

AN EXPLORATION OF THE EXPERIENCES OF ADOLESCENTS LIVING WITH HIV

By

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Summary

The research endeavoured to voice the told and untold stories of adolescents living with HIV undergoing continual disease management at the Kalafong Hospital Paediatric HIV Clinic. Through the telling of their stories the adolescents had the opportunity to make sense of their illness experiences. Some of the participating adolescents had limited opportunities to discuss their experiences with friends or family members.

The research was completed within the qualitative social constructionist narrative approach. Six adolescents from the clinic participated voluntarily in the research. The participants attended the clinic regularly for disease management and were on ART. The study explored the experiences of the adolescents by means of two semi-structured individual interviews. Expressive art in the form of drawings and poetry were used to aid storytelling. Through collaborative exploration of the adolescents' stories, it became possible to co-construct the meanings that they attached to their experiences of HIV, which informs their identity.

The interview transcripts were analysed, re-storied, and placed within a narrative framework of understanding, based on the three-dimensional space approach by Clandinin and Connelly (2000). The framework of understanding aided the researcher to look at the different contexts, identities, and social significant aspects found in the adolescents' stories. Multiple identities were constructed in their stories such as patient, scholar, friend, family, and athlete identities. These were constructed based on their experiences in the family and cultural, school and social, and medical contexts. The adolescents attributed different meanings to their stories of living with HIV such as that of normality, sameness, realism, and difference.

The unique and similar aspects that were found in the adolescents' stories were identified and discussed with reference to various concepts such as disclosure, adherence, and ART. It was found that status disclosure was done by staff at the clinic and it occurred during young adolescence. All the adolescents, except one who was not aware of her status, showed insight into the chronic nature of their disease. Five adolescents' statuses have not been disclosed to anyone outside the families. In only one instance, the family was not aware of his status. Most

adolescents assumed primary responsibility for ART. They expressed conflicting ideas about the role of ART. Some adolescents had to cope with side effects, the possibility of accidental status disclosure and non-adherence, and fears of rejection.

The research, employing a narrative approach, endeavours to contribute to create a holistic understanding of HIV/AIDS in the context of health care. Lack of communication and impersonal staff interactions with patients were identified as barriers to disease management. The research recommends that the clinic should provide ongoing support to the adolescents with regards to disclosure of their status to friends, family, and partners, and adherence to medication. The social significant aspects found in the adolescents' stories will be disseminated to the staff at the clinic. This will assist the multi-disciplinary team to gain a better understanding of the reality of the adolescent and how these experiences inform their identity.



Key words

HIV, AIDS, ART, health care, disease management, chronic illness, adolescent, adolescence, identity development, narrative, story, social constructionism, narrative approach, identity, context, experience

Sleutel terme

MIV, VIGS, ART, gesondheidsorg, siektebestuur, kroniese siekte, adolessent, adolessensie, identiteits ontwikkeling, narratief, storie, sosiaal konstruksionisme, narratiewe benadering, identiteit, konteks, ervaring



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Chapter one

Research background

1. Introduction

The declaration, “health for all”, was made more than thirty years ago, at the Alma Alta conference on Primary Health Care (PHC). South Africa based its health care delivery strategy on this PHC philosophy since 1994. The declaration adopted at the conference reaffirmed that health, which is a state of complete physical, mental, and social well-being, and not merely the absence of disease, is a fundamental human right (Lutge, Friedman & Mbatha, 2008). The Human Immune Deficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS), a pandemic disease of worldwide proportions, was listed as the number one national health priority in 2006 (Lutge et al., 2008). HIV/AIDS has impacted our nation severely for more than ten years, but has only recently been given primacy. Delivering holistic health care that incorporates complete physical, mental, and social well-being is proving to be difficult, as holistic health care in South Africa faces many challenges.

Health care in South Africa should aim to provide holistic curative and preventative care that is more than just the management of a disease. There is a need to develop a broader understanding of health and disease. This requires a multi-sectoral approach that takes a broader range of health determinants such as education, employment, culture, environmental, personal, social, and community influences into consideration (Bradshaw, 2008). The health care system that is rooted in the medical model needs to incorporate a broader understanding of health and disease into its conceptualization. One manner in which a wider understanding of health and disease could be achieved is by including the experiential world of the individual, which is receiving health care, into the conceptualization thereof.

1.1. HIV/AIDS

HIV/AIDS is a condition that is indicative of pathological changes within the body (Radley, 1994). As an epidemic, HIV/AIDS has reached an unexpected and enormously high level,

affecting a large number of people over a short period of time (Barnett & Whiteside, 2006; Pratt, 2003). HIV/AIDS were first identified in the early 1980's and is presently still raging on with devastating effects. HIV attacks and destroys the human body's immune system, leaving the body susceptible to other infectious diseases. HIV is transmitted through contact with infected bodily fluids (Pratt, 2003). HIV has a long incubation period between the time of infection and the onset of illness. Therefore an individual can be asymptomatic for more than ten years before showing any symptoms. AIDS refers to a group of various diseases that attacks the human body due to a weakened immune system as a result of the presence of the virus (Barnett & Whiteside, 2006).

HIV/AIDS is considered a chronic illness. This conceptualization of HIV/AIDS brings about an understanding of the individual's experiences of living with such a disease. Therefore the term 'illness' refers to the experience of disease and pertains to the feelings and thoughts of the individual regarding bodily changes (Radley, 1994). Chronic illness is a disruptive event that allows for the meaning of the illness to be situated within time, space, and an individual's course of life (Bury, 1997). Radley (1994) refers to two features of a chronic illness. Firstly, chronic illness is long lasting. Illness symptoms may not always be present however; symptom recurrences are always likely and will have various implications for prospects of recovery. Therefore, the awareness of the underlying disease is always present. Secondly, chronic illness has a temporal character; it is linked to the experience of time. The experience of the illness is viewed in the light of past experiences and future possibilities. Chronic illness takes meaning in how it will affect the remainder of the person's life.

1.1.1. Epidemiological research

Epidemiological studies on HIV/AIDS provide information regarding the distribution, impact, and effect of the disease on global and national populations. These studies provide crucial information with regards to the magnitude of the problem that all nations are faced with. The Joint United Nations Programme (UNAIDS) reported that in the year of 2008, the total number of people living with HIV globally were estimated to be 33.4 million, of this 2.1 million were children under the age of fifteen years (UNAIDS, 2009). Sub-Saharan Africa alone accounted for

22.4 million people living with HIV (UNAIDS, 2009). Globally the estimated number of AIDS-related deaths in the year of 2008 was 2 million people, with children under the age of fifteen years accounting for 280 thousand deaths.

UNAIDS reported South Africa to be home to the world's largest population of people living with HIV (UNAIDS, 2009). In South Africa the total number of people estimated to be living with HIV were 5.7 million in the year of 2007 (UNAIDS, 2009; World Health Organization, 2008). Of this total, an estimated 240 thousand children under the age of fifteen years were living with HIV. Dorrington, Johnson, Bradshaw and Daniel (2006) reported that in the year 2006, an estimated 1.01 million youths between the ages of fifteen and twenty-four years of age were living with HIV in South Africa. Male youths accounted for 180 thousand and female youths accounted for an estimated 831 thousand. Gauteng province alone accounted for 60 thousand children under the age of fifteen and 175 thousand youths between the ages of fifteen and twenty-four years, that were living with HIV in 2006 (Dorrington et al., 2006). The predominant cause for the large number of infections amongst child and adolescent populations are due to mother-to-child transmission during child birth and breast feeding. In South Africa there is still no evidence of a decline in infections amongst HIV positive pregnant women. Therefore the young child population has an extremely high risk of infection (UNAIDS, 2009). With antiretroviral treatment (ART) being administered to pregnant women during child birth the possibility of transmission to the newborn could be drastically reduced. Despite this, mother-to-child transmissions still continue to be substantial. This also accounts for the high number of HIV infections amongst adolescent populations.

The introduction of ART is having a profound impact on the HIV/AIDS mortality rate (UNAIDS, 2009). In South Africa, the national ART programme launched in April 2004 and it has been running for a period of five years (Andersen & Seedat, 2009). This is a relative new programme that has been incorporated within South Africa's health care system aiming to provide medical treatment and management for those infected with HIV/AIDS. The introduction of the ART programme has had a significant impact on the course of the HIV/AIDS epidemic. Before the commencement of ART, due to rapid disease progression in infected children, the mortality rate in this group was high. The roll-out of ART has increased HIV positive children's life span,

making it possible for them to reach adolescence and young adulthood. Therefore, the adolescent population that is currently living with HIV has increased. It was estimated that the number of deaths per annum, as a result of AIDS, could have been reduced by 100 thousand in 2010 as a result of the commencement of ART (Dorrigton et al., 2006). The World Health Organization (WHO) (2008) reported that there were 460 thousand people receiving ART during 2007 in South Africa, with only 362 sites reported to provide ART. Of this, an estimated 32 thousand children under the age of fifteen years were on ART in 2007 (WHO, 2008). One of these sites, The Kalafong Hospital Paediatric HIV Clinic, treated forty-three children aged thirteen to eighteen years and fifty-two children aged eleven to thirteen years of age, as at November 2008 (Vlug, Feucht & Kruger, 2008).

1.2. Kalafong Hospital Paediatric HIV Clinic

Health care and disease management plays an integral part in the daily functioning for those infected and affected by HIV/AIDS. The Kalafong Hospital Paediatric HIV Clinic has been operational for a period of five years. The clinic aims to provide ongoing disease management and health care for children and adolescents living with HIV/AIDS. A multi-disciplinary team that performs various functions maintains ongoing management of those infected by HIV/AIDS. Initially, it was aimed that the clinic would provide treatment services to infants and children born with HIV due to mother-to-child transmission. At first, there were no adolescent patients, due to rapid disease progression in children with HIV, causing a high mortality rate in this age group. The adolescent division of the clinic was formed in 2007. It was formed due to a growing need to serve the first group of children that was reaching puberty, so that they could then enjoy a healthier and prolonged life, due to the availability of ART (Vlug et al., 2008).

In a quest to provide holistic all encompassing care to children, adolescents, and caregivers infected and affected by HIV/AIDS, the clinic invited the Department of Psychology, at the University of Pretoria, to become part of their multi-disciplinary team. Honours and masters students, from the Psychology Department, now form part of an ongoing venture to establish and provide psychological services for those attending the clinic. As part of the ongoing development of these services various projects have been launched to define and develop psychological

services as part of the clinic team. Vlug et al. (2008) identified the need for psychosocial support for patients through peer-support groups. An adolescent support group was thus established at the clinic, and became operational in June 2009.

As a student psychologist involved in the process of project development at the Paediatric HIV Clinic, I am cognisant of how the health care environment and the ongoing management of a disease, such as HIV, is intrinsically part of the life of the adolescent attending the clinic. Many of the adolescents' experiences of living with HIV and undergoing continual disease management remain unknown. I have come to question what the experiences of these adolescents are and how these experiences come to inform their identity, as they are still developing emotionally and physically. As the adolescent clinic functions primarily on a medical level, in order to further incorporate psychological services into this multi-disciplinary team, it is essential to come to an understanding of the adolescents' experiences and dilemmas as faced with disease management and living with HIV.

Conversations with clinic staff and caregivers brought various dilemmas to the foreground. Clinic staff faces the dilemma of working with- and treating adolescents that are not yet aware of their HIV status. Clinic staff have reported stigma to be a barrier in the effective treatment and combat of HIV. Caregivers refrain from disclosing their child's HIV status, as they are afraid of the emotional and behavioural consequences such as blame, guilt, denial, rejection, acting- out etc. Furthermore, clinic staff is concerned about issues pertaining to sexuality and identity, as many adolescents are reaching biological maturity, however, cognitively and psychologically they are still developing.

1.3. The adolescent and identity development

In order to come to an understanding of the experiences of the adolescent attending the clinic, it is necessary to first come to an understanding of the term 'adolescence' and what it entails. Adolescence is defined as the transitional period between childhood and adulthood. There are many different definitions of the age span of adolescent years, though it generally is the period between ten to twenty-two years (Goossens, 2006). The onset of adolescence is marked by the

biological changes of puberty, and this period is characterized by growth and maturation in all areas of functioning. The process of identity development is a lifelong process. However, during adolescence identity development is at a critical stage due to the physical and psychological changes set in motion by puberty (Thom & Coetzee, 2004). This period is characterized by self-exploration and discovery, as adolescents have the increased capacity to question attitudes, values, and beliefs (Thom & Coetzee, 2004). Identity development in the adolescent is thus affected by the changes occurring within him and the socio- cultural context of the adolescent. Identity development can be understood as the establishment of an awareness of self. Identity then refers to an individual's awareness of being an independent unique individual, being continuous over time and space (Thom & Coetzee, 2004; Thom, Louw, van Ede & Ferns, 1998).

Identity development takes place within the specific social context that the adolescent is situated within. As Van Hoof and Raaijmakers (2002) state, an individual participates in various social contexts and come to an understanding of the kind of person that he is, based on his function in a specific environment such as at school. At the same time, an individual develops an understanding that he will remain the same person throughout time and in different contexts. The clinic, as a context that the adolescent functions within, therefore shapes the experiences that the adolescent has of himself, which informs his identity. During the process of identity development, the adolescent has to explore various socially acceptable roles that are associated with specific contexts.

1.4. Motivation for the research

The motivation for this research is influenced by a variety of factors. Lutge et al. (2008) stated that the number of health research relating to the field of HIV/AIDS has dramatically increased since 1994. HIV/AIDS research has grown to such an extent that it currently dominates all health research. Even with the overflowing number of literature relevant to HIV/AIDS, Onyanha (2006) found that the total number of HIV/AIDS research papers that focused on young people were limited. Most research pertaining to the adolescent age group is focused on the prevention of infection amongst this group. However, there is more limited information available about adolescents infected with HIV. This is an area in need of further exploration.

Secondly, as stated earlier in this chapter, ART programmes have only recently been implemented into the health care system of South Africa. Adolescents' experiences related to health care and ART remain an area open for exploration. Health care and disease management forms an integral part of the life of the developing adolescent living with HIV. In the context of HIV/AIDS the adolescent population faces multiple challenges. The developing adolescents have to make sense of their illness experiences and come to form a healthy understanding of who they are as individuals. There is limited research available that focuses solely on the experiences of adolescents undergoing disease management with the aim of exploring how these experiences inform their identity. The present research aims to explore the experiences of the adolescents living with HIV and undergoing disease management to describe how these experiences informs the developing adolescents' identity.

Thirdly, the health care system is founded on the medical model that is based on the positivistic paradigm. It does not focus on the exploration of the individual's experiences relating to ongoing disease management and health care in living with a chronic illness. There is a need to expand and elaborate current positivistic knowledge by means of creating depth of understanding relating to personal experiences in the context of HIV/AIDS. By achieving depth of understanding it could contribute to provide a better understanding of the context that HIV/AIDS is situated within (Lutge et al., 2008). This contributes to creating a holistic understanding of the individual living with HIV in the health care system. This research aims to achieve depth of understanding in the context by employing the narrative mode of inquiry within the health care domain.

In the field of HIV/AIDS a narrative mode of inquiry can bring forth a renewed understanding of the experiential world of the individual living with HIV/AIDS. The narrative mode of inquiry in the context of HIV/AIDS is a means of voicing and listening to the told and untold stories of those infected and affected by this chronic illness. By means of storytelling an understanding of the experiential world of the individual is brought forth. In chapter two, three narrative studies are outlined that highlights how this could be achieved. In chapter three the theoretical underpinning of this concept is fully discussed and the applicability accentuated.

1.5. Objectives of the research

The research aims to give a voice to the told and untold stories of the adolescents living with HIV that attends the Paediatric HIV Clinic at Kalafong Hospital for continuing disease management. Through the exploration of the adolescents' stories, it may prove to be beneficial to the adolescents involved. As the adolescents are still in the process of identity development, the research provides the opportunity to explore and make sense of these illness experiences. Frank (1995) describes becoming ill as a call for the telling of stories. Stories about illness are seen as a means of repairing the damage that chronic illness has caused to the individual's sense of self. Through the telling of stories, the self is being formed in what is being told. Through the exploration of the adolescents' stories by means of expressive art, the self is formed and explored in the art. Therefore, the act of telling stories through art becomes a meaning making activity. Crossley (2000b) also outlines that living with a chronic illness brings about change in a person's outlook of his basic sense of time. Storytelling can be used to sustain a sense of life-course in the face of illness by means of weaving a story together, and accounting and reinterpreting events surrounding the illness experience (Radley, 1994).

Through exploring and describing the experiences of adolescents living with HIV, and who are undergoing continual disease management at the Paediatric HIV Clinic, an understanding of the challenges and dilemmas that adolescents are faced with could be gained. The research aims to assist the multi-disciplinary team at the clinic to gain a better understanding of the experiences of the adolescents and how these experiences inform their identity. Clinic staff will gain a holistic understanding of the reality of the adolescent. The research could assist in creating sensitivity towards the experiences of those infected and affected by HIV, when visiting the clinic for disease management.

1.6. Overview of the research

The research explores and describes the experiences of adolescents living with HIV, undergoing continual disease management at the Kalafong Hospital Paediatric HIV Clinic. The research was undertaken from the qualitative paradigm from a social constructionist narrative approach. The

experiences of six adolescents were explored by means of individual semi-structured interviews. Storytelling with the adolescents was aided by means of employing expressive art in the form of multiple drawings and poetry. A follow-up individual interview was arranged with all the adolescents. This served as a debriefing session and to make sure that all the adolescents were comfortable with the researcher's interpretation of their stories, collected in the first interview. Clandinin and Connely's (2000) three-dimensional space approach was used to re-story all data gathered through the interviews. Through the process of exploring the experiences of the adolescents it was possible to identify how they construct their identities through these experiences.

In this chapter, HIV/AIDS was discussed with attention to the scope of the epidemic both globally and nationally. Here the uniqueness of the adolescent group with regards to HIV was highlighted. The reader was introduced to the Kalafong Hospital Paediatric Clinic and the nature of the researcher's involvement at the clinic was described. The concept of adolescence was discussed and the importance of this developmental stage outlined. The chapter was concluded by outlining the motivation for and the objectives of the research.

In chapter two, health care and disease management are discussed, with reference to the adolescent. Here various obstacles, in the health care of the adolescent living with HIV, are highlighted. Attention is given to biopsychosocial factors that impact on the developing adolescent giving an account of the dilemmas that health care providers are faced with in working with the adolescent. Three narrative studies in the context of HIV/AIDS are discussed that illustrates how this approach could bring about a broader understanding of the experiences of those infected and affected by HIV/AIDS.

In chapter three the theoretical point of departure that informs this research is discussed. An introduction to postmodern thought is given that serves as prelude to the discussion on the social constructionist narrative approach. The development of the social constructionist approach is discussed where after the key concepts that define the essence of this approach are outlined. Hereafter an outline to the development of the narrative mode of thought is given where after the narrative structure is discussed. The narrative approach is framed within the social constructionist

approach, giving an account of the key concepts that informs the narrative approach. This approach is also discussed from the perspective of working with children and adolescents, thereby highlighting the applicability of this approach to the research.

In chapter four, the research methodology is discussed and the method and process is outlined that was followed in conducting the research. Here it is outlined that the research was conducted from a qualitative social constructionist narrative approach. Six adolescents from the Kalafong Hospital Paediatric HIV Clinic voluntarily participated in the research. With the assistance of the clinic doctor, the purposive sampling technique was used to identify the adolescents. The adolescents were between the ages of twelve and eighteen years of age, on ART and are undergoing continual disease management at the clinic. Data was collected by means of semi-structured individual interviews and expressive art was used to aid storytelling. Narrative data analysis was done by means of the three-dimensional space approach. The adolescents' stories of living with HIV and how these experiences inform their identities were re-storied and interpreted. Follow-up individual interviews with each adolescent were arranged that served as a debriefing session, and to make sure that all the adolescents were comfortable with the researcher's interpretation thereof.

In chapter five, all the adolescents' stories of living with HIV are interpreted and discussed. Here attention is given to the adolescents' experiences and how various identities are constructed based on these experiences and the meanings that are attached to it. Each adolescent's story is discussed separately according to the different contexts such as medical, cultural, familial, and social that informs the adolescent's story. The adolescent's multiple identities are discussed as it was constructed through their experiences. The interplay of these identities is also highlighted. Each story is discussed by giving reference to the narrative approach.

In chapter six, the research is concluded by discussing the research results. Here the unique and similar aspects that were found in the adolescents' stories are outlined. Aspects such as disclosure, adherence, and ART are discussed as it is found in the adolescents' stories. The research shortcomings and limitations are discussed and recommendations are provided for possible intervention and future studies. Thereafter, the dissemination of the research results is

discussed and the chapter is concluded by reflecting on the researcher's thoughts pertaining to the study. The chapter is finalized by providing a summary of the research.

Chapter two

Health care and the adolescent

2. Introduction

South Africa's health care system is devoted to providing health care for all that is aimed at achieving a state of complete physical, mental, and social well-being. Health care provision faces many challenges as many of the determinants of health lies outside the direct influence of health and social care (Bradshaw, 2008). In order for the health care system to reach its aspiration of providing holistic care to those suffering from disease, it will have to employ an approach that brings about a broader understanding of health and disease.

In this chapter, health care and disease management is discussed with reference to the adolescent in the context of HIV/AIDS. Hereafter the obstacles and dilemmas that health care is faced with are outlined. Attention is given to the biopsychosocial factors that impact on the developing adolescent, and the dilemmas that health care providers are faced with in working with the adolescent living with HIV, is mentioned. Hereafter three narrative studies in the context of HIV/AIDS are discussed. These studies are discussed with reference to how the narrative approach could bring about a broader and deeper understanding of the experiences of those infected and affected by HIV/AIDS, giving an account of the social and cultural context within which the disease are situated. This understanding could contribute towards creating a holistic understanding of health and disease.

2.1. The health care system

Health care and disease management plays an integral part in the daily functioning of the individuals infected and those affected by HIV/AIDS. Health care systems should aim to provide holistic care and support for those living with the chronic illness. Amon (2002) reported that few programmes have been implemented that provide comprehensive and integrated HIV prevention, care, and support services to youths of all ages that are living with HIV/AIDS, or are affected by it. Programmes should aim to tailor care and support services to the differing needs of infants,

children, and adolescents. These groups have special concerns and specific physical and emotional needs. These groups are however united through causes of vulnerabilities such as loss of a parent and disruption of families. Amon (2002) reported that most HIV/AIDS prevention programmes focussed their efforts on primary prevention for older adolescents, while the care and support programmes for youths were focussed on newborns and younger children infected by HIV. Amon (2002) states that by incorporating the goals of an improved health infrastructure, and strengthening families and communities, one can only move towards building sustainable and credible programmes. When this is attained, improvement in the quality of life and the simultaneous prevention of future infections can be achieved.

Ayres et al. (2006) also state that the attainment of the highest standard of health for young people living with HIV/AIDS is not merely just infection control, but a striving towards quality of life, with the emphasis on mental and social well-being. Amon (2002) places the emphasis on community mobilisation, strengthening referral systems, and developing a nature of care through a network of support groups in a given community. Thom (2009) furthermore states that support services such as support groups, counselling, psycho-education, social work, and occupational therapy interventions should form part of the health care system's basic preventative services in the context of HIV/AIDS. It is found that when these services are available in health care systems, they are usually only focused on providing support during treatment initiation. Anderson and Seedat (2009) stated that it is imperative that ART is complemented by psychosocial support services to ensure adherence to treatment, and to improve treatment success.

Goudge, Gilson, Russell, Gumede and Mills (2009) have identified various barriers in health care for the chronically ill. Few health care systems are organized to meet the needs of chronically ill patients, especially poor patients with limited resources that are in need of regular health care. Poor households with little or no income and limited social networks are often prevented from seeking or accessing health care. Findings show that monthly cost burdens for repeated trips to, and from health care facilities, can be exceptionally high. Complex treatment seeking patterns, where patients continually consult with a variety of providers, also prevent the provision of regular chronic care. This results in incomplete or inaccessible health records leading to difficulty in monitoring a patient's blood count and ART adherence. In South Africa barriers to effective

services in chronic care have been identified as: increased patient numbers, acute staff shortages, short consultation times, poor communication between staff, lack of continuity of care by the same doctor, availability and continual access to medicine, and a shortage of equipment. Communication between health care provider and patient has various influences over the acceptability of health services. In many instances Goudge et al. (2009) have found that patients did not know their diagnoses, because no diagnosis information was given to the patient, or insufficient explanations or attempts to make sure that the patient understood the information, was given. Therefore effective chronic care treatment requires productive interactions between informed and prepared patients, and organized and well-equipped health care teams, in the context of an informed and supportive community (Goudge et al., 2009).

Ayres et al. (2006) undertook a study to gain an understanding of the health care needs of young people living with HIV/AIDS as narrated by caregivers and adolescents. Delayed disclosure was identified as a step taken by caregivers to protect adolescents from perceived and potential harm. Caregivers aimed to protect adolescents from being perceived as being abnormal. Talking to young people about sexual matters was also perceived as being potentially harmful to young people's psychosexual development. Caregivers delayed disclosure so that adolescents did not have to deal with potential conflicts, pertaining to the disclosure of their status to friends and partners. Caregivers feared that it would lead to the adolescent having to deal with possible rejection and losses in these relationships. It was found that these beliefs were due to fear, stigma in the community, and lack of clear information and knowledge pertaining to HIV. Through their study Ayres et al. (2006) identified the need for programmes to incorporate the goals of informing and raising providers, caregivers, and young people's awareness about children's and youth's rights in the context of HIV. Programmes should also strive to provide young people with complete and accurate information on sexuality and HIV. Providers should establish guidelines that would support careful management of HIV status disclosure to young people and their families.

Fear, stigma, and discrimination are continuing to accompany HIV/AIDS. Stigma is conceptualized as a social process that is founded upon inter alia, lack of knowledge pertaining to HIV/AIDS (Goudge, Ngoma, Manderson & Schneider, 2009; Sadoh, Sadoh, Fawole, Oladimeji

& Sotiloye, 2009). HIV/AIDS related stigma has damaging consequences such as causing delays in testing, poor treatment adherence, and a greater number of new infections (Goudge et al., 2009). Furthermore, HIV/AIDS stigma brings about difficult psychosocial circumstances to those infected and affected by HIV/AIDS, such as fear of disclosure because of the possibility of discrimination (Anderson & Seedat, 2009). Additionally stigma has been reported to prevent clear communication and understanding between health worker and patient. Stigma may prevent the patient from absorbing, accepting, or reporting the diagnosis. This illustrates the social and cultural gap between health workers and patients (Goudge et al., 2009). Limited social support proves to be the key determinant that affects an individual's ability to resist stigmatization (Goudge et al., 2009). Additional stressors, related to stigma and lack of social support, increase the risk for psychological problems in people living with HIV/AIDS (Thom, 2009).

2.2. Biopsychosocial factors

Thom (2007) identified a spectrum of psychiatric and psychosocial factors that has an impact on the physical well-being and the quality of life of the adolescent infected by HIV. These factors bring forth various challenges with regard to the comprehensive care of the adolescent. Neurocognitive disorders, psychotic disorders, and depression can be found as part of the psychological presentation of the adolescent. Neurocognitive disorders develop as a direct result of infection to the brain. This may manifest as cognitive, motor, behavioural, and visuomotor problems. Thom (2007) reports that common presenting symptoms include school failure, hyperactivity, poor concentration, mood changes, and specific motor difficulties. Psychotic disorders may present as a primary condition or a secondary condition due to HIV/AIDS. Psychotic disorders are mostly a presentation of late-stage HIV disease. Depression is found to be common in adolescents with HIV infection. Depression might present with somatic complaints, conduct problems, irritable mood, poor concentration, and poor school performance. Depression also threatens overall quality of life, as depression affects adherence to medication, resulting in an increase in viral load, affecting the efficacy of ART (Anderson & Seedat, 2009).

Psychosocial factors that have an impact on the adolescents' well-being relates to issues of adherence, disclosure, bereavement, and development. Identity development, sexual, and social

development becomes of paramount importance in the developing adolescent. As noted in the previous chapter, adolescence is characterized by growth and maturation in all areas of functioning. The primary developmental task in the developing adolescent is to establish a sense of identity. Thom (2007) explains that the adolescent has an increasing cognitive capacity to understand abstract concepts and can therefore question the circumstances in which they find themselves. The adolescent has the capacity to focus on future orientated activities. This brings a renewed awareness of their status and future possibilities. Biological maturity in the adolescent results in an increased focus on sexuality and relationships. Therefore acceptance of their peer group becomes very important for the developing adolescent and may result in risk behaviour. HIV status disclosure, by a caregiver or health worker to a child or adolescent, is important for the adolescent to take responsibility for his behaviour. Disclosure is not a once-off event. Disclosure might be accompanied by reactions of anger, sadness or shock. Thom (2007) states that disclosure is a process that happens over time in children and adolescents as they develop. At each age they will have different concerns and questions. HIV status disclosure should always be given in relation to the individual's capacity for understanding.

Adherence to medication and treatment becomes an area of increasing concern during adolescence. As adolescents at this stage have the capacity for understanding their illness, denial may be used as a way of coping with fear. Furthermore, a strong orientation to the present often means that risks associated with the disease, such as death, are seen as distant or in the future. Thom (2007) states that factors, specifically characteristic of adolescents, may result in inconsistencies with adherence to medication and treatment. These include the need to express independence, to adhere to peer pressure, not wanting to be and feel different, and feelings of being invincible resulting in increased risk-taking behaviour. It furthermore includes distrust or rejection of figures of authority, an attraction to alternative or unconventional sources of information and hormonal changes. Thom (2007) states that the level of responsibility that the adolescent enjoys, should be negotiated between caregiver and adolescent, to aid the transition between independence and supervision that becomes of importance during adolescence.

2.2.1. Identity development and context

As discussed above, adolescents in the process of development have the increased capacity to explore and come to a renewed understanding of their illness and the environment that they find themselves in. Identity development is influenced and defined by the experiences related to the various contexts that the adolescent comes in contact with. Culture, ethnicity, race, and gender can be described as contexts as they refer to socially constructed characteristics that society attribute to an individual (Cote, 1996). In understanding identity development in the adolescent it is necessary to incorporate the concepts of ‘culture’, ‘multiculturalism’, ‘self-concept’, and ‘self-esteem’ into the study. Identity development is affected by both the individual’s socio-cultural context and the individual, and therefore these concepts cannot be separated from the discussion (Thom & Coetzee, 2004).

Thom and Coetzee (2004) states that culture reflect the historical background of a group of people and this is handed down from one generation to another. Customs, religion, values, norms, laws, behavioural rules, and languages are representative of culture. Jensen (2003) defines the formation of a cultural identity as a process of taking on beliefs and related behavioural practices that unite individuals within a community. Jensen (2003) state that adolescents are growing up in an era that is considerably more multicultural, due to the processes of globalisation that they are exposed to. Thom and Coetzee (2004) found that in the South African context, adolescents are in contact with various cultures that differ in nature. All South African adolescents have been subjected to socio-political changes, and therefore had to form their identities in a society that is undergoing transformation. Adolescents have to form a cultural identity that is ideally a synthesis between traditional and modern cultures. For the adolescent growing up in South Africa’s new democratic society, it is a complex process that takes place within a multicultural society.

As identity development is affected by the individual, it is important to refer to the terms ‘self-concept’ and ‘self-esteem’ when forming an understanding of identity development. The term ‘self-concept’ refers to the attributes of an individual and therefore contains a descriptive element (Alsaker & Kroger, 2006). The term ‘self-esteem’ can be viewed as an evaluation of one’s own personal attributes (Alsaker & Kroger, 2006). For the adolescent living with a chronic illness it

becomes a dual challenge to incorporate various experiences related to disease management, culture, and society, into a healthy and sustainable view of him. In coming to an understanding of the experiences of an adolescent living with a chronic illness and how this informs his identity, it is necessary to understand how his social world and the meanings that he attribute to these experiences influences his perceptions of self.

2.3. Narrative research studies within the context of HIV/AIDS

Employing a narrative approach in the context of health care and HIV/AIDS may bring about a better understanding of the cultural and social context that these constructs are situated in. The narrative approach also brings a deepened understanding and appreciation of the experiences of individuals infected and affected by this disease. The narrative approach can expand knowledge that is based on positivistic epistemologies, to create a wider understanding of the meaning of health care and disease in South Africa. This could aid the health care system to be able to provide more holistic care.

Herewith follows an outline of three narrative studies in the context of HIV/AIDS. These studies highlight how the narrative approach could be employed to broaden our understanding of HIV/AIDS. The three narrative studies were used differently but the approach endeavoured to bring about renewed understandings of the social and cultural context that HIV/AIDS are situated within. It focuses on the experiences of individuals infected and affected by HIV/AIDS. In listening to individual experiences and exploring the meanings attached to them it became possible to frame how people make sense out of HIV/AIDS in different contexts.

2.3.1. Using narratives to develop a hermeneutic understanding of HIV/AIDS in South Africa

Baxen (2008) argues using the narrative method of inquiry to develop a hermeneutic understanding of HIV/AIDS in South Africa, which will bring about and expand current epistemologies. In using a narrative approach, it becomes possible to broaden current methodological orientations that are concerned with ‘what’ is known about the pandemic to include a focus on ‘how’ and ‘where’ knowledge is produced. The aim of the study was to

expand dominant epistemologies by using the narrative approach. This gave insight into the social and cultural practices that shapes prevention strategies in schools. South Africa has placed the emphasis on schools as the sites for teaching children about sexuality and HIV/AIDS. What is taught and who mediates learning in schools became a relevant question to this study. Teachers bring their own understandings and experiences of sexuality and disease into the classroom. These experiences and understandings come from the teacher's own wider social and cultural context where they are situated within. These experiences come to inform their individual and collective identities as teachers. Baxen (2008), from a qualitative perspective, employed a case study approach to examine the life stories of teachers who teach life skills in the classroom. The research was conducted in two pre-selected schools in the Western Cape and Mpumalanga. Thirteen secondary school teachers and seven primary school teachers participated voluntarily in the research.

Through her study Baxen attempted to understand what teachers do when they teach sexuality and HIV in the South African school context. Baxen (2008) identified various influences that teachers drew on that informed their identity. Influences such as marital status, class, gender, race, and religion were some of the aspects found to define how teachers viewed themselves. She found that dominant discourses relating to sexuality and disease in their communities, based on practices of silence and stigma, to be the framework from which teachers made meaning of themselves as individual's and as teachers in the classroom. Some teachers reported that they themselves were not using condoms whilst in polygamous relationships and marriages. Teachers reported that they were eager to discuss protection with their partners however, they were afraid of the consequences. Discussing the topic of protection would lead their spouses to question their fidelity in the relationship. Even with the knowledge of infidelity in marriages some teachers were afraid to use protection as their spouse would question their fidelity. Teachers also reported that their experiences related to sexuality were associated with silence and shame within their communities. Sexuality was therefore not discussed and information obtained regarding sexuality was through older siblings, relatives or the experiences of unwanted pregnancies. Baxen (2008) found that teachers drew from these personal experiences to make sense of HIV in the classroom. It was also found that the teachers modelled gender roles of silence and obedience to the children

in the classroom. Baxen (2008) employed the use of narratives to shift the focus to understanding the social nature of the disease and its social and material effects.

The research contributed to create an understanding into what the social and cultural influences are that govern how teachers make sense out of disease and illness in the classroom. These cultural and social stories were found to be situated within dominant discourses that still govern knowledge and perceptions about disease, where in this study these discourses were informing knowledge practices in classrooms. The narrative approach presented an alternative way to most studies through exploring the context in which knowledge is generated that influences classroom teachings. It shifted the focus from the content of life skills programmes to focus rather on the individuals that deliver these programmes. This allowed for a wider perspective of the underlying factors that govern programme implementation and preventative strategies in schools.

This research cannot be generalized however the narrative case study approach provides important information on how the cultural and social context tends to inform knowledge practices. This research brings about awareness that teachers cannot deliver neutral information, as their personal and professional identities are situated within, and influenced by the cultural and social context that informs how they themselves conceive of the disease. This research study contributes to create awareness of possible discourses and knowledge practices that may come to influence and dictate how knowledge with regards to sexuality is shared with the adolescent at the clinic. The clinic is a context where the staff's interactions with the patients are informed by the cultural and social influences that shape their understanding of the world. Possible future studies could explore how nurses and doctors make sense of sexuality and HIV/AIDS, and how these knowledge practices inform their interactions with patients at the hospital.

2.3.2. Narratives of sexual abstinence: A qualitative study of female adolescents in a Cape Town community

Kahn (2006) conducted narrative interviews from a critical health psychology perspective in Cape Town. She explored decision-making about sexual abstinence amongst female adolescents living in a poor coloured community. The research was completed with six adolescent girls

between the ages of sixteen and eighteen years of age in the Ocean View community. Stories were obtained by means of focus group discussions and one to two individual in-depth semi-structured interviews with each participant. It was found that sexual abstinence was part of a broader strategy of making and taking opportunities to escape from the destructive cycles of life in their community.

In this study, HIV/AIDS interventions were not found to be the reason for sexual abstinence, rather that sexual decision making was informed by other factors. Kahn (2006) reported that sexual decision-making amongst adolescents were embedded in the psychosocial and material elements of their social context. Abstaining from sexual relations was instrumental in securing positive outcomes in two key areas of the adolescents' future, namely their reproductive and productive future. By abstaining, these adolescents could entertain new possibilities for their future that was previously inaccessible in the past and in their current lives. Many of these adolescents reported familial stories such as divorce, children born out of wedlock, and unstable and abusive relational dynamics. Abstaining from sexual relations was also reported to be a general approach to maintain their independence, personal control, and agency. Many theoretical models assume that sexual decision-making is primarily based on health-related concerns however, sexual-decision-making may be independent of health-related concerns. Kahn (2006) argues for theoretical models to incorporate psychosocial determinants in their sexual health models, which will proceed beyond the biomedical and behavioural orientation of many theoretical models that underlie intervention programmes.

The research employed a narrative approach to provide knowledge that would move away from pre-defined theoretical models governed by objective, authoritative, and value-free assumptions that informs health psychology. The narrative approach used in this research moved towards creating knowledge about 'how' people subjectively conceptualise healthy and risky behaviours through their personal experiences. This research has shown that it cannot be assumed that all behaviours could be explained by theoretical models or traced back to the effects of intervention programmes. The research endeavoured to broaden current positivistic knowledge in the field of health psychology and adolescent sexual behaviour. It also provided insight into how adolescents make sense of their experiences in their cultural and social context. The current research also

aims to describe how adolescents make sense out of their illness experiences within the different social and cultural contexts that their stories are situated in. This study moves to broaden current positivistic knowledge by gaining an understanding of the experiences of adolescents undergoing disease management and living with HIV.

2.3.3. The unheard stories of adolescents infected and affected by HIV/AIDS about care and or the lack of care

The narrative study conducted by van Niekerk (2003), about the unheard stories about care and lack of care of adolescents infected and affected by HIV/AIDS, is of importance to the current research. The study was conducted with teenagers living in the inner city of Pretoria. Twenty teenagers between the ages of fourteen to eighteen years participated in the research on a voluntary basis. The study focussed on the teenagers' experiences of limited resources and about their knowledge and perceptions pertaining to HIV/AIDS. The study was done from a narrative social constructionist approach employing the fiction writing metaphor technique as a method of doing research. The research undertaking was framed within the parameters of the field of practical theology. Data collection was done by means of qualitative and quantitative questionnaires, observations, semi- structured and un- structured interviews, and fieldwork. The processes of triangulation, member checking, and peer examination were used to enhance the credibility of the research. Feedback was given by means of reflection groups.

It was found that infected and affected adolescents and parents were marginalized. In their stories about care and lack thereof, it was found that children's and mothers' voices were not taken seriously in the context of health care. Within the inner city of Pretoria, the teenagers had to make due with limited resources within a system where there are imbalances in formal structures with regards to the availability of medical, social, legal, and other resources. This research gave a voice to the unheard stories of teenagers and aimed to bring about awareness of their daily experiences, dilemmas, and perceptions that are situated within societal discourses. The research also proved to be beneficial to the teenagers involved as they explored and made sense of their experiences by means of their participation in focus groups. Through the participation in the focus groups various issues came to the foreground that is significant to the current study. It was

found that young people still had myths and misconceptions about HIV/AIDS. People infected and affected by HIV were stereotyped and families and culture play a role in the influencing of young people's thinking and choices with regards to HIV and sex. The research was informed by the researcher's subjective experiences of lack of care in the inner-city in working with the teenagers. These experiences and the assumptions of the researcher could have influenced the research process. She did however state that she was aware of her subjective assumptions and personal interest in the research undertaking, as she has been working with the teenagers for a number of years.

The research was limited on the grounds that, as a narrative study the research did not report on the identities of the teenagers, as it was constructed through their experiences within the context that their stories were situated within. This research will report on the identities of the adolescents as constructed through their experiences of living with HIV. The research study conducted by Van Niekerk has important similarities to the current research. The current research also aims to give a voice to the told and untold stories of adolescents by means of individual interviews employing the narrative approach. The research will also report on the adolescents' experiences pertaining to health care and disease management. However, the focus of the research is on the experiences of adolescents living with HIV at the Paediatric HIV Clinic in Pretoria.

2.4. Summary

In this chapter the health care system was discussed, and some of the numerous difficulties faced in the context of HIV/AIDS amongst adolescents, highlighted. It was noted that most health care systems does not provide holistic care and support to those infected and affected by HIV/AIDS. Therefore programmes should aim to incorporate the combined goals of psychological and social support to move to provide quality of life and not merely infection control. The health care system itself faces challenges with regards to holistic and optimal care relating to shortage of staff, short consultation times, poor communication between health care provider and patient, and poor access to medical equipment and medication, to name a few. Furthermore, the psychological and social context that HIV/AIDS is situated within poses challenges to the optimal and holistic treatment of adolescents. Delayed disclosure, lack of adherence to medication, stigmatization,

lack of information, and support, affects the treatment of the adolescent. In the context of HIV/AIDS and health care, the narrative approach to research can provide to widen and deepen our understanding of the social and cultural context that HIV/AIDS are situated within, proceeding to expand positivistic epistemologies. This may serve to bring health care closer to the objective of providing holistic care as there would be a greater understanding for the experiential world of the patient and the context that HIV/AIDS is situated within.

Chapter three

Theoretical point of departure

In chapter two it was highlighted how the narrative approach in the context of HIV/AIDS could bring about a greater understanding of the different contexts that HIV/AIDS is situated in. Three studies are referred to that showed how the narrative approach could be used to broaden our knowledge of the meaning of health and disease. In this chapter the narrative approach is discussed based on the social constructionist paradigm that forms the foundation for the research. Throughout this chapter, the foundation of the research is based on the notion that our realities are socially constructed, and that our reality is kept alive and passed along in the stories that we live and tell. These stories are situated within a social and cultural context that shape our stories and the identities that we construct through the stories that we live and tell.

The chapter begins by giving a brief introduction on postmodern thought, serving as a prelude to the discussion on social constructionism. Hereafter the narrative approach is discussed by first introducing the reader to the narrative structure. This acquaints the reader with necessary terminology. The narrative approach is hereafter located within the social constructionist paradigm, thereby giving an account of the key concepts that informs the approach. The narrative approach combined with expressive art is discussed, when working with children and adolescents, thereby highlighting the applicability of this approach to the research.

3. Introduction

The introduction of postmodern thought stimulated the development of new and alternate modes of knowing and methods of inquiry across various disciplines. The social constructionist paradigm originated simultaneously from postmodern thought and various theoretical multidisciplinary influences. Postmodernism developed in opposition to modernity, rejecting the assumptions that this intellectual movement is founded upon. Postmodern thought goes on to expand our current methods of reason, moving beyond the cognitive and scientific domains, to include the domains of ethics and aesthetics (Kvale, 1992). Postmodern thought challenges the

dominant notions of power and knowledge to incorporate knowledge into our understanding that is based on social interaction and language.

3.1. Postmodern thought

Postmodern themes came to the foreground in the 1950's and the 1960's within the domains of architecture, literary criticism, and sociology in the United States. During the 1970's and 1980's the concept of 'postmodernity' was addressed by French philosophers, introducing the concept of the movement to the general public (Kvale, 1992). According to Kvale (1992) there is no coherent postmodern philosophy but rather a magnitude of writers that focuses on different aspects of the postmodern condition. The terms 'postmodernity', 'postmodernism', and 'postmodern thought' are ambiguous and create confusion as they are used interchangeably in literature. Kvale (1992) defines three meanings attached to the term 'postmodern' to aid understanding of this term. 'Postmodernity' refers to the age after the Enlightenment period that goes on to question the belief of an objective reality. 'Postmodernism' refers to a cultural expression that encompasses art forms and different means of expression. Lastly, 'postmodern thought' replaces the concept that reality is independent of the observer moving towards an understanding of reality through language that constitutes our social reality.

The modernist thought originated in the Renaissance period which was later replaced by the search for certainty and rationality, characteristic of the Enlightenment period (Kvale, 1992). The term 'postmodern' becomes descriptive in that it describes the period which follows modernity (Crossley, 2000a; Kvale, 1992). Postmodern thought is guided by a critical stance aimed at dismantling modernist assumptions and practices (Gergen, 2001). It depicts a new way of knowing that moves away from modernistic thought. Crossley (2000a) outlines that the task of postmodernity is to deconstruct society's linguistic structures and socio-historical narratives with the aim of finding out what our knowledge is really based upon. In postmodern thought, knowledge is not determined by logic or rationality, but through language. Postmodern thought rejects the modernist belief that there are ultimate and universal truths that can be discovered and known. It rejects the belief that there are deeper realities underlying the surface of features of the world that could be revealed by analysing these structures (Burr, 1995). Postmodern thought

moves on to argue that the world cannot be understood in terms of grand theories and metanarratives that provides universal systems of knowledge (Burr, 1995). In postmodern thought there is a shift from knowledge seen as abstract, objective, and universal to rather socially useful and local knowledge (Kvale, 1992).

3.2. Social constructionism

Social constructionism is a theoretical orientation that emerged against the backdrop of postmodern thought as an approach to human inquiry that takes on a critical stance towards taken-for-granted assumptions about the social world. Social constructionism is multidisciplinary in nature with roots in philosophy, sociology, and linguistics (Burr, 1995). No single definition can fully encompass and describe social constructionism due to the multidisciplinary influences that shaped its development. According to Burr (1995), no single description would be adequate to refer to all the works done by different writers in this field. Social constructionism as theoretical orientation underlies the development of various approaches such as discourse analysis and the narrative approach that attempts to provide alternatives to the field of psychology and other disciplines (Burr, 1995).

3.2.1. The development of social constructionism

The development of the social constructionist approach cannot be traced back to a single source (Burr, 1995). Burr (1995) states that the approach emerged from the combined influences of North American, British, and European writers that dates back to over thirty years. The social constructionist approach developed in opposition to the history of science and the sociology of knowledge which underscores the positivist and empiricist tradition. The key contributors in the development of social constructionism can be traced to M.M. Gergen and Son, Kenneth Gergen, Shotter and Sarbin in North America, and Harré, Foucault, Parker, and Hollway in Britain.

The development of social constructionism within the field of psychology is dated back to the work of Kenneth Gergen in his paper called “Social Psychology as History” written in 1973 (Burr, 1995). Here Gergen argues that all knowledge is historically and culturally specific and

thus all inquiries should be extended to include the context, moving beyond the individual. Gergen also pointed out that no one description of people or society will be sufficient, as social life is continually changing. For Gergen, social psychology became a historical undertaking as one could only account for how the world appeared to be at present time (Burr, 1995). Gergen presented this paper during a time in the 1960's and 1970's in which social psychology was at a time of crisis as there were growing concerns about the discipline implicitly promoting the values of dominant groups (Burr, 1995). A number of works followed by different writers such as Harré, that attempted to address these concerns by proposing alternatives to positivist science and by challenging oppressive and ideological uses of psychology. According to Gergen (2001) the most significant shift towards constructionist principles in the discipline of psychology came from the systems-orientated family therapy. The therapy represented a shift from mind to language moving towards the understanding of the process of communication.

The development of the social constructionist approach has firmly situated the approach across various disciplines. Social constructionism gained depth through the contributions made from various disciplines such as critical theory, feminism, literary theory, and rhetoric. The contributions made by these disciplines and the dialogues set forth by the increase in appeal for the social constructionist assumptions, have contributed to the movement in significant ways. For Gergen (2001) these dialogues, spanning through various disciplines, define social constructionism as a metatheory, a social theory, and a societal practice. As a metatheory social constructionism challenges empiricist accounts of knowledge founded on claims of truth and objectivity located within communities of meaning making. For Gergen, social constructionism as a metatheory does not outline or contain specific requirements for theory, method or practice but rather moves to delineate relevant questions with regards to these domains into its legitimacy and practices. Social constructionism is also applied as a social theory reflective of an expanding body of knowledge that is descriptive and explanatory in nature relating to knowledge in all domains such as in government, the justice system, business world, medicine etc. Lastly, Gergen outlines that many disciplines are drawing constructionist principles to foster new forms of practice within disciplines. Within the social sciences social constructionist principles are sparking developments in research methodology as evident by discourse practices and narrative methods.

3.2.2. Key concepts of social constructionism

As already stated in the introduction of this section, the social constructionist approach cannot be summarized by a single sentence due to the multidisciplinary contributions that influenced the approach. Rather, Burr (1995) outlines four guiding concepts that go on to frame the essence of what the approach is about. Herewith follows an outline of the core concepts of the social constructionist approach.

Firstly, the social constructionist approach takes on a critical stance towards taken-for-granted knowledge. In taking on a critical stance, this approach challenges the view that conventional knowledge is based upon objective and unbiased observations of the world. It questions the belief that the nature of the world can be revealed by observation and that what exists is exactly how we perceive it to be. Therefore social constructionism questions and challenges the beliefs held by positivism and empiricism reflected in traditional science (Burr, 1995).

Secondly, from a social constructionist approach our understanding of the world is historically and culturally specific. Our knowledge and understanding of the world is directly related and only relevant to the period and context that the knowledge was generated within. Therefore our understanding of the world is dependent upon the social, economic, and political context of the particular culture that the knowledge was created within. The understanding that we have of a particular context becomes a product of that context as our understanding is informed by the conditions that governed the formation of knowledge within that context (Burr, 1995).

Thirdly, social constructionism holds that our knowledge is sustained by social processes. Knowledge of the world is constructed between people through daily interactions in the course of social life. These processes of social interaction are informed by the language that we use. Knowledge is created between people in the social interactions that occurs and not through objective observations of the world (Burr, 1995).

Lastly, from a social constructionist perspective, knowledge and social action go together. The social constructions that occur between people by means of social processes take on a variety of

different forms and leads to a multitude of different constructions. These constructions, varied in nature bring about the possibility of different actions that can stem from the constructions (Burr, 1995). Therefore, a construct such as ‘HIV/AIDS’ can be interpreted differently in different contexts as guided by different constructions between people. For instance, HIV/AIDS might be constructed differently in the context of Primary Health Care than in a rural community, as different social processes leads to different accounts of knowledge.

3.2.3. Social constructionism and the field of psychology

Social constructionism within the discipline of psychology challenges traditional beliefs held within the discipline in a number of ways. Social constructionism takes on an anti-essentialist and anti-realist position. This approach proposes that there are no predetermined natures or structures within the world or within people that can be discovered, as we are products of social processes (Burr, 1995). The knowledge that we have is not a direct perception of reality as commonly assumed. Rather, people construct their own versions of reality through social processes. Therefore, social constructionism holds that there are no objective facts as knowledge is always relative to the context. This implies that within the discipline of psychology, theories and explanations are bound by the time and culture that it was created in and should therefore not be seen as universal timeless constructs (Burr, 1995). The premise rests on the notion that when one attempts to articulate what exists and to put it forth into language, one enters a world of socially generated meanings. Social constructionism recognizes the significance of truth in context. In any community there will be commonly shared modes of discourse that is essential in sustaining the community’s tradition (Gergen, 2001).

Within the social constructionist approach language is seen as a pre-condition for thought (Burr, 1995). Traditional psychology holds that language only conveys our thoughts and emotions. However, social constructionism postulates that one is born into a social and cultural context where one learn about the constructs of that particular context through the acquisition of language. Our framework for understanding is actively provided by the language that we use (Burr, 1995). Language becomes more than a verbal act. Language acquires its meaning from its use within human interchange. Language is fundamentally viewed as a relational phenomenon.

For Gergen (2001), tracing human action to psychological sources sustains a view of the individual as isolated and self-sufficient, rendering the social aspect secondary to the personal. Gergen (2001) outlines that within traditional psychology, mental processes are the primary subject of inquiry brought forth to explain human action. From a social constructionist perspective our understanding is not located in the psyche, however rather in the processes of relationships. Therefore from a social constructionist position the social domain is given primacy over the individual. Language is a social action that actively shapes our understanding of the world through the constructions that we make in social processes. The social process that occurs between people renders accounts of knowledge placing the focus on how people create knowledge through interactions.

3.3. The narrative approach

The development of the narrative mode of thought was influenced by the social constructionist premise that knowledge is situated in the co-construction between individuals thus located in social processes. The narrative approach is reflected as theory, method, and practice and is guided by the concept that people seek to make sense of their lives and experiences by ascribing meaning through the stories that they tell. Through the process of telling stories people are provided with a sense of continuity and meaning that functions to order their lives and facilitate the interpretation of further experiences (White & Epston, 1990). The varied applicability of the approach is unified by the foundational structure of the narrative, discussed later in this section.

3.3.1. The development of the narrative mode of thought

The narrative mode of thought came to the foreground in the 1980's amongst social philosophers and social scientists (McAdams, 2006). Contributions made by authors such as Sarbin (1986) and Polkinghorne (1988), argued that all lived experience essentially has a narrative structure. These authors introduced the notion that people make sense of their own lives through the stories that they tell. These stories aim to reconstruct the past and they are anticipative of the future, providing life with identity, meaning, and coherence (McAdams, 2006). The development of the

narrative mode of thought is interdisciplinary in nature and can be found in disciplines such as literary theory and anthropology (Kirkman, 2002). Within the field of psychology, Sarbin (1986) embedded the narrative mode of thought within the discipline when he argued for the use of narrative as a root metaphor that guides our understanding of human thought and action (Kirkman, 2002).

During the same period, the narrative mode of thought entered the practice of therapy and moved on to influence many psychoanalysts to take on a narrative form of thought (Mcadams, 2006). This movement inspired new approaches to counselling and psychotherapy, from which narrative therapy emerged. Narrative therapy was developed in 1989 by White and Epston as a form of family therapy (Besley, 2002; Mcadams, 2006). Narrative therapy did not solely develop from psychological theories, but represented a coming together of works done by numerous social theorists. Foucault grounded in post-structuralist thought, was a seminal contributor to the development of narrative therapy with his ideas centring on the distribution of power in society (Besley, 2002). The practice of narrative therapy continues today with ongoing contributions by authors such as White and Epston (1990) in “Narrative Means to Therapeutic Ends”, White (1997) in “Narrative of Therapists’ Lives” and Payne (2000) in “Narrative Therapy: An Introduction for Counsellors”.

3.3.2. The narrative structure

The word ‘narrative’ is a synonym to the word ‘story’ (Polkinghorne, 1988; Sarbin, 1986). Sarbin (1986) defines a story as a symbolized account of actions that has a temporal dimension. A story is characterized as having a beginning or past, middle or present, and an ending or future that is held together by recognizable patterns of events, termed plots (White & Epston, 1990). The plot structure of the story is identifiable by the predicaments and attempted resolutions that are found within the story (Sarbin, 1986). A plot serves to organize these actions or events into a meaningful whole by means of highlighting and recognizing the contribution that the event has made to the development of the outcome of the story (Polkinghorne, 1988). Terms such as, ‘tragedy’, ‘satire’, and ‘romance’ are used to classify plot structures based on their contribution to the outcome of the story. As Sarbin (1986) describes, the story held together by the plot, depicts

people, reflecting of goals, purposes, and judgements that will come to influence the flow of action of the narrative figures in the story (Crossley, 2000a; Sarbin, 1986).

Sarbin (1986) introduced the concept of the narrative that functions as an organizing principle that structures human life and action. He proposed that human beings think, perceive, imagine, and make moral choices according to narrative structures. The narrative organizing principle allows the individual to impose structure on the flow of experience as it allows for the incorporation of actions, accounts of actions, time, and place. Polkinghorne (1988) supports the concept of the narrative, being a mode of knowing, that functions to organize human experience as told through stories, to provide a framework from which one can derive meaning. As a meaning structure the narrative organizes events and human actions into a whole, attributing significance to individual actions and events according to their effect on the whole (Polkinghorne, 1988; White, 2000). Clandinin and Connelly (2000) similarly argue that experience happens narratively and that experience has a temporal character. An event or experience is something that happens over time. Therefore, any event is seen as having a past, a present, and an implied future. Czarniawska (2004) writes that narrative is understood as a spoken or written text that gives an account of an event or action, or series of events or actions that are chronologically connected.

Stories become a natural way to recount experience (Sarbin, 1986). Storytelling or narrative accounting reflects the capability to structure events in a way that demonstrates coherence and a sense of movement through time (Sarbin, 1986; White & Epston, 1990). The story teller in any instance relies on prior knowledge and experience. No story accounts for all the details of the experience, the story teller includes those details that are relevant to the recollection (Robinson & Hawpe, 1986). As stated by White and Epston (1990), all people have diverse accounts of lived experiences, and at any given moment in time, only a fraction of those lived experiences can be storied or expressed. Storytelling invites openness to different interpretations of events due to the fact that events can be organized around different plots. Therefore meanings can be negotiated and renegotiated, as it is not static (Czarniawska, 2004; Polkinghorne, 1988).

White (2000, p. 6, 7) states that:

The development of a sense of personal authenticity is the outcome of social processes in which specific claims about one's identity, claims that are socially negotiated, are acknowledged or 'verified' by others.

Identity or personal authenticity is established through the process of engaging in a social world. The self is socially constructed through language and maintained through narrative. The construction of the self is a temporal process through which the different images of the self are mediated by the past and future (Crossley, 2000b). Distinguishing the self becomes an activity and a process that occurs between people. Our sense of self can be viewed as an activity that comes to light through our connections with other people (Crossley, 2000a). The social world has many influences on the development of the individual's identity. Scheibe (1986) states that human identities can be considered to be evolving constructions as they emerge out of continual social interaction in the course of one's life. Interpretations about experiences are not static and therefore multiple experiences and influences can be reflected as multiple identities or selves. Multiple identities can be seen as the outcome of people living out their lives in various contexts for example school, hospital, work, and play (White, 2000). Contexts may include elements such as temporal, spatial, and social contexts (Clandinin & Connelly, 2000). The contexts is essential in making sense of any individual as person and of their experience, as all people grow up and are situated within a context. Self-narratives proceed to establish personal identity by means of integrating past events into a coherent story. This also includes the construction of a future story that sustains the individual's sense of continuity (Polkinghorne, 1988).

3.3.3. The narrative approach situated within the social constructionist paradigm

The narrative approach is guided by four underlying social constructionist principles about the nature of reality. Freedman and Combs (1996) give an outline of these guiding principles that provides an understanding about the nature of reality from a social constructionist narrative approach. The principles outlined by Freedman and Combs directly relate to the guiding concepts defined by Burr (1995), discussed under the heading of social constructionism in this chapter. These principles can be viewed as a more specific outline of Burr's concepts placing an enhanced focus on the practical applicability of social constructionist principles to the narrative concept.

Firstly, realities are socially constructed, meaning that our beliefs, social customs, habits, and laws form the foundation of our reality. These arise through social interaction over time and are constructed as people live and interact with one another creating a reality as it is lived. By examining lived socially constructed realities, insight into how individuals interact with one another to construct, modify, and maintain what society holds to be true, real, and meaningful becomes evident.

Secondly, realities are constituted through language. Through the use of language, societies construct their views of reality. Language is an interactive process of sharing and making meaning between individuals. People understand themselves through the use of language, by means of talking and writing. People are therefore constantly in the process of creating themselves, through the processes of language (Crossley, 2000a). Therefore, the only reality that we can know is the reality that we share in language. Speaking is not a neutral or passive act. Every time we speak, we bring forth a reality created through our shared language (Freedman & Combs, 1996).

Thirdly, realities are organized and maintained through stories. As outlined by Freedman and Combs (1996), our lived realities that we construct socially through language are kept alive and passed along in the stories that we live and tell. Narration or storytelling is a mode of communication and informs our everyday life. It is a means of making sense of social action (Czarniawska, 2004). Through storytelling and interpretive acts it becomes possible for people to give meaning to their experiences of the world (White, 2000). Stories are situated within culture and context. Culture and context are socially constructed realities that inform our living and guide our experiences. Cultural and contextual stories determine and shape our individual life stories.

Fourthly, there are no essential truths. Within a socially constructed reality, reality cannot be objectively known. Reality is created between people by means of interaction through language. Reality can only be interpreted and negotiated between people. The interpretation of an experience or lived reality will produce many possibilities however no interpretation is really true. As giving meaning is a subjective act of negotiation between people.

Social constructionism holds that our reality is guided by society's beliefs and practices that come to govern our interpretation of reality. These beliefs and practices make up our social reality and are constructed by members of a culture whom interact with one another from generation to generation. These rules guiding our interpretations take on the form of taken-for-granted knowledge. Discourses can be defined as a reflection of a particular worldview that reflects systems of statements, practices, and structures that share common values in cultures. The experience we have of ourselves as individuals is guided by the interchange that we have with those around us and thus shaped by discourses that govern our behaviour and thoughts. Taken-for-granted knowledge and truths reflect discourses of power. Society determines what knowledge is true and accurate in a particular context. These given truths can be seen as dominant discourses or narratives held within a society or culture. Individuals tend to internalise these dominant narratives held in their culture, ultimately informing their identity (Freedman & Combs, 1996). The stories told by the adolescents in this research are situated within a specific social and cultural context. Within these contexts various discourses surrounding HIV/AIDS and disease management may be identified that inform the adolescents' stories and underlie their experiences. Therefore, it is essential to situate the adolescents' stories within a social and cultural context to identify and understand how various discourses may be informing their identity.

The narrative approach is governed by the not-knowing position. Realities are socially constructed through interaction between people, therefore no objective essential truth can be derived at. Thus, interpretation is based on negotiated truths. The not-knowing position motivates the researcher to move towards that which is not yet known. From this position, the researcher does not inquire from a position of pre-understanding, as research will be guided and influenced by assumptions. Rather, the researcher takes on an attitude of genuine respectful curiosity to negotiate understanding. This guides the researcher to ask facilitating and clarifying questions that is not preconceived by assumptions, taken-for-granted knowledge or expert interpretations. From the not-knowing position the researcher disavows the expert position. As interpretations about stories are negotiated between people and reality cannot be objectively known, every storyteller is the interpreter of his or her own story (Freedman & Combs, 1996). This enhances the collaborative relationship between the researcher and the storyteller as power is equally

distributed. The storyteller is viewed as the expert of his or her own life, whereas the researcher only offers respectful and interested attention (Czarniawska, 2004).

3.3.4. The narrative approach in working with children and adolescents

Engaging with children and adolescents from a narrative approach requires the incorporation of creative means to engage the child and adolescent in storytelling and discovery. Many alternative and playful ways to communicate with children and young persons can be integrated into the narrative approach (Freeman, Epston & Lobovits, 1997). The narrative approach combined with expressive art is applicable in working with children representative of any age group. In this context the term ‘children’ is used as a common denominator to refer to children of all ages. This approach draws on children’s natural ability to perform and engage in artistic and playful acts. The integration of expressive arts and play within the narrative approach is a fun and natural means to help children communicate (Ahn & Filipenko 2006; Bennet, 2008). Freeman et al. (1997) identify expressive narratives as effective in working with children who have language difficulties, are shy, and those that may speak another language. Expressive art and play combined with storytelling serves as a straightforward means to broaden expression.

As stated by Freeman et al. (1997), one does not have to be an expert in expressive arts or play since the child and young person is already an expert at play. In combining expressive arts and play with storytelling children and young persons are invited to make meaning of their own expression. The act of expressing the self by means of using art or play becomes facilitative to storytelling, as the expressive act in itself is an account of a story. Ahn and Filipenko (2006) state that children show who they are through dramatic play, oral storytelling, and visual art. This constitutes an integral part of any child’s self-representation. Children’s expression through visual modes such as drawings is a reflection of their experiences, their knowledge, and a means to express what they want to reveal about themselves. Art allows children to communicate their experiences and furthermore it is a form of personal externalization representing an extension of self.

Externalisation is a linguistic practise employed by the narrative approach that separates persons from problems. The narrative approach is guided by the notion that the problem is the problem, the person is not the problem. In working with children, Freeman et al. (1997) deem externalisation, when used in conversation, as a playful means to motivate children to face or diminish difficulties. As children tell stories, statements are reframed in such a way to assist children to view the problem as something outside of themselves over which they have control (Bennet, 2008; Crossley, 2000a). Freeman et al. (1997) view identity in children as exploratory and relatively fluid well into adolescence. Externalisation preserves the fluidity of identity formation. It allows the child to explore variations of attitudes, behaviours, and identity (Freeman et al., 1997).

In narrative research with children, through collaboration with the child, the researcher aims to become an active participant in the child's world of meaning (Freeman et al., 1997). When expressive art and play forms are integrated with questions, the performance of meaning in any art or play form becomes multidimensional and enriched. Questions are used as an aid that will assist the child and young person in connecting with his knowledge and imagination to expand possible meanings related to his or her story. By asking clarifying and reflecting questions the researcher allows the child as storyteller to be empowered to express his or her point of view through the story (Cattanach, 1997). The developmental stage of the child and young person should be taken into account when asking questions as children do not have the cognitive and abstract ability and social maturity to respond to complex questions (Bennet, 2008; Vetere & Dowling, 2006).

3.4. Applicability of the narrative approach

The narrative approach is highly applicable to the research. As method of inquiry and mode of understanding, this approach is devoted to the exploration of lived experience through engaging in the act of storytelling. The foundation of this approach fosters an attitude of curiosity and respect from where inquiry into lived experiences may be done in a manner that is conducive to understanding, meaning, and acceptance. It brings about an understanding of life as it is reflected through social and cultural experiences broadening existing knowledge. In the context of

HIV/AIDS the approach serves to broaden understandings of health and disease by incorporating the lived experiences of those infected and affected by HIV/AIDS, thereby expanding positivistic epistemologies to gain a holistic understanding of health and disease.

The narrative approach combined with expressive art will allow the adolescent to engage in storytelling in a natural and playful manner. This approach allows the adolescent to communicate his experiences through art. The incorporation thereof broadens the level of interaction that is possible between the adolescent and the researcher. Expressive art allows the adolescent to develop the story portrayed through drawings and poetry by allowing flexibility through multiple interpretations. This creates a relationship where the researcher as listener and co- constructor, and the storyteller as both teller and character in the story, can engage in a process of collaboration and mutual exploration. This approach lends the opportunity to explore and reflect on the adolescents' experiences and meanings in a creative non threatening way.

3.5. Critical evaluation

As researcher working from a narrative approach located within social constructionism, it is important to be cognisant of the limitations and strengths of working within this approach. Critique against social constructionism surely centres on its postmodern grounding. This approach challenges the traditional views which are held by the scientific method that strives for truth, objectivity, reliability, and quantifiability of knowledge. Therefore critics claim that social constructionist's critique poses a threat to traditional empirical science as it undermines professional truth claims (Gergen, 2001). The social constructionist approach have been accused of being nihilistic, however Gergen (2001) states that by no means are these critical claims themselves grounded or legitimated. Gergen argues that criticism is no less constructed than the traditional objects of research. According to Gergen (2001) there is nothing within constructionist premise that argues for the elimination of any form of discourse. The approach moves to create sensitivity towards how we generate and evaluate knowledge granting the individual the capacity to step outside the taken-for-granted assumptions allowing one to invite possibilities for reconstruction.

The narrative approach strives to move beyond the discourses held by the scientific method that governs the kind of knowledge that is sought and generated. The narrative approach does not strive to replace existing modes of knowing rather to expand current knowledge. The narrative approach introduces flexibility that is above and beyond the methods of scientific thought. The very act of story creation is dependent upon the person that does the storytelling. Therefore narrative accounts of people's experiences understood from a social constructionist approach cannot be evaluated for truth or reliability but rather it is evaluated to be seen as a believable account of personal, social, and cultural events. Stories are viewed differently by different people, this allows for flexibility where the scientific method is rigid in principle (Robinson & Hawpe, 1986). This should not be viewed as a limitation as the knowledge that is generated should be seen as relevant to the context it was created in.

3.6. Positioning

The research is located within a postmodern, social constructionist paradigm with the narrative approach as the primary mode of inquiry. As student psychologist and researcher I find myself at ease within the narrative approach as it allows the researcher to journey alongside people as collaborator and co-constructor. This approach gives people merit and it acknowledges their experiences as human beings. It gives people the opportunity to share and make meaning out of life.

3.7. Summary

In this chapter, the development and key concepts related to the social constructionist approach, which sprouted from postmodern thought, was discussed. Here it was outlined that the social constructionist approach strives to foster a critical stance towards taken-for-granted knowledge about the world. This approach challenges dominant discourses held by the scientific method and challenges traditional views held by the discipline of psychology. Furthermore, the development and structure of the narrative approach was discussed and located within social constructionism, rendering an account of the key concepts that governs the narrative approach. It was highlighted that people tell stories to make sense out of- and to ascribe meaning to their lived experiences.

The stories that people tell inherently have a narrative structure that is located within the social and cultural context that it was created within. Hereafter the narrative approach was discussed with regards to how the approach could be incorporated with expressive art when working with children and adolescents. This combined approach is a natural and fun means to engage children and adolescents in storytelling. The applicability of the narrative approach to the research was discussed. Here it was outlined that it is an approach that fosters respectful curiosity within a collaborative relationship that allows for enhanced communication between the adolescent and the researcher. Furthermore, the narrative approach moves to incorporate the lived experiences of those infected and affected by HIV/AIDS into the constructs of health and disease. This aspires to move towards a broad and holistic understanding of health care in South Africa.

Chapter four

Research methodology

The research methodology, which was informed by the qualitative social constructionist narrative research approach, is discussed in this chapter. The Kalafong Hospital is discussed as the research context and the reader is introduced to the process of sampling, data collection, and the procedures followed during the completion of the research. The chapter is concluded by outlining the process of data analysis from the three-dimensional space approach.

4.1. Research strategy

The research was conducted within a qualitative research paradigm, employing the social constructionist narrative research strategy as both philosophical underpinning and method of research. This is a form of descriptive narrative research as the aim is to render an accurate description of the interpretive narrative account of an individual with the aim of ordering events and making temporal events meaningful (Polkinghorne, 1988). Data was collected by means of semi-structured interviews where stories and art were gathered as data sources. The process of re-storying entailed data gathering, analysis, and interpretation. Data was analysed using the three-dimensional space approach thereby rewriting the stories of the adolescents and placing it within a conceptual framework of understanding.

4.2. Research context

The study was conducted at the Kalafong Hospital Paediatric HIV Clinic in Pretoria. The clinic serves the Atteridgeville community and broader areas. As a clinic they mainly serve HIV positive infants, children, and adolescents however, it also renders an educational service to the caregivers of the children attending the clinic. The clinic adolescent group is within the age range of between twelve to eighteen years. Disease management at the clinic entails regular medical screening, blood tests, CD4 count tests, ART, occupational therapy, and dietician visits. Most of the adolescents visit the clinic once a month or three-monthly on Monday's, depending on whether more regular visits are scheduled by the clinic doctors to tend to medical needs.

4.3. Participants

The adolescent population attending the Paediatric HIV Clinic was estimated to be forty-three adolescents between thirteen to eighteen years in November 2008 (Vlug et al., 2008). The study focussed on the adolescent population that attends the clinic for ongoing disease management through continual ART treatment. The non-probability sampling method purposive sampling was used to identify possible participants. The purposive method is used to identify particular cases that illustrate a particular feature that is of interest to the study (Strydom & Delpont, 2002). The identification of possible participants were based on the criteria that the adolescent attended the clinic on a regular basis for ART and disease management and fell within the age group of twelve to eighteen years of age. Furthermore the adolescent had to be fluent in English as a second or third language. Six adolescents volunteered to participate in the research from more than fifteen that were invited to participate in the research. Three male and three female adolescents ultimately participated voluntarily in the research. The process followed in identifying possible participants is described in the next paragraph. As researcher it was decided to have a small sample group due to logistical reasons and the intensive nature of the research method. These reasons are further discussed in chapter six.

The doctor individually informed the identified adolescents about the research being conducted in the clinic. The doctor obtained the adolescents' permission to disclose their information to the researcher. These details were used to establish from the administration department when the adolescent was scheduled to attend the clinic for disease management. The researcher approached each adolescent individually in the clinic on the day when they were attending for disease management. The research and voluntary participation was discussed with the adolescent. Throughout the process of identification and making contact with possible participants, no information was disclosed to the staff about the identities of the adolescents participating in the research. This was done to limit the possibility of future accidental identification of the adolescent once the research results were disseminated to the staff. Each adolescent and parent or caregiver (those present with the adolescent) was approached individually whilst they were attending the clinic. A co-researcher, who was fluent in Tswana, was available at all times in

order to help explain the research on account of the fact that the participants and or their caregivers did not understand what the research was about. Here they were invited to participate in the research. The purpose of the research was explained and the research process and outcome was discussed with the possible participants. The adolescent and or parent or caregiver were provided with the necessary documentation, i.e. participant information sheet and consent form in English (included in Appendix A). All queries regarding the research were discussed, and parent or caregiver proxy consent, and the participating adolescent assent were obtained, as the adolescents are under age. Before the commencement of the interviews all consent forms were signed by the adolescents and parents or caregivers and returned to the researcher. Three interviews were held on the same day when participation was voluntarily established and the consent forms signed by both adolescent and parent or caregiver. One interview was scheduled for a day, other than one when the adolescent had to attend the clinic for disease management.

In only two cases the parents or caregivers were not present with the adolescent at the clinic. In these cases the research was discussed with the adolescents and they were instructed to deliver the documentation to their parents or caregiver to inform them about the research. Thereafter, the parents or caregiver were contacted telephonically to discuss any queries that they had regarding the research and or the documentation. This served to finalize parent or caregiver consent as well as adolescent assent and the research schedule. The interviews with these two participants were then arranged on dates suitable to them. The two adolescents in question then returned the consent forms on the day of the interview.

4.4. Data collection

Data was collected by means of semi-structured interviews. Interviews are the primary source of material used in narrative research (Murray, 2008). All data were collected between March 2010 and September 2010. Stories and art in the form of drawings and poetry were the main sources of data collected during the interviews. Two interviews were scheduled with each participating adolescent on two separate occasions at the hospital in a room separated from the clinic. This served to reduce the risk of accidental identity exposure of the adolescent to clinic staff. The first interview served to collect stories and art. The second interview served as a follow-up debriefing

session aimed at discussing the stories obtained in the first interview. An interview schedule was constructed to serve as a guideline to broadly structure tentative questions that could be asked during the interview (included in Appendix B). Two main questioning themes were outlined in the interview schedule. The first theme centred on the exploration of the adolescent's knowledge and relationship with HIV and the second theme centred on exploring the adolescent's experiences of disease management at home, school, and at the clinic. The interview schedule was used as a flexible instrument during the interview process, as storytelling is a collaborative process of sharing and exploration, so that an understanding of the story is reached by both the participant and researcher (Polkinghorne, 1988). Questions used during the interviews were both closed and open-ended in nature.

Before the onset of the interviews it was established whether the adolescent was fluent in English and comfortable in conducting the interview in English. All interviews were conducted in English. A co-researcher, who is fluent in Tswana, assisted me during the interviewing process. As co-researcher she provided assistance during three interviews where the adolescent was not completely fluent in English. She provided assistance with the interpretations and provided assistance when difficulties arose on account of language. This collaboration as a research team enhanced our common understanding of the nature of the inquiry, the underlying dynamics of the narrative interview process and the themes of the research. This served to minimize the possibility of losing important nuances during the interview process, such as feelings, non-verbal patterns, and language meanings.

The first interviews with the participants lasted approximately sixty minutes each. Each adolescent was interviewed individually. All interviews were audio-recorded with the permission of the parents or caregivers. The first interview served to collect stories and art. Refreshments after the interviews were provided to the adolescents. Two adolescents had to travel to the clinic in order to participate in the research on days that they did not attend the clinic for disease management. In these two cases they were remunerated for travelling expenses, to ensure that they did not have to incur extra costs.

Before commencing each interview various ethical considerations were discussed with the adolescent. The nature of the interview process was discussed with the adolescent. It was highlighted that questions will be asked and that they would be requested to make drawings. It was emphasized that no questions had to be answered, should they wish not to do so. It was again emphasized that they could withdraw at any stage and if any questions were unclear, they could feel free to ask for clarification. The audio-recorder was introduced and the necessity of it explained to the adolescent. The notion of confidentiality was also discussed with the adolescent. It was explained that no names would be attached to their stories and that pseudonyms would be used.

The interview commenced with a general inquiry into biographical information, serving as introduction. Thereafter the adolescent's knowledge of his illness was explored by means of asking the adolescent about his reasons for attending the clinic. This was to establish whether the adolescent was aware of his HIV status. As part of the selection criteria all the adolescents were on ART. It was therefore implicit that all the adolescents were HIV positive. However, not all the adolescents attending the clinic were aware of their HIV status. This was identified by the clinic staff and parents or caregivers as a moral dilemma. Therefore, to conduct the research ethically and not to risk accidental disclosure of their status, the adolescent's knowledge of his illness, and his understanding of the reasons for attending the clinic, was used as the point of departure for the interview. In only one case, the adolescent was not aware of her status. In this interview the adolescent's understanding of illness was used to guide the conversation. Here the researcher used words in the interview differently by referring to 'illness' or 'sickness' and therefore did not refer to 'HIV' in any way. In the other interviews the adolescents openly discussed HIV and their status. The researcher used the same words that the adolescent introduced and the researcher was free to explore the adolescent's knowledge and understanding of HIV.

After establishing why the adolescent was attending the clinic he was asked to draw a picture based on that understanding. Expressive art in the form of drawings and poetry were used to facilitate storytelling and enhanced communication between the adolescent and the researcher. Multiple drawings were used to explore various stories related to the adolescent's reality. The theme or understanding that the adolescent introduced was used as the point of departure for the

first drawing. Thus in the first drawing the adolescent was asked to draw a picture of himself in relation to HIV, illness or medication. Here the adolescent's knowledge of- and relationship with HIV was explored. The questions used during the interview process served to further develop the story as portrayed through the adolescent's drawing and served to enhance the meaning attached to his experiences. The second theme of the research was introduced by asking the adolescent to draw a second picture of himself at the clinic. The second drawing was used to explore the adolescent's experiences of disease management at home, school, and at the clinic.

During the course of the interview three adolescents were comfortable to draw two pictures, as outlined by the above described process (attached as appendix C, D, F). During the interviews only Mary was not aware of her HIV status. The other adolescents were all aware of their status and introduced HIV on their own during the interview. Mary was a very shy and soft spoken girl. In Mary's first drawing her drawing depicted herself at the hospital. Mary told that she attends the hospital to collect her medication as she was ill. In her second drawing she depicted herself at the hospital, receiving her medication (appendix C). Dan was very excited about the drawings during the interview. He indicated that he loved drawing and was excited about the interview. In his first drawing he depicted himself with a red ribbon that represents HIV. In his second drawing he drew himself at the hospital (appendix D). In Julie's first drawing she made a picture of herself in relation to the virus (HIV). She described her relationship with HIV by using a metaphor to describe the battle that she had with HIV. In her second drawing she drew a picture of herself where she was a grown-up at the hospital.

One adolescent Bongi, indicated that he wanted to draw only at the end of the interview as he felt it was rude to do this during the interview. This interview continued for ninety minutes, where he only made one drawing at the end of the interview due to time constraints. His journey with HIV was metaphorically described through his drawing (attached as appendix G). One male adolescent indicated that he could not draw. He was satisfied to proceed with the interview without drawing. During the course of the interview it was established that he enjoyed poetry. He indicated that he could write a poem about HIV, and would bring it along during the second interview. However, he did not bring his poem along when he arrived for the second interview, but could write down part of the poem (attached as appendix E). Another adolescent indicated

that she was not good at drawing, and was comfortable to continue the interview without drawing. As data collection in narrative research is a collaborative process, the use of expressive art was flexible throughout the process. During the interview meanings were negotiated with the adolescent. This served to lessen the gap between what was being represented through their expressive art, told in their stories and what was being reported by the research (Ollerenshaw & Creswell, 2002).

After analysing the data from the first interview, a second interview was scheduled with the participants. They were contacted telephonically and follow-up interviews were arranged. The second interview lasted approximately fifteen minutes each. These interviews were also conducted at the hospital in a room away from the clinic. The second interview served as a follow-up debriefing interview. Here the researcher's interpretation of the adolescent's story was introduced and discussed. The second interview was concluded by exploring the feelings and thoughts of the participants regarding the interviews. Most of the adolescents indicated that they felt comfortable during the interviews and talking about HIV was not a difficulty. Most of the adolescents indicated that they enjoyed the drawings.

Should any crucial information pertaining to the treatment of the adolescent, as a patient at the clinic, have come to the foreground during the interview process, this information would have been included in the adolescent's clinic and hospital file. The eventuality of this was discussed with the parents or caregivers of the adolescent before the interviews. However, no information came to the foreground relevant to their treatment. After the interviews, in the event that an adolescent needed further psychological support, the hospital psychologist that forms part of the multidisciplinary team at Kalafong Hospital, was available to discuss any difficulties. None of the adolescents reported that they were uncomfortable or felt any distress after the interviews, thus this was not required.

The interview process was therapeutic for the adolescents involved. Through their stories many of the difficulties that they have to deal with in living with HIV in the different contexts of their lives, came to the foreground. The adolescents mostly assume primary responsibility for the use of medication at home. Most of the adolescents described the difficulties that they experience

regarding adherence to medication, and the frustrations of using medication daily. Some adolescents reported that they did not speak much about HIV at home, or share their feelings with family, even though they did receive some support at home. All the adolescents were very aware of death, and some adolescents expressed fear of dying early. In almost all the cases the adolescents HIV status was not known to people outside of the home. These adolescents could not speak to friends or teachers about their illness. Other adolescents reported fear of rejection and frustrations with wanting to be normal teenagers that could sleep over at friends, and have intimate relationships. Therefore the interview was therapeutic as the adolescents could discuss these difficulties that they were experiencing that they could not share with family, friends or medical staff.

4.5. Data analysis

The three-dimensional space approach based on Clandinin and Connelly's (2000) work in "Narrative Inquiry" is used as method of data analysis. This method entails the process of re-storying. This involves the process of the gathering of stories, analysing the interview transcripts for key elements of the story (interaction, continuity, and situation), and then rewriting the story, placing it within a chronological sequence (Ollerenshaw & Creswell, 2002).

4.5.1. The three-dimensional space approach

Clandinin and Connelly's (2000) three-dimensional space approach to narrative research was inspired by the philosophical thoughts of J. Dewey's work on the theory of experience. Dewey's work provided a framework from where Clandinin and Connelly could think about human experience in the context of research. These authors were concerned with the different contexts in which narrative inquiry unfolds. Lending from Dewey's theory, the concepts of 'interaction', 'continuity', and 'situation' were used and elaborated upon, to form the different 'spaces' of a narrative inquiry. Clandinin and Connelly (2000) were interested in exploring how these terms define the participant, shape what passes for evidence and determines what passes as research data in a narrative inquiry.

Clandinin and Connelly (2000) elaborated on these concepts to include the elements of personal and social (interaction), past, present, and future (continuity), and place (situation). These concepts combined, creates a metaphorical three-dimensional narrative inquiry ‘space’, with temporality along one dimension, the personal and social context along the second dimension, and place along the third dimension. In the process of analysing the data the researcher looks to identify these elements of experience in the interview transcript. To aid the researcher in identifying these elements, four directions of inquiry is used. The four directions are defined as ‘inward’, ‘outward’, ‘forwards’, and ‘backwards’. When looking at the transcript to identify personal interactions, the researcher looks inwards towards the internal conditions of the storyteller such as feelings, hopes, aesthetic reactions, and moral positions. When looking to identify the social interactions that the storyteller is engaged in, the researcher looks outwards to identify external social and environmental conditions such as other people’s assumptions or beliefs referred to in the transcript. By looking outward, the researcher is also able to identify the situation, place or context in which the story is situated. To identify elements of continuity the researcher looks backwards and forwards in the story to identify the aspects of temporality that refers to the past, present, and the future. Narrative inquiry according to these terms refers to temporal matters i.e. past, present, and future and it focuses on personal and social experiences as they occur in different places. The context in which the interview occurs is also included as a place where interaction occurs between the researcher and the participant and where the individual’s story is situated within.

4.5.2. Re-storying

All the interviews were transcribed verbatim from the audio recordings. The drawings and poetry were used to situate and make sense of the adolescents’ stories, as throughout the process of analyses and interpretation it is also referred to.

The process of re-storying as outlined in Ollerenshaw and Creswell (2002) based on the three-dimensional space approach, formed the foundation for the analysis of data. Firstly, the interview transcripts were analyzed for personal experiences of the adolescent and interactions of the adolescent with other people. Secondly, elements of continuity or temporality of the story was

identified. This entailed transcribing information about past and present experiences of the adolescent. Present experiences expressed in actions of an event or actions to occur in the future was also analysed. Thirdly, the situation or place in which the story unfolds was analysed by looking at specific situations in the adolescent's landscape. During this process the four directions of inquiry were used to identify important internal and external conditions in the adolescent's story such as internal, moral, and affective elements and the actions, reactions, and assumptions of other's. This aided the researcher to look at the social significance of the adolescent's story as it is situated in different contexts. After the process of identifying key elements of experiences found in the stories of the adolescents, these were re-written to form a coherent chronological story. Each adolescent's story is discussed individually in chapter five and placed within a framework of understanding according to the social constructionist narrative approach. To aid narrative understanding, each story is interpreted according to the context the story was situated in, the identities constructed through the adolescents' stories, and the aspects of temporality found in these stories. This structure of interpretation allows for each adolescent's story of living with HIV to be described and the meanings that are attached to these experiences reproduced.

4.6. Summary

In this chapter the research methodology was discussed outlining how the research was conducted. The research stemmed from a qualitative narrative approach. Semi-structured interviews were conducted with six adolescents from the Kalafong Hospital Paediatric HIV Clinic. Stories and art were collected as data sources. Data analyses were done using the three-dimensional space approach. Elements of experiences found in the stories of the adolescents were identified and re-written into a coherent chronological story. The re-constructed stories, placed within a framework of understanding according to the social constructionist narrative approach, are discussed in chapter five.

Chapter five

Discussion of the adolescents' stories

The stories and expressive art collected through the semi-structured interviews were analyzed according to the narrative analyses method based on the three-dimensional space approach, discussed and outlined in chapter four. In this chapter, the six re-constructed stories of the adolescents will be presented and discussed, with reference to the social constructionist narrative approach outlined in chapter three.

The chapter begins with a brief overview of the narrative concepts of context, identity, and continuity that are situated within the social constructionist narrative approach. These narrative concepts provide a framework of understanding in which the adolescents' stories are placed and discussed. Hereafter the reader is introduced to the outline that governs the discussion of each story. Each adolescent's story is discussed individually within this framework of understanding. The chapter is concluded by providing a summary of the chapter.

5. Introduction

The stories of the adolescents were analyzed for various elements of their experience of living with HIV. The elements of an experience refer to the concepts of interaction, continuity, and situation as discussed in chapter four. By looking at the adolescents' stories various contexts or situations were identified in which the adolescents' stories of HIV were situated or placed. These contexts were identified as the family and cultural context, the school and social context, and the medical context. The adolescents' experiences of living with HIV in these different contexts, and the meanings that the adolescents attached to these experiences, are described and discussed under the heading 'context'. Through the description of their experiences of living with HIV in these contexts various identities were constructed. These multiple identities are identified and discussed under the heading 'identities'.

5.1. The narrative approach to understanding stories

5.1.1. Context

Stories are situated within different contexts (place, situation, physical landscape) and culture. Experiences in these contexts are socially constructed between people and are shaped by the discourses that govern interactions, practices, and beliefs in these contexts. These discourses come to govern people's behaviour and thoughts. Cultural and contextual stories thereby determine and shape our individual life stories. Identities come to light through our interactions with other people in different contexts (Crossley, 2000a). Therefore multiple identities can be seen as the outcome of people living and interacting in various contexts, for example school, hospital, work, and play (White, 2000).

Identifying the context that stories are situated in, is essential in making sense of individuals' stories and of their experience. The adolescents' stories were situated within three dominant contexts that shaped and informed their stories of living with HIV. The adolescents told their unique stories within each of these contexts. Within these contexts various discourses surrounding HIV/AIDS and disease management were prevalent that informed the adolescents' stories.

The Kalafong Hospital Paediatric HIV Clinic is situated in the medical context. All the adolescents' stories of living with HIV and ongoing disease management are situated within this context. The adolescents told of their experiences of discovering their HIV status, ongoing disease management, and interactions with staff at the clinic. The medical context is primarily governed by positivistic epistemology and practices based on neutrality and objectivity. There are set procedures that guide interpersonal interactions in this context. It does not always accommodate the subjective expression of the emotion of the patient. Medication is practiced where the physical body is inspected to assess for disease or to diagnose. Hereby the medical context informs the stories of the adolescents as it shapes their illness experiences.

The family and cultural context identified in the adolescents' stories refers to experiences at the home with family. The adolescent tells of their experiences of family relationships, gender roles, cultural practices, and stories of illness and disease management at home. Thereby the family and cultural context informs and shapes the adolescent's experience of living with HIV.

The school and social context identified in the stories of the adolescents refers to the context outside the home or family. This context refers to the interpersonal relationships that the adolescent has with others outside of the home. The context of the school refers to the relations and experiences that the adolescent has at school in the academic context. In their stories the adolescents relates experiences with teachers, subjects, sports, HIV in class, and illness at school. The social context refers to interpersonal experiences with friends and other learners at school and other social situations.

5.1.2. Identity

The social world has many influences on the development of the individual's identity. Scheibe (1986) states that identities are evolving constructions as they emerge out of continual social interaction in different contexts through the course of life. Interpretations of experiences are not static and therefore multiple experiences through different contexts are reflected as multiple identities. As people attach meaning to their experiences in their personal narratives, they are actively engaged in creating their identities and constructing meaning in their lives. People thereby do not just story their experiences they construct themselves through it (Crossley, 2000a; White & Epston, 1990). Through the adolescents' experiences of living with HIV and the meanings that they attached to these experiences, various identities were constructed in the stories. In each adolescent's story these identities are highlighted and discussed with reference to the interplay between these multiple identities.

5.1.3. Temporality

Stories organize human experience as they provide a framework from which one can derive meaning (Polkinghorne, 1988). Stories have a temporal character that demonstrates coherence

and a sense of movement through time (Clandinin & Connelly, 2000; Sarbin, 1986; White & Epston, 1990). An event or experience is something that happens over time. Therefore, any event is seen as having a past, a present, and an implied future. Personal stories such as the adolescents' stories proceed to establish personal identity by means of integrating past and present events into a coherent story. It also includes the construction of a future story that sustains the individual's sense of continuity (Polkinghorne, 1988). This allows the adolescent to construct his identity through time and it allows for those identities to continue into the future (White & Epston, 1990).

5.2. Discussion of the adolescents' stories

Each adolescent's story will be discussed individually. Each discussion will follow the same outline. In the discussion of each story the original wording, as used in the adolescent's story, will be used in the text. This serves to give authenticity to each story. In each discussion the adolescent's story of living with HIV will be situated within the three contexts that informed his story. The specific experiences that the adolescent had in each context and the meanings attached to this are described and highlighted. Hereafter the multiple identities of the adolescent, as they were constructed through experiences of living with HIV in different contexts, are highlighted and discussed. Each identity is discussed separately and reference is given to the experiences and the meanings that inform the construction of that identity. The interplay of the different identities is discussed with reference to the contexts of the story, the elements of continuity (past, present, and future), and personal and social interactions. The discussion on each story is concluded by providing a narrative understanding of each story.

5.3. The adolescents' stories of living with HIV

5.3.1. Story one: Mary

5.3.1.1. Narrative understanding

Mary tells her story of disease management in the medical context from the position of being a patient. Mary is not aware of her HIV status, thus the meaning that she attaches to her

experiences of disease management and illness is understood in the context of her being physically ill. She describes and understands herself through her physical attributes and characteristics and through the roles and activities that she occupies in different contexts.

5.3.1.2. Contexts

5.3.1.2.1. Family and cultural context

Mary is a thirteen year old girl that is currently completing grade five. She lives and attends school in Kwaggafontein. Mary describes herself in her story as a girl that likes to play, watch TV, and help her grandmother in the house (line 42). She lives with extended family and they are all staying together in one house (line 14 & 15). This means that she stays with her grandmother, grandfather, aunt, uncle, sister, and brother. Mary has lived with her grandparents since she was a baby as she did not know her mother (line 175-178). In her story she describes the family roles that guide family interactions. Mary's aunt likes to help her grandmother in the house. She buys them clothes (line 55 & 56) and she likes to watch TV. Mary likes to help her grandmother to wash clothes (line 42 & 43), to clean the home, and to cook (line 53). Mary's brother is nineteen years old and she sometimes plays with him (line 172). Her aunt or grandmother always accompanies her to the hospital (line 57 & 58) and they both help her at home to drink her medication (line 102 & 103). When Mary feels sick she tells her grandmother and then they take her to the clinic (line 89).

In Mary's story she describes the different roles of the family members. The women's roles in the family are based on traditional societal roles of caring for the family and the home by cleaning, cooking, and washing. Mary has a good relationship with her grandmother and aunt and they both support her.

5.3.1.2.2 School and social context

In Mary's story she describes herself as a girl that likes to play and she is engaged in sport activities. Mary plays tennis and volleyball at school and at home with her friends (line 49, 50 &

51). Mary likes playing these sports because it makes her happy and it is fun (line 164). She feels that she sometimes is a good player, but that other children do not play better than she does (line 165-168). None of Mary's friends are ill but she believes that other children at school are ill (line 111 & 113). They also use medication (line 115). Mary does not talk to them about the medication (line 117). She knows that they are sick because the other children also go to the hospital. These children's parents go to the school to inform the teachers that their children should take their medication, otherwise they might become sick (line 119 & 120). When Mary attends the clinic she is absent at school (line 142 & 143). It is bad for her to miss a day of school, especially when they are writing a test (line 145). Mary has been ill at school before, but the other children do not tease her about it (line 83, 84, 181 & 182). When Mary is sick at school her grandmother fetches her (line 84).

In this context Mary describes her experiences of illness at school. She believes that other children are ill and that they also use medication, however it is not spoken about at school. She does not elaborate on other school activities in this context. She only refers to teachers and other children that form part of the characters in her story about illness at school. She does describe herself in this context through the sporting activities that she engages in.

5.3.1.2.3. Medical context

Mary describes her experiences of disease management. She illustrated her story of disease management through two drawings (appendix C). In Mary's first drawing she describes herself through her physical attributes by referring to her hair, eyes, mouth, and nose (line 36). She describes herself as a girl wearing red clothes (line 36). She identified her aunt as a character in her story of attending the hospital (line 24). In Mary's drawing she described the hospital as a house that people pass into (line 30) and drew an entrance to the hospital that people pass through. Here Mary refers to the mass of people that attends the hospital and is moving through the doors of the hospital. She placed the hospital in a setting with clouds and a tree (line 24 & 26). Mary attends the clinic to receive her medication (line 18). Through her story she tells that she feels good to come to the hospital and that she likes attending the hospital (line 105 & 107).

Mary describes the hospital as a place where they help her when she is sick (line 109). The doctor helps her by prescribing medication that makes her feel better (line 99 & 109).

Mary travels to the hospital with a bus and a taxi and then only does she arrive at the hospital (line 135). She has to wake up at four in the morning to go to the clinic (line 139). It takes her approximately two hours to travel to the hospital (line 141). Mary has never attended the hospital alone (line 59 & 60). Her aunt or grandmother always accompanies her (line 58). When Mary is at the clinic she firstly goes to fetch her file. Then she sees the dietician and goes back to the reception waiting area to see the doctor (line 62). After this she goes to the pharmacy and fetches her medication (line 63). Mary does this every time that she attends the clinic (line 64 & 65). She feels that the staff at the clinic is nice and she likes them (line 128 & 130).

In Mary's second drawing she tells her story of disease management by referring to two contexts where this occurs. In her drawing she is in the hospital with the doctor holding her file (line 155). When Mary is with the doctor, the doctor asks her questions (line 159) and she feels fine when they ask her these questions (line 161). When Mary sees the doctor, the doctor examines her and writes her a prescription. The doctor also asks her how she feels and where her body hurts (line 67). In the same drawing Mary also drew herself in the context of home, drinking her medication (line 156).

Mary describes her experiences of illness and ongoing disease management. She refers to her illness by referring to her physical body. When Mary's body hurts she feels ill (line 75 & 83). Her eyes are sore (line 80) and at the clinic they give her ART and other medicine for her eyes or nose (line 92). She describes ART as medication that she has to drink. Mary uses her medication at seven in the morning and evening and also at eight in the evening (line 95). She uses her medication daily (line 96 & 97) and the medication makes her feel better (line 99). When she does not drink her medication she becomes ill (line 180).

The medical context informs Mary's story and how she describes herself. She describes this context as a place where her physical body is examined to see where it hurts (line 67). Mary gives meaning to this context by constructing the clinic as a place where people helps her to feel better

by giving her medication (line 99). She refers to her experiences of illness in relation to her physical body that hurts, and she is able to identify body parts that hurt.

5.3.1.3. Identities

5.3.1.3.1. Family identity

Mary lives with her grandmother, grandfather, aunt, uncle, sister and brother. She has lived with them since she was a baby (line 175-178). She constructs her family identity through the different family interactions and the roles that she identifies in her story. Mary identifies herself as a girl that likes to help her grandmother with duties in the home like cleaning and cooking. These roles are identified and discussed in section 5.3.1.2.1. Mary ascribes meaning to these duties and responsibilities by indicating that she enjoys these responsibilities. She attributes significance to her identity as a girl being part of a larger family.

5.3.1.3.2. Scholar identity

Mary is a scholar currently completing grade five. She is thirteen years of age. Mary does not elaborate on this identity in her story. However, she refers to the school context and activities that she does in this context. Mary refers to writing tests (line 147) and playing with friends at school. Her scholar identity is constructed through the activities that she does in the school context.

5.3.1.3.3. Athlete identity

Mary enjoys sports. She describes sport as something that is fun and it makes her happy (line 164). Mary enjoys playing tennis and volleyball (line 45 & 47). She describes herself as an athlete at home and at school. She views herself as a good player but not always (line 166). Mary's identity as an athlete is constructed through the activities that she does. As an athlete she can have fun and she enjoys these activities.

5.3.1.3.4. Friend identity

In Mary's story she refers to her friends. She does not elaborate much on her friend identity however, identifies herself as a friend. As a friend she plays sports with other friends at home and at school (line 50, 51, 110 & 111). This identity is constructed through the activities that she engages in with her other friends.

5.3.1.3.5. Patient identity

Mary's identity of being a patient was established through her previous and current experiences of illness. She constructs her patient identity by referring to her illness that affects her physical body. When Mary's physical body hurts she feels ill (line 75 & 83). In her first drawing she identified herself through her physical characteristics (line 36 & 37). Here she referred to her hair, nose, mouth, and eyes. Mary also explains that the doctor examines her body at the clinic, (line 67) referring to how her physical body is inspected in the medical context. She identifies that when she does not drink her medication she becomes ill (line 180). Mary's identity of being a patient is constructed through her illness experiences. This identity is maintained by her ongoing experiences of illness and disease management.

5.3.1.4. Interplay of identities

Mary tells her story from the position of being a patient in the medical context. This identity was constructed through her past and present illness experiences. In Mary's story she does not talk about her patient identity in the future. Her identity of being a patient is based on her experiences of illness that affects her physical body (line 67, 80, 92). She gives meaning to these experiences by describing that she is ill and that she has to visit the clinic to receive her medication in order to feel better (line 18 & 99). She describes the medical context as a place where one's physical body is examined to determine illness. Her experiences of disease management in the medical context inform how she constructs her patient identity. She describes herself as being physically ill. She does not know about her HIV status thus she refers to her general illness experiences.

At home Mary's patient, family, athlete, and friend identities are prevalent. She tells her story of taking medication at home and of becoming ill in this context, referring to her patient identity (line 89). At home she receives support from her aunt and grandmother when she is sick. This refers to how her family identity comes to interact with her patient identity at home. However, her identity of being a family member is dominant in this context. She describes her responsibilities and roles in the home (line 42). Mary also refers to her friend and athlete identity at home. She describes how she interacts with her friends and plays sport at home (line 49 & 164).

At school Mary's scholar, athlete, patient, and friend identities come into play. As a scholar she goes to school and writes tests. As an athlete she plays tennis and volleyball at school with her friends (line 49 & 51). Mary has been ill at school before and thus her patient identity is also present in this context (line 84). At school she is aware that the other children are also ill and that they have to drink medication (line 120).

5.3.1.5. Narrative understanding

Mary tells her story from her patient identity. At present her patient identity is dominant and it comes into play in every context in Mary's story. At home her family identity is prominent however it interplays with her patient, athlete, and friend identity. In her story she does not look forward to possible experiences in the future. She only tells of past and present experiences. Her experiences of illness described in her story, and her interaction in the medical context, informs how Mary experiences herself and her body. She constructs herself as an ill girl that has to attend the clinic to receive her medication to help her feel better.

5.3.2. Story two: Dan

5.3.2.1. Narrative understanding

Dan tells his story in the medical context primarily from his patient identity, however also moves to his compassionate provider identity when telling his story. Dan is aware of his HIV status and

he makes sense of his illness experiences and disease management by wanting to eliminate illness in the world. His story of living with HIV is a story of love and compassion towards others that also experiences illness.

5.3.2.2. Contexts

5.3.2.2.1. Family and cultural context

Dan is a fifteen year old boy currently completing grade nine. He lives with extended family in Atteridgeville. He lives with his grandmother and two younger brothers (line 29). His youngest brother is three years old and the other brother is ten years old (line 31). Dan also has a cousin that he refers to as his sister (line 52). Everybody at home knows about his HIV status (line 99). When he is sick at home they take him to the hospital (line 136). At home Dan's family members, especially his ten year old brother, remind him to take his medication (line 302). Dan can also talk about his feelings with his brother and grandmother. His grandmother forces him to eat his porridge, though sometimes he doesn't (line 346). Dan knows that the porridge is important because it helps him to gain weight (line 349).

Dan lives with extended family and he describes his experiences of illness and disease management at home. He also refers to the roles that family members occupies and also refers to family interactions in this context. Dan describes how his family supports him in living with HIV at home.

5.3.2.2.2. School and social context

Dan likes school activities and he does not like being absent at school (line 163 & 165). He likes to play sport and he especially likes cricket (line 178). Dan has six friends (line 101). Only Dan and his one friend are well behaved at school (line 110). He describes that he is different from his other friends in that they have different subjects, some smoke, and others are naughty at school (line 106 & 108). At school Dan has informed teachers that he is HIV positive (line 89 & 91). When he told them they felt bad for him (line 93). When he is absent from school they know that

he is at the clinic (line 94). When he feels ill, they phone home and the teachers then send him home (line 96 & 97). At school the teachers educate them about HIV (line 119 & 132). The teachers tell them that they are too young to sleep around, they should not mix blood, they shouldn't drink beer or smoke, and that when you are HIV positive your body cannot tolerate drugs (line 119, 121, 122 & 125).

In this context the teachers educate the children about HIV. Dan has learnt things about HIV at school that he did not learn at the hospital (line 129 & 130). HIV is spoken about at school. When Dan found out about his status he felt bad because he has heard about HIV previously at school (line 57 & 60). The teachers are aware of his status and they help him when he is ill.

5.3.2.2.3. Medical context

Through Dan's first drawing (appendix D) he illustrates his current relationship with HIV and he tells his story of being HIV positive (line 34). Dan found out about his status in 2009. He went to the clinic because he felt ill (line 7 & 72). His sister accompanied him to Kalafong Hospital where they had to draw blood to conduct tests (line 7). After the results came back he found out that he was HIV positive (line 7 & 8). Dan was with his sister when they told him the news in the doctor's office (line 54 & 55). The news made Dan feel really bad because he knew what HIV was (line 59). He has heard of HIV before at school (line 57 & 60). At that stage, Dan felt bad and lost weight (line 63). He doesn't know who the person was but someone at the clinic told him (line 37) that people die with HIV and that it is painful. It kills a lot of people and it has no cure (line 38 & 39). Dan explains that when AIDS kills you, you have pain, you get thin, get diarrhoea, lose weight, get sores, your hair changes, and your lips become pink (line 41, 43, 45 & 47). The doctor also told him he will always be HIV positive (line 51).

Dan had to return to the clinic in January 2010. There they gave him pills that he is still taking (line 9 & 10). The first time that Dan came to the hospital, his CD4 count was low, only at ten (line 144). When he started using medication he drank his medication but he missed one time (line 10). When this happened he informed the doctor about it and she told him that he should not forget to take his medication again (line 11). Dan's CD4 count fluctuated and went from ten to

two hundred and then dropped to fifty. Then it went to eight hundred and fifty up to one thousand (line 147, 149 & 151). Dan explains that his CD4 count dropped the first time as he didn't take his pills on time (line 153). Since then he takes his medication at seven in the morning and at seven in the evening (line 11 & 292). Dan is feeling all right as he has gained weight and he can eat now (line 65, 66 & 70).

In Dan's drawing he describes his journey of finding out about his status. When Dan was told about his status he was already ill. His face was red and it had sores (line 81). Since he started on medication he is no longer sick. In his drawing he describes himself as a boy that looks happy (line 75 & 77). In his story he explains that his physical body is better. His face is not as it was before and he has gained weight (line 79 & 83). Through his drawing he portrays himself as a happy boy that is knowledgeable about HIV.

When Dan visits the clinic he sees the doctor and social worker (line 254). When he consults with the doctors they write him prescriptions for medication, they take his blood, and give him feedback on his blood test results (line 257, 260 & 264). They test his blood three-monthly to check his CD4 count (line 270). Dan travels to the clinic by foot or sometimes by local taxi (line 317 & 319). He gets up at half past six in the morning and it doesn't take him long to get to the clinic (line 322 & 324). He leaves home at seven and he arrives at the clinic by eight when he walks (line 325). When he travels with the taxi he leaves at seven-thirty and arrives at the clinic in a shorter time (line 325 & 326).

Dan receives his medication once a month from the hospital (line 289). When he attends the clinic for his check-up they give him the next date when he should receive his medication from the pharmacy (line 289). He remembers on his own to fetch his medication every month (line 295). Dan describes medication as something that cures, but that does not really cure as it just makes you feel better (line 287). He feels bad about taking medication as the medication is tiring as he has to drink it every day (line 307 & 310).

Through Dan's second drawing he tells a story of Kalafong Hospital (line 183 & 186). In his story he is from the hospital. At the hospital they gave him his medication and he is happy as they

helped him (line 183 & 185). Dan describes that a lot of people are sick at the hospital (line 189). The hospital is not like home and it doesn't belong to anybody (line 191 & 195). Dan describes that it is not nice at the hospital as most people are sick and others die (line 197). He feels happy because Kalafong helps him to get better but he feels bad when he is at the hospital (line 205) as he can see that people are sick (line 213 & 217). According to Dan that is the reason why nobody likes to go to hospital (line 222). According to him there shouldn't be a hospital as nobody should be sick (line 281). He doesn't want doctors or nurses to work at a hospital, because he doesn't want people to be sick (line 276 & 277). In Dan's drawing he drew a big red heart. Through this he indicates that he loves people and that he doesn't want them to be sick (line 328 & 329).

Through Dan's story he indicated that he had a good knowledge about HIV. He could describe the relationship between strict adherence to medication and his CD4 count. He could also describe the physical symptoms that are associated with AIDS (line 41, 43, 45 & 47). Dan constructs HIV as a disease that is painful and it is a disease that kills. He constructs the medical context as an environment where sick people go to. He associates this context with death and dying (line 197). Dan realizes that the hospital is a place that is there to help him and other people (line 185). It makes him happy when he feels better, however he wishes that illness would not exist (line 278 & 279).

5.3.2.3. Identities

5.3.2.3.1. Family identity

Dan's family identity is constructed through his interactions with his family. Dan is a brother, a cousin and a grandson. He lives with his grandmother and two younger brothers (line 29). Dan also has a cousin that he calls his sister (line 52). His family identity is founded on the relationships that he has with his extended family. These roles are described and elaborated on in section 5.3.2.2.1.

5.3.2.3.2. Scholar identity

Dan is a scholar attending grade nine in a school in Atteridgeville. He describes himself as a boy that enjoys school activities (line 163). As a scholar he is well behaved and he doesn't like to be absent from school (line 161 & 165). He does different subjects than his friends (line 106) and he loves to draw (line 161 & 338). Dan's identity as a scholar is based on the activities that he does at school. He attributes meaning to this identity by indicating that he likes school.

5.3.2.3.3. Athlete identity

In his story Dan does not elaborate on his athlete identity, however, establishes himself as an athlete. Dan describes that he likes sports and cricket (line 178). This identity is established based on the sporting activities that he participates in. Dan likes sports and thereby attributes personal meaning to this identity.

5.3.2.3.4. Friend identity

Dan identifies himself as a friend. In Dan's story he has six friends (line 101). He differentiates himself from other friends by describing himself as a well behaved boy (line 110 & 161). As a well behaved boy he does not smoke and he is not naughty (line 106 & 108). Dan does not elaborate in his story about his interactions with his friends, however, explains what a friend should be like by describing what they should not do.

5.3.2.3.5. Patient identity

Dan's patient identity was constructed through his illness experiences and diagnosis in 2009. Before this identity was confirmed Dan was ill. He initially went to the clinic because he felt sick (line 7 & 72). Here they conducted tests and informed him that he was HIV positive. Dan's story of finding out about his status and his illness experiences are described in section 5.3.2.2.3. In his journey with illness he has moved from being ill to feeling better (line 68). Dan constructs himself through his story as a responsible patient. He remembers on his own to take his

medication every month from the hospital (line 295). As a responsible patient he drinks his medication in the morning and the evening (line 11).

5.3.2.3.6. Compassionate provider identity

Through Dan's story of disease management he constructs himself as a compassionate provider. He tells the story of the ill people that attends Kalafong Hospital for health care. This story is described in section 5.3.2.2.3. Here he constructs himself as a compassionate boy who cares about people. He believes that hospitals should not exist because then people would not be ill.

Dan constructs himself as a compassionate provider in his future life story by identifying things that he would like to do for himself and other people. Dan would like to have his own family (line 175). He would like to buy a house and a Lamborghini (line 173 & 177). He establishes himself as a future husband that provides for his family. Dan further elaborates on this identity by describing that he would like to take his family to other places outside of Atteridgeville so that they can see the world (line 171). He demonstrates his compassionate provider identity through wanting to help his family and give them something that they don't have. Dan's compassionate provider identity is constructed through his interactions with other people. He is caring and compassionate to people around him and he wants to provide them.

5.3.2.3.7. Explorer identity

Dan constructs himself as a future explorer. When he grows up he wants to be a pilot and see the world (line 167 & 169). He wants to take his family with so that they can also see the world (line 171). Here Dan looks to the future and constructs his explorer identity by identifying an occupation that will allow him to accomplish this.

5.3.2.4. Interplay of identities

At home three of Dan's identities are prominent. His family, patient, and compassionate provider identities are described in this context. Dan is a family member and has various interactions with

his family (line 31, 52 & 346). At home Dan's family helps him by reminding him (line 302) to take his medication. Here the interplay between his family and patient identity is seen. As a patient at home Dan describes his ongoing disease management. He takes his medication in the morning and evening (line 292). He also elaborates on his family identity by looking to the future and describing possible experiences (line 175, 173 & 177). He establishes himself as a future husband that provides for his family. Through Dan's family and patient identities he constructs his compassionate provider identity. His experiences at home of being a family member and through his experiences at the hospital of being a patient, he constructs this identity. In Dan's story this identity comes into play in the past, present and future. Dan also constructs himself as a future explorer. When he is older he would like to become a pilot (line 167). Here he looks to the future and constructs his explorer identity by identifying an occupation that will allow him to explore the world.

In the medical context Dan describes that he moved from being an ill patient in the past to being a responsible patient at present. He is aware that his patient identity is fixed and that it will persist into the future and form part of his future story. Dan's experiences of being a patient informed his compassionate provider identity. He describes that most people are sick and that other people die at the hospital (line 197). Dan clearly states that he does not like this and it is not nice. He furthermore doesn't want there to be any hospitals as no one should be sick. As a compassionate provider in this context he cares for people (line 328).

At school Dan is a scholar, a friend, an athlete, and a patient. His patient identity is known in this context and his patient identity interplays with his other identities. At school Dan only informed his teachers about his status (line 89 & 91). When he is absent they know that he is at the clinic. As a scholar when Dan feels sick they phone home and then they send him home (line 96 & 97). This indicates the interplay between his patient and scholar identity at school, home, and at the clinic. Dan does not like it when his patient identity interferes with his scholar identity (line 163 & 165). He describes his athlete and friend identity in the school context (line 178). He refers to the activities that he does as an athlete and refers to the qualities of friendship.

5.3.2.5. Narrative understanding

Dan tells his story from the position of being a patient. Through his story his patient and compassionate provider identities are dominant in the family and medical contexts. His other identities, those of being a scholar, friend, athlete, and explorer are prominent in the school context. Dan is able to tell of his past and present experiences of living with HIV and is able to look to possible positive future experiences in his story of living with HIV.

5.3.3. Story three: Petrus

5.3.3.1. Narrative understanding

Petrus tells his story within the medical context from his identity of being a patient. He only learned about his HIV status this year. His story of living with HIV is a story of acceptance and sameness, as he incorporates his new identity of being a patient into his life story. Petrus attributes meaning to his story of living with HIV by establishing himself as a normal boy that is the same as everybody else.

5.3.3.2. Contexts

5.3.3.2.1. Family and cultural context

Petrus is a fourteen year old boy. He lives with his uncle and his four children in Pretoria (line 135). His uncle used to be a pilot but now he is a driver and works shifts (line 157 & 286). Petrus also wants to be a pilot when he is older. Petrus sometimes visits his mother's place in Limpopo during holidays. He calls her his mother however she is his cousin's mother (line 207). When he visits his mother he plays soccer with his friends and watches TV (line 213, 215 & 216). At home, his cousins do not know about his status (line 138 & 139). His uncle said that he should tell them when he is ready or grown-up (line 141). Petrus has a good relationship with his uncle. His uncle helps him with his medication by reminding him to drink it on time and he attends the

clinic with Petrus (line 104 & 286). When Petrus feels bad he can talk to his uncle (line 288 & 289).

Petrus lives with extended family. He does not give much detail about this context however he refers to family interactions. He describes his relationship with his uncle and he identifies with his uncle. In this context only his uncle knows about his status, his illness experiences is not known to the rest of the family.

5.3.3.2.2. School and social context

Petrus attends school in Pretoria. Petrus is new at the school and he is still getting to know the teachers at school (line 226, 229 & 230). He enjoys the new school and the subjects Afrikaans, English, and Social Sciences because he finds that they are easy (line 219, 220, 241 & 248). Petrus likes poetry and the teachers give them themes to write about (line 78 & 82). He also likes to play soccer with his friends. Petrus would like to play hockey at school, yet as he is new there he does not play (line 236).

At school the teachers and his friends do not know about his status (line 43, 45 & 46). Petrus does have friends at the new school (line 221 & 222). Petrus believes that he is not different from his friends but that they are all the same (line 183, 187 & 189). His friends also like poetry and soccer (line 188). Petrus believes that he is not different from his friends, because they don't know if he is positive or negative (line 185). He does not get sick at school (line 257 & 258). When he is absent from school he just tells them that he went to the doctor and he gives the teacher a sick note (line 165 & 167). At school, they teach the children about HIV in the subject Natural Science (line 169). Petrus does not always remember what kind of things they are taught but he does learn from it and he asks questions (line 171, 261 & 263). At school the other children believe that HIV kills but Petrus does not believe it (line 266 & 268). He believes that you can live with HIV.

In the school context Petrus feels as if he is a normal boy that is no different from other children. He participates in the same activities as the other children. In this context, the children and

teachers are not aware of his status. However, it seems that Petrus does not want to incorporate his experiences of HIV into this context. He feels that even though he is living with HIV, he is still the same boy, just living his life like all the other children. In this context, there is awareness about HIV/AIDS. However, it seems that the children at school have limited knowledge about HIV. Their outlook on HIV is influenced by their age appropriated capacity to conceptualize HIV. These children believe that you die from HIV, however Petrus believes that you can live with HIV.

5.3.3.2.3. Medical context

Petrus describes his experiences related to the medical context when he very recently found out about his HIV status. Petrus found out that he was HIV positive in February of this year (line 10 & 14). The doctor told him that he is HIV positive and that he should drink his medicine properly (line 27). That is why he comes to the clinic. At that time they did not tell him much more but someone told him that in two years time there will be a new medication that will cure HIV (line 35). When he found out about his status he cried, as the news was terrible for him (line 69 & 72). Afterwards he just accepted it (line 29). He saw that crying won't help or change his status. If he continues to cry he will cry for the rest of his life (line 69 & 70). For Petrus, accepting means that if something happens there is no way to change it (line 63). Petrus feels the same as before he found out about his status (line 149). He is just living his life (line 153). For him, finding out about his status did not change the way he perceived himself. He accepted his status as he was aware that he could not change it. He realized that life will continue as before.

Petrus describes his experiences of disease management. He started coming to the Paediatric HIV Clinic in February when he found out about his status. The first time he attended the clinic, he went to the preparation meeting and then he started using the medication (line 90 & 91). Petrus experiences headaches and some pain for short durations, where after he feels better (line 48, 50 & 52). When he came to the clinic he had thrush but now he is feeling better (line 97). He wakes up at five- thirty to come to the clinic and he usually finishes around ten (line 177 & 179). His uncle comes with him to the clinic and they travel approximately twenty-two kilometres by car to

reach to the clinic (line 104, 106 & 175). Petrus feels that the staff at the clinic are good but he does not really know other people at the clinic (line 101 & 110).

Petrus tells his story of living with HIV at home. His experiences of disease management at home are still informed by the medical context as this context outlines practices that have to be performed. At home Petrus takes his medication at six-thirty in the morning and in the evening and then again at eight (line 113). He feels that taking medication is boring but he knows there is nothing he can do about that (line 117). Petrus accepts that he has to take his medication because of his illness. The medication is boring as some of the pills are sour (line 121). He drinks the liquid medication first as it tastes sour and then he drinks water (line 125). The medication sometimes makes Petrus feel dizzy and he often loses his appetite (line 276). When Petrus feels like that it is still not difficult for him to take the medication (line 278). He feels better since he started on the medication (line 281 & 282). His uncle helps him with the medication by reminding him or waking him to take his medication (line 132, 133 & 286).

Petrus wrote a poem (appendix E) about HIV for the interview. His experiences of living with HIV informed his writing. Through his poem Petrus identified the main problems that society experiences with regards to the disease (line 310 & 311). Petrus describes that HIV is a disease that can kill both rich and poor people (line 304). He explains that HIV/AIDS is a disease that does not choose people and that anyone can contract it (line 319). When you have the disease there is nothing that can be done to change your status (line 304, 305, 325 & 326). Petrus feels that the most important thing that one can do is not to blame your partner or parents (line 305 & 306). Petrus describes that you have to take responsibility for the disease (line 316 & 317). What you can do is to take your medication on time and to always believe in yourself (line 306). When you take your medication on time one can live (line 332 & 333).

In this context Petrus describes his experiences of finding out about his status, the process he engaged in to accept his status, and of his experiences related to disease management. Through his story he describes himself as a boy that was ill but since he is using medication he is feeling better. His story in this context is of acceptance and assuming responsibility for living with HIV.

5.3.3.3. Identities

5.3.3.3.1. Family identity

Petrus lives with his uncle and his four cousins in Pretoria. His family identity is based on the relationship that he has with his extended family. His relationship with his uncle is representative of a father-and-son relationship. Petrus does not fully describe this relationship but establishes himself as a son by describing his relationship with his uncle. He has a good relationship with his uncle. His uncle helps him with his medication by reminding him to drink it on time and he attends the clinic with Petrus (line 286 & 104). When Petrus feels bad he can talk to his uncle (line 288 & 289). He also establishes his identity as a son by referring to his relationship with his cousin's mother and the activities that he engages in with his cousins (line 213). His identity as a son and a cousin is constructed based on his familial relationships with his uncle, cousins, and his cousin's mother.

5.3.3.3.2. Scholar identity

Petrus is a scholar currently completing grade nine. He is fourteen years old. As a scholar Petrus enjoys the new school that he is attending in Pretoria. Through Petrus' story he elaborates on his scholar identity by referring to the subjects that he enjoys and by describing the activities that he is engaged in at school (line 78, 82, 219, 220, 241 & 248). These are described in section 5.3.3.2.2. Petrus' identity as a scholar is based on his attendance of school, his participation in school activities, and his relationship with teachers and other scholars. He identifies with the activities such as poetry and likes to write about things. He describes himself as a scholar that is the same as the other children at school as they all participate in school activities.

5.3.3.3.3. Athlete identity

Petrus identifies himself as a boy that likes sports. He likes to play soccer with his friends and his friends also participate in other sporting activities. He constructs his identity as an athlete by identifying sports that he wants to participate in as it is an enjoyable activity that he likes (line

233-240). All his friends also play hockey and soccer (line 237 & 238). Petrus' identity as an athlete is constructed based on the sport that he do play with his friends and he identifies hockey as a sport that he will participate in, thereby confirming his athlete identity in the future.

5.3.3.3.4. Friend identity

Petrus identifies himself as a friend. He has friends at school and describes his interactions with his friends (line 221 & 222). As a friend Petrus believes that he is not different from his friends and that they are all the same (line 183, 187 & 189). They all enjoy poetry, soccer, and hockey (line 188). His friend identity is based on his interactions with his friends and the activities that they do together such as sports and poetry.

5.3.3.3.5. Patient identity

Petrus' identity as a patient was established when he found out about his status in February of this year (line 10 & 14). He describes in his story that he was sad and shocked when he found out about his status. After this he realized that the emotions that he was feeling would not change his status. Petrus describes how he decided that he will not stay sad otherwise the sadness will stay with him his entire life. After this realization he accepted his status (line 29). Petrus incorporated his patient identity into his life. Finding out about his status did not change the way he perceived himself. Petrus moved from shock to acceptance. He constructs his patient identity as a normal part of his life.

5.3.3.3.6. Pilot identity

Petrus looks to the future and identifies himself as a pilot (line 155). He is able to construct possible experiences for the future by identifying with his uncle that used to be a pilot (line 157). Petrus wants to be a pilot when he is older because he is interested in that career.

5.3.3.4. Interplay of identities

Various identities are constructed in Petrus' story. Through his experiences in different contexts his identities of being a family member, a scholar, an athlete, a friend, a patient, and a pilot are constructed. In the medical context Petrus' identity of being a patient is dominant. This identity was established very recently, however, Petrus realizes that this identity will inform his future story (line 69 & 70). Through Petrus' story the meanings that he attaches to his experiences of living with HIV and disease management is that of acceptance and normality. He believes that he is no different from any other child and that he is living his life in the same way as before (line 183, 185, 187 & 189). Throughout his story, normality informs the meaning that he attaches to his experiences in all other contexts.

His other identities are informed by his experiences of being a patient. At school, Petrus' identity of being a patient is not known to others however this identity still informs how Petrus views himself in this context (line 45 & 46). In the school context his identities of being a scholar, an athlete, and a friend come into play. Petrus describes himself as a normal scholar, athlete, and friend that is the same as all the other children. He identifies himself as a normal boy that participates in the same activities and sports as his friends (line 345-353). He believes that he is not different at all.

At home, Petrus' identity of being a patient is also not known to his cousins however, this identity comes into play in the family context (line 139). At home Petrus takes his medication and his uncle supports him in using the medication properly. Petrus' experiences that form part of his family identity inform his identity of being a pilot. His uncle is a pilot and Petrus also wants to be a pilot in the future. Petrus' family identity is dominant at home however his scholar and athlete identities also come into play. In this context his relationships with his uncle and cousins are described. Petrus also refers to his scholar identity where he had to study for a test (line 181). He refers to his athlete and friend identity where he plays soccer with his friends (line 213 & 215).

5.3.3.5. Narrative understanding

In Petrus' story various identities come into play. He tells his story from his patient identity. This identity is only known to his uncle, however, this identity is prevalent across all contexts of his story but it is not fully incorporated. At home his family identity is prominent and at school his scholar, friend, and athlete identities come into play. The meaning that Petrus attaches to his identity of being a patient informs his other identities. For him, normality is important in his story of living with HIV.

5.3.4. Story four: Julie

5.3.4.1. Narrative understanding

Julie tells her story of living with HIV in the medical context from her identity of being a patient and a self-sufficient young lady. In Julie's story of living with HIV she constructs herself as a conqueror in her battle with HIV.

5.3.4.2. Contexts

5.3.4.2.1. Family and cultural context

Julie is a sixteen year old girl who lives in the Atteridgeville community. She is currently completing grade ten in a catholic school in the area. Julie lives with and is being raised by extended family. She lives with her mother who works full time, her mother's brother, and her mother's uncle. Her grandmother also lives in this community and she has no brothers or sisters. Julie's biological mother (line 215) passed away when she was one year old and she therefore did not know her biological mother. Her "real" mother as she describes, was her current mother's cousin.

Julie is a proud African girl. She describes her heritage through various poems that she has written. In the one poem Julie describes the journey of a young black girl that goes to the country

(line 107 & 108). Julie describes her new life in Africa and describes how this girl feels about being an African (line 110). When this girl is older she tells everyone that she is proud and that she likes culture and enjoys following family rules (line 112 & 113). Through Julie's writings she explains the importance of culture and describes how important it is to follow family rules in her culture. For Julie it is important to appreciate one's heritage. She views herself as a proud African woman that likes to represent herself through creative activities like singing, dancing, and writing poetry.

Family has an important function in Julie's life. She receives a lot of support from her mother and her family. Her mother plays an important role in her life as caregiver and as a life teacher. Julie's mother used to be a HIV counsellor so she supports Julie (line 153). She tells her stories and teaches her how to take care of herself (line 153 & 154). As caregiver Julie's mother feels angry and bad when she becomes sick (line 169). She worries about her and takes her to the hospital when she feels that something might happen to Julie (line 170). Julie's family also supports her by telling her she will be well and that she should just continue living her life (line 376).

Julie has a supportive family however, not all things are openly discussed in the family. Julie only found out about the reasons for her biological mother's passing on when she learned about her HIV status. She knew about her mother, however does not remember how she found out about her biological mother (line 232). Julie does not know about her biological mother's personal history as her current mother said that it was not time to know about it yet (line 236). Julie feels that it was ok because she was not close to her biological mother as she never knew her (line 234).

In this context Julie describes her cultural heritage through poems that she has written. Julie finds meaning through her cultural heritage as an African woman and values cultural practices. She also describes her relationship with her mother as supportive. Through her relationship with her mother Julie learns important values and life skills.

5.3.4.2.2. School and social context

Julie attends a catholic school in the community. At school HIV is something that is spoken about in class. The teachers educate the children about HIV. They talk to them about how they can become infected and what to do when they have contracted HIV (line 136 & 137). However, no one at school knows about Julie's HIV status. Her friends and teachers think that she has asthma (line 346). Everybody knows that she is absent from school once a month on a Monday and they don't ask questions about it, as they believe it is from asthma. Julie did tell two friends in primary school about her illness, however, she is not friends with them anymore. She is not friends with the one girl anymore as she was a naughty girl (line 148). Julie is scared to tell her friends about her status. She fears that they might think that she could infect them somehow, and that they then would reject her by telling her to be on her own (line 141). When she becomes sick at school, her teacher can identify it immediately and then calls her mother to fetch her (line 163). Through singing and acting Julie wants to be famous (line 408). She feels that then she would be proud to tell people about her status (line 416).

In the school context Julie's friends doesn't know about her status. Julie is scared that they would reject her (line 141). Even though Julie is proud of being an African woman and proud of being a healthy self-sufficient girl in dealing with HIV, she is scared to share these accomplishments with her friends (line 191). In the social and school context discourses that are founded on false and stigmatized beliefs govern beliefs and perceptions about HIV. Even though they receive HIV education various misconceptions still exist amongst peer groups as to how HIV could be contracted. Lack of knowledge, fear, and prejudiced beliefs still accompany social and community interactions. These beliefs hinder Julie sharing her experiences of HIV and her accomplishments with her social group.

5.3.4.2.3. Medical context

Julie's first visit to a hospital was in the year 2000 when she was six years old. She had to stay over in the hospital as she was ill with asthma (line 330 & 348). Julie was hospitalized again in 2001. She doesn't remember these experiences and only saw this information in her medical file,

but thinks back to these events and believes that she must have been ill then. Julie's journey with illness began long before she officially became a patient at Kalafong Hospital. She remembers that she was surprised as she was always falling ill. Julie was always wondering what was happening to her (line 198). In the year 2005 she found out about her HIV status (line 196). This also marks the year that Julie started attending the Paediatric HIV Clinic on a regular basis. Julie remarks that the sister told her that she had HIV and that they want to fight the virus (line 27). She moved from being an ill girl to one of being a patient. Since Julie became a patient she attends the clinic once a month for disease management (line 328).

Julie describes her experiences of attending the clinic for disease management. When Julie has to attend the clinic she wakes up at six-thirty in the morning in order to prepare to go to the clinic (line 320). Her visit to the clinic sometimes takes from eight until two o'clock in the day (line 281). On the day that Julie has to visit the clinic she is absent from school, but she receives a sick note to take to school (line 321-324). She usually walks to the clinic because she does not stay far (line 342). Julie sometimes attends the clinic alone or is accompanied by her grandmother or mother that comes between twelve and one o'clock to see how she is doing (line 335-338). She always follows the same routine when she attends the clinic (line 274- 279). The first thing that she does is go to the receptionist to receive her file. She then goes to the nurse that pricks her finger. She is however not sure why this is done but knows that the nurse also takes her temperature. Julie then goes to the dietician where they ask her questions about her weight and how she feels. After this she returns to the waiting area and falls in line to wait to see the doctor. When she sees the doctor, the doctor does a routine examination. After seeing the doctor she goes to the pharmacy to take her medication.

Julie describes her experiences of medication and the role it plays in her life. She describes that the medication is important. Here medication refers to ART. She is proud to state that she has never forgotten to take her medication (line 255 & 256). Julie describes medication as something that helps the warriors in her body to be healthy and to fight and kill the virus (line 245 & 246). Therefore Julie takes her medication daily at six-thirty am and pm (line 252 & 254). The medication helps her to be healthier and she currently doesn't experience any negative effects from the medication (line 261-264). Various other things help her to be healthy and strong. She

believes that God helps her to be healthy and she also lives a healthy lifestyle by eating healthy foods, fruits, vegetables, and by exercising (line 269 & 271).

In her story Julie further describes her experiences of interactions with the staff members at the clinic. She identified one doctor as a doctor that asks her questions regarding boys and sex (line 286). She always tells her what to do and tells her to be positive (line 288). Julie feels that not all doctors do that (line 284). She describes these interactions as helpful and they get along well. Her interactions with this doctor are clearly significant as she describes these interactions as something that others won't do. Her experiences with the other staff members are not as memorable. She feels that she does not get along with the other staff members. Julie feels that this doctor takes time to talk to her, whilst the other staff members are always busy (line 299). She feels that they just run around (line 307).

Julie's experiences highlighted various discourses that are associated with the hospital context. Her interactions with the staff are formal and impersonal while her interactions with the doctor are different. Staff are busy and do not have time to interact with patients. Patients typically follow the routine as outlined by the hospital; no room is allowed to interact freely or behave outside these rules.

5.3.4.3. Identities

5.3.4.3.1. Expressive identity

Julie likes to sing and act and also enjoys writing, especially poetry (line 89, 90 & 99). She does dancing as a drum major at school (line 121). These are ways in which she can express herself. She also used poetry to express her cultural identity in writing about African women (line 101). Julie aspires to become famous through singing and acting (line 408). Through these activities she distinguishes her expressive identity.

5.3.4.3.2. Family identity

Julie's family identity is constructed through her family interactions. She elaborates on her family identity through her relationship with her mother. Julie has a good relationship with her mother. She is a role model to Julie as she teaches her how to be self-sufficient. Being self-sufficient is an important value for Julie and she refers to this quality numerous times (line 153, 154 & 191). Julie's relationship with her mother is described in section 5.3.4.2.1. As a daughter Julie is aware of culture and follows family rules (line 112 & 113).

Julie dreams about being a mother one day and having children (line 385). She also dreams about being a grandmother when she grows old, and desires to have a long life (line 385). Julie also describes herself in her second drawing as an old lady, thereby she foresees herself as being grown-up (line 355 & 357). Through describing these dreams Julie constructs her future identity as a mother and grandmother. These are important dreams for Julie as she explained that she is afraid of dying (line 381). This is mostly present when she is ill. She then feels that everything is over.

5.3.4.3.3. Young lady identity

Julie refers to herself as being a young lady numerous times (line 43 & 179). As a young lady she is very proud of herself. She describes herself as self-sufficient as she already knows what she must do to take care of herself (line 191). She is healthy and strong (line 43, 53 & 54). Part of Julie's young lady identity means that she needs to be determined and optimistic (line 53, 81 & 82). Therefore through this identity she portrays herself as a self-sufficient healthy and strong girl that is determined to stay positive and fight HIV.

5.3.4.3.4. Scholar identity

Julie is a scholar currently completing grade ten. As a scholar she likes the subject Commerce (line 92). She does not elaborate on this identity, however, refers to the activities and interactions

that she is engaged in at school. She is engaged in other activities such as singing and dancing and plays sport in the form of table tennis (line 121).

5.3.4.3.5. Friend identity

Julie has more than ten friends (line 125). Even though Julie is shy she is very talkative, especially with friends and people that she knows (line 89). As a girl she sees herself as caring and supportive (line 94). As a friend she values good behaviour. She explained that a previous friend was naughty and that she is not friends with her anymore because of that (line 148). Her identity as a friend is based on being a good and supportive girl.

5.3.4.3.6. Patient identity

Before Julie was diagnosed with HIV in 2005 she was already ill. Julie explains that she was wondering what was happening to her, as she was surprised that she was always getting sick (line 198). During this period Julie portrays being an inquirer into her experiences of illness. Here she was questioning what was happening as she did not have any answers. When Julie first attended the Paediatric HIV Clinic in 2005 with her mother that is when she learned about her HIV status. The doctor told Julie that she had HIV and that they wanted to fight this virus (line 27). Here her illness experiences was named, she was officially diagnosed with HIV. This marked the beginning of Julie's patient identity. As inquirer Julie was angered at this news. Julie did not know how she was infected with HIV and wanted answers to why she was HIV positive.

Julie tells the story of becoming a patient. For Julie, the unfolding of events of how she learned about her status and how others informed her about it, was important in her story. Before the doctor had told her about the virus, she already knew (line 207). On the day that Julie and her mother had to visit Kalafong Hospital, Julie's aunt had told her about the virus that morning (line 205). Julie's mother was not aware that her aunt had told her about her status. At the clinic, when the doctors wanted to confirm if she knew about her status, she surprised them when she told them that she already knew (line 206 & 207). The staff asked if she knew what was happening to her and Julie said that she knew she had the (HIV) virus. Her mother was surprised that she had

not told her about her aunt sharing this information. Julie was however waiting for her mother to personally tell her about this (line 209). After Julie's status was confirmed at the hospital she saw a counsellor that informed her about the medication and how she had to take it (line 241). At first when she found out about her status she was angry (line 213) and she wanted to know from her mother how she came to be infected. Julie expresses how she was inquiring into her illness experience. Her mother told her the story about her biological mother that got sick and that passed away when she was one year old (line 215). Julie explained that with this new information she started to understand why she was infected (line 216). She could come to an understanding and through family support cope with the news.

Before Julie was diagnosed with HIV she had already taken on an inquiring position into her illness experiences. When Julie was officially diagnosed with HIV her patient identity was established. Here she continued being an inquiring patient as she was seeking answers to her illness experiences. After Julie found out about her biological mother and how she contracted HIV, she could move from being an inquiring patient during her initial stages of illness to that of becoming an understanding patient.

After Julie was told about her status her battle with HIV began. At the clinic the sister told her that they needed to fight this virus (line 27). Julie tells a story about her experiences with HIV by using a metaphor to describe the fight that she had to take on since she found out about her status (line 40-84). Julie illustrated this metaphor in her first drawing (appendix F). Julie's battle with HIV has led her to take on various positions in her patient identity through her journey in disease management.

Julie tells a story of her immune system (great warriors), HIV (the virus) and infectious diseases (bad germs) through a metaphor. She explains that the virus is bad and dangerous and that it is a virus that attacks her body's white cells and it makes her body weak (line 47, 48 & 79). The virus kills and fights the white cells of her immune system that she calls her warriors (line 36 & 48) When Julie becomes sick due to her weakened immune system she feels that there is nothing that she can do. When her body is weak the virus makes her sick and she feels that it is over (line 59 & 63). When she becomes sick she becomes weak and lazy. She cries all the time and describes

that she says silly things such as she is going to die (line 61 & 63). When she is sick she feels like giving up (line 66). Sickness made Julie helpless to HIV. At the beginning of Julie's journey with HIV she described herself as a sick and hopeless girl that became weak and fearful due to her illness. Being a patient meant that she was sick and that she was surrendering to the effects that HIV had on her body. Here Julie's identity as a patient could be described as surrendering.

Through Julie's metaphor she describes how she moved from being a surrendering patient when she was sick to that of being a conquering patient when she felt better. Julie describes that the great warriors inside her body kills the bad germs (line 35 & 36). These warriors are her proud protectors (line 37) as they find and kill the bad germs inside her body (line 35). She describes that the bad germs think that they can enter her body and that they are stronger than her warriors; however, she knows that she is the healthiest person in this world and feels like nothing can make her sick (line 43, 44, 48 & 49). Julie explains that when she is healthy it is when God helps her through the difficult times (line 71). God helps her to be healthy by answering her prayers and by listening to her when she cries (line 74). Here Julie constructs herself as being self-sufficient, optimistic and being stronger than HIV when she feels better.

Julie is engaged in a battle between fighting HIV and surrendering to its consequences. When she feels better, this is when she finds the willingness to fight and be the conqueror in this battle (line 81 & 82). Julie describes herself as happy as she was sick and now everything is all right. She is willing to fight the virus (line 81 & 82). The resolution to this story is portrayed in Julie's second drawing. In this drawing she describes herself as being ready for any action and looking forward to hearing her results (line 176). Here she describes how she attended the clinic to receive feedback on her blood tests to see whether her medicine is working and boosting her immune system (line 179). In this story Julie describes herself as strong and very proud because she already knows how to take care of herself (line 180 & 191). She reaffirms that she is self-sufficient, healthy, and optimistic. She portrays herself presently as being a conquering patient.

5.3.4.3.7. Religious identity

Julie attends a catholic school and religion is very important to her. Julie describes that she prays a lot and that she sometimes attends church. She describes her relationship with God using her story of HIV. Julie describes that God helps her to be healthy and that He helps her to get through difficult times (line 71). He listens to her when she cries and He answers her prayers (line 74). In Julie's second drawing she drew a necklace around her neck, which symbolizes a cross (line 359). Here Julie visually represented her religion as an important aspect of her identity.

5.3.4.3.8. Chartered accountant identity

As a scholar Julie aspires to becoming a chartered accountant (line 389-391). She clearly described how she envisions her future. She expressed that she likes money and does commerce at school (line 92).

5.3.4.4. Interplay of identities

In the family and cultural context Julie's family, patient, expressive, and young lady identities are prominent. Julie's family identity is constructed through her family relations in the familial and cultural context that informs her story. As a daughter, she has a good relationship with her mother which is supportive and caring, and functions as a life teacher to Julie. These characteristics are associated with women's traditional roles in society and reflect on society's discourses that govern women's roles. Julie recognizes these qualities in her and identifies herself as supportive and caring. She is a patient at home and she described her experiences of medication and disease management at home.

Julie's family identity informs many of her other identities as they are founded on her experiences of being a daughter and having family values and beliefs. Her identities of being a friend, young lady, expressive girl, and patient, are informed by Julie's daughter experiences as part of her family identity. Julie identifies herself as caring and supportive, something that forms part of Julie's interactions with her friends in a social context. Her mother also taught her to be

self-sufficient in order to take care of herself. These qualities and values are strongly affirmed through Julie's identities of being a young lady and a patient. As a young lady she sees herself as self-sufficient and strong. She also refers to these qualities as part of her patient identity, where she views herself as a conqueror as she knows how to take care of herself. The cultural and familial context informs Julie's future dreams of becoming a mother. Julie identifies herself as taking on the identity of being a mother and a grandmother, thereby she is able to construct an implied story for her future. As a scholar, Julie likes the subject Commerce and aspires to becoming a chartered accountant in the future thus wishing to take on a professional identity.

Julie's identity as a patient was established in 2005 and is dominant in the medical and family context. This identity will continue in Julie's future life story. At present, Julie is not able to integrate her experiences in the medical context with that of the social context. Through her experiences of being a friend she expresses that she fears disclosing her status to her friends. She is afraid of being rejected. At present time, as a friend, Julie is caring and supportive however, she is afraid that she will not receive the same commitment back from her friends. Her experiences as a patient, as described above, cannot be shared with her friends and at school. In her identity as a patient she has achieved a lot in fighting her battle with HIV. She is currently feeling strong and proud of her achievements since she moved from being a surrendering patient in the past, to that of being a conquering patient at present. However, she is not able to share these experiences with her friends.

Julie's experiences with illness and disease management in the hospital context together with her experiences of being religious and a daughter, has informed her identity as both a young lady and being expressive. These experiences have led Julie to construct herself as proud, strong, healthy, and self-sufficient. Even though Julie is not able to integrate her experiences in these different contexts she aspires to unite these experiences by building on her expressive identity and becoming famous in the future. She wants to use singing and acting as a means to achieve this. This will enable her to tell people about her status. Therefore people will look up to her and she could be an ambassador when she is famous. Then she can openly be proud about her status. When Julie further develops this identity she would be able to incorporate her past and present

experiences of being a patient and incorporate these experiences in the future into other contexts such as professional, social etc.

5.3.4.5. Narrative understanding

Julie's story was told from the medical context through her conquering patient and young lady identities. In the interview she spoke from her identity of being a conquering patient. However, she moved between the positions of being a surrendering patient in the past to that of being a conquering patient at present. Her telling of this story was informed by her dominant present identity of being a self-sufficient young lady. Thus, she looked back to her experiences of being a patient but did that from a position of being a conqueror and self-sufficient. Her identity of being a young lady and a conquering patient grew out of her past experiences in her family and cultural context from her family identity. At present Julie is not able to integrate her experiences of being a conquering patient with that of being a scholar and a friend. Julie looks to the future and identifies her expressive identity as a means to unite these experiences in order to be a conquering patient in all the contexts of her life.

5.3.5. Story five: Sera

5.3.5.1. Narrative understanding

Sera's story is told within the medical context. She tells her story from her identity as a realist. Her story of living with HIV is one of realism and normality.

5.3.5.2. Contexts

5.3.5.2.1. Family and cultural context

Sera is a fourteen year old girl turning fifteen. She is currently a scholar in grade nine and goes to school in Pretoria East. She lives with her aunt, uncle, and two cousins in the same area. Sera has an older sister and brother that live in Angola. Her one cousin is seventeen years old and the other

cousin is twenty-seven and she has a good relationship with them. This relationship is based on having fun and entertaining each other. Her oldest cousin is a DJ and at home he often plays the music very loud, makes them dance, and tells jokes (line 260 & 261). Sera has lived with her aunt and uncle ever since her parents passed away (line 162). She didn't know her parents and don't know what happened to them (line 166 & 172). She does not see the point of knowing as she never knew them (line 171). In Sera's family certain things are not spoken about and she does not feel like asking questions about her parents (line 168). Sera's uncle and aunt rarely talk about her parents at home but her aunt will sometimes say how she does things like her mother (line 170). Sera's aunt and uncle gives her support by telling her that it is not the end of the world and that she can still live with it (HIV) as she has been living with it her whole life (line 314 & 315). Sera's cousins and family knows about her status. They were fine when they heard the news (line 269). However, Sera finds it awkward to share her feelings with her aunt and uncle. She would rather keep it private from them (line 302 & 304). Sharing feelings and open discussions are not encouraged in Sera's familial and cultural context. HIV is not actively referred to or openly discussed in this context.

Sera and her family came to South Africa in 2002 from Angola (line 180 & 184). In Sera's story she relates very different past and present experiences of these two countries that form the foundation of her upbringing. Angola is viewed as her country of origin. For Sera, it is a place that reminds her of family but it is now very far away (line 182). Sera's brother and sister stays back in Angola as they are old enough to take care of themselves (line 178). She also describes Angola as a place where the people are friendlier and that the country has a better educational system than South Africa (line 189). Her uncle believed that the education was better in SA, but Sera does not agree (line 184 & 185). It is difficult for Sera in South Africa as they have no family here. They have many friends in Angola but they were left behind (line 192- 194). During holidays Sera and her cousins have to stay home and watch TV while her friends visit their families (line 194 & 195).

In this context Sera describes her experiences of culture and family. She identifies with her country of origin and through her story in this context describes some difficult adjustments that

they had to make as a family that moved from Angola to South Africa. Sera also describes her family interactions and the roles that she performs as a family member in the home.

5.3.5.2.2. School and social context

Sera's knowledge of HIV is something that she gained through school and reading (line 58). She has never been ill at school before (line 102 & 103). Sera's friends does not know about her status, she keeps it private for now and will tell them when she feels the time is right (line 99 & 101). Sera and her friends have discussed HIV before at school (line 281). They talk about what a person with HIV would feel like (line 281). She tells them what she thinks and feels about the matter and she can still share her feelings with them indirectly (line 282 & 294-296). They are often surprised about her insight into HIV (line 282). Sera's friends explain that they feel sorry for those people and feel that they would comfort a person with HIV and help later in life if they could (line 291-292). Through Sera's interactions with her friends she describes in her story that her peer group identifies HIV as something that happens out there to other people. They clearly see caring and helping people with HIV as something that they would do one day. They feel that such experiences are not part of their immediate context. Sera believes that her friends will be surprised one day when they find out about her status (line 293). She describes herself as a very open person that would rather share things with her friends than with her family (line 305 & 306). Therefore the school and social context plays an important role in Sera's life as places where she can share her feelings except for her experiences related to HIV.

5.3.5.2.3. Medical context

Sera talks about her experiences of finding out about her status in the medical context. Sera started coming to the Paediatric HIV Clinic in 2005 after she had her appendix removed at Kalafong Hospital (line 202). Before she had her appendix removed she was constantly sick (line 68). When Sera was constantly sick she visited another hospital in Pretoria (line 42). Her experiences of illness at the time were different compared to what other people experienced. She describes her illness experiences as weird as her sickness could not be explained. Therefore there was uncertainty surrounding her illness experiences. She either had flu or other weird diseases

that nobody else had (line 71 & 72). Sera didn't know then that she had HIV and did not understand her illness (line 68).

After she had her appendix removed they took a blood test and found out she was HIV positive (line 34). Sera's story of finding out about her HIV status tells of how she gained clarity over her illness experiences. She had to return after six months to verify her results again (line 23). When she returned in 2006, to check her results, the clinic staff informed her that she had to return to the clinic the Monday (line 23 & 24). That was when she started attending the Paediatric HIV Clinic every month (line 218). At the clinic they informed Sera how HIV will be in her life (line 36). Sera describes how she had to incorporate the experience of living with HIV into her understanding of how her life was to be in the future.

Sera describes her experiences of disease management. She started using medication in 2006 and started on ART in 2009 (line 76). Ever since she started on ART she had to take it twice a day (line 78). She has to drink two pills in the morning and three at night (line 78). The one pill that she adds in the evening makes her dizzy and she feels a bit hot (line 78 & 79). Other than that she experiences no side effects and feels fine since she started on them (line 85). Sera takes ART at six-fifteen in the morning and at night. She assumes responsibility for that at home (line 81 & 92). She knows that ART is important and she is aware of the consequences if one does not take medication. She describes that if you don't take your medication it can weaken your immune system and you can become ill from any disease (line 60 & 61). Sera is knowledgeable about the factors involved in the spreading of HIV. She described in her story that one can contract HIV through sexual relations, from a mother that has HIV to her child, through cutting yourself or if a person has a blood transfusion and the blood was not tested for HIV (line 53-56).

Sera describes her experiences of disease management at the clinic. Sera interprets these experiences of disease management as an obligation, it is something that she has to do (line 214) and she has no choice. She also describes her experiences at the clinic as monotonous, as having to do the same thing every time (line 247 & 248). In her story she explains that she does not like to attend the clinic as she experiences it as boring (line 206). She does not like waking up earlier and having to travel far to get to the clinic (line 221 & 222). She wakes up at five-thirty and

travels to the clinic with her aunt in her aunt's car from the other side of town (line 225 & 227). She has to be at the clinic at seven-thirty to wait for the doctors to come and they only arrive at nine-thirty (line 222 & 223). Sera experiences all aspects of attending the clinic as boring. She describes that everything about it is boring, waiting, looking at people, and having nothing to do (line 212).

Sera describes her experiences with the staff at the clinic as fine (line 230). They laugh a lot and she goes along with the doctors and the ladies at the pharmacy (line 230). The doctor often reminds Sera about using her medication and the consequences of not using the medication (line 250 & 251). Her experiences of the interactions with the other staff members are different. These interactions are more formal and structured, they are often busy and she does not interact with them (line 240).

5.3.5.3. Identities

5.3.5.3.1. Family identity

Sera's family identity is constructed through her interactions with her family. She is a sister, a cousin and a daughter. Sera's parents passed away and she did not know them. She has been living with her mother's sister ever since (line 162). She is a sister to her older brother and sister that live in Angola (line 175 & 176). Being the younger sister Sera has to live with extended family in South Africa away from Angola that she associates as being her home (line 16). Sera has good relations with her two cousins. Sera's aunt is like a mother to her. She gives her support by travelling to the clinic with her and by encouraging her to live her life (line 314 & 315).

5.3.5.3.2. Scholar identity

Sera is a scholar currently in grade nine and goes to school in Pretoria East. Sera does not like the subject Science and her marks aren't good in that subject (line 148 & 150). As a scholar Sera is also engaged in school activities such as tennis. She is interested in basketball and netball but does not want to join because the other girls are rough that participate in those sports (line 135).

She does not elaborate much on this identity in her story, however, refers to her interactions with other children and teachers at school and describes some activities that she does in this context.

5.3.5.3.3. Friend identity

Sera describes herself as a person that likes to make friends with everyone (line 113). She describes herself through her story as a person that gets an intuitive feeling about people's character (line 126 & 127). She describes this as an instinct that she has. When she looks at a person's face she can see if they are good or bad (line 114 & 115). Sera likes becoming friends if she has a good feeling about that person (line 113). Sera describes a bad person as someone that treats other people badly, by not respecting people's privacy and through not respecting others (line 129 & 130). She describes herself as different from other girls. Other girls are too bitchy and they expect others to do things according to what they want. She is not that type of person (line 140 & 141). Sera's identity of a friend is based on being an intuitive person that likes becoming friends with the right people that respects others, their privacy, and treat them well.

5.3.5.3.4. Realist identity

Sera describes herself as a realistic person (line 283). As a realist she is open and expresses her opinions and what she believes in. She does not feel pressured to conform to other's pressures (line 142-144 & 185). For Sera, being a realistic person means following principles and universal rules. She feels that there are ways that things should be (line 141). In Sera's story of living with HIV she constructs herself as a realist that accepts the way she is living now and she deals with it (line 277 & 278, 279). In living with HIV, she also accepts the possibility of death, saying that when her time comes to go she will say it is ok (line 274). Sera also describes herself as a friendly and happy person though sometimes things can happened that brings her down (line 113 & 116). Here she describes how she has normal experiences and that she faces them and accepts them. She constructs herself as a realist that accepts things that come her way as she knows she cannot change them. She also likes to do things according to principle and is able to express her beliefs and opinions that she is steady in.

5.3.5.3.5. Patient identity

Sera's illness experiences already established her identity as a patient, before 2005. She had her appendix removed and she was constantly ill at that time (line 68). Her illness experiences were different from what other people experienced and they could not explain her illness. Therefore there was uncertainty surrounding her illness experiences (line 71 & 72). After Sera had her appendix removed in 2005 she found out that she was HIV positive (line 34). She still does not know how she contracted HIV. Her aunt believes that she contracted HIV through a blood transfusion and believes that is the biggest possibility (line 315 & 317). Sera started attending the Paediatric HIV Clinic in 2006 as an official patient (line 22). When the doctor informed Sera about her status she was calm and fine (line 27). She describes in her story that she did not panic or feel that the world was falling on her (line 27, 37 & 38). She also did not feel pity for herself as she was fine (line 27). She describes her identity as an accepting patient that has no other choice than to incorporate the changes and consequences that living with HIV has brought into her life.

5.3.5.3.6. Helper identity

Ever since Sera was a child she wanted to become a doctor (line 152). She feels that as a doctor she would have enough money to open a free clinic where people can receive help (line 157). Thereby she will be helping the poor (line 158). Currently Sera is still deciding on this as she does not like the subject Science and her marks aren't so good. Sera also thought about opening an orphanage to help children that doesn't have a home (line 158 & 159). She is looking towards the future and constructing possible experiences. Sera's dreams of becoming a doctor and opening an orphanage are reflective of her identity as a helper in the future.

5.3.5.4. Interplay of identities

Throughout Sera's story her dominant identity is that of being a realist and this identity are predominant in various other contexts. In the medical context Sera's patient and realist identities are prominent. At present Sera tells her story from the position of being a realist situated in the

medical context. Her patient identity was established before 2005 and was reaffirmed in 2006 when she was informed about her status (line 22 & 200). At the clinic she was told how it is going to be in her life (line 36). Sera describes how she had to incorporate being HIV positive into her understanding of how her life was to be in the future. Therefore she anticipates her identity of being a patient to extend into her story of the future. She gave meaning to this notion from her realist identity. Through her story of finding out about her status, and through her past experiences of disease management, she constructs her patient identity as that of being an accepting patient (line 27, 37, 38 & 277). As a patient Sera fulfils her duties and obligations that is outlined in the medical context.

Her dominant identity of being a realist informs her experiences of disease management and of living with HIV. Therefore her dominant realist identity helped her to give meaning to her patient identity in the past when she found out about her status. Being a realist helps Sera to accept her life of living with HIV and will therefore inform her future experiences of HIV (line 274). Being a realist in the medical context she is open and expressive about her experiences of disease management. She is able to express that she feels it is an obligation that she has no choice in, but she knows she has to do it as it is part of her life (line 214 & 277).

Sera constructs herself as a realist in the school and social context. Her other identities of being a scholar and a friend comes into play in this context. In Sera's interactions with her friends she portrays her realist identity (line 140, 141 & 283). Her friend identity is constructed on her intuitive nature and her need to share with others, respect them, and treating friends well. As a friend she is also a realist as she openly expresses her opinions (line 284). Her interactions with her friends are governed by her beliefs, principles, and set ways of doing things (line 141). In this context her patient identity is not known to teachers and friends. They don't know about her status (line 99 & 101). Sera will incorporate this identity into the social and school context when she thinks the time is right (line 101).

At home in the family context Sera can incorporate all her identities. Her patient status is known to the family and they support her (line 267, 314 & 315). In this context Sera takes responsibility for being a patient by taking her medication (line 92). At home her family identity is

predominant. As a daughter she has certain duties such as cleaning (line 263). As a cousin her interactions are those of doing things with her other cousins and that of having fun (line 261). In the family and cultural context Sera experiences difficulty since her origins are in Angola. It is difficult for Sera in South Africa as they have no family here and she had to leave her friends behind in Angola (line 192- 194). Her identity as a helper is constructed by her need to help people by becoming a doctor or opening an orphanage in the future. Sera is able to look forward to the future and describe possible experiences that she would like to incorporate into her life.

5.3.5.5. Narrative understanding

Throughout Sera's story her identity of being a realist is dominant and she tells her story from this position. She often speaks about her other identities and experiences in other contexts from her realist identity. Her experiences relating to her realist identity and the meaning that she attached to them has helped Sera to give meaning to her other identities. Sera's story of living with HIV is one of realism, principle and normality. She accepts her life and interprets her experiences of living with HIV as part of herself and her future.

5.3.6. Story six: Bongi

5.3.6.1. Narrative understanding

Bongi tells his story in the medical context from three identities. He alternates between his patient and fun identity, and uses his identity as artist to help him express his story of living with HIV. As Bongi tells his story in the other contexts his other identities come into play. His story of living with HIV is a story of conflict between wanting to be normal and being different, because of the limitations that HIV has brought into his life.

5.3.6.2. Contexts

5.3.6.2.1. Family and cultural context

Bongi is a seventeen year old boy currently completing grade eleven. He lives with his grandparents in Atteridgeville (line 15). Bongi has a good relationship with his grandfather and he talks with him more (line 194). His grandfather visits the clinic with him each and every time (line 121). Bongi is inspired by his grandmother. She is sixty-four and still works. She rises at four-thirty, gets on a bus to go to work till four, and then goes home (line 196 & 197). Bongi's father lives in KwaZulu Natal and Bongi sometimes visits him during the holidays (line 15 & 17). Bongi's mother left when he was little and he did not have a relationship with her (line 253 & 254). His mother passed away in 2000 (line 244). He has a half-brother from his father's side, that is eighteen years old (line 23). His half-brother used to live with them from grade zero to grade seven, but his grandparents could not support him anymore (line 25). His half-brother is now staying with his mother (line 25 & 26). Bongi has a good connection with him, as they grew up together (line 30).

Bongi tells his story of contracting HIV. His story is situated in the family and cultural context. His dad told him that his mom had a relationship with another man (line 233). During that time she did not know she was pregnant and that man infected his mother (line 234). He sometimes gets angry because he doesn't understand why his mother left (line 233). He wonders where his dad was when that happened, as he was supposed to take care of her (line 235). He was shocked and angry when he heard this about his mother (line 248 & 250). Bongi tries to move on as it is in the past and he feels he just has to get over it (line 250).

Bongi tells of his experiences of living with HIV at home. Bongi thinks that his grandmother has lost hope (line 38). She says he must not go to girls and things like that. For him, there is a difference between a one night stand and a relationship. He feels that he needs a relationship (line 39 & 40). Bongi's grandmother thinks that he is being irresponsible by being interested in girls (line 40). He has a girlfriend, his grandfather knows but his grandmother doesn't know about her (line 192). They decided not to tell her as she is overprotective (line 192). He understands that

she should be, as it shows that his grandmother cares (line 200). At home they don't really talk about HIV (line 349). Bongi wants to visit friends and sleep over (line 147). He was supposed to go on a trip to Germany to visit his friend but his grandmother was afraid that they would find out about his status (line 148 & 149). Bongi wanted to tell a teacher about his status, as she was a great inspiration to him, but he has to think about his grandmother (line 158). He slept over at a friend's house once, but his grandmother did not know (line 167). That morning he was five minutes late to drink his medication (line 167). Bongi told his grandmother the day after and she was a bit angry at him (line 168 & 170). Bongi believes his grandmother is scared of what people might think. His grandmother believes that they will burn down the house (line 160 & 161). It is more his grandmother not his grandfather (line 163). Bongi does not care if they find out about his illness (line 149).

In this context Bongi describes his relationship with his extended family. He has an open relationship with his grandfather and they talk about everything. In this context Bongi's grandfather knows more about Bongi's personal life, as his grandmother is overprotective. She feels that Bongi should not have relationships with girls and she does not want him to sleep over. She is afraid of how other people would react or think when they find out about his illness. His grandmother is also more rigid in her views and beliefs, compared to his grandfather that is more accepting and open. His grandmother's views might be informed by misconceptions or stigmatized beliefs regarding HIV. He believes that his grandmother is scared. Many stigmatized beliefs are based on fear. Bongi respects his grandmother and obeys her wishes by not telling people, though it limits his social activities. Bongi also illustrates how in his culture, the elderly are respected and obeyed. At home they also don't really talk about HIV (line 349). In the family context various stories exist regarding Bongi's mother. It is difficult for him to hear of the stories and to make sense of them. His relationship with his dad is strained and he expresses anger and resentment towards his father. Bongi feels that his father should have taken care of his mother. He believes his father as the husband, should have provided physically and emotionally. He should have protected his wife and children.

5.3.6.2.2. School and social context

Bongi describes himself as a mysterious guy that is fun to be with (line 267). He feels that one will never know what to expect from him (line 269). He loves going out with his friends (line 269). Bongi has never used his fists or shouted at someone before (line 262). They've shouted at him but his friends provide him with back up (line 262 & 263). Bongi has many friends that he can depend on. He has lots of friends from different places, and lots of different kinds of friends in rugby and in soccer (line 265 & 340). They help each other with money and homework (line 340). Bongi and his friends are good guys, as they don't drink or smoke (line 342). If there is a fight he'll avoid it and rather go around it (line 278). He sees himself as a typical teenager (line 270). He plays rugby, soccer, and a bit of cricket at school, but he especially likes rugby (line 228 & 230). He gets his exercise by playing sports. Sometimes when he gets angry, he envisions the guy that he will spear in the game of rugby as his dad (line 236). Bongi does not want to hurt anyone so he still tries to be gentle and therefore does not tackle too hard (line 261).

Bongi describes through his story of his friends that he is a fun and sociable guy. He has many different friends and they help each other. He does not like physical violence and would rather avoid confrontations than hurt someone. He uses the medium of rugby to deal with his feelings of frustration and anger towards his father. As teenagers they do not engage in smoking or drinking behaviour. They are engaged in sports.

At school Bongi feels that the teachers give them too much assignments and homework (line 204). They put too much pressure on them, and the teachers don't understand that they need to do other work and sports activities, and they need to break a bit as well (line 208 & 209). His favourite subjects are History, English, and Cooking (line 213). In class he is quiet like a mouse and he does not speak at all (line 274). His friends know that if he's in class he works. Through Bongi's personal drawings he illustrated the pressure that the world brings (line 381). Bongi feels that all teenagers are faced with it, and that is why there are teenage suicides, as they can't handle the pressure (line 385). He feels that he will deal with the pressure and he does that by having fun (line 386).

Bongi tells through his story in the school context that teenagers are subjected to a lot of pressure. Teenagers experience pressure in school through having to juggle many activities and responsibilities. Bongi rationalizes teenage suicide by explaining that he understands what all teenagers are going through. However, he feels that he deals with life's pressures in an acceptable way by having fun as a typical teenager.

At school the children seem to be accepting and understanding of HIV. Bongi tells of his experiences of HIV at school. Bongi's one friend's girlfriend has HIV so they know about HIV at school. Bongi's friends do not know about his status, but he feels that he will tell them in grade twelve, and then they have to accept him or not (line 299). Now he won't tell them because of his grandmother (line 303). Bongi feels that nowadays everybody is more understanding of HIV at school, especially the grade eleven pupils (line 305). The grade eight and nine pupils are not that understanding as they are still focused on having fun (line 306). The grade ten pupils have some knowledge of HIV but the higher grades are more knowledgeable (line 306). Bongi feels that living with HIV is a hefty responsibility, especially for the younger children. Younger children don't understand how come they have to wake up early in the morning to take pills (line 323 & 324). Bongi feels that they need to know about their status early, so that they can face up to life (line 330). These days, children think of things like pornography at early ages and they might engage in sexual relations without knowing their status (line 330 & 331).

Through Bongi's story of HIV at school he explains that HIV is a subject that is known and talked about. At school his friends does not know about his status, however, Bongi feels that he would tell them later on. For now, he respects his grandmother's wishes. He feels that children are more understanding with regards to HIV. Bongi explains that the younger pupils at school are still focused on having fun and thereby they might not be that responsible in their behaviour. Thereby Bongi feels that it is important for younger children to know of their HIV status as they might engage in risky behaviour. Younger children are exposed to more things like sex and pornography. Therefore children should assume responsibility early on. Higher grades are more understanding and know more about HIV.

Bongi had the subject Art until grade nine however the school did not offer the subject in higher grades. Bonggi discovered his talent for drawing at age six (line 219). His grandfather taught him how to draw but at age eleven he became better than his grandfather (line 220). He started by drawing little pop-eyes (line 219). Bonggi feels that there is nothing in particular that inspires him to draw, he just feels like drawing and it comes natural to him (line 223). When he is bored he just takes the pencil and draws (line 223).

5.3.6.2.3. Medical context

Bonggi tells his story of finding out about his status and starting his journey with medication. Bonggi has been using ART since 2005 when he was in grade six (line 85 & 75). He still remembers the day of January the 14th clearly (line 85 & 89). At the clinic, the staff told his grandfather about his status, as they were afraid that he would receive the news in the wrong way (line 91). They thought he would react negatively by saying things, such as he is going to die. However, he took the news easily (line 92). Bonggi was with his grandfather when they told him but the staff thought that he would not understand, as he was still young. They said that his immune system will fluctuate but he believed that his CD4 count will increase (line 95). His grandfather was a bit shocked at the news and Bonggi heard him cry in the bedroom (line 99). He told his grandfather that everything will be fine and that he will live a long life (line 100). Together they supported each other through that time (line 102).

Bonggi describes his experiences of disease management and using ART. Bonggi goes to the clinic to receive his medication so that he can get better (line 37). He has been using medication for ten years and ART for five years (line 87), and takes his medication every morning and evening (line 82). He takes pills at six o'clock in the morning and at eight at night (line 65 & 77). He wakes up at five-thirty and then he has to take his medication at six. By six-thirty he is out of the house (line 79). He doesn't like to use medication in the morning, because six o'clock is a little early for him and he takes a long time in the bathroom to finish (line 79). When he uses the medication at night he becomes a bit dizzy (line 65 & 66). He usually has a lot of energy at night but after he has swallowed his pills he becomes tired (line 66 & 67).

Bongi expresses resentment toward taking his medication so early in the morning. Sometimes he has to wake up just for the damn pills, especially the six o'clock ones (line 145). He wants to visit friends and sleep over (line 147). Bongi believes the medication is good (line 177), however, he wishes that he could forget about his pills just once (line 82). Taking the medication makes him think that he is not human, as he has to rely on something else to keep him alive (line 314). He just wants to forget about it for one day and not have to think about a single pill in his body (line 313). He wants to be a normal human being (line 316). He was supposed to go on a trip to Germany to visit his friend, but his grandmother was afraid that they would find out about his status (line 148 & 149). Bongi believes that his grandmother is afraid of what people might think and believes that she has lost hope (line 38).

Bongi tells of the limitations that HIV and using ART has brought into his life as an adolescent. He cannot sleep over or go on trips due to fears of disclosure of his status and the possibility of not adhering to his medication. Furthermore, family fears with regards to community rejection and disclosure is prohibiting him from being a typical teenager. As a teenager he is in need of a relationship with a girl. Family fears are keeping Bongi from sharing his personal life with his grandmother. Bongi indicates that his grandmother has lost hope. Here Bongi indicates that he can still have a normal life even though he is living with HIV, however, his grandmother has difficulty incorporating this into her belief system. She believes he is irresponsible in his behaviour by wanting a girlfriend. Bongi expresses his frustration towards his medication. Using medication is making him feel as if he is not human, as he has to rely on the medication to keep him alive. As a teenager he would just like to forget about his medication for one day, as he has carried the responsibility of using medication with him for ten years.

Bongi thinks about how he is different from other kids (line 177 & 178). Other children can go to sleep anytime they want and they don't have to think about taking their medication. They can do what they want, but someone that is HIV positive could not (line 318 & 319). Medication takes his mind off other things like sex (line 177). Bongi has to think about a healthy life and other children can just experiences life (line 178). He feels that if he did not have his medication maybe he would have been using drugs (line 104 & 105). Bongi feels that is why medication has helped him (line 105). For him, a healthy lifestyle entails having a good relationship with your parents,

grandparents, and your girlfriend (line 187). It also entails exercising and eating healthy food but Bongi wants to live like a normal person (line 180).

Bongi expresses his frustrations towards the use of medication and the different lifestyle that he had to take on since finding out about his status. Bongi distinguishes between us (people living with HIV and them (uninfected people) and compares how he has to live differently from others. He is able to identify that as a teenager his different healthy lifestyle has made him aware of life thereby he does not engage in risky behaviour.

Bongi elaborates on his story of disease management. He travels to the clinic either by foot or by taxi (line 311). Bongi feels that he is old enough however his grandfather always wants to accompany him to the clinic (line 118). That is why everyone knows him at the clinic because his grandfather goes with him every single time (line 121). He attends the clinic three monthly (line 124) and he follows the same process every time (line 118). When Bongi comes to the clinic he takes his ticket and then he goes up to the dietician. There they measure his head with a measuring band and weighs him (line 111 & 114). After that he goes down and waits for the doctor (line 114). After that they call his name and then he can see the doctor (line 115). When he sees the doctor they give him information about sex but Bongi feels that he already knows it. That makes him wonder why they talk about it (line 135 & 137). He then goes and takes his medication at the pharmacy. Hereafter he goes back to the reception area to get a new date to attend the clinic. He is only finished at the clinic after this process (line 115 & 116).

Bongi describes that he has fun at the clinic as he loves to make jokes and tease the staff (line 54 & 126). The staff at the clinic is happy for him (line 56) as they know that he brings life into the clinic. Bongi tries to have a positive outlook on life where other patients are negative (line 58 & 59). He believes that you should live now or you will regret it later (line 59). Some of the old folks at the clinic are depressed and angry, and they don't greet him. He feels that the patients will die early at the adult clinic because of their negative attitude (line 355 & 356).

Here he describes that he follows the same process every time when he attends the clinic. He has good relationships with all the people at the clinic and he likes to have fun and be different.

Bongi has fun at the clinic and uses this as a means of coping with the frustrations and the limitations that HIV has brought into his life. Bongi explains that he does not enjoy the Adult HIV Clinic as he feels that the patients are negative there. He tries to have a different attitude to life.

Bongi has been living with HIV his entire life. He had to deal with it early and he has accepted his status (line 354). He still feels that it hasn't sunk in at times (line 346). Bongi describes this by using a metaphor of a little box that is locked away somewhere. He explains that he just needs a key to open the box (line 347). Through his metaphor he explains that his HIV status is locked away or hidden in a little box. His HIV status cannot be seen and therefore it is difficult for him to incorporate it into his understanding. He explains that he needs to find a key to open the box that his status is hidden away in. The key would open up his status and make visible for him to see.

Bongi describes his journey with HIV through his drawing of a metaphor (appendix G). Bongi illustrates this metaphor through a picture of a door that is opening, so that you can see what is really happening in the world (line 367 & 368). In this metaphor there are stairs that all humans need to take, but especially him to reach hope (line 370). There is a fence that humans need to cross but people can't cross it because it has wires and spikes. This is a short cut and therefore people have to take the stairs (line 377 & 378). There are obstacles in the way that people need to pass, such as life and death. For Bongi, hope is between life and death (line 372). He believes that people are trapped in a world that only tells lies about people and about HIV (line 373). Bongi wonders if scientists are really trying to make a cure for HIV (line 375).

Bongi describes how he needs to find hope in living with HIV. Hope in this metaphor is characterized as a cure for HIV. For Bongi a cure for HIV makes the difference between living and dying. For him, hope is on the other side of the fence but he needs to pass through the door to reach hope. He describes that he cannot take a short cut over the fence because of many obstacles in his way. He has to take the journey of living with HIV. Bongi wonders how far he is from hope as he feels trapped in a world that tells lies about HIV. He wonders if a cure for HIV will be found. He knows that he has to journey with HIV as there is currently no cure for HIV.

5.3.6.3. Identities

5.3.6.3.1. Family identity

Bongi constructs his family identity through his family interactions. Bongi is a grandson, son, and half-brother. He lives with his grandparents in Atteridgeville (line 15). He has a good relationship with his granddad and he is inspired by his grandmother (line 194, 196 & 197). Bongi's father lives in KwaZulu Natal and Bongi sometimes visit him during the holidays (line 15 & 17). Bongi's mother left when he was little and he did not have a relationship with her (line 253 & 254). He has a good relationship with his half-brother as they grew up together (line 30).

Through Bongi's story he illustrates family beliefs and roles. Bongi has an open relationship with his grandfather. His grandmother is overprotective and therefore he does not tell her about everything in his personal life (line 192). He has great respect for his grandmother's feelings and beliefs even though he does not agree with them. Bongi does not disclose his status as his grandmother fears that there will be negative consequences. Such as people burning down the house (line 158 & 160). He feels that it is more his grandmother and not his grandfather that feels this way (line 163). He tells of how his grandfather and he respect his grandmother by not disclosing his status to others and accommodating her beliefs. Bongi's family identity is constructed though his family relationships, and cultural values and beliefs, that guide family interactions. As a family member he is respectful and he obeys the wishes of the elders.

5.3.6.3.2. Scholar identity

Bongi is a scholar at a school in Atteridgeville. He is currently completing grade eleven. As a scholar his favourite subjects are History and English (line 213). Bongi constructs himself as a hard working scholar that has to engage in a multitude of activities. He describes himself as quiet and focussed in the class (line 274). Engaging in all these activities puts pressure on him as a scholar. At school Bongi feels that the teachers give them too much assignments and homework (line 204 & 206). His engagement as a scholar puts pressure on him and thereby he experiences this identity as demanding.

5.3.6.3.3. Artist identity

Bongi constructs himself as an artist in his story. As part of his artist identity he draws and engages in creative expression through the use of metaphors. This identity was established when he was six years old (line 219). Bongi's skill as an artist was further developed at school where he had the subject Art till grade nine. He does not view his activities as an artist as a hobby. He describes this identity as something natural to him (line 223). Bongi engages as an artist when he is bored. Through the telling of Bongi's story of living with HIV he used numerous metaphors to express himself (line 347, 367 & 381). Bongi also presented a book at the interview filled with drawings. Most of his drawings in his art book told a story of something significant in his life.

5.3.6.3.4. Athlete identity

Bongi constructs himself as an athlete through the sporting activities that he is engaged in, the meaning that he attaches to these activities, and through the characteristics that he embodies as an athlete. Bongi plays sports at school. He plays rugby, soccer, and cricket (line 228 & 230). He feels there is too much drama at soccer (line 231). At soccer practice they easily complain about getting hurt as compared to the game of rugby. Through playing sports Bongi gets his exercise as part of a healthy lifestyle. Bongi also uses his sport to deal with his anger and frustrations in an acceptable manner (line 236). As an athlete he is not aggressive and does not want to hurt someone (line 261). He constructs himself as an athlete that likes to engage in contact sports. As an athlete he is not aggressive and he uses the physical aspect of the sport as a means to deal with his emotions.

5.3.6.3.5. Boyfriend identity

Bongi identifies himself as a boyfriend. He has a girlfriend but his grandmother doesn't know about his girlfriend (line 192). His grandfather knows and they decided not to tell his grandmother (line 192). He does not elaborate on this identity, however, does refer to this identity

as an important part of his life. He does construct himself as a boyfriend that is interested in having an emotional relationship with his girlfriend (line 39 & 40).

5.3.6.3.6. Friend identity

Bongi construct his identity as a friend by describing the roles and interactions that guides friendship. He describes himself as someone that loves to go out with his friends (line 269). He describes that he has many friends from different places (line 265 & 340). For Bongi, friends are like books you don't always use them but you know where they are (line 336). Through this comparison he describes that he has different types of friends. He does not engage with all his friends all the time but knows that they are there. He describes himself as a friend that has never used his fists or shouted at someone (line 262). Bongi has lots of friends that he can count on and that will stand by him in situations of conflict. Friends also help each other with money and homework (line 340). Bongi and his friends are good guys as they don't drink or smoke (line 342). He constructs himself as a good guy that has lots of friends that support each other. They do not engage in behaviour such as smoking or drinking and they stand by each other. As a good guy he is not a fighter but can rely on his friends to stand by him.

5.3.6.3.7. Fun identity

Bongi constructs his identity of being a fun guy through his interactions with other people (line 126 & 267). He likes to make jokes and tease people. He describes himself as spontaneous and unpredictable in his interactions with people by saying that you'll never know what to expect from him (line 269). Bongi defines himself as someone that has a different outlook on life (line 56, 58 & 59). This identity is constructed through the interactions that Bongi has with other people. He has fun with people by joking and teasing them. Through having fun Bongi is living life to the fullest. In his interactions he is optimistic and spontaneous.

5.3.6.3.8. Patient identity

Bongi's identity as a patient was established in 2005 when he found out about his status (line 85 & 75). As a patient he is experiencing conflict between wanting to be a normal person and being different. Living with HIV and undergoing continual disease management has confronted Bongi, as a typical teenager, with numerous challenges. These challenges are fully described in section 5.3.6.2.1. and 5.3.6.2.3. Bongi expresses his desire to be normal but he establishes himself as different from other teenagers. He just wants to be a normal human being (line 316) however he describes how his patient identity makes him different from other teenagers (line 177 & 178). The resolution to the conflict that he experiences as part of his identity as patient is described when Bongi feels that living with HIV has contributed positively to his life. He does not engage in risk behaviour such as using drugs (line 104 & 105). He had to deal with HIV early on in his life and he has accepted his status (line 354). However, he describes that the conflict that he experiences as a different patient striving to be normal is ongoing, as it hasn't sunk in (line 346).

5.3.6.3.9. Lawyer identity

Bongi constructs his lawyer identity by envisioning a future occupation. He is contemplating studying law (line 285 & 287). In constructing this identity Bongi defines future experiences that would define his identity as a lawyer. Bongi feels that the profession of law allows for more engagement in conversation. He also wants to add something unique to the profession by wearing something different (line 288 & 289). He would also add something different to the occupation by incorporating into his lawyer identity an aspect of fun and difference. Through this identity Bongi describes possibilities for his future life story.

5.3.6.4. Interplay of identities

In the medical context Bongi's identities of being a patient and fun guy is predominant. Bongi's identity of being a patient was established in 2005 and the construction of this identity will extend into his future life story. As a patient, Bongi undergoes continual disease management at

the clinic by attending the clinic three-monthly. At the clinic his fun identity is also predominant. As a fun guy at the clinic he likes to have fun by making jokes and teasing people (line 126). Through his fun identity he adds life to the clinic. When this identity was established is not told in his story.

At home his identities of being a patient, family, scholar, and artist are described in his story. Bongi's patient identity is more dominant at home than at the clinic. He describes his experiences of disease management at home through his story of using medication. Bongi tells of his conflict of wanting to be normal and being different. He refers to this conflict pertaining to wanting to sleep over at friends, going on trips, having a girlfriend, and sharing his status with others. He relates these experiences to his home, school, and social context. His family identity is also dominant at home. He tells of his experiences in the family context and describes his interactions with his grandparents and father. As part of this identity Bongi is respectful towards his grandparents and their beliefs, however he doesn't agree with it and he goes along with it. Bongi believes his grandmother is scared of the consequences of disclosing his status. His family story influences his patient identity and contributes to the conflict that he is experiencing as part of his patient identity. As a scholar at home Bongi describes that he engages in homework activities. His artist identity was established when he was young and his grandfather taught him how to draw. This identity is also prevalent in the school and medical context. Bongi had Art as a subject at school until grade nine. As he could not continue with the subject at school this identity is primarily part of the home context. Here Bongi draws for his own pleasure. During the interview Bongi used his artist identity to express his story of living with HIV. He used drawings and metaphors to express himself.

In the school context Bongi's scholar, athlete, friend, and boyfriend identities are prominent. As a scholar Bongi engages in his school work and refers to his activities in class. As an athlete he engages in sporting activities at school. He uses this identity to deal with his emotions that stems from his experiences in the home context. Bongi's friend identity is also constructed in the school context. He has lots of different friends. He referred to his friend identity in the classroom and in the social context of sports. Bongi's identity of being a boyfriend is known in the school context however, it is limitedly incorporated in the family context. Bongi has a girlfriend but his

grandmother doesn't know it (line 192). His patient identity is not known to others in the school and social context (line 154 & 155). His conflict of being a patient is carried over into the school and social context, however, it is not known to his friends or teachers. Bongi wanted to inform a teacher about his status thereby describing that he wants to incorporate his patient identity into this context. He does not disclose his status due to fears that his grandmother has. Due to the obligations he has as part of his family identity he will not disclose his status yet. In the school context Bongi does not directly refer to his fun identity however he does refer to his fun identity in the social context with his friends. Bongi's lawyer identity is informed by his fun identity. Bongi looks to the future and constructs his lawyer identity. Here his fun identity informs how he constructs himself as a future lawyer.

5.3.6.5. Narrative understanding

Bongi constructs different identities through the telling of his story of living with HIV. He tells his story primarily from his identities of being a patient, a fun guy, and an artist. He makes use of his artist identity to express himself. He uses his fun identity to deal with life's challenges and to entertain others. Bongi's family identity informs his story of living with HIV. It shapes his experiences of HIV and therefore shapes his patient identity. As a patient he experiences conflict between wanting to be normal and being different, because of his status and ongoing disease management that is prohibiting him from living a normal life. Furthermore the cultural beliefs and family values are prohibiting him from bringing a possible resolution to his conflict. Bongi describes that the conflict that he experiences, as a different patient striving to be normal is ongoing. He still feels it has not sunk in (line 346). Until Bongi can fully integrate his patient identity into the other contexts of his life and integrate his family and patient identities, the conflict that he experiences will continue to persist.

5.4. Summary

In this chapter the re-constructed stories of the six adolescents were individually discussed and placed within a social constructionist narrative framework of understanding. The different contexts in which these stories were situated in were described and discussed. The multiple

identities that the adolescents constructed through their stories of living with HIV were described and discussed. Reference was also given to the interplay of these identities within the different contexts of their stories.

Chapter six

Discussion of the research results and recommendations

The stories of the adolescents will be discussed in this chapter with reference to the unique and similar aspects that were found in their individual stories. The aspects are related to how HIV manifests in the lives of these developing adolescents. Here disclosure, HIV in different contexts, the adolescents' knowledge of HIV, disease management at the clinic, adherence, and medication will be discussed as it presents in the adolescents' stories. Hereafter these aspects will be discussed with reference to the implications thereof on disease management. The research shortcomings and limitations, research recommendations, and the dissemination of the research results are then discussed. Hereafter the researcher's experience of the study is reflected upon, and the closing thoughts discussed. The chapter is concluded by providing a summary to the research.

6. Introduction

In chapter five, the told and untold stories of the adolescents that are living with HIV that attend the Paediatric HIV Clinic were presented and placed within a narrative framework of understanding. The reader gained an understanding of the experiences of the adolescents undergoing continual disease management. Furthermore the multiple identities, as constructed through the meanings that the adolescents attached to their experiences, were highlighted and discussed. This gives the reader an understanding of how the adolescent constructs their self through their experiences of HIV.

Through the adolescents' stories it became apparent that the adolescent, in an important stage of identity development, living with a chronic illness, is faced with numerous additional challenges due to their illness. Adolescents living with HIV are faced with the responsibility of ongoing disease management that is prevalent through the different contexts of their lives. The adolescent living with a chronic illness is faced with various psychosocial factors that affects and challenges their well-being such as disclosure and adherence (Thom, 2007). Through the adolescents' stories

various unique aspects of living with a chronic illness came to the fore that highlights the uniqueness of the adolescent living with HIV.

6.1. HIV and the adolescent

The unique and similar aspects that were found in the adolescents stories will be highlighted and discussed in this section.

6.1.1. Adolescents living with HIV

Each adolescent has a uniquely different story of living with HIV. In all the adolescents' stories, their experiences of living with HIV were interpreted differently and the meanings attached to these experiences were uniquely incorporated into their view of self.

Mary's story of living with HIV is based on her experiences of illness and the use of medication. Her story is one of illness that is prevalent across all the contexts of her life. She makes sense of her illness experiences by identifying and attributing illness to her physical body and by describing herself through her physical characteristics. Petrus' story of living with HIV is a story of sameness and normality. He views himself as similar to his peers and does not distinguish himself from his peers through any other means. He expresses his sameness and establishes his normality by describing himself as a boy just living his life. Dan's story of living with HIV is a story of responsibility and compassion towards others experiencing sickness. In his story he progressed from being ill to assuming responsibility for his disease management. Dan is a caring boy that lives to help others. Julie's story of living with HIV is grounded on optimism. She is a proud self-sufficient young lady that takes care of herself in living with HIV. In her battle with HIV she has moved between surrendering to HIV when she is ill to being the conqueror in this battle when she feels better. She accomplishes this by taking care of herself and relying on God to help her. She is proud of her accomplishments in living with HIV. However, she cannot share these accomplishments with her peers out of a fear of rejection. Sera's story of living with HIV is one of normality and realism. She views herself as a normal girl that accepts her life as it is. She is realistic about how she is living her life with HIV now. Bongzi's story of living with HIV is a

one of living differently. In Bongi's story he describes his conflict between being different from others and striving to be normal in living with HIV. HIV brought limitations and responsibilities into his life that distinguishes him from his peers.

6.1.2. The adolescent and status disclosure

Only one adolescent, Mary, was not aware of her status. Her experiences of illness and the use of medication were significant in her story. All the other adolescents knew about their HIV status and discussed this openly. Most of the adolescents were informed about their HIV status in early adolescence. Dan and Petrus were both fourteen when they found out about their status. Dan has been using ART for nine months and Petrus for seven months. Julie and Sera found out about their status when they were eleven years old. Both have been using ART for approximately five years. Bongi came to know about his status when he was twelve years old and has been using ART for five years.

All the adolescents were informed about their HIV status by clinic staff. Julie is the only adolescent whose HIV status was revealed to her by a relative. However, in her story she describes that she surprised the clinic staff when she informed them that she knew about her status. All adolescents describes through their stories that they came to know about their status because of previous experiences with illness. These experiences with illness led family members or hospital staff to inquire into their illness by conducting blood tests that led to their diagnoses of being HIV positive.

It seems that in most of the adolescents' stories there are various stories surrounding the way they contracted HIV. Family members are reluctant to disclose such information to the adolescents. This could be due to the young age of the adolescents and the family members wanting to wait until they are older to discuss such information with them. Bongi explains in his story that he contracted HIV through his mother possibly during labour. Sera explained that she contracted HIV through a blood transfusion. Julie, Dan, and Petrus did not know or did not disclose how they became infected.

In most cases only the adolescents' families are aware of their HIV status. In Petrus' story only his uncle knows, none of his other family members know. Only Dan disclosed his status to teachers at school. None of the other adolescents disclosed their status to other people. Julie disclosed her status to a friend when she was younger. They are not friends anymore because her friend was naughty. Julie is the only adolescent that expressed that she feared rejection by her friends should they come to know of her status. Sera, Bonggi, and Petrus felt that they would disclose their status when they felt ready, or when they are older. In Bonggi's story he clearly wanted to disclose his status on previous occasions, however, due to family expectations, values, and beliefs, he did not disclose his status. His grandmother fears discrimination should they find out about his status.

In the stories of the adolescents the disclosure of their status at the time were mostly described as a once-off event. Many family stories exist with regards to how the adolescents contracted HIV and many questions remain unanswered for these adolescents. As these adolescents grow older and will gain an increased cognitive capacity to question and reason, they might have more questions with regards to HIV in their lives. As described by Thom (2007), status disclosure should be a continual process over time to assist the developing adolescent with other questions and difficulties that might arise with regards to their illness. Furthermore these adolescents have to cope with the conflict of disclosing their status in the future to other family members, friends, and partners. Bonggi, Sera, Julie, and Petrus specifically described in their stories that they are considering the disclosure of their status. They are aware that this has to occur in the future and they are considering the consequences of disclosure. The adolescents also find themselves exposed to increased social and peer pressure, coupled by the need to feel accepted by their peers (Thom, 2007). Thus, the adolescent is in need of guidance and support regarding status disclosure as notions of stigma, fear of discrimination and rejection were identified as obstacles in ongoing status disclosure. These factors bring about difficult psychosocial circumstances and pressure that the adolescent and family have to deal with in living with HIV (Anderson & Seedat, 2009).

6.1.3. The adolescent living with HIV at home

For all the adolescents HIV is treated differently at home. Petrus' family is not aware of his HIV status. Only his uncle is aware of his status and supports Petrus by helping him to adhere to the guidelines of drinking his medication. His uncle often wakes him up to take his medication, or phones him to remind him. Bonggi, Sera, and Dan assume primary responsibility for taking medication at home. In Bonggi's family story he explains that he receives support from his grandmother and grandfather, however HIV is not openly spoken about at home. His grandfather accompanies him to the clinic and his grandmother is overly protective of him. Bonggi appreciates this support. However, he feels frustrated by the limitations that this is imposing on his life as a teenager. He respects his grandmother by not disclosing his status and not sleeping over at friends. His grandmother's over protective nature has led Bonggi to keep information from her to allow him space. Dan's younger brother helps him with his medication by reminding him sometimes to take it on time. Dan attends the clinic alone. Sera's aunt always accompanies her to the clinic. She describes in her story that her family supports her by encouraging her to live her life. Sera does not discuss personal matters with her family as it makes her feel awkward. She assumes primary responsibility for disease management at home. For Julie, HIV is openly discussed at home. She receives a lot of support from her mother who also educates her on HIV and how to take care of herself as a young lady.

The adolescents receive support at home in living with HIV. The support that they receive seems to be in the form of others helping them to adhere to their medication and support with physical aspects such as helping them to attend the clinic for disease management. It appears as if open discussions about HIV are limited in the home context. The adolescents' feelings associated with living with HIV are not openly and freely discussed at home. As found by Ayres et al. (2006), caregivers often refrain from discussing important issues with adolescents due to fear of emotional and behavioural consequences, which may follow such discussions and due to lack of clear information pertaining to HIV. The adolescents also do not receive emotional support through the school and social context, as their HIV status is not known to others in those contexts. Thereby the adolescents do not have many of opportunities to discuss HIV openly.

6.1.4. The adolescent and HIV/AIDS at school and in the social context

All the adolescents indicated that teachers at school educate them about HIV/AIDS. Dan and Sera learnt more about HIV/AIDS at school than in the medical context and they could clearly articulate facts about the disease. Julie however learnt about HIV/AIDS through her mother's teachings as she was a HIV counsellor. She has in-depth knowledge about immune system functioning. In most of the adolescents' stories HIV/AIDS is a topic that are discussed in the school and social context amongst scholars. Even though all the adolescents have knowledge about HIV/AIDS some adolescents and their fellow scholars expressed a clear lack of knowledge. Petrus explained in his story that he heard that there would be a cure available for HIV in the next two years and he believes this statement. Other children at Petrus' school show limited knowledge with regards to HIV and their outlook on HIV is possibly influenced by their age appropriated capacity to conceptualize HIV. These children believe that you die from HIV however Petrus believes that you can live with HIV. Bonggi was aware of the studies in search of a cure for HIV, however he questioned the validity of these claims. Bonggi, who is older than Petrus, hopes for a cure. He however realizes that this is still in an experimental stage. Bonggi is the only adolescent that explained that he feels that scholars at school, especially the higher grades, are more accepting and open to HIV. He describes that younger children are still focused on having fun and therefore they do not pay as much attention to HIV/AIDS. Bonggi felt that children should be made aware of their HIV status sooner, rather than later. They should assume responsibility sooner due to the fact that younger children are sexually active. Bonggi also feels that his friends would be more accepting should they find out about his status. Julie, who has in-depth knowledge about HIV, expressed fear of rejection. She specifically explained that she feared that her friends would think that she would infect them somehow, even though she knows how HIV is transmitted. Sera also explained that she felt her friends would be surprised if they knew she had HIV. She described that her friends are ignorant and that they view HIV as something that happens out there in the world to other people.

Through the adolescents' thinking and reasoning it became apparent that each adolescent is developing differently. As stated by Thom (2007) various specific factors, that are characteristic of the adolescent, may result in inconsistencies of behaviour and adherence to treatment.

Adolescents are easily attracted to alternative sources of information, they express a distrust or rejection towards authority figures, they express a strong orientation to the present, they have a clear need to express independence, they do not want to feel different, and are susceptible to peer pressure. Through Petrus, Julie, and Bonggi's story these characteristics of thinking and reasoning were described and are apparent. Furthermore, stigma continues to accompany HIV/AIDS. Stigma brings about difficult psychosocial circumstances that these adolescents have to cope with (Goudge et al., 2009). Limited social support, as identified in the adolescents' stories, decreases their ability to resist stigma and may increase their risk for psychosocial problems.

6.1.5. The adolescent and disease management at the clinic

Most adolescents indicated that their experiences at the hospital of disease management were good. They all indicated that they got along with the staff members. Julie indicated in her story of disease management that she felt the one doctor was different than the other staff members. She interacted with Julie and made her experiences at the clinic more memorable. Julie and Sera's interactions with other staff members were not that memorable. They described other staff members as too busy and formal. These staff members do not have time to greet or to engage with the patients. Dan expressed that he loved the staff members and the patients, and that he did not want anybody to ill. Dan reasoned that if nobody was sick, then there would not have been hospitals. He did not want staff to work at the hospital, as it meant that people were sick. Bonggi described that he has fun at the clinic as he entertains the staff with jokes and makes them laugh.

All the adolescents described in their stories about disease management that they follow the same routine and procedures every time that they attend the clinic. Through their descriptions of the process of attending the different departments in the clinic, some adolescents explained that, they are not always aware what and why procedures are performed on them. For instance, pricking fingers or measuring their head. All the adolescents identified the clinic doctor as the only person of the staff that asks them personal questions and gives advice with regards to sexual relations.

Through the adolescents' stories of disease management, they described the processes, procedures, and personal interactions in the medical context that govern their experiences of

disease management. The adolescents identified lack of communication, formal, and impersonal interactions between patient and staff as barriers in disease management. These were also identified by Goudge et al. (2009) and Ayres et al. (2006) as barriers to health care.

6.1.6. The adolescent's knowledge and future perceptions of HIV

Most of the adolescents were knowledgeable regarding HIV and various health constructs. In the conversations with the adolescents, aspects such as virus transmission, immune system functioning, CD4 count, physical symptoms of illness were referred to. Only two adolescents, Mary and Petrus, had limited knowledge of HIV.

The adolescents, except Mary, were aware that their illness were chronic and would be part of their future life story. Dan, Julie, Sera, Petrus, and Bongsi clearly referred to the concepts of death and dying through their stories of living with HIV. Furthermore all the adolescents, except Mary, described future dreams and careers. Dan and Julie specifically described future family identities and gender roles in their stories. These adolescents' capacity to think about abstract concepts was prevalent throughout their stories. They could focus on future orientated activities, which bring a renewed awareness and focus of their status and future possibilities to the fore (Thom, 2007).

6.1.7. The adolescent, ART and adherence

All of the adolescents were aware of the importance of adhering to ART. The adolescents could describe their specific daily routines that formed part of disease management at home. All the adolescents were aware of the importance of using the medication and they acknowledged that the medication is something that helps them to feel better or to stay healthy. However, the adolescents had conflicting ideas about the role that ART played in their lives. For Mary and Julie the medication was positive as it helped them to feel better and to stay healthy. The other adolescents clearly expressed negative feelings towards the use of ART. Bongsi expressed a lot of frustration towards the use of medication, as it contributed to limitations in his life as a teenager. He condemns ART as he has to rely on pills to keep him alive. He also could not sleep over at friends and he always has to be consciously aware of taking his medication on time. Bongsi and

Petrus experience some side effects from the medication when they use it at night. Petrus felt that it was boring to take medication and Dan expressed that taking his medication was tiring. Sera describe medication as an obligation, something that has to be done.

In the adolescents' stories of ART it seems that most of the adolescents assume primary responsibility for the use of their medication. Family members assist them with adhering to their medication by reminding them to take their medication at their scheduled times. Medication forms an integral part of the everyday life of the adolescent. Strictly adhering to their medication became a huge responsibility for these adolescents. The use of medication is a hindrance to their social lives. They cannot sleep over at friends due to fears of accidental status disclosure or the possibility of non-adherence to their medication. These adolescents have to rise very early in the morning to take their medication on time and they also have to cope with the side effects of the medication. Taking medication daily was identified as a burden. These limitations may lead to future inconsistencies with adherence to medication. As described by Thom (2007), adolescents may not want to feel different from their peers. The current limitations that ART imposes on the lives of the adolescents may lead to increased risk-taking behaviour.

6.2. Implications for disease management

The research describes the experiences of the adolescents receiving continuous disease management and ART. ART has only recently been incorporated into the health care system. The exploration of the meanings that these adolescents attach to their experiences of disease management and ART brings to light how these adolescents cope with this as part of their everyday lives. Through the adolescents' stories they attributed different meanings to their disease management in the medical context and at home.

Mary views disease management as important as the use of medication helps her to feel better. Dan experiences disease management being tiresome. He takes his medication as he knows that it helps him to stay healthy, however he experiences drinking medication demanding. Petrus experiences disease management as boring. He dislikes the taste of the medication and endures the side effects. He knows that he has to take his medication in order for him to feel better. Sera

experiences disease management at the clinic and at home as an obligation. It is not something that she looks forward to, as disease management is a tedious process that involves waking up early, travelling far, and going through the same process each time. Sera knows she has to adhere to her treatment and accepts this in her life because she has no choice. Bongi experiences disease management at home as frustrating. He condemns the fact that he has to use pills to sustain his life. Bongi has the wish that he could forget about his medication for one day, to experience being normal again. Julie attaches a different meaning to disease management. She is proud of her achievements in living with HIV. She experiences disease management as an important part in being the conqueror in her story of living with HIV.

These adolescents are aware of the importance of ART and its life sustaining function. To the adolescent, the everyday use of ART is a demanding and tiring process, that brings limitations into their lives as teenagers. Normal things like sleeping over at friends or going on school trips becomes stressful situations for the adolescent as it can interfere with disease management. Mary, who is not aware of her status, Petrus and Dan are still young adolescents and might therefore come to question the role of ART in their lives once they become older adolescents, such as in Bongi's case. The development of the adolescent may lead them to question the use of medication in their lives as they gain the increased cognitive capacity to do so (Thom, 2007). The multi-disciplinary staff and parents or caregivers should be aware of the need for ongoing status disclosure and support in adhering to ART.

6.3. Limitations and shortcomings in research

Due to the intensive nature of the qualitative narrative research method and data analysis, the researcher decided to keep the research sample small. Only six adolescents participated in the research. As mentioned in chapter four, fifteen adolescents were invited to participate in the research but only six volunteered to participate with the necessary parental consent. Should the researcher have had more time to invite and follow-up on possible participants attending the clinic for disease management, more adolescents could have had the opportunity to participate in the study. The research had to be completed within the given time frame of a year. However, more adolescents could have been accommodated if there was no time frame in which the

research had to be completed. Logistical problems such as time constraints, patients living distantly, patients relying on public transport for travelling to the clinic, and language barriers prohibited the recruitment of more participants. Furthermore, due the fact that the adolescents only visited the Paediatric HIV Clinic once a month or three-monthly on Monday's for disease management, it was difficult to follow-up on possible participants. Due to the logistical constraints it was not possible for the co-researcher to be available to conduct more interviews in Tswana. The co-researcher however was only available during three interviews where the adolescents weren't completely fluent in English.

6.4. Recommendations

Future research should anticipate and prepare to minimize logistical barriers that would allow for the participation of more adolescents in such research. The stories of the adolescents are rich and unique and therefore more stories of adolescents living with HIV could be told. Only then can an in-depth understanding regarding the experiences of adolescents living with HIV be gained.

As the adolescent group that participated in the research was young, future research could strive to tell the stories of older adolescents. Older adolescents would be able to verbalize and tell more in-depth stories related to their experiences of living with HIV, such as in the case of Bongi. Richer stories could be obtained that would allow for better appreciation of the experiences of adolescents. Furthermore, an interpreter or researcher that is fluent in the mother tongue of the adolescent interviewed would allow for richer stories to be told. Therefore, greater resources are needed when such research is planned and executed.

The stories of the adolescents contained various issues that came to the fore, which could be identified as areas of potential improvement in their ongoing disease management at the Paediatric HIV Clinic in the context of Primary Health Care.

Through their stories it was prevalent that the adolescents did not always have clear knowledge of the medical procedures, and the reasons for the procedures, being performed on them. The research recommends that the multi-disciplinary team should strive to inform each adolescent

about the performed medical procedure and its necessity. This shall give the adolescent a better understanding of disease management and stimulate a sense of autonomy and control over disease management.

Adolescents experienced their interaction with the doctors as significant. The other interactions with the multi-disciplinary staff were indicated to be less significant. It is recommended that the staff members strive to interact with the adolescents on a more personal level and allow for questions and feedback to be given in these relations. This will improve service delivery and eliminate the possibility of miscommunications in the process of disease management.

Through their stories, the adolescents demonstrated that they had relevant knowledge of HIV/AIDS. However, it was evident that some had limited knowledge of treatment modalities and that some beliefs were guided by notions of stigma. It is recommended that the Paediatric HIV Clinic specifically inform adolescents with up-to-date information on treatment modalities and accurate knowledge of HIV/AIDS.

Some of the adolescents received limited emotional support at home and others did not want to discuss their feelings with family members. The adolescents' statuses aren't known to people outside their home environment and therefore they could not share with friends or teachers. It seems that these adolescents have limited social support systems available to them. It is recommended that the Paediatric HIV Clinic provide emotional and social support services to the adolescent. This could be in the form of support groups or educational workshops at the clinic. This would assist the adolescent in adhering to their medication and help them to cope with the increased demands and responsibilities of living with HIV. Most of the adolescents indicated the need to have a family in the future. Therefore family planning should also be discussed with the adolescents to educate them earlier on regarding partner relationships, partner disclosures, and family planning in the context of HIV.

It is recommended that family education also be incorporated into disease management. This should be aimed at dismantling stigmatized beliefs and educating the parents and or caregivers

about the growing needs of the adolescent. Here issues such as ongoing status disclosure to the adolescent, adolescent autonomy, and independence could be discussed.

6.5. Dissemination of research results

The research results will be disseminated to the management of Kalafong Hospital and the multidisciplinary team at the Paediatric HIV Clinic. No identities will be disclosed to the team and pseudonyms will be used when the stories are discussed. The important aspects found in the adolescents' stories relating to their experiences of living with HIV will be discussed with the team. The team shall gain an understanding of the broader personal, social, and community determinants that influence the ongoing disease management of the adolescent. This will assist the multidisciplinary team to gain better understanding of the reality of the adolescent and how these experiences inform their identity. This could create greater sensitivity towards the experiences of those infected and affected by HIV when attending the clinic for disease management.

6.6. The researcher's reflection

Working with the adolescents from a narrative approach within the medical context proved to be challenging. The narrative approach requires the telling of stories. The adolescents' interactions with nurses and doctors are more formalized and structured in the medical context. It was difficult at times to engage the adolescent in the conversation during the interviewing in the medical context, as their interactions are strongly shaped by the discourses that govern interactions in this context. The questions posed by the staff to the patients are often foreclosed in nature and only requires short responses. It was difficult to engage with the adolescent in a different manner, as not all of the adolescents freely engaged in the conversation. In the context of the interviews it required the researcher to engage the adolescent in a creative manner in order to encourage them to tell their stories of living with HIV. The use of expressive art gave the adolescent the opportunity to engage in a different way than what was usually required of them in this context. It served to engage the adolescent in the conversation and allowed for greater interaction between the adolescent and the researcher. Some adolescents engaged more freely in

the conversation. Rapport during these interviews was established easily. The researcher found that this was more prevalent with the older adolescents and those that were at a higher cognitive developmental level. The younger aged adolescents, and the difficulties in language, did not allow for detailed stories to be told. Working with the adolescents in a language other than their mother tongue were challenging at times. Simple and understandable language had to be used at all times and questions often had to be rephrased. The adolescent could not always comprehend the question and the researcher had to be very aware of the language used.

The experiences encountered during my ventures as student psychologist and researcher at the Kalafong Hospital Paediatric Clinic were enriching and life changing. Through working with the adolescents the researcher became humbled by their resilience and their optimism for life, despite the difficult and challenging circumstances that they find themselves in. These adolescents presented with perseverance in the face of struggles and doubts. Through the collaborative exploration of their stories the researcher was privileged to journey alongside these adolescents. They allowed the researcher to share in their experiences of living with HIV, granting the opportunity to learn through their stories about life.

6.7. Summary of the research

The research voiced the told and untold stories of the adolescents that participated voluntarily in the research, living with HIV and undergoing continual disease management at the Paediatric HIV Clinic. The study explored the experiences of the adolescents by means of storytelling through expressive art. The research gave the adolescents the opportunity to discuss and make sense of their illness experiences. Many of the participating adolescents had limited opportunities to discuss their experiences of living with HIV with friends or family members. Through collaborative exploration of their experiences it became possible to co-construct the meanings that were attached to these experiences that ultimately informed the adolescents' self-identity. The adolescents' experiences were described and re-storied and placed within a narrative framework of understanding based on the three-dimensional space approach by Clandinin and Connelly (2000). The framework of understanding aided the researcher to look at the context of the adolescents' stories, the identities that were constructed through their experiences, and the

social significance of the adolescents' stories. Multiple identities were constructed in their stories such as patient, scholar, friend, family, and athlete identities. These were constructed based on their experiences in the family and cultural, school and social, and medical contexts. The adolescents attributed different meanings to their stories of living with HIV such as that of normality, sameness, realism, and difference.

Various significant aspects could be identified in the adolescents' stories. Most of the adolescents discovered their HIV status during young adolescence and disclosure took place at the clinic. Only two adolescents knew how they contracted HIV. The adolescents' statuses have not been disclosed to anyone outside the families, only in one instance the adolescent disclosed his status to a teacher at school. In one instance, the family of the adolescent was not aware of his status. Most of the adolescents were knowledgeable regarding HIV. However, stigmatized beliefs were still prevalent. All the adolescents except one girl, who was not aware of her status, showed insight into the chronic nature of their disease. The adolescents had good experiences of disease management at the clinic but identified lack of communication and impersonal staff interactions as barriers to disease management. The adolescents were aware of the importance of adhering to ART and most of them assumed primary responsibility for their medication. They expressed conflicting ideas about the role that ART played in their life. Some adolescents had to cope with the side effects of the medication and some expressed frustration towards the limitations that it brought into their lives as teenagers.

In exploring and describing the experiences of adolescents, it provided an understanding of the challenges and dilemmas that the adolescents are faced with in living with HIV. The research recommends that future research explores the stories of older adolescents living with HIV. This would allow more detailed stories to be told and would allow for a better understanding of the experiences of older adolescents. The research found that most adolescents received physical support and that emotional support was more limited. The research recommends that the clinic should strive to provide support to the developing adolescent that would assist the adolescent with adherence to their medication and the disclosure of their status to friends, family, and partners.

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Appendix A: Participant information sheet and consent form

_____ 2010

Participant Information Sheet

Dear Participant,

Research about the adolescent's experience of illness at the Kalafong Hospital Paediatric Adolescent Clinic

In this research, I would like to talk to you about your experiences of visiting the clinic for case management, and find out how this affects you. I would like to give you the chance to share your experiences about illness, yourself, friends, and being at the clinic, consulting with doctors and staff and receiving and using medication.

I would like you to participate in this research. The research is voluntary, and you can decide if you would like to participate or not. Any information gathered in the research is private and confidential, and your name will not be used or disclosed to anyone. You will not be penalised in any way, if you decide not to participate. The benefit of participating in this research is that you get the opportunity to tell your story about your experiences in a playful way. Through drawings, we will be exploring your story. This will help us, and the clinic to better understand your experiences about coming to the clinic and dealing with illness. This will help us to develop better programmes for you and fellow adolescents' attending the clinic, as we will then have a better understanding of how you feel.

If you decide to participate in the research, I will be asking you questions about your experiences. We will be talking, making drawings and I will ask you questions about your story and drawings. Refreshments will be provided to make sure that you are comfortable during our conversation. The conversation will be about 60 minutes long. An interpreter, that can understand your language, will also be in the room to make sure that we understand each other. The conversation

will be audio-recorded with your parents or guardians permission. After our first conversation, another meeting will be arranged to discuss your story and make sure that you are comfortable with the outcome of your story.

There is minimal risk involved in participating. If you do not want to answer a question, you do not have to. If you experience any difficulty in sharing your experiences, or feel uncomfortable during our conversation, you may stop and withdraw at any stage. Should you want to withdraw, you will not be penalised and your story will not be used. If you would like to talk to someone after the interview, an intern psychologist will be available at the clinic to do so.

The research is for the purpose of completing my MA Counselling Psychology degree. Information obtained during the interview by means of your story and your drawings will form part of the research that will be published. Your name will not be used when the research is published. Research results will be shared with the clinic staff but your name will not be used. The information from the study will be stored for 15 years at the University of Pretoria, but it does not have your name on it and will be confidential.

I would like to arrange a meeting with your parents or legal guardians to discuss any questions and to finalize arrangements. If you have any questions or need more information about the research, you can talk to me, Leanie Coetzee (X), Prof Maretha Visser at the Psychology Department of the University (X), or Dr. Ute Feucht at Kalafong Hospital.

Regards,

Leanie Coetzee
Researcher
Ma Counselling Psychology

Prof Maretha Visser
Supervisor

Declaration of Informed Consent

In signing this form, I hereby acknowledge that I have been informed about the research. I agree that I am willing to participate in the research. I acknowledge that I have read the research information sheet, attached to this form. I know that I don't have to answer questions if I feel uncomfortable and I am aware that I may withdraw from the research study at any stage.

Adolescent Permission:

Name and Surname: _____

Signed at: _____

Date: _____

Signature: _____

Parent, Guardian or Caregiver Permission:

I, _____ acknowledge that I read and understood the research information sheet attached to this form. I agree that my child can participate in this research. I acknowledge that the interview and drawings will be published and that no names will be disclosed. Hereby I also give consent that the interview with my child can be audio- recorded and that the drawings may be published.

Name and Surname: _____

Signed at: _____

Date: _____

Signature: _____

Contact Number: _____

Postal Address: _____

Witness:

Name and Surname: _____

Signed at: _____



Date:

Signature:

Researcher:

Name and Surname:

Signed at:

Date:

Signature:

Supervisor:

Name and Surname:

Signed at:

Date:

Signature:

Should you have any question, please feel free to contact me.

Leanie Coetzee

Appendix B: Interview schedule

Biographical information

1. Could you please tell me your name?
2. How old are you?
3. Do you go to school? Where?
4. In which grade are you?
5. Where do you live?
6. Who do you live with?

Drawing 1: Exploring the adolescent's knowledge and relationship with HIV

1. Do you know why you come to the clinic?
2. Could you tell me why you come to the clinic?
3. Could you please draw a picture of yourself and HIV/ illness?
4. Could you tell me about yourself in this picture?
5. What would you like to do in the future?
6. Could you tell me more about HIV/ illness?
7. What do you know about HIV?
8. What does HIV/illness do to you?
9. How does it make you feel?
10. What does it do to your body?

Drawing 2: Exploring disease management

11. Could you please draw a picture of yourself at the clinic?
12. Could you tell a story about this picture?
13. Could you tell me about yourself in this picture?
14. How would you describe yourself?
15. What are you doing in this picture?

16. Are there other people in the story?
17. Do you remember when you started coming to the clinic? Could you tell me more about that?
18. What happens when you visit the clinic?
19. How do you feel when you visit the clinic?
20. How do you feel about the staff at the clinic?
21. What happens to your body when you visit the clinic?
22. Do the doctor/ nurse give you any homework? Do they tell you what to do?
23. Do you have to take medication/ ART?
24. Could you tell me more about your medication?
25. How do you feel about the medication?
26. What happens with HIV/illness at home?
27. Could you tell me more about the clinic in this picture?
28. Does anyone come with you to the clinic? (Who)
29. How do you travel to the clinic?
30. How long does it take you to get to the clinic?
31. For how long are you at the clinic?
32. How often do you visit the clinic?
33. What happens with HIV/ illness at school?
34. Do any of your teachers know you are HIV positive/ ill?
35. What do they teach you at school about HIV?
36. What do other people say about HIV/ illness?
37. Are any of your friends ill?
38. Do they know you are HIV positive/ ill?
39. How are you different/ similar to your friends?

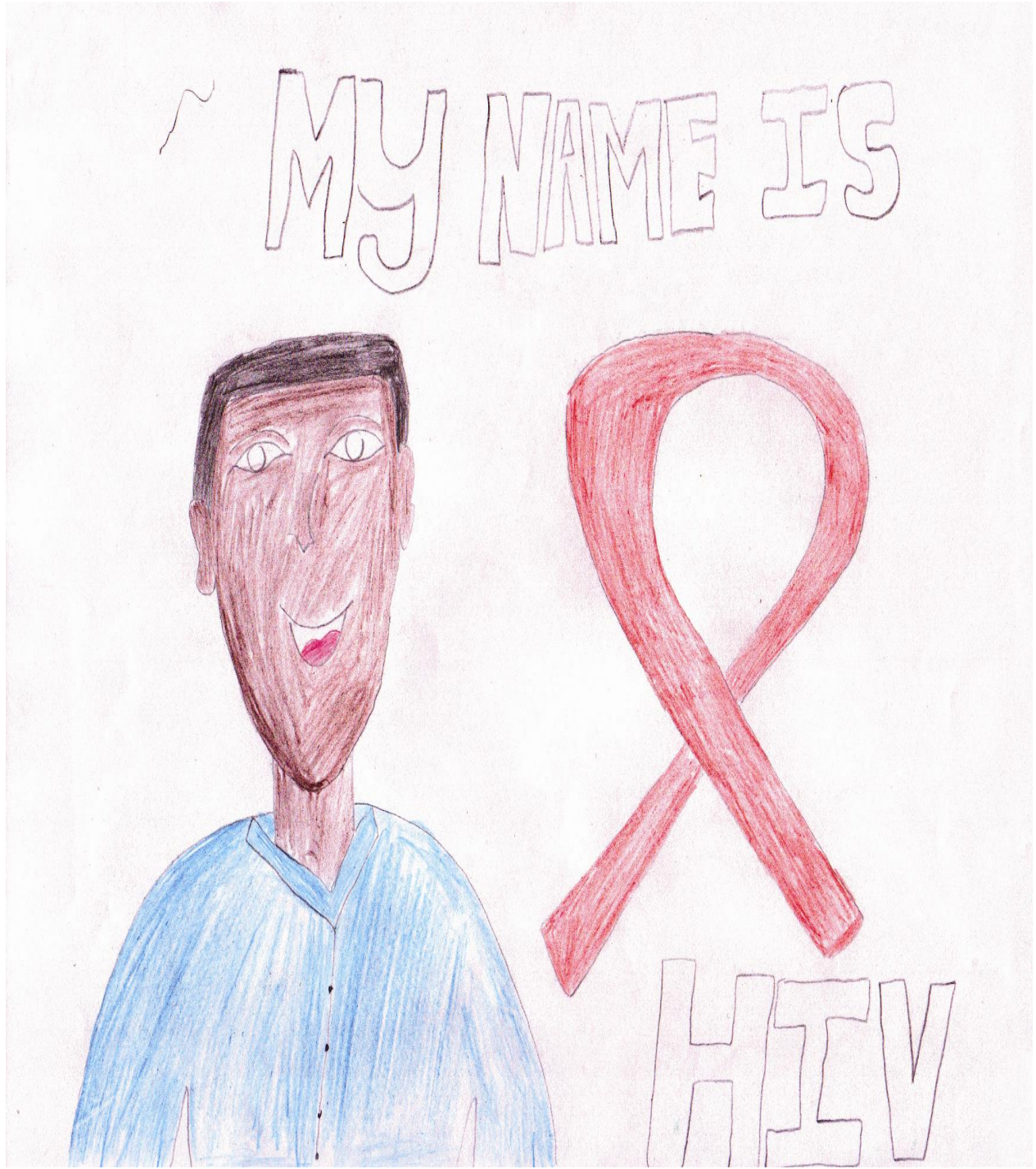


Appendix C: Mary's drawings





Appendix D: Dan's drawings







Appendix E: Petrus' poetry

Ladies and gentlemen I'm hardly telling u
about HIV & Aids,

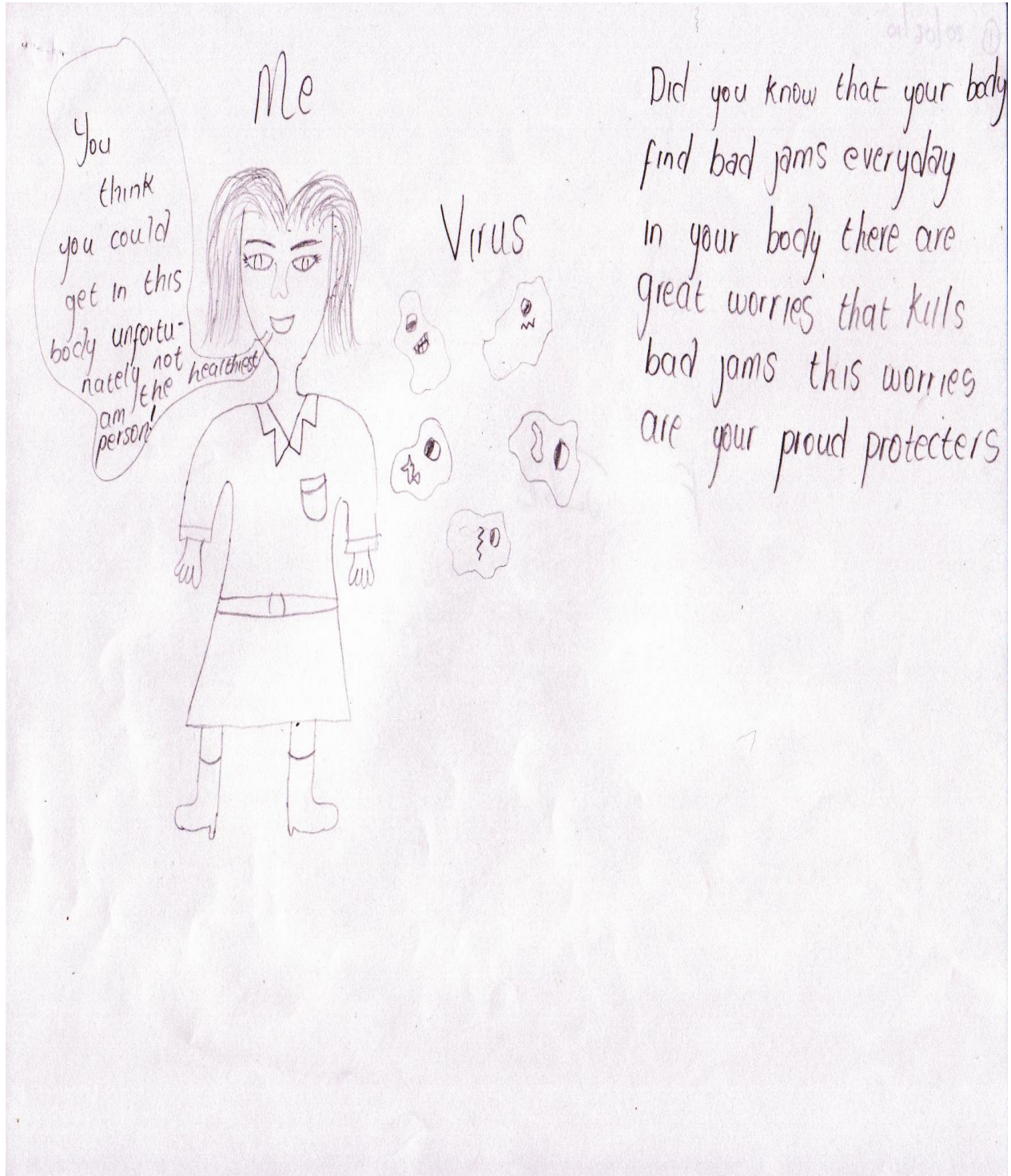
This disease is a disease that can attack
both rich and poor people. °

but there is nothing u can do
the most important thing for u is to not
blame ur partner or your partner's,
what u can do is to °

- ① Take ur medication on time always.
- ②



Appendix F: Julie's drawings







Appendix G: Bongi's drawing

