can be contracted though touching or anything like that?

P3: It can also be transmitted through blood, like when someone has a wound or starts to bleed and then someone touches that blood or wound without gloves then they can get it

R: Okay, so it can also be through blood? Okay and do you all know any other ways that HIV can be transmitted?

Ps: No, just sexually

R: Okay, so let’s say someone finds out that you have HIV, do you think that the person would think that you got it through unsafe sex?

P5: No

R: What would they think?

P5: That we got it from our mothers

R: Okay, and you?

P3: Also

R: You also got it from your mother?

P4: Yes

R: Oh okay, so it’s not just through unsafe sex but through blood and mother to child?

Ps: Yes

R: Okay, so taking these three ways of transmission into account, is it possible that it can be transmitted through someone touching you?

Ps: No

R: Mm, so is it that people are still scared or what do you think makes people think that being touched by another person can transmit HIV?
P5: I don’t know

R: Why do you think people still think like this about HIV? Do you think that they are scared or that they do not have enough information? How it is transmitted or what do you think people do not know about it?

P5: I think that people don’t know much about HIV and that they don’t have the right information, hence they say that one can just get it like that

R: Okay, and they don’t say how it is transmitted hey?

P5: Yes

R: Oh okay. And you?

P4: Eish…

R: What do you think about what we are talking about?

P4: It doesn’t bother me

R: Do you think that people have information or understand it?

P4: No

R: Okay. And how do you cope knowing that you have HIV? On a daily basis if you think of your illness, knowing you have to go to school, do homework etc. even when you are not feeling well, how do you cope? (Long Silence). What is it that makes you feel better? (Silence) Let me ask it this way, what is it that makes you get out of bed and go to school every day, for example is it because you like school, friends, sports? Anything.

P4: So that I can pass at school

R: Okay so that’s what makes you happy?

P5: So that I can please my parents because they said that they would like to see me pass this year so that’s what forces me. I want to make them happy.

R: Oh okay, you?

P3: So that I can go to school and carry on with life

R: So all you feel motivated because of school? Okay

Ps: Yes

R: Alright, what do you find challenging about your life? And how come?

P3: I am scared of playing sports because I am afraid of getting hurt or breaking my bones

R: Oh okay, so you’re afraid of getting hurt, not because you have HIV?
P3: Yes
R: Okay, you
P5: I don’t know
R: Okay so there’s nothing that comes to mind right now? Okay. You?
P4: Nothing
R: Okay so you all do what you want to do. So having HIV does not prevent you from doing what you want to do? What you are all saying is that you live a relatively “normal” life?
Ps: Yes
R: Okay, if you could change anything about your lives, what would it be? Like you S? You? Anything?
P5: I wish I could change how I eat because I eat too much (chuckles) and want to be skinny
R: I see, chuckles, good luck, we women are not so lucky with that
P3: I want to stop beating up girls (smiles) because they like to bother me a lot
R: (Chuckles), you hit girls? How come?
P3: They bother me
R: Perhaps they are interested in you?
P3: They tease me a lot
R: How do you know that they don’t like you?
P3: They say that I have a big nose and when I run after them they run away
R: I see, but I think that they may like you, okay. And you S?
P4: I would change that I drink my pills and be healed
R: But you do drink you pills do you not?
P4: I do, but I want to recover
R: Okay, I hear you. How come you don’t ask me what I want to change?
Ps: Chuckle
R: Okay, is there anything that you would like to ask me though?
Ps: No, nothing
R: Nothing? I asked you so many questions though. So nothing?
Ps: No
R: Okay. We are done for the day. How do you feel?
Ps: We are okay
R: Okay. So good luck with your medications, and as long as you follow the directions with your medication from doctors and your parents and eat well you should be okay right?
Ps: Yes
R: Thank you so much for coming today. Thank you for your time. (Greets children with hugs as they leave.)
Ps: Thank you too
P3: Thank you, it was important

GROUP INTERVIEW L

R: How many times do you come to the hospital to collect medication? (Silence) Do you come once, twice a month etc.?
P1: Once
P2: Once
R: Okay, you?
P3: Three or two
P4: Five or two
R: Okay, you?
P5: Three or two
R: Three or two? How come you come so often? What is their explanation for you coming so often to come and get medication? No you don’t have to lift up your hand, you can talk freely, don’t worry
P1: So that we can be like other children and be okay.
R: When you say so that you’re like other children what do you mean?
P1: Mumbles, but says that so that people don’t know what illness I have and that they don’t keep asking what is wrong with me or looking at me strangely
R: What do you say?

P2: I say that I come to hospital so that I can be like other children. (One child is fetched from the interview room to see the doctor)

R: Okay, so what do you say?

P3: So that I can be like other children and be healed

R: When you say healed, what illness do you have?

P3: I don’t know

R: Okay, so when you say so that you can be healed, what is it that bothers you medically?

P3: Kidney stones

R: When did that start bothering you?

P3: I would be lying, I don’t remember

R: MM, okay, so every time you come to collect pills here at the hospital, do they tell you what you are taking them for?

P3: Yes

R: What did they say they are for?

P3: They tell me it is for the pain

R: Pain from the kidney stones?

P3: Yes

R: Okay, and then did your mom tell you whether you have another illness besides kidney stones?

P3: No

R: Oh okay, and you?

P4: My mother told me that I have HIV, and there’s no way you can tell people that you have it, only your family, so that if my mom is no longer on this earth then they (family) can take care of me and take me to the hospital so that I can be healed

R: How do you understand HIV?

P4: In order for me to get well I have to drink my pills on time and when they ask me if I have taken my medication I should say yes, and not have spat them out outside or flushed them down the toilet

R: Oh Okay, I hear you. And you? What do you understand HIV to be?
P5: HIV? Smiles…silence…I don’t know

R: Okay. Do they teach you about HIV at school?

P5: They do teach us

R: Okay, what do they say it is?

P5: Smiles…I don’t know

R: Okay so you don’t know what HIV is? Okay, and have you ever seen adverts on television about it, or in magazines?

P5: I have seen them write about it (smiles and chuckles)

R: What are you smiling about?

P5: Nothing (chuckles again)

R: Oh Okay, (to participant 3), do you and your mom ever talk about HIV?

P3: No

R: Okay so she has not mentioned it to you? I see. So then how often do you come for treatment for your kidney stones?

P3: Once a month only

R: And when you don’t go to school, what do you or your mom say to the school?

P3: That I have kidney stones

R: Okay. And what about you?

P4: I just say I have them and when I come to hospital and people ask me where I am from I just say that I don’t tell people. (One participant had to leave as well)

R: I just wanted to know why you come to hospital, how often you come here and how that makes you feel, okay? Like when you have kidney stones for examples, how do you cope at school?

P3: I am okay, I drink water every day. Even at school they tell us to keep healthy by washing our hands with soap before and after eating so that we don’t contract germs

R: Okay so they ensure that you keep good hygiene so that you don’t get sick hey?

P3: MM (Yes)

R: Okay girls, that’s what I wanted to talk to you about today. Thank you so much for your time. Are you all okay? Okay. Thank you so much, bye. (NON DISCLOSURE- couldn’t continue with full interview)
Group 1 A

R: To start off, how often do you come to the hospital?
T, L & S: Once

Okay. So when you come here- remember I spoke to each of you individually- but I want to be certain that we all know and understand why you come and collect medication here. T

T: Because I have HIV

R: HIV? Okay, what about you L?
L: So that our illness can go down

R: Okay, and you S?

S: Because of HIV

R: Oh okay, so you understand that you must take this pills so that you don’t fall ill or so that the viral load goes down, right? So I guess we all understand the same thing right?

P’s: Yes

You come to the hospital to get checked? What do they check exactly?

L: They draw blood and check if everything is okay

R: Okay, and T?

T: The same as him

R: Okay, so when you take the medication correctly or not, what happens?

T: They say you will get AIDS if you don’t take them correctly

R: So S if you don’t take pills what happens?

S: Then the viral load will go up.

R: Oh okay. So I think we all understand the same thing. So as we are all different, live and school in different places, so who told you that you have HIV and who explained what it is?

S: My sister

R: Okay, is it your older sister and do you live in the same house?
S: Yes she is my older sister and we stay in the same house.

R: What did she say to you can you remember?

S: She said because I drink pills like my mom then I have HIV

R: Oh okay, so she said because mom had HIV you also had HIV?

S: Yes

R: And that you must drink your pills. Okay, and you who told you?

L: My aunt

Your aunt? Did you stay with her at that time?

L: No, I was staying with my mom and dad but they hadn’t told me by the time they died. So even my aunt when she found me here in hospital she had to tell me.

R: Where were you at the time, here at the hospital or at home?

L: We were at home

R: Do you remember what she said to you?

L: What I remember is that she first asked me if I knew why I was taking these pills. Then I told her that I didn’t know and that it surprises me that I do. I remember that I also told her that I got ill and I am also surprised that this illness is not going away and I have been drinking these pills. Then she said that it is because I had HIV and then I started to understand when she explained it all to me.

R: Okay, so she explained it thoroughly, okay. So your parents died before they could tell you?

L: Yes

R: Okay, alright, I hear you. And you S? Who told you?

S: My grandmother

R: Okay, so what did she say to you, do you remember?

S: No

R: What happened? Was it you who asked her or did she tell you?

S: I asked her

R: Okay, what did you want to know from her?

S: I wanted to know what was wrong with me
R: What did she say?
S: She said HIV
R: Did she explain in detail to you what that is?
S: No
R: Who explained to you what HIV is?
S: Nobody did
R: Okay so they didn’t fully explain to you what HIV is?
S: No
R: So you just know the name, that you have HIV and that if you do not drink your pills you’d get sick?
S: Yes
R: Okay, I hear you. So as you all heard from different people that you have HIV, can you remember how you felt at the time? Can you try to remember how you felt-like were you angry, sad etc.?
L: Okay, I was surprised and then I asked my aunt how come my brother who is my mother’s child does not have it and yet I was infected. Then my aunt explained to me that my brother and I do not share a father but a mother. She said that this means that my father was probably HIV positive and was not taking any treatment, hence I was infected and my brother was not.
R: Oh okay, so you had questions, you couldn’t understand why you are different, he’s your brother? And yet he doesn’t come here (hospital) and you do, so you were confused as to why this was the case? And she explained to you and you understood?
L: Yes
R: Were you angry, confused or what was happening at the time?
L: No, I did not get angry. Isn’t it she explained to me so I understood, well.
R: Oh okay. So what about you S? T? You two? So you were sitting with your sister when she told you that you drank pills because you have HIV, what did you do when she told you that you had HIV? Like straight when she told you what did you do? Did you get angry? Or were you ok and go watch TV? What happened?
T: I got up and left.
R: Where did you go?
T: I went to my friends
R: Okay, and when you got to your friends, how were you?

T: I wasn’t ok

R: Hey?

T: I wasn’t okay

R: You weren’t ok? Until when?

T: Until night time then I was okay

R: Okay so what happened night time?

T: I came back, took my pills and I watched some TV and then I went to sleep and then I forgot about it

R: So you forgot about it all? Even now? When you have to come here you don’t feel different in any way?

T; Hmm mh (No)

You’re okay? So since then you were okay and went and played with your friends and never had questions or confusion?

T: No

R: You were okay? Oh okay…and for you S?

S: I was okay.

R: You were what?

S: I was okay

R: What did you say after your grandmother disclosed to you?

S: I said okay and that I will be okay or be healed and that the illness (virus) will go down

R: Oh okay you said that you will be healed and that it (virus) would go down, so you were okay? So you did not get angry or feel sad?

S: No

R: Alright. So now, we watch TV and they like to talk about HIV and we see posters and things like that, and today when you think that you are HIV positive, how do you feel about that? You know we all have thing that stress us or that we think about so sometimes it is possible to forget about your status and then you see a reminder about your status on TV or that you have you have to come here to the hospital, or when you hear people talk about it, how do you feel about that? Like now, how do you feel? (SILENCE) Remember there is no right or wrong answer, nobody is going to laugh at you, we are just all here to talk,
I am also here to try to understand what is happening. So don’t be afraid, I won’t laugh, I won’t be angry, I won’t do anything. I am here to listen to you. Okay? T’s hand was up?

T: I don’t feel proud

R: What do you mean by that? Please explain that to me? What happens in your mind?

T: It makes me angry

R: Explain to me what makes you angry or stressed?

T: Why do they keep advertising it?

R: Okay, alright, so sometimes you’re able to forget about it but when they advertise it on TV it reminds you and makes you angry hey?

T: Yes

R: Alright. And you L?

L: I don’t care anymore because I know that everyone has an illness that they have to deal with.

R: Oh okay. So you don’t feel stressed about it even if you see an advertisement or hear people talk about it your still okay?

L: Yes

R: Okay. So it seems for you understand that some people have diabetes, and others have whatever varied health issues and we are not the same and we all live with these things thus this does not make you feel bad hey?

L: Yes

R: Okay, I hear you. And you S?

S: I don’t have a problem, even if they talk about it

R: Okay, you don’t have a problem. And then let’s say at school, during Life Orientation-do you know Life Orientation (L.O.)?- do you tell people about it or have you told some of your friends or have you just kept it to yourself?

L: I don’t tell them

R: You don’t tell them? And you S?

S: I don’t tell them

R: And you T?

T: I don’t tell them
R: You don’t tell them. So when it comes up during L.O. you just keep quiet? Okay, alright. Phone of participant rings. (Participant is almost next to see the doctor). So do you feel that finding out that you are HIV has changed your life somehow? Do you feel that knowing has changed your life?

L: No I don’t feel that way, I feel like I am the same person. I don’t feel that it has changed anything. I still feel like other people

R: So at school you still feel like that same L?

L: Yes

R: Okay, others?

T: I still feel like the same person

R: So you haven’t changed at school, at home you still behave like the same person, do you still behave the same way you used to?

T: Yes

R: Even for you S?

S: Yes

R: Alright, okay. And even your friends, you haven’t told them but at home, do you feel that they treat you differently, do you feel that they treat you the same or how is it, especially for you L, because you said your brother isn’t HIV positive?

L: No, well my brother doesn’t live where I live he lives in Hammanskraal.

R: Oh okay, so at home, you don’t have stress?

L: Yes

R: Okay, and then do you feel like you are coping with being HIV positive? Do you know what coping means?

P’s: No, to get angry?

R: No. Okay so it means to deal with it, to manage, to be okay, like to understand what HIV is and to deal with it and to continue with life. Like T & S, do you feel like you’re dealing with and continuing with life okay?

T& S: Yes

R: It doesn’t stress you?

T & S: No
R: Okay, uhm, there are things that are…okay, I will ask in English, are there things that happened since you found out that you are HIV positive that made your life difficult?

P’s: No

R: You’re okay? You’re coping and managing?

P’s: Yes

R: Okay, if-we’re almost done. (Sends one participant (S) to inform grandmother that the interview is almost done). Okay, so long, if you could change anything in your lives what would it be and how come? Participant walks back in and she informs him of the question and explains what the question means.

L: I’d ask that you’d remove the HIV

R: How come?

L: Because…eish, because you find that at times I am playing with friends and I have to keep looking at my watch to ensure that I can leave on time and don’t miss my dosage. I’d tell my friends that I have to be sent somewhere by an elder so then I had to leave. But my friends ask me the same question all the time and they are surprised at that all the time.

R: Okay, so it seems like it permeates and messes up your life when you’re playing with friends like others but you have to keep the time for when you have to leave? (One participant gets uneasy wants the last question so he can leave to see the doctor)

L: Yes

R: I understand. And then for the two of you? You heard what L said? As sometimes whilst playing with his friends he has to lie and go drink his pills, but what he would change would be that he doesn’t want to be HIV positive right? Which one thing would you like to change from your life?

T: To change the HIV status

R: How come for you?

T: Because sometimes when I am with my friends I would get called by my family to tell me that I need to go home and go take my medication.

R: So like L you also have an alarm or get called to go home and take your medication and so you don’t feel like other children, so it interrupts you and you must keep to the specific time right?

T: Yes

R: Alright, and then for you S, what one thing would you change, anything in your life?

S: Mumbles about also changing status

R: I can’t hear?
S: About HIV…

R: Okay, how come? Hm? (Long silence) Don’t be afraid, just speak what you are thinking of right now. Just speak what you’re thinking of

S: Inaudible

R: Okay, so that you will be like others? Okay, is there anything that you’d like to add or ask me or something I haven’t mentioned that you’d like to know? (S’s phone rings and he is excused—he leaves)

L: What I would like to know is that if you drink your medication well, can they tell you to stop drinking them at some point?

R: Mmm well pills right, I think you need to stick to drinking them I think when you get to a particular point you still come for check-ups but you can come and get your meds only, but from what I understand, you need to drink them through and through and through, right, so that you don’t become resistant so that the pills are always effective so that they keep working at the same level, or else they’d stop working, you see, so then they’d move you to a new regimen. So you need to keep drinking them and they could change them and tell you to change them you see? But every time you go for a check-up, they will tell you or explain to you what you should do you see?

L: What surprises me is that when I initially started drinking this HIV treatment I had started drinking my treatment at 6 am and 6 p.m. but now that I am becoming okay they are halving my treatment to so that I drink at 6 p.m. only. I asked my aunt that if I am halving my treatment and only drinking the evening pills, will they stop them.

R: MM, remember that they could be giving you different pills, so you’d find that they’d changed them so you may not need to drink two pills a day anymore, so they may be using one pill to control everything, and for time purposes as well you see? So this pill thing, as long as they told you to drink them in a certain way, do that. If they change them, then ask them to explain to you exactly what is happening. Right?

L: Okay

R: So that you don’t make a mistake and so that you don’t stop them without the doctor telling you to top or to change them, you shouldn’t do that. You see, but now there are different things, like they have come up with many strategies for example have you heard that there is one pill that you can drink? Like long ago people had to drink many pills, so now the pills have been decreased and there are changes that have occurred and thus your doctor would inform you and how come the changes should be made. You see?

T: Okay

R: And then T and questions?

Ps: No
R: Okay, no questions? Thank you for your time, and I want to tell you that I know that sometimes it is difficult and that sometimes you may feel that you are not like other children and that it may feel bad to you. As you said L that every person has their own burden like diabetes etc. you should behave well, eat well and exercise so that you can always be healthy right? And being HIV positive does not mean that you are different from other children or people well, you are a person, you have feelings, you are okay, there is nothing wrong with you, it’s not something wrong that you did right? So remember that as long as you take your medication, and keep safe you’ll be okay your medication you’ll be okay. Right? And if you feel that you cannot deal with something and you need to talk to someone like when you come here, they can refer you to Psychology okay? So that you can talk to someone like me who can to talk to you about anything do not be afraid. Even if it is about the pills, when you are here then ask the doctor if you don’t understand. Thank you so much for your time. Please find your sister and do not get lost okay, go straight to her and do not get lost. Thank you!