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GROWING UP ON HAART: THE EXPERIENCES AND NEEDS OF HIV  
POSITIVE ADOLESCENTS IN CARE AND TREATMENT IN THE  
WESTERN CAPE PROVINCE OF SOUTH AFRICA

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A minor dissertation submitted in *partial fulfillment* of the requirements for the award of the  
degree of Masters in Philosophy in HIV/AIDS and Society

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COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: Signed by candidate

Date: Nov. 5 2008

Signature removed

## Keep your Head up High

Don't let the virus get you down.  
You can do everything when you put your mind on it,  
Because it doesn't matter where you coming from.  
It matters where you're going to!

- *Written by the 18 year old sister of a research participant, August 2008*

University of Cape Town

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University of Cape Town

## ABSTRACT

HIV positive adolescents are becoming a progressively more sizeable and prominent sub-group in the South African HIV/AIDS epidemic. As HAART becomes increasingly available, vertically infected children can be expected to survive into adolescence and adulthood. Additionally, sexual transmission of HIV remains a problem, and incidence and prevalence rates among South African youth are high. Experience from the developed world indicates that providing effective care and treatment for youth can be a challenging task. In light of the antiretroviral rollout in South Africa, this exploratory study aimed to identify the experiences and needs of adolescents growing up in care or on treatment for HIV in the Western Cape.

To this end, a review of the existing literature on the psychosocial aspects of HIV infection in adolescents was undertaken. Relevant articles were identified, summarized and entered into a database, and particular attention was given to research conducted in the context of sub-Saharan Africa. Additionally, focus groups interviews were conducted with 26 young people attending an adolescent infectious diseases clinic at a tertiary hospital in the Western Cape. Focus groups proceeded according to a pre-set discussion guide and investigated participants' current life experiences, views on the future and self-perceived needs. All interviews were recorded, translated into English, and transcribed, and data were coded and analyzed using NVivo qualitative data analysis software.

The study revealed that the psychosocial issues associated with HIV infection in adolescents coalesce around five central themes: knowledge and understanding about personal serostatus, mental health, networks of support, treatment management, and healthy behaviour. These issues present challenges to HIV positive adolescents in the present, and affect their outlook on the future. Findings reveal that despite the fact that young seropositive South Africans live in a country where social contexts, available resources and healthcare systems differ markedly from those in developed countries, they share similar concerns and face many of the same challenges as other HIV positive young people around the world. Future studies should investigate each of the five identified themes in greater depth by determining the contextual correlates of individual views, experiences and needs.

# CHAPTER 1

## INTRODUCTION

Thirteen year old Amy loves watching *High School Musical* and can prattle endlessly about Zac Efron and Vanessa Hudgens, the film's teenage stars. A grade 6 student, she enjoys school, likes playing table tennis, and dreams of being an actress. In many ways, her life resembles that of a typical teenage girl. However, unlike most of her peers, Amy visits the hospital once every two months and swallows five tablets every day. Amy is one of approximately 5.4 million South Africans (Dorrington et al., 2006) living with the human immunodeficiency virus (HIV).

This dissertation examines the experiences and needs of young people like Amy, who are growing up with HIV in the Western Cape province of South Africa. In a rapid situation analysis of the pediatric antiretroviral therapy rollout in South Africa, adolescents were identified as a unique group who pose particular challenges to health care providers (Michaels et al., 2006). However, very little research has explored the present lives of HIV positive young people, or the ways in which the virus affects their outlook on the future. Understanding the perceptions, experiences and needs of this group is integral in order to inform policy and interventions which will help adolescents to live healthily and happily with HIV. This study takes a preliminary step towards filling the knowledge gap by reviewing the existing literature, and reporting what a group of young people have to say about their illness and their lives.

### Study Rationale: Why Study HIV Positive Adolescents?

My choice to study young people living with HIV was inspired by the changing nature of the global AIDS epidemic and the recognition that adolescents have distinct needs. The advent of highly active antiretroviral therapy (HAART)<sup>1</sup> has essentially transformed HIV from a fatal disease to a chronic condition. When the virus is left to its

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<sup>1</sup> HAART, frequently referred to as triple therapy, combines three or more drugs which inhibit different steps in the HI virus's replication cycle. As HIV loses its ability to reproduce, the number of viral copies in the blood drops and the immune system is given a chance to recover.

natural course, fewer than 50% of perinatally infected children survive beyond the first two years of life, and only a fraction are still alive at five years (Brahmbhatt et al., 2006; Dabis & Ekpini, 2002; Dabis et al., 2001; Spira et al., 1999). However, HAART has proved remarkably effective at delaying disease progression and reducing the risk of death in both adults and children (Aber & Aboulker, 1996; Hammer et al., 1997; Palella et al., 1998; Wiznia et al., 2000; Resino et al., 2006; McConnell et al., 2005; deMartino et al., 2000; Gortmaker et al., 2001; Patel, K. et al., 2008). In recent years, initiatives such as the World Health Organization's (WHO) '3 by 5'<sup>2</sup> have generated mounting political and financial support for treatment rollout in resource limited settings, resulting in a sevenfold increase in the number of individuals on HAART since 2003 (WHO, UNAIDS & UNICEF, 2008). Due to improving treatment access, the population of vertically infected children surviving to adolescence is expected to rise in the near future. This shift has already occurred in the developed world, where HAART has been widely available since 1996. A French study of 293 perinatally infected children born before January 1<sup>st</sup> 1993 found that 58% of the cohort was still alive and in care in 2006 (Dollfus et al., 2006b cited in Dollfus et al., 2006a). And in their analysis of data from two national studies conducted in the United Kingdom and Ireland, Judd et al. (2007) observed that between 1996 and 2005, the proportion of children in their cohort aged 10-14 years increased more than threefold from 11% to 35%, while those aged 15 years and older jumped from 0% to 9% of the study population. This shift stemmed from reductions in mortality rates after the introduction of HAART into the cohort in 1997. Experience from the developed world therefore suggests that as the global treatment rollout proceeds, vertically infected adolescents will become a progressively more prominent group within the world's HIV-infected population.

In addition to the growing number of vertically infected adolescents, the number of horizontally infected adolescents continues to be of concern. Recent figures do indicate that in some countries, prevalence among young pregnant women is on the decline (UNAIDS, UNICEF & WHO, 2008). However, global figures suggest that HIV incidence remains highest among 15-24 year olds – approximately 40% of horizontal transmission occurs within this age bracket, and 5000 to 6000 youths are newly infected every day

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<sup>2</sup> The 3 by 5 initiative aimed to have 3 million people on treatment by 2005. This target was not achieved but was pivotal in spearheading the drive for HAART access in the developing world.

(UNAIDS, UNICEF & WHO, 2008; UNICEF, UNAIDS & WHO, 2002). HIV positive youth have been called a 'hidden population' because they tend to occupy marginalized positions in society and are difficult to distinguish from their uninfected peers (Bell et al., 2003). Few people in this age bracket are aware of their serostatus, making care and treatment difficult.

The mounting number of vertically infected adolescents combined with continuing high rates of HIV incidence among youth poses distinct challenges for health care providers who wish to provide quality care and treatment to this group. Beyond the issues posed by the numerical swell of individuals living with the illness, adolescents are more than 'big children' or 'little adults' and have special needs that are particular to their developmental phase (Joffe, 2000).

Adolescence<sup>3</sup>, comprising roughly the second decade of life, is a key phase of human development during which children transition into adulthood. These years are characterized by major changes at the biological, psychological, and social levels, differentiating them from other stages of development. With the exception of early infancy, the changes which occur during adolescence are greater than in any other period of life (Feldman & Elliott, 1990). At a biological level, adolescents undergo puberty, during which they develop primary and secondary sex characteristics, the capacity for reproduction, and a mature physical appearance (Neinstein & Kaufman, 2002). These physiological events also have psychosocial implications, as adolescents adjust to their changing bodies, redefine their self-image, and learn to manage their emerging sexuality. At a cognitive level, adolescents develop decision making skills, greater short and long term memory, and the ability to think critically and abstractly (Inhelder & Piaget, 1958; Weithorn & Campbell, 1982; Rew, 2005). Cognitive development is accompanied by an enhanced ability to self-conceptualize and accordingly, identity formation is also a crucial task of this period (Erikson, 1968). At a social level, parent-child relationships are transformed, as adolescents learn to make decisions independently and function autonomously (Steinberg, 1990). Simultaneously, the peer group becomes increasingly important as young people seek intimacy and acceptance outside of the family unit

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<sup>3</sup> Adolescence should be characterized as a fluid phase of change, rather than a period defined by age. Nonetheless, for the purposes simplicity, I adopt the WHO's definition in this dissertation, which identifies an adolescent as any person between the ages of 10 and 19 years.

(Crockett & Petersen, 1993). Progression through school, entry into the labour force and all the adjustments which accompany these events, also occur during this period. These local interactions take place within wider societal frameworks, which carry dominant streams of expectations, values and ideologies. Adolescents must learn how to navigate these structures in order to become successful and active participants in society.

HIV affects adolescents at each of the three previously mentioned axes of development. Biologically, perinatally infected children go through puberty significantly later and are smaller than their HIV negative peers (deMartino et al., 2001; Buchacz et al., 2003). HIV can also leave physical marks, such as scarring from skin infections or lipodystrophy<sup>4</sup> from medications, which may impact the adolescent's sense of self. Psychologically, the virus has been associated with neurocognitive delays and a high prevalence of several mental illnesses (Scharko, 2006; Misdrahi et al., 2004; Steele, Nelson & Cole, 2007). And from a social standpoint, autonomy from parents, peer acceptance and participation in society are complicated by the desire for secrecy about serostatus and fears of stigma or rejection (Hefez, 2002; Rhem & Franck, 2000; Menon et al., 2007). In addition to dealing with these direct encumbrances to standard developmental processes, HIV positive adolescents must also confront a number of extra challenges. For these young people, the transition from childhood to adulthood is interlaced with concerns about medication regimens, doctor's appointments, life expectancy, disclosure, and transmitting HIV to others. Of course, the virus poses similar concerns for HIV positive individuals at other life stages. However, the extensive changes that characterize adolescence make the second decade of life particularly unique. The combination of ordinary developmental issues with HIV-related worries creates a distinctive environment, which frames adolescents' daily experiences and their interactions with health care systems. From a developmental perspective, it is thus important to consider the ways in which the adjustments associated with HIV interact with the normative changes that occur during adolescence. This calls for research which examines adolescent HIV on its own merits, rather than as a subset of pediatric or adult knowledge about the virus.

While a modest body of work on adolescents living with HIV has been established in North America and Europe, there is a paucity of similar research conduct in the sub-

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<sup>4</sup> Lipodystrophy is a side effect of some antiretroviral drugs, which results in the redistribution of fat in the body. This may take the form of a localized accumulation (lipohypertrophy) or loss (lipoatrophy) of fat.



Saharan African context. Yet, such context specific research on the subject is necessary for two reasons. Firstly, in the developed world, the virus is concentrated among individuals who occupy marginalized societal niches and engage in a range of high risk behaviours (Woods et al., 2000, Dodds et al., 2003). In sub-Saharan Africa, where the epidemic is more generalized, young people's experiences may diverge from their western counterparts. Secondly, experiences of adolescence are fluid and vary with social context (Mead, 1928). Over the last century, rapid changes in the social, economic and political spheres have altered conceptions and experiences of adolescence in sub-Saharan Africa. Among many people groups in the region, the end of childhood was once marked by rites of passage, after which individuals assumed adult responsibilities (Balmer, 1994:2 cited in Mensch et al. 1999). However, in recent times, such traditional images of adolescence have been disrupted by modern institutions which have created new challenges for young people and prolonged the transition to adulthood. Increased school enrolment for example, has had the effect of delaying the age of marriage and first pregnancy, and increasing extramarital sexual relations and childbearing (Blesdoe & Pison, 1994; Mensch et al., 1999). Additionally, the sub-continent's integration into the world economy has led to a greater need for skilled labour, making it difficult for young, inexperienced individuals to find work (Blum, 2007). More than in any other region of the world, young people in sub-Saharan Africa are growing up in an environment characterized by social disruption and limited opportunities (Bradford Brown, Larson & Saraswathi, 2002; Blum, 2007). As the number of young Africans living with the virus increases, it is imperative to generate knowledge which considers the unique constructions of adolescence which surround their illness experiences.

#### HIV Care and Treatment in South Africa's Adolescent Population

South Africa is currently the country with the most HIV positive people in the world (UNAIDS & WHO, 2007). The virus affects individuals of all ages, including adolescents. According to a nationally representative 2005 Human Sciences Research Council (HSRC) survey, prevalence in 10-14 year olds was 1.7%, the lowest rate of any age group (Shisana et al., 2005). This low figure can be explained by the fact that prior to the rollout of HAART, the vast majority of perinatally infected children died before reaching

adolescence. Additionally, most younger adolescents are not yet sexually active, resulting in low rates of horizontal infection (Shisana et al., 2005; Flisher et al., 2003a). As individuals enter late adolescence and the likelihood of sexual initiation escalates, HIV prevalence rises steeply. In the HSRC survey, prevalence was 5.9% among 15-18 year olds (Shisana et al., 2005), while a second national survey measured rates of 15.5% and 4.8% in 15-24 year old females and males respectively (Pettifor et al., 2005). Both studies show that adolescent females, who are more biologically susceptible to contracting the virus, experience higher rates of sexual abuse, and are more likely to have a relationship with an older partner (Pettifor et al., 2005), are at higher risk of being sexually infected than young males.

In absolute terms, South Africa is also the country with the greatest number of people on HAART. In September of 2006, over 200,000 people were receiving antiretroviral therapy through the public sector, 21,000 of whom were children under the age of 15 (DoH, 2006). There are no public reports on the number of adolescents who are currently on, or in need of treatment, as data about this population are most often subsumed into child or adult categories<sup>5</sup>. However, using demographic modelling, it is possible to generate estimates of figures pertaining to adolescents. The Actuarial Society of South Africa (ASSA) has developed the ASSA2003 AIDS and Demographic Model<sup>6</sup>, which makes use of empirical HIV research in order to make projections about a wide range of epidemiological data. ASSA2003 can be used to estimate treatment need and coverage for adolescents between the ages of 10 and 19 years.

According to ASSA2003 projections, there are currently 12,000<sup>7</sup> adolescents between the ages of 10 and 19 who, medically-speaking, should be on treatment countrywide. This group includes individuals who are in untreated WHO clinical stage 4 HIV, those who are currently on antiretroviral therapy and those who were receiving HAART but subsequently discontinued their treatment (Figure 1.1). The model shows that younger adolescents are more likely to need HAART than older adolescents; in fact

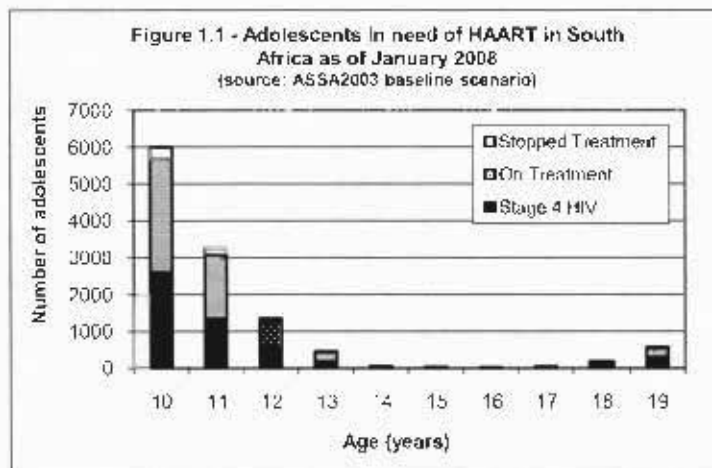
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<sup>5</sup> Figures about younger adolescents, between the ages of 10 and 14 years, are usually incorporated with those concerning children (considered to be all persons under the age of 15), while information on older adolescents between the ages of 15 and 19 years, are reported under youth (15-24 years) or adult (15+ years) categories.

<sup>6</sup> The ASSA2003 AIDS and Demographic Model is available publicly at <http://www.actuarialsociety.org.za/Models-274.aspx>

<sup>7</sup> All figures generated by ASSA2003 are rounded to avoid the perception of spurious accuracy.

over 90% of individuals who need treatment are between the ages of 10 and 13 years. From the age of 10 years, the proportion of adolescents needing treatment increases, peaking at 98.2% of 13 year olds. Thereafter, the figures drop drastically, to 0.1% at 15 years before rising to 0.7% at 19 years (Table 1.1).



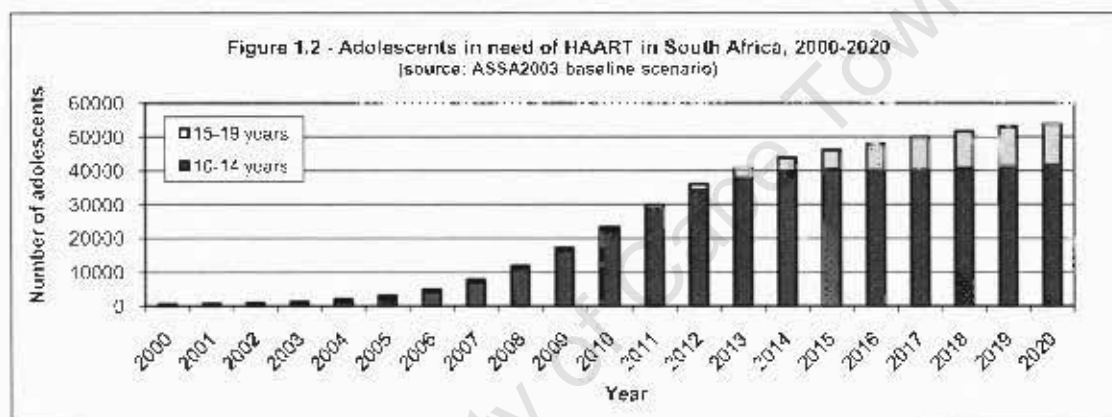
**Table 1.1 - Proportion of adolescents needing HAART in 2008 by age**  
(source: ASSA2003 baseline scenario)

Age (years)	% needing treatment
10	81.5
11	93.7
12	97.9
13	98.2
14	47.2
15	0.6
16	0.1
17	0.1
18	0.3
19	0.7

This pattern reveals that there are currently two discrete groups of HIV positive adolescents in South Africa. Younger adolescents, up to the age of around 14 years have been perinatally infected and having lived with the virus for more than a decade, are now either on or in need of antiretroviral therapy. On the contrary, older adolescents, aged 15 years and older, are much more likely to have been infected sexually and having acquired the virus more recently, are less likely to need treatment. Numerically, the latter group is much larger. However, by virtue of the longstanding nature of their infection, and the poor uptake of voluntary counselling and testing (VCT) by older adolescents, the former group comprises the majority of adolescents who are currently in care or on treatment.

The size and composition of the HIV positive adolescent population is expected to change significantly over the next 10 years due to the rollout of HAART through the public health care system. The HIV & AIDS and STI National Strategic Plan for 2007-2011 aims to increase the number of new children starting HAART to 40,000 by the year 2011 (DoH, 2007). A recent United Nations (UN) report on universal access shows that the country is making good progress towards this goal: antiretroviral coverage for children under the age of 15 years improved by a factor of 2.6 between 2005 and 2007, with 32,060 children on treatment at the close of 2007 (WHO, UNAIDS & UNICEF,

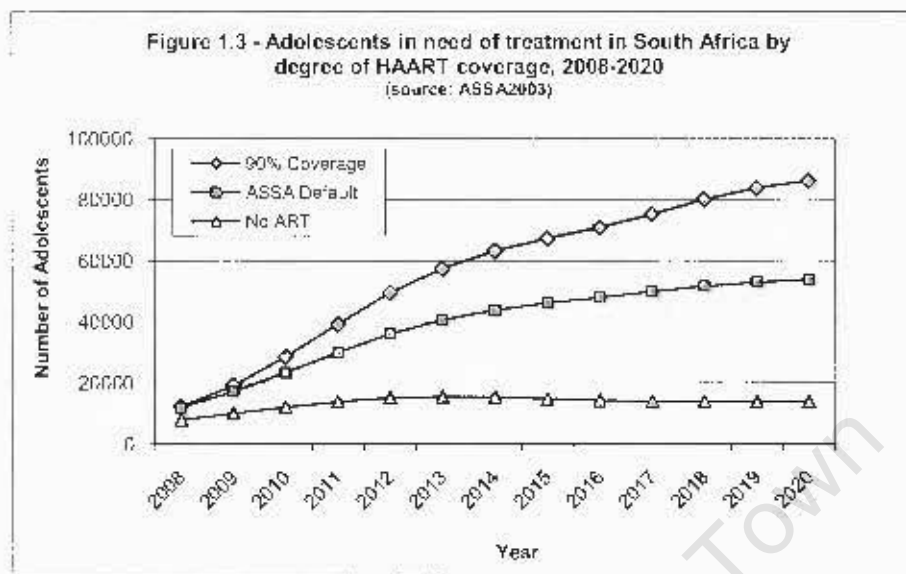
2008). These figures suggest that HIV positive children in South Africa have a greater chance of survival than ever before. In light of the government's commitment to continue scaling up treatment, we can expect that a large proportion of these children will live to see adolescence. In 2000, there were 560 adolescents in need of treatment in South Africa. This number has increased to 12,000 today, and is expected to continue rising before steadying around 53,000 in 2020 (Figure 1.2). This represents a 26-fold increase in the 16 years since antiretrovirals first became available through the public healthcare system, with the greatest part of this growth occurring before 2015. When compared to the total adolescent population needing HAART, the proportion of 15-19 year olds needing treatment is also expected to increase, from 7% of all adolescents in need of treatment in 2008 to 22% in



2020. This increase will be attributable to the aging of the vertically infected population, as the need for treatment in the horizontally infected population is expected to remain constant or decline.

These figures were generated using ASSA2003's default settings, which assume 8% HAART coverage in 2004, 44% coverage in 2008 and 50% every year thereafter. However, given that the survival of pediatric patients is dependant on the availability of treatment, the actual number of adolescents needing treatment in 2020 may be higher or lower, depending on the success of the South African rollout (Figure 1.3). For example, without antiretroviral therapy, there would be fewer than 15,000 adolescents needing treatment in 2020. Conversely, if HAART coverage reached 90% from 2008 onwards, approximately 67,000 infected adolescents would be in need of treatment. It is therefore evident that the

number of adolescents needing treatment in the future is a function of the degree of access that children have to HAART today.



Comparison between ASSA2003 outputs and population studies indicate that the model correlates well with overall HIV prevalence in South Africa (ASSA AIDS Committee, 2006). However, it should be noted that the model projected significantly lower prevalence among children and adolescents than was found in the 2005 HSRC survey. While ASSA2003 predicts a prevalence of less than 0.1% among 10-14 year olds in mid-2005, the HSRC survey reported a much higher prevalence of 1.7% in the same age group (Shisana et al., 2005). Additionally, the model projects an infection rate of 0.3% among 15-19 year old males, which is a mere tenth of the 3.2% prevalence measured in the HSRC study (Shisana et al., 2005). These discrepancies suggest that the figures and projections presented in the previous section are gross underestimates of the actual number of HIV positive adolescents in South Africa both in the present and the future. The ASSA AIDS Committee is unsure of the source of the discrepancy between ASSA2003 outputs and the 2005 HSRC survey, though it is currently investigating the issue (ASSA AIDS Committee, 2006). Nonetheless, ASSA2003 projections were included in this dissertation because they effectively illustrate current and expected trends, even if the absolute values are most likely inaccurate. These trends reveal that South Africa's population of HIV positive adolescents is currently in a period of transition because perinatally infected

children are receiving treatment and surviving longer. They demonstrate the dramatic scale of the imminent increase in this group and suggest that the previously neat age delineation between perinatally infected 10-14 year olds and sexually infected 15-18 year olds is becoming increasingly blurred. The changing nature of this population calls for research which concerns South African young people, who are making the critical shift from childhood to adulthood, whilst figuring out how to live with HIV.

### The Aim of this Study

In light of the expected increase in the number of HIV positive adolescents, I undertook this research project with the aim of answering the research question “what are the psychosocial needs of adolescents receiving HIV care or treatment in the Western Cape Province of South Africa?” Given that there is virtually no published research in the area, I adopted an exploratory approach, keeping the research question broad in order to provide space for pertinent issues to emerge. I sought to answer this primary question by investigating two sub-questions, each of which I discuss briefly below.

#### *1. What does research from other contexts say about the needs of adolescents living with HIV?*

Because HAART was not made publicly available until 2004, the population of adolescents in care or on treatment in South Africa is still relatively small (though it is growing rapidly). Consequently, information about this group is limited. In the developed world, where HAART has been available for more than a decade, the population of adolescents living with HIV burgeoned earlier, and there is a small but established body of research on the subject. Additionally, there are a handful of recent studies on the matter from other resource-limited settings. While healthcare systems, resources and social and cultural environments in other parts of the world differ markedly from those in South Africa, I nonetheless felt that this existing pool of knowledge would provide a much-needed starting point for an exploration of the issues facing HIV positive adolescents in this country. With this in mind, I undertook a review of the literature on the psychosocial aspects of HIV in young people. I made a concerted effort to highlight studies from a sub-Saharan African context, but as aforementioned, such research is sparse. I do not claim that

findings from North America, Europe or even other parts of Africa can be directly extrapolated to the experiences of adolescents living in South Africa. Yet, it would be imprudent not to look at the knowledge accumulated elsewhere, as the lessons learned by others can be instructive, flagging areas of interest or concern that might be considered in the midst of our own epidemic.

*2. What are the needs of a group of adolescents receiving care or treatment for HIV/AIDS at a tertiary institution in the Western Cape?*

In addition to learning about the experiences and needs of HIV positive adolescents from the work of other researchers, this study explores the issue from the perspectives of young people themselves. This component of the dissertation was conducted at an outpatient clinic serving 75 adolescents infected with HIV between the ages of 10 and 19 years. The vast majority of patients acquired the virus perinatally, though a small number of individuals were sexually infected (several through sexual abuse). The adolescent program is a part of a larger family infectious diseases clinic at a tertiary hospital in the Western Cape, and was established at the beginning of 2008 by clinic staff who recognized that the growing group of adolescents attending the family clinic had distinct needs. Patients attend the clinic every two months to visit a doctor, participate in a support group run by a social worker, and if necessary, see a counselor or social worker individually. While their children are busy, caregivers also have the option of participating in a support group run by a counselor.

Over 6 months in the middle of 2008, I volunteered in clinic support groups, and conducted focus group interviews with 26 patients. Through my interactions with adolescents both in support groups and focus groups, I sought to ascertain their needs by understanding the positive and negative aspects of their present lives and their hopes and dreams about the future. Additionally, because I believe that young people can offer valuable perspectives about their own lives, I gave focus group participants the opportunity to express their self-identified needs.

## Navigating the Dissertation

The chapters that follow consist of my journey through this research project and a report of its findings. In Chapter 2, I discuss the methods I used to generate data, as well as the epistemological and ethical issues surrounding the research process. The subsequent five chapters consist of the presentation and analysis of my findings, arranged into the five main themes that I identified in the literature review component of the project. In each of these chapters, I begin by presenting the existing body of knowledge on the subject, and then proceed to discuss the subject as it relates to adolescents attending the clinic where I conducted focus groups. Chapter 3 looks at the importance of deepening adolescents' knowledge and understanding about their serostatus, first through disclosure to the child and then through ongoing education and communication about the virus. Chapter 4 examines the mental health of HIV positive adolescents and the factors associated with their sense of wellbeing. In Chapter 5, I consider the complex relationships between support networks, disclosure and stigma, before moving on to discuss the challenge of transferring treatment management from caregiver to child in Chapter 6. The last theme of risky and healthy behaviour is detailed in Chapter 7, which touches on the issues of substance use, sexual behaviour, and reproductive health. In the final chapter, I conclude the dissertation by summarizing and synthesizing the experiences and resultant needs of adolescents living with HIV.



## CHAPTER 2

# EPISTEMOLOGY AND METHODOLOGY

As discussed in Chapter 1, the aim of this study was to determine the psychosocial needs of adolescents living with HIV in the Western Cape. In this chapter, I briefly discuss the epistemological backdrop that informed research design, describe research methods and procedures, consider relevant ethical issues, and disclose the study's limitations.

### Epistemological Roots

This study is based on the assumption that young people have the ability to speak about their experiences and are capable of contributing to the worlds in which they reside. In the past, decisions about young people have been made by adults, and minors have been excluded from research. This exclusion was based on questions about the reliability of their testimonies and concerns that the research process might be exploitative (Walsh, 1998; Kirk, 2007). However, in the last 30 years, critical feminist and postcolonial scholarship has drawn light to the fact that dominant epistemological understandings have placed greater value on the knowledge of some over others, and has challenged the assumption that the researcher can speak on behalf of the other (Mohanty, 1988; Harding, 1987; Mbilinyi, 1992; Spivak, 1988; Sow, 1997; Sprague & Kobrynovicz, 2006). Mirroring this shift towards a more inclusive social science, there has been a growing consensus that children and adolescents can provide insight into their own lives, and have distinct 'voices' that adults cannot presume to know (Thomson, 2008; Dixon-Woods et al., 1999; Beresford, 1997). In recognition of this, the rights of young people to speak and be heard are now enshrined in international law (UNHCR, 1989). Undeniably, minors constitute a vulnerable group in society and their entitlement to protection throughout the research process must also be upheld. However, ethical challenges and logistical issues should not dissuade researchers from engaging with young people. Doing so fails to acknowledge their agency, and robs them of a basic human right.

## Methods and Procedures

Finding ways to listen to the voices of young people can be methodologically difficult for the adult researcher. The generational gap between children and adults creates differentials in perspectives, experiences and power that cannot be fully bridged (Kellett & Robinson, 2004). However, when research tools are carefully designed with sensitivity to developmental stage, it is possible for young people to have their voices represented in research. In this particular study, three data collection methods were employed to gain insight the lives of HIV positive adolescents: a literature review, participant observation, and focus group interviews.

### *Reviewing the Existing Body of Knowledge*

The first phase of data collection involved a review of the English and French literature on the psychosocial aspects of HIV in young people since the advent of HAART. PubMed<sup>8</sup> was used to find relevant journal articles while Google Scholar<sup>9</sup> facilitated the retrieval of grey literature. Early searches combined broad terms such as 'adolescent', 'HIV' and 'HAART' and searching proceeded iteratively as specific themes in the literature were identified. In addition, bibliographies and 'related articles' lists in PubMed were checked to pick up on any literature that was missed by database searches. In total, 116 publications were retrieved, summarized, and entered into a Microsoft Excel spreadsheet. These publications were subsequently coded and categorized according to theme. While all relevant literature was considered, particular attention was given to research conducted in the context of Sub-Saharan Africa in the writing up of results.

### *Volunteering at the Adolescent Clinic as a 'Participant Observer'*

In addition to reviewing the relevant literature, I sought to engage a group of HIV positive young people directly. During the formative stages of this project, contacts at the

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<sup>8</sup> PubMed is a free database maintained by U.S. National Library of Medicine of more than 18 million citations relating to biological, psychological and sociological aspects of health. It is the most comprehensive database of health related citations in the public domain.

<sup>9</sup> Google Scholar is Google's search engine designed to retrieve scholarly literature. In addition to peer-reviewed journals, it also searches literature from professional societies such as the United Nations group of organizations.

University of Cape Town and Stellenbosch University introduced me to staff at an adolescent HIV clinic, who in turn facilitated access to the study population. While my intention was to run focus group interviews, my first interactions with research participants were as a volunteer and 'participant observer' at the clinic. As a volunteer, I assisted with adolescent support groups, helped with small administrative tasks, and attended the clinic's annual three day camp. Throughout this phase of the project, I kept detailed notes on my experiences at the clinic, documenting the day to day workings of support groups and the behaviour of patients.

It is sometimes argued that in order to avoid bias, a researcher should be unfamiliar with participants prior to a focus group interview (Hennink, 2007; Sandelowski, 1986). However, given that my research was qualitative, I adopted the view that extensive interaction allows the researcher to better understand the world through the eyes of the researched (Avis, 2005). In fact, I would contend that it was my very familiarity with the study population that enabled focus groups discussions to be positive and productive experiences, both for me and the adolescents involved. While volunteering at the clinic, I gained valuable background information which facilitated the design of a focus group discussion guide that was appropriate to the developmental level of the study population. Simultaneously, I had an opportunity to build rapport and trust with potential research participants, which helped them to share their views more comfortably during group discussions. In addition, volunteering allowed me to be of practical assistance to the research site, which had so graciously agreed to host me. Not only did this help maintain good relations with clinic staff, but it was also a personally enriching experience.

#### *Conducting Focus Group Interviews*

After volunteering at the adolescent clinic for four months, I conducted focus groups with clinic patients in August and September of 2008. Focus group interviews are a qualitative form of data collection, which involve group discussion and interaction around a specific set of issues (Hennink, 2007; Morgan, 1998; Kitzinger, 2005; Barbour, 2007). Because questions are answered by multiple, rather than single participants, the method is particularly useful for uncovering a wide range of ideas on a given topic.

I chose to use focus groups in this study for a number of reasons. Firstly, the method is qualitative and allows participants to convey their experiences and perspectives in their own words, thereby facilitating the expression of their voices. Secondly, my research question was very broad and focus groups enabled the generation of an assortment of views on several topics. Thirdly, research in a group context more closely resembles everyday social interaction, and is less intimidating than a one on one interview, especially for young people (Hennink, 2007; Barbour, 2007; Hill, Laybourn, & Borland, 1996). In this study, research participants were already involved in support groups and accustomed to a group format. Focus group discussions therefore seemed like a participant-friendly way to proceed. Finally, given the space, time and resource constraints, it was easier from a logistical standpoint to run a smaller number of group discussions than a larger number of individual interviews.

### Procedures

All adolescent patients who were aware that they were HIV positive, able to give informed consent and attended the clinic on a day that a focus group was held, were invited to participate in the study. Informed consent was obtained from both caregivers and adolescents during their respective support groups. Consent forms were available in English, Afrikaans and Xhosa (Appendix C), and interpreters were present to assist where necessary.

Focus groups commenced immediately after the informed consent process had been carried out and took place in the same room that support groups were ordinarily held. At the beginning of each focus group, I administered a five item survey in order to collect basic demographic data on the participants (Appendix D). With the consent of participants, I recorded the interviews, which lasted between 60 and 75 minutes and unfolded according to a preset discussion guide (Appendix E) (Krueger, 1998). However, because of the qualitative nature of the study, the plan of inquiry was flexible and different probes emerged out of the various discussions (Avis, 2005).

Snacks and refreshments were served during groups, and at the conclusion of each interview, caregivers of participants were given R20 towards the cost of transport for the day. Adolescents received a beanie (a knitted hat) as a token of appreciation, though they

were not informed of this gift at the time of enrolment in order to prevent coercive recruitment.

### Facilitating Expression

One of the major challenges I faced while designing my line of questioning concerned the necessity of finding unique ways to facilitate expression. During support groups, I observed that many adolescents were hesitant to participate in group discussions. I suspected that a part of this lack of communication might be due to the fact that about 40% of the adolescents spoke Xhosa as a first language (while support groups were run in English and Afrikaans). Furthermore, it was apparent that many of the patients were uncomfortable expressing themselves through speech or had difficulty responding to abstract questions.

I attempted to resolve the language issue by employing Mbali, a native Xhosa speaker, and Beauty, an Afrikaans and Xhosa speaker, to act as interpreters during focus groups. These two women played a pivotal role in group discussions, mediating the conversation between participants and myself. Using interpreters undeniably had an effect on the flow of the discussion and my ability to fully grasp and understand what was being said. Nonetheless, I felt that this option facilitated significantly better expression than the alternative, which would have been to conduct focus groups in English.

My solution to the second dilemma was to shift the presentation of questions to emphasize not only talking, but also seeing and doing. Visual methods provide an effective and enjoyable way for young people to express their ideas (Thomson, 2008; Moss et al., 2007; Leitch & Mitchell, 2007), and I sought to make use of such methods to spur discussion. For example, two focus group questions involved a resource package entitled "Every Picture Tells a Story" (Appendix F, Item II). The resource consists of 48 black and white images from around the world, chosen to evoke "inspiring reaction and reflection". Adolescents were invited to answer questions on how they felt, and their perceptions about HIV, by selecting a picture and explaining their choice. For another question, I introduced a poster board with faces and words representing 15 different emotions (Appendix F, Item I). Each participant was given stickers of a particular colour, and asked to place their stickers on the faces which best represented how they felt about the future.

The final key question involved creating a message about HIV using words, pictures or both. Adolescents were given paper, felt pens and paint, allotted time to put together their messages, and invited to share their messages with the group. I found that these visual activities were an effective way to encourage expression and generate discussion. Because images are more tangible than words, they helped ground questions and make them more concrete. However, since they are subject to interpretation, they also left room for the preservation of individuals' voices. Additionally, visual methods helped make the research process enjoyable for adolescents and gave those who didn't want to speak a means by which they could actively participate in groups.

### Data Management and Analysis

In addition to recording interviews, I took notes on body language and non-verbal communication throughout focus groups. Each interview was followed by a debriefing session with the interpreters, during which additional observations about the day's proceedings were noted. All focus group discussions were transcribed and coded using NVivo qualitative data analysis software, and given that translation had occurred during the interviews and participants' responses tended to be short and simple, I transcribed most of the interview content myself. However, where required, I solicited the help of an interpreter to translate longer passages verbatim. The coding process began with repeated readings of transcripts, during which an overarching sense of the data was acquired. Each focus group was then coded individually and like themes from across the transcripts were clustered and reduced.

### **Ethical Considerations**

A consideration of ethical issues is necessary in any research involving human subjects and especially when working with minors. To this regard, the protocol for the project was approved by the Committee for Human Research in the Health Sciences Faculty at Stellenbosch University (Appendix B), and care was taken to ensure that patients' rights were upheld during the research process.

As aforementioned, informed consent was obtained from both caregivers and adolescents. Before approaching adolescents, disclosure status was extracted from hospital records and verified with caregivers in order to prevent accidental disclosure. Informed consent was treated as a continual process, and young people were told that they could stop their participation and any time, and did not have to answer any of the research questions. In activities involving visual aids, I ensured that there was always a 'pass' or 'I don't want to answer' option.

HIV is a sensitive topic, and the study therefore carried a risk of being psychologically distressing for some adolescents. Nonetheless, most adolescents responded positively to the opportunity to take part in focus groups, with only one young person declining participation. In order to minimize participant discomfort during interviews, I kept my line of questioning as broad as possible so that adolescents had some choice about what they wanted to share. Debriefing was held after each session to identify any emotional discomfort that may have arisen, and counsellors were available to speak with any participants who had exhibited psychological distress. Their services were however, not needed.

Several measures were taken to ensure that focus group content remained confidential. Transcripts were stored on a password encrypted flash drive and pseudonyms were used both on transcripts and in this report. Additionally, in research outputs, I excluded personal details which would have made participants' identities evident to individuals who were familiar with the clinic population.

### Study Limitations

The methodology used in this study limits findings in several ways. Firstly, the sample size was small and therefore, results cannot be generalized. Additionally, the adolescents I sampled for the purposes of this dissertation are not representative of the total population of adolescents in need of treatment in the Western Cape. Research participants lived in an urban environment and were attending a well-resourced, family-centred, multidisciplinary clinic where doctors were readily available and clinic staff had specialized training and experience in the field of HIV/AIDS. With the incumbent decentralization of HAART programs from tertiary hospitals to primary care units, it will

become increasingly common for adolescents to receive care and treatment at community clinics, a context which is not addressed in this study. Furthermore, because of the hospital's geographic location and the demographics of its catchment area, coloured<sup>10</sup> adolescents are overrepresented in this sample, comprising almost fifty percent of focus group participants. Comparatively, ASSA2003's baseline scenario predicts that in 2008, coloureds constituted only 23% percent of the HIV positive population in the Western Cape. The role of race remains unexplored in young people living with HIV, and it is therefore unknown how the high proportion of coloured participants in this sample might have affected study findings. However, I did not observe any obvious or systematic differences between coloured and black adolescents in focus groups.

The study is also limited in the sense that it regards adolescents as a homogenous group and does not situate them in the multiple contexts of their lives. During the research process, I employed age as the primary unifying factor among young people, leaving the effects of race, socioeconomic status, and other historical and environmental characteristics largely unexplored. Through my volunteer work at the clinic, I was familiar with many of the participants' life stories. However, I did not use this background knowledge to explain individuals' responses during focus group discussions for two reasons. Firstly, ethical approval had been sought and granted for focus groups alone and hence, I was careful to confine my analysis to the content of interviews. Secondly, I felt that reporting too much detail about adolescents' personal lives would compromise the confidentiality I had promised them. Study findings were to be made available in the public domain and reported back to caregivers and healthcare providers at the clinic. Including in-depth information about individuals' contextual backgrounds would have made it easy for anyone familiar with the clinic population to ascertain the identities of respondents. Undeniably, this separation of person from context reduces the power of this study. It therefore needs to be reiterated that this research is exploratory in nature, aiming to identify some of the issues affecting HIV positive adolescents in South Africa. While research which links contextual factors to individual outcomes is necessary, such an endeavour was beyond the scope of this study.

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<sup>10</sup> In the South African context, the term 'coloured' refers to people of mixed race.



Finally, as a researcher, it must be noted that I will never be fully able to understand the worlds of the researched. Both the interactions I had with adolescents and my presentation of research findings are a function of our respective positioning in the social and political worlds (Mama, 1995). While I undertook this project hoping to facilitate the expression of young peoples' voices, it must be acknowledged that in this study, my voice has shaped theirs. In the pages that follow, I make use of my identity, assets and skills in an attempt to faithfully represent the voices of young people growing up with HIV in contemporary South Africa.

University of Cape Town

# CHAPTER 3

## KNOWLEDGE AND UNDERSTANDING ABOUT HIV STATUS

‘Why do you have to take the medications?’

‘I don’t know . . . nobody has ever told me.’

- Simone, 11 years old (quoted in Abadia-Barrero & LaRusso, 2006)

### Literature Review

As the old adage goes, “knowledge is power”. This statement rings particularly true for the HIV positive adolescent. As infected young people grow up, their awareness of their bodies and social worlds increases, and they must become knowledgeable about the virus which inhabits their bodies. This is a fundamental task because understanding personal serostatus forms a necessary foundation which enables self sufficiency and guides decision making about personal wellbeing. Even when adolescents are not told about their infection, they often suspect or figure out their serostatus by piecing together information from outside sources (Trocmé et al., 2002a; Lee & Johann-Liang, 2001). This is a highly undesirable situation, as it creates confusion and distress and destroys trust in the child-caregiver relationship (Trocmé et al. 2002a; Trocmé et al. 2002b; Lee & Johann-Liang, 2001). For all of these reasons, it is pivotal to ensure that adolescents develop an accurate knowledge base about HIV and AIDS from trustworthy sources.

The acquisition of knowledge and understanding about personal HIV status usually begins in childhood and continues throughout adolescence. The initial step towards this developmental goal involves disclosure of HIV status to the infected child by a parent, caregiver or health care provider. Disclosure<sup>11</sup> involves the difficult task of telling a child that he or she has a communicable and potentially fatal virus for which there is currently no cure. The literature makes a distinction between *partial disclosure*, where a child is given general information about his or her illness, and *full disclosure*, where the child’s condition is named and identified as HIV. Wiener et al. (2007) and Lesch et al.’s (2007) reviews

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<sup>11</sup> A second genre of disclosure, which involves sharing one’s serostatus with others, merits a discussion of its own and will be addressed in Chapter 5.

examine the multiple aspects of disclosure more comprehensively and should be consulted for further information on the subject.

While most children who are HIV positive have been told their status by the time they enter adolescence, a significant proportion of young adolescents remain unaware that they are infected with the virus. North American studies conducted among older cohorts of children<sup>12</sup> in the era of HAART have measured disclosure rates ranging from 43% to 77% (Wiener et al., 2007; New, Lee & Pao, 2003; Bachanas et al., 2001; Mialky, Vagnoni & Rutstein, 2001; Thorne et al., 2002), and reports on average age at disclosure have varied from 6 to 10 years (Wiener et al., 2007; Mialky, Vagnoni & Rutstein, 2001; Riekert, Wiener & Battles, 1999; Thorne et al., 2002). However, differing sample characteristics make it difficult to draw any general conclusions about either of these two sets of figures. In recent years, a small number of studies have looked at disclosure in the context of sub-Saharan Africa. In a sample of Ugandan children between the ages of 5 and 17, only 29% of children had been told they were HIV positive (Bikaako-Kajura et al., 2006). A second Ugandan study found a significantly higher disclosure rate of 59% in children between the ages of 8 and 18 years (Nabukeera-Barungi et al., 2007). In a Zambian cohort of 127 adolescents between the ages of 11 and 15, only 37.8% of participants had undergone disclosure (Menon et al., 2007). Finally, in Vaz et al.'s (2008) study of Congolese young people, disclosure did not occur until a mean age of 15 years, though this figure was influenced by the fact that most of the sample was not diagnosed with HIV until adolescence. While there is significant variation in the above findings, in 3 out of 4 of these studies, disclosure occurred later than in North American studies. On the other hand, these results fall more in line with research done in other resource-limited settings, such as Thailand (Oberdorfer et al., 2001). Differences suggest that context plays an important role in the decision whether and when to speak with children about HIV, and points towards the significant challenge that disclosure poses to caregivers and service providers in the region.

Among caregivers, the most common reason for non-disclosure is that the child is too young or immature to understand his or her diagnosis (Lesch et al., 2007; Wiener et al., 2007). However, there is no general consensus on what qualifies a child as 'too young'. In a

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<sup>12</sup> In these studies, the mean age of the cohort was 9 years or greater.

South African study, caregivers thought that a mean of 11 years and 12 years were the most appropriate ages for partial and full disclosure respectively (Moodley et al., 2006). Conversely, healthcare workers recruited from the same site favoured partial disclosure at 6 years and full disclosure at 10 years (Myer et al., 2006). In rural Zimbabwe, community members and healthcare workers preferred a mean minimum age of  $10.8 \pm 4.2$  years for partial disclosure and  $14.4 \pm 4.5$  years for full disclosure (De Baets et al., 2008). As in the South African case, healthcare providers advocated disclosure from a significantly earlier age than caregivers (De Baets et al., 2008). This disjunction between caregiver and healthcare providers' perceptions has also been observed in the North American literature (Flanagan-Klygis et al., 2001), and may be due to the fact that healthcare providers work in a context where HIV/AIDS is openly discussed on a day to day basis (Lesch et al., 2007).

Apart from age, caregivers have cited a variety of other reasons for non-disclosure including a lack of skill or knowledge about how to disclose (Kouyoumdjian, Meyers & Mtshizana, 2005), concern that disclosure will have negative psychological consequences on the child (Blasini et al., 2004; Oberdorfer et al., 2006), parental discomfort talking about their own HIV status (Lee & Johann-Liang, 1999), parental feelings of guilt about infecting their child (Waugh, 2003; Lee & Johann-Liang, 1999) and fear that the child will disclose to others, resulting in the stigmatization of both the child and the family (Waugh, 2003; Moodley et al., 2006; Kouyoumdjian, et al. 2005, Flanagan-Klygis et al., 2001). On the other side of the spectrum, reasons for disclosure have included the caregivers' belief that a child has a right to know their status (Vaz et al., 2008; Waugh, 2003; Moodley et al., 2006), fear that the child might learn his or her diagnosis from another source (Blasini et al., 2004), concern that the child will become sexual active and might infect others (Vaz et al., 2008; Waugh, 2003; Blasini et al., 2004), and hope that disclosure will lead to better mental health or adherence (Vaz et al., 2008; Blasini et al., 2004; Moodley et al., 2006).

While some caregivers have expressed concern that disclosure might have a detrimental effect on their child's mental health, empirical research does not verify this assertion. Rather, studies have found either no relationship (Lester et al., 2002), or a positive correlation between disclosure and mental health. Lower levels of psychosocial distress (Bachanas et al., 2001; Riekert, Wiener & Battles, 1999), fewer internalizing problem behaviours (Bachanas et al., 2001), and trends towards less depressive symptoms (Mellins et al., 2002) have been reported among children and adolescents who are aware of

their HIV status. The only published report which addresses this issue in the Sub-Saharan African context reported that Zambian adolescents who did not know their status were significantly more likely to exhibit emotional difficulties than those who had experienced disclosure (Menon et al., 2007). Variations in mental health repercussions highlight the importance of context in shaping outcomes, and existing studies are limited by the fact that they do not consider how other variables, such as age at disclosure or disclosure method might impact mental health. Still, there is no evidence to suggest that disclosure impacts negatively on the adolescent's mental health. Considering that adolescents themselves feel that it is better to know (Vaz et al., 2008; Blasini et al., 2004), mental health concerns should not impede caregivers from talking to their children about HIV.

The link between disclosure and adherence also remains somewhat ambiguous. A Ugandan study found that 75% of children and adolescents who had had been told their status reported perfect adherence to medication, while only one fifth of those who had not undergone disclosure reported similar rates of adherence (Bikaako-Kajura et al., 2006). Two North American studies have however, shown an opposite effect, where disclosure was associated with poorer adherence even after adjusting for age (Marhefka et al., 2006; Mellins et al., 2004). Like mental health studies, these studies did not address the manner in which disclosure occurs, and disparate results indicate that the relationship between status awareness and treatment behaviour is complex. Disclosure facilitates discussion about medication regimens but while it is a first step towards treatment responsibility, it is not sufficient to ensure adherence. Rather, once disclosure occurs, adolescents are presented with a complex set of new challenges which affect their interactions with their treatment regimens. These challenges will be discussed in greater detail in Chapter 6.

The development of knowledge and understanding does not stop once disclosure has occurred but there is very little information on children's experiences after they have learned that they are HIV positive. The few studies that have explored the issue have highlighted the pressing need for ongoing communication about HIV/AIDS and the implications of living with the virus. Research has shown that knowledge about HIV is poor among both vertically and horizontally infected adolescents (Wiener, Battles & Wood, 2007; Johnson & Buzducea, 2007). For instance, in a group of 122 Romanian young people, most of whom were infected iatrogenically, only one respondent could answer all nine questions about HIV correctly (Johnson & Buzducea, 2007). In an ethnographic study

of children living in a Brazilian institutional home, adolescents possessed a poor understanding of the way that HIV related to their own lives (Abadia-Barrero & LaRusso, 2006). While they had all technically undergone disclosure, HIV was not openly discussed and as a result, research participants felt invulnerable to the virus' effects and held misguided expectations about the future (Abadia-Barrero & LaRusso, 2006).

These findings shift the focus from the event of disclosure, suggesting that what happens before and after the naming of the disease may actually be more important for promoting knowledge and understanding than the disclosure event itself. Throughout the literature, there is a growing recognition that disclosure should constitute more than a single interaction between the child and caregiver or healthcare provider. Rather, it should entail a process which unfolds as the child grows up (Lesch et al., 2007; Waugh, 2003; Lee & Johaan-Liang, 1999; Abadia-Barrero & LaRusso, 2006; Gerson et al., 2001). Process-oriented models focus on presenting developmentally appropriate information to HIV positive children, which becomes increasingly thorough and comprehensive as they develop the emotional and cognitive ability to understand and apply the knowledge. Lesch et al. (2007) suggest that the disclosure process should begin with an assessment of the caregiver and child's needs that considers the caregiver's preparedness to discuss HIV, and the family's cultural beliefs and practices surrounding communication about sex. Once their needs and fears have been addressed, caregivers can begin working with healthcare providers to find developmentally appropriate ways to discuss HIV with the child (Lesch et al., 2007). If this process is started while the child is still young, it affords caregivers the time and opportunity to formulate a disclosure plan which is consistent with their familial, cultural and religious backgrounds, and enables the child to adapt to their diagnosis gradually.

To date, most existing research works with the assumption of a single-event definition of disclosure and very few researchers have investigated the long-term process of developing knowledge and understanding. Studies have approached disclosure as a univariate, without considering the age of disclosure or the manner in which disclosure occurs. As process-oriented models are put into practice, there will be a need for original research which evaluates this more gradual view of disclosure. Longitudinal studies, which examine the consolidation of knowledge over time, would be particularly helpful in this regard. In the case of the seropositive adolescent, whose societal awareness and cognitive

ability are increasing, research should focus on the ways that personal understandings of HIV are reshaped during this phase. This is particularly important, as the meanings and understandings through which adolescents view and process the virus form the undercurrent which runs through the other four aspects of adolescent HIV discussed in this dissertation.

## Knowledge and Understanding at the Adolescent Clinic

### *A Note about Focus Group Results*

Before moving on to consider knowledge and understanding at the adolescent clinic, it is necessary to pause briefly in order to describe the characteristics of research participants, and explain the way in which focus group results are presented in this, and the following four chapters.

In total, I conducted four focus groups with 26 participants. Groups were segmented according to age - a division which was facilitated by the fact that adolescents of different age groups visited the clinic on different days. The characteristics of the sample population are given in Table 3.1, and further details about the composition of each group are listed in Appendix A.

As aforementioned, each chapter addresses a psychosocial aspect of HIV that was identified during the literature review component of the dissertation. Additionally, three themes, which transect these aspects of HIV, emerged out of the coding of focus group transcripts: (1) experiences of life in the present, (2) views on the future and (3) self-identified needs. In each chapter, I present focus group results which pertain to the relevant aspect of

<b>Table 3.1 – Characteristics of focus group participants</b>		
	<b>Frequency</b>	<b>%</b>
<b>Gender</b>		
Male	16	62
Female	10	38
<b>Age</b>		
Less than 10 years	2	8
10-11 years	7	27
12-13 years	14	54
14 years and older	3	12
<i>Mean age: 12.5 years</i>		
<b>School participation</b>		
In School	26	100
Grades 1-2	1	4
Grades 3-4	5	19
Grades 5-6	12	46
Grades 7-8	8	31
<b>First language</b>		
Afrikaans	11	42
Xhosa	13	50
Zulu	1	4
Sotho	1	4
<b>Primary caregiver(s)</b>		
Two biological parents	7	27
One biological parent	9	35
Other relative(s)	6	23
Institutional home	4	15
<b>HIV transmission</b>		
Perinatal	16	62
Sexual*	2	8
Don't know/No answer	8	31

\*Both these cases of sexual transmission resulted from sexual abuse.

adolescent HIV, and where possible, I structure my presentation in accordance with the three themes that surfaced during the coding process. However, in certain cases, a particular theme did not intersect with a chapter topic. For example, in this chapter, I do not address respondents' views on the future because the theme did not come up during exchanges about knowledge and understanding. At the conclusion of each chapter, I identify and discuss the needs of HIV positive adolescents by integrating focus group findings with the existing literature.

With this mind, it is now possible to turn to the subject of knowledge and understanding, as it relates to adolescents attending the infectious diseases clinic.

#### *Experiences in the Present: Disclosure and Ongoing Communication*

During my period of involvement at the adolescent clinic, disclosure was a focal issue for both staff and families. The clinic had recently instituted a disclosure policy, which stipulated that staff would work for up to 4 months with caregivers to help them talk to their children about their HIV status. If disclosure still had not occurred after this period of time, healthcare providers had the prerogative to disclose to adolescents themselves. The clinic was therefore in a period of transition, during which staff were working with caregivers towards a 100% disclosure rate in the adolescent population. Because of this, the disclosure rate in the clinic population was high in comparison to figures from North America, as well as other parts of sub-Saharan Africa: over 80% of clinic attendees were aware of their serostatus<sup>13</sup>.

While the disclosure event was not specifically probed during focus groups, in one discussion, participants brought the issue up themselves by describing their personal reactions when they found out they were HIV positive. Adolescents mentioned disclosure in order to illustrate the negative feelings that they associated with the virus. Disclosure was described as a painful event which prompted responses of distress. Thirteen year old Pieter<sup>14</sup> said that HIV was 'not nice' and proceeded to tell the group that when he learned of his serostatus, he wanted to run away. In response, 13 year old Grace, who had earlier

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<sup>13</sup> Disclosure was extrapolated from the clinic register. The exact disclosure rate is not reported here, as it was constantly changing (as more families proceeded with disclosure) and the disclosure status of a few adolescents remained unclear.

<sup>14</sup> All names of research participants used in this dissertation are pseudonyms.



stated that HIV made her feel like killing herself, shared that she had undergone disclosure at the age of 12. Twelve year old Thandi had only recently been told about her condition, and exhibited high levels of distress while recalling the event, saying that she tried to hang herself when she found out that she was infected. While disclosure was undoubtedly necessary for these three young people, it was also a difficult experience which provoked negative feelings about HIV.

Despite the fact that the disclosure rate at the clinic was high, a number of patients had yet to undergo disclosure and consequently, HIV and AIDS were not openly discussed in adolescent support groups at the time that focus groups were held. Rather than speaking specifically about HIV, the social worker led young people in activities based on general health-related topics such as personal hygiene, puberty, leisure activities and family and peer relationships. The exclusion of non-disclosed adolescents from the focus groups created an opportunity for candid communication about HIV during interviews. For many of the focus group members, this represented the first time that they had spoken openly about HIV amongst their clinic peers and generally, adolescents responded enthusiastically to the chance to talk about their illness. In some cases, adolescents behaved differently during focus groups than in clinic support groups, listening more attentively and speaking with greater frequency and depth than I had previously observed. For example, while Pieter often spent support groups trying to escape from the room, he paid close attention to research questions and was among the most vocal members of his focus group. At the conclusion of another interview, Beauty asked participants whether they had preferred the support group or the focus group that day. In response, 15 year old Temba stated that he enjoyed the focus group because we had spoken about AIDS, and 13 year old Amy declared "I love this one, because I'm HIV and it opens up my mind". Comments such as these illustrate that in a context where HIV/AIDS was not ordinarily discussed, youth welcomed focus groups as a safe place to engage with their condition. Focus groups constituted a space where their illness was acknowledged and validated. The eagerness with which most of the participants approached the research project speaks loudly about their desire to communicate about HIV.

Ongoing communication is important because it allows for the transmission of information about the virus. The demographic survey I administered at the beginning of the focus group sheds limited insight on the current state of knowledge within the clinic

population (see Table 3.1). One of the questions asked participants whether they had been infected by a parent, through sex, or through another vector of transmission. The survey also gave young people the option to respond with 'don't know' or 'no answer'. In response, one third of participants indicated that they did not know how they had acquired HIV. Whilst my ability to comment on knowledge levels is restricted to one question, the fact that a significant portion of adolescents were unaware of this important piece of information points to a need for information dissemination.

*Self-Identified Needs: 'I Want to Learn'*

Significantly, respondents themselves expressed a desire for more information. While discussing what could be done at the clinic to make their lives better, 13 year old Emile and 12 year old Jabulani initiated the following exchange:

*Emile* Here's a plan, here's a plan: Communicate.  
*Rachel* Communicate. About what?  
*Emile* About - I want them to talk to you about this stuff.  
*Jabulani* About learn.  
*Rachel* About what?  
*Emile* More like this one, sickness. *Makes gestures around the table.*  
*Rachel* You want to talk about HIV?  
*All* Yes. Mmmmmm. *Nods around the table.*  
*Jabulani* I want to learn.  
*Rachel* You want to learn about HIV.  
*Jabulani* Yes.  
*Rachel* What would you like to communicate...what kind...you want information?  
*Emile* Information.  
*Jabulani* I want to learn more, more, more then.  
*Rachel* About what?  
*Jabulani* About this HIV/AIDS.  
*Rachel* What kinds of information?  
*Emile* HIV...HIV and AIDS. It is not one thing.  
*Rachel* That's right. So you want to talk about it.  
*Emile* Yes. You don't have AIDS. You have HIV.

As Emile addressed the difference between HIV and AIDS, Jabulani and the other group members listened intently. The topic clearly drew the attention of adolescents, pointing to their shared interest in 'learning more'. Notably, the desire for information and learning was not restricted to the domain of HIV, but also extended to include other aspects of life. In response to the same question about how the clinic staff could improve her life, 9 year

old Sibongile said that she wanted to learn and write, whereas 13 year old Thabela appealed for instruction in what was right and wrong. Respondents also drew attention to the importance of school, highlighting that learning was a good and important aspect of their lives.

While most youth expressed a desire to communicate and learn more about HIV, a minority of the participants were against the idea. For the most part, these individuals indicated their dissent through silence and body language which signalled discomfort (for example, by looking at the ground) when the subject of the virus came up. Fourteen year old Chantal felt that there was already too much talk about HIV, and stated that it would make her life better if people “stopped talking about AIDS”. She said that references to HIV made her feel nervous and scared and consequently, she tried to keep the virus out of her mind. However, despite her personal reluctance towards receiving more information, she was quick to agree that other children should be educated about HIV so that they might become more comfortable around those who were living with the virus.

#### Discussion: Meeting Knowledge and Understanding Needs

By the time HIV positive children reach adolescence, they need to be aware of their serostatus. It has been noted elsewhere that engagement at the family level is integral in promoting disclosure (Wiener et al. 2007; Vaz et al., 2008; Bikaako-Kajura et al., 2006), and the fact that the disclosure rate was so high at the adolescent clinic was a testament to the time that doctors, nurses, social workers and counsellors had spent urging and supporting caregivers to disclose. This work was facilitated by the clinic’s multidisciplinary and family-oriented approach, with counselling appointments and support groups providing venues for caregivers to ask questions, express their concerns and receive assistance with disclosure. Still, adolescents reacted negatively to the news that they were HIV positive, which is unsurprising given that they were old enough to have developed an awareness about the devastating implications of living with the virus. A key future challenge will be to encourage a more process-oriented approach within the family clinic’s younger pediatric population in order to avoid the necessity of the one-time disclosure event once a patient reaches adolescence. A South African study conducted at a similar clinic found that

caregivers did not favour engaging in even general conversations about their child's illness until the age of 11 years (Moodley et al., 2006). In such a context, work with caregivers needs to begin while the child is still young in order to encourage communication from an earlier age and facilitate a gradual and developmentally sensitive process of revealing the child's serostatus. In the abovementioned study, 96% of caregivers expressed a desire to discuss disclosure with a health care provider (Moodley et al., 2006), drawing light to the opportunities that clinics have to assist and support such a process.

The need for ongoing communication about HIV was evident among patients attending the adolescent clinic. In a group of HIV positive Brazilian children and adolescents living in institutional homes, Abadia-Barrero & LaRusso (2006) observed that in the absence of open communication about HIV/AIDS, young people grow increasingly confused about their illness and mistrustful of adults. Environments that are conducive to honest and developmentally appropriate communication about HIV therefore need to be encouraged and created. Findings from focus groups indicate that the value of communication is twofold. Firstly, it has therapeutic value on its own, as young people welcomed the opportunity to speak about HIV, and specifically stated that they enjoyed talking about the virus. Secondly, communication allows accurate information about the virus and other aspects of life to be passed on to adolescents. The fact that young people expressed such eagerness to learn is a promising sign, pointing to an opportunity for teaching that should not be overlooked.

Communication about HIV can occur through a number of venues. Media campaigns and the Life Orientation classes offered in South African schools represent a good opportunity for general information dissemination HIV/AIDS and sexuality. However, such methods do not take into account the highly personal nature of HIV infection in seropositive adolescents. Ongoing communication with trusted adults about what it means to be live with the virus is therefore necessary. While this can be achieved to a certain extent in clinic support groups, it must also occur in the context of the home, where the day to day implications of being HIV positive play out. The fact that a significant proportion of focus group participants did not know how they had acquired HIV points to the difficulties surrounding caregiver-child communication about the virus. Given that parental guilt and fear of blame have been cited as major barriers to disclosure (Waugh, 2003), it is possible that similar sentiments could be preventing caregivers from

discussing the mechanisms of HIV transmission with their children. Discussion about HIV in the home is complex and goes beyond the simple provision of information; it may also necessitate a consideration of the very nature of the caregiver-child relationship. Caregivers may therefore need to be empowered with the knowledge, skills and support to help them to communicate openly with their seropositive children about HIV.

Finally, adolescents need to develop a personal understanding of what it means to be HIV positive. Learning constitutes more than the intake of facts and information, but also the process of figuring out how to reconcile understandings of self with conceptions of the virus. Undeniably, adolescents need to be taught the logistics about the way the virus and their treatment regimens work. Yet, learning about HIV is also a lifelong process during which individuals' understandings of their illness evolve as they integrate new meanings of HIV and AIDS into their lives (Abadia-Barrero & LaRusso, 2006). Adolescents must find ways to sort through these multiple meanings in order to live positively with their illness. Neither Chantal, who was too afraid to talk about AIDS, nor Pieter, Grace nor Thandi, who felt so negatively about being HIV positive, had yet to develop a competent personal understanding of the virus. Developing this level of understanding will require more than simple communication about the virus, and it is this challenge that I address in the next chapter.

## CHAPTER 4

# MENTAL HEALTH

“When you depressed you really don’t care about a lot of stuff. You just don’t care. And that’s how I was for a while. I just didn’t care. I threw my medications out the window. I tried to forget it”. - *HIV positive adolescent* (quoted in Rao et al., 2007)

### Literature Review

Beyond physical health, an integral part of wellness involves attaining and sustaining a state of mental health. While mental health is frequently defined in the negative, the WHO recognizes that mental health constitutes more than an absence of psychiatric disorder, encompassing rather “a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community” (WHO, 2007). Considered through this lens, it is evident that mental health is inherently valuable because it lays the foundations for personal contentment and increases an individual’s ability to direct his or her own life. Beyond this intrinsic worth, competency in this domain is also important because mental health has been repeatedly shown to correlate with healthier behaviours across multiple spheres of life. For example, among HIV positive adolescents, depression has been associated with poorer school performance, higher rates of alcohol and drug abuse, non-adherence to medication regimes, and a greater likelihood of engaging in unprotected sex (Murphy et al., 2001b).

Adolescence is an important period for mental health development. Up to 50% of adult mental disorders emerge during this phase and today, the average age for the onset of depression is 15 years (Belfer, 2008; Evans & Seligman, 2005). Global figures indicate that within this age group, an estimated 20% of individuals suffer from a clinically significant mental illness and suicide is the third leading cause of death (Belfer, 2008; Evans & Seligman, 2005). Yet despite these figures, the plasticity of adolescence means that young people are particularly amenable to change (Evans & Seligman, 2005). This stage of life is therefore ideal for both the prevention and treatment of mental health disorders and the promotion of positive patterns of living.

The mental health of young people living with HIV is affected by the normal pressures of adolescence, along with a number of additional biological, psychological and social stressors, which are related specifically to their seropositivity. Though HAART has done much to relieve the physical symptoms of HIV and AIDS, medications often have severe side effects and chronic pain remains common among young people (Veinot et al., 2006; Lee et al., 2006; Lolekha et al., 2004). Furthermore, perinatally infected individuals typically reach puberty later than their peers, raising questions about personal identity (Aka Dago-Akiribi & Cacou Adjoua, 2004). At a psychosocial level, adolescents must face the fears and insecurities which stem from living with an incurable disease and the stigma and shame which continue to be associated with AIDS in many communities (Strydom & Raath, 2005). Additionally, by virtue of the virus's epidemiological character, a large proportion of perinatally infected adolescents have also had to cope with the AIDS induced illness or death of a parent or sibling (Battles & Wiener, 2002; Ferrand, Miller & Jungmann, 2007; Brown, Lourie & Pao, 2000).

In light of these stressors, it is frequently postulated that individuals living with HIV might suffer from particularly poor mental health. A handful of studies have attempted to test this hypothesis by quantifying the prevalence of mental illness in seropositive adolescents. Scharko (2006) conducted a meta-analysis of 8 studies reporting on DSM IV psychiatric disorders in HIV positive children and adolescents. Pooled data yielded a total sample size of 328 individuals between the ages of 4 and 21 years, and an average prevalence of 28.6% for ADHD, 24.3% for anxiety disorders and 25% for depression (Scharko, 2006). However, it is significant to note that prevalence diverges significantly across studies. Reports indicate that anywhere from 32% to 85% of HIV positive adolescents have some kind of psychiatric disorder (Ferrand, Miller & Jungmann, 2007; Johnson et al., 2003; Naar-King et al, 2006a; Mellins et al., 2006; Pao et al., 2000), with 12% to 47% of individuals suffering from clinical depression (Kadivar et al., 2006; Pao et al., 2000, Misdrahi et al., 2004). Though these figures appear extremely high, the only controlled study which has been conducted in the post-HAART era suggests a more nuanced perspective. In a group of 6 to 16 year olds, Bachanas et al. (2001) found that while HIV positive children and adolescents exhibited high rates of emotional and behavioural problems, rates were even higher among a demographically matched group of HIV negative individuals.

While prevalence figures are useful for highlighting trends in mental illness, the great variation in figures, and Bachanas et al.'s (2001) findings, draw attention to the importance of contextual factors in shaping mental health outcomes. Given that HIV is found in a high risk population in the developed world, it is possible that vertically infected children are genetically predisposed to psychiatric disorders. Alternatively, the high rates of disorder among HIV positive children and adolescents may be a reflection of stressful living environments rather than the result of HIV itself (Bachanas et al., 2001; Mellins et al., 2003; Donnenberg & Pao, 2005). A Brazilian study has even suggested that HIV positive adolescents experience better quality of life than some groups of uninfected youth because they have access to targeted services and help networks (Abadia-Barrero, 2002). Notably, the vast majority of existing research has been conducted in the United States, where HIV infection is concentrated within a particular, marginalized, high-risk population. In addition to their illness, many of these young people face other adverse living conditions such as parental abandonment, parental substance abuse, juvenile incarceration, physical and sexual abuse, running away, housing instability, and drug and alcohol addiction (Eastwood & Birnbaum 2007; Kadivar et al., 2006). In sub-Saharan Africa, where the AIDS epidemic is generalized, it should be anticipated that social and familial contexts will pose different stresses on adolescents living with HIV.

Only one study has quantified mental health disorders in young people living in sub-Saharan African. Members of the study sample, which consisted of 127 Zambian adolescents between the ages of 11 and 15 years, were administered the youth version of the Strengths and Difficulties Questionnaire and results were compared to an age and gender matched British sample of HIV negative adolescents (Menon et al., 2007). Results showed that when compared to British norms, HIV positive adolescents in Zambia were 2 times more likely to have mental health problems, 3.6 times more likely to exhibit emotional symptoms and 7.1 times more likely to experience peer problems (Menon et al., 2007). These findings suggest that like HIV positive adolescents in the United States, Zambian young people face significant mental health challenges. However, the use of a British control group rather than a Zambian control group makes it difficult to ascertain the extent to which these differences are attributable to HIV infection or to other environmental factors.



Several North American studies have attempted to determine both the individual and contextual factors that are correlated with mental health in HIV positive adolescents. At the level of the individual, young people with higher viral loads and lower CD4 counts are more likely to exhibit mental health symptoms (Lam, Naar-King & Wright, 2007; Misdrahi et al., 2004). From an environmental standpoint, social support, open communication about HIV in the home, and disclosure of serostatus to friends and family appear to play a buffering role against mental health problems (Lam, Naar-King & Wright, 2007; Battles & Wiener, 2002). However, telling too many people can also be detrimental, as young people who disclose publicly experience poorer global self-concept than those who do not (Wiener, Battles & Heilman, 2000; Lam, Naar-King & Wright, 2007; Battles & Wiener, 2002). The family context also plays a pivotal role in shaping psychological outcomes, with caregiver substance abuse, depression and psychosocial distress having each been associated with higher levels of internalizing and externalizing problems among perinatally infected children and adolescents (Bachanas et al., 2001; Mellins et al., 2006). Furthermore, young people who do not live with a biological parent experience fewer mental health problems, which in the developed world, is most likely a reflection of more stable living conditions with a relative or foster parent (Bachanas et al., 2001). The impact of stressful life events, such as the death of a parent, remains a more ambiguous area of inquiry. While some studies have shown that parental death is associated with higher rates of anxiety and depression (Murphy et al., 2000), other research has failed to find any association between the two factors (Menon et al., 2007; Lester et al., 2002; Bachanas et al., 2001).

There is a paucity of information regarding the strategies that HIV positive adolescents employ in order to cope with the multiple stressors they face. Research on the family unit has shown that caregivers try to keep family life as normal as possible in order to enhance the physical, emotional and social health of infected children (Rhem & Franck, 2000). Yet, the complexity of treatment regimens and the need to shield young people from stigma ultimately preclude full normalization and families must find alternate ways to manage the specific challenges that the virus poses (Rhem & Franck, 2000). Most often, families adopt emotion-based or passive coping strategies to deal with the child's condition, avoiding their problems or releasing control of their circumstances to others (Martin et al., 2004). However, the literature on adult populations suggests that HIV positive individuals

who cope with their condition by actively trying to change their situation experience lower levels of psychosocial distress (Moneyham et al., 1998; Turner-Cobb et al., 2002; Sun, Zhang & Fu, 2007). The only study that has examined the issue in children and adolescents echoes these findings, reporting that young people who employ adaptive coping strategies experience better mental health outcomes than those who rely on emotion focused coping strategies (Bachanas et al., 2001).

Though there have not been any published studies specifically about coping in HIV positive adolescents in sub-Saharan Africa, research on general coping among uninfected adolescents and adults indicates that passive, emotion-based coping strategies predominate over active, adaptive coping strategies (Magaya, Asner-Self & Schreiber, 2005; Demmer, 2007). Results from North American studies would suggest that in such a context, promoting active problem solving would be an effective intervention to boost mental health. However, it has also been argued that in an environment where community interdependence is high, gender relations are unequal, and HIV is stigmatized, passive and emotion based forms of coping may actually increase the likelihood of physical, psychological, and social survival (Dageid, & Duckert, 2008). In light of these diverging opinions, context sensitive research on coping in HIV positive adolescents is urgently needed in order to plan effective interventions which give young people the knowledge and skills to optimize their mental health.

There is also a need for research that goes beyond measuring and examining mental disorders and focuses on the positive dimensions of mental health advanced by the WHO. Studies on both adults and adolescents with chronic disease have looked at how wellbeing is achieved in the context of illness (Berntsson et al., 2007; Kim & Kang, 2003; Lindsey, 1996). Similar studies with HIV positive adolescents would deepen our understanding of what it means to live healthily with HIV enable the development of programmes that build on the assets and strengths that individuals and communities already possess.

### Mental Health at the Adolescent Clinic

I made no attempt to measure psychiatric disorder in this study. However, adolescents in focus groups spoke widely about their outlook on their illness and their

lives, both in the present and the future. The perceptions and experiences of respondents proved instructive about the ways in which adolescents were coping with life.

*Experiences of Life in the Present: Good and Challenging Aspects of Life*

Unsurprisingly, most adolescents regarded HIV as a negative part of their present-day lives, conveying feelings of sadness and anxiety about their illness. As noted in the previous chapter, two girls went as far as to speak about suicide when discussing their perceptions of their condition. Many respondents were angry about being HIV positive, and one boy spoke about the self-imposed isolation the virus prompted. HIV was also described as being both physically and emotionally painful, making adolescents feel 'hurt' and 'sore'. Twelve year old Talitha drew herself standing next to an AIDS ribbon encased in a broken heart, symbolizing her smallness in relation to the virus, and her sadness about her status (Figure 4.1). A number of adolescents expressed concern about their health and the lifelong nature of their condition. When asked about the challenging aspects of her life, Amy replied: "The fact that I will never be healed of HIV. The fact that there is no cure". This thought was echoed by 12 year old Fundiswa in Figure 4.2.

In one activity, adolescents were asked to select one of 48 images to portray how they felt about HIV. Though the package of images that I employed was originally designed for use in a North American setting, the pictures came from around the world, and portrayed people of different ages and races (though young, white people were overrepresented in the images). While it may have been preferable to have employed pictures tailored to a South African context,



Figure 4.1 – Talitha's message about HIV

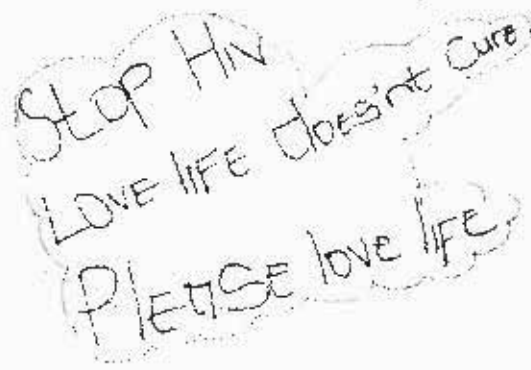


Figure 4.2 – Fundiswa's message about HIV

adolescents did not appear to pay much attention to the gender, age or race of those in the photographs when making their choices. Instead, they seemed to focus on the feelings conveyed by the images. I found that pictures proved effective at facilitating expression on a sensitive subject. A selection of pictures and corresponding quotes are given in Box 4.1.

Even with visual aids, it was clear that some participants felt uncomfortable speaking about HIV or had difficulty expressing themselves verbally. In several groups, adolescents described their fear or sadness while giggling or smiling. Many younger participants were quick to select a picture but had trouble conceptualizing or specifying their feelings, resorting to broad statements such as "I don't feel alright" (*Siyabonga, 12 years*) or "I don't feel too good" (*Xolelwa, 11 years*) in order to describe their sentiments. In some cases, participants chose an image without giving an explanation. However, in these instances, the chosen picture, combined with the body language of respondents often spoke volumes about the individual's distress.

While the majority of adolescents felt badly about HIV, a small number of respondents did purport to feel okay or happy about the virus. These positive feelings had their roots in gratitude, either for their improved health status or the support of their families. Those who stated that they felt good about HIV were aware of what the virus could have cost them and were thankful for what they still had. For example, Emile felt 'happy' about HIV "Because I still have my mom and my dad and my sister". Others, having lost their parents, were simply grateful to be alive.

Box 4.1 - Adolescents' feelings about HIV, expressed through pictures and words



"Angry"  
"What makes you feel angry?"  
Silence. "Because I have HIV"  
- Anthony, 13 years



"You feel sad and want to kill yourself" - Grace, 13 years



"If you don't feel comfortable with HIV, you won't be alright"  
- Bongani, 10 years



"I feel like I don't want to see people" - Thabo, 11 years



"It feels hurtful" - Amy, 13 years



"It's painful. It makes me sad and sore. It makes me so sad"  
- Pieter, 13 years



"I feel better" - Lindwee, 11 years

Beyond HIV, adolescents identified a variety of other factors that affected the way they felt in the present. In fact, when asked an open-ended question about the things that made them feel badly, only the oldest focus group mentioned HIV at all. Instead, adolescents referred to a range of other problems that they encountered in their daily lives. A number of focus group participants cited sources of distress in the home, including being hit by a caregiver, being separated from a parent, or having an ill or overworked mother. Family poverty was also mentioned as a stressor. Others were discontent or angry about their school environments, either because they found class boring, disliked their teachers, or had problems with other children. At the level of the community, crime and violence were identified as a source of stress. Youth brought up stealing, drugs, and 'tsotsis' (i.e. thugs or criminals), and 12 year old Sipho stated that he was "always afraid of guns" where he lived.

Difficulties with peers were cited in all four groups as a negative aspect of respondents' lives, particularly among male respondents. Some boys said they were laughed at, made fun of, or stared at by others, while others reported more physical forms of conflict, such as being hit or beaten. Reasons for these instances of aggression were not clear, though all of the respondents who described physical problems with peers were very small for their age, most likely as a result their HIV infection. Some boys also had other physical marks, such as a long-term tracheostomy tube<sup>15</sup> or small lesions on their faces, which made them outwardly deviant from other children. Adolescents said that being bullied left them feeling depressed and indifferent, and made going to school unenjoyable. Several boys responded to these peer difficulties by choosing to stay at home instead of playing with other children:

The grade 6 children hit me. They are bullies. Because of where I stay, I don't have friends where I stay because the children there, in the streets and make trouble so I usually go to my uncle on weekends because I don't want to play with them. -  
*Thabo, 10 years*

For adolescents like Thabo, problems with other children thus prompted them to isolate themselves from others.

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<sup>15</sup> A tube inserted directly into the trachea which helps an individual to breathe. Individuals with a tracheostomy tube can lead fairly normal and active lives, though the tube may affect the quality or volume of the person's voice.

In addition to identifying the challenging aspects of their lives, focus group participants were asked to identify things that helped them to feel happy and healthy. In response, participants spoke about the support they received from a wide range of sources, including family, friends, religion, and the hospital. The support they received from others was seen as integral in helping adolescents manage both their illness and their lives. Participants also described pleasure in participating in activities that they enjoyed or felt they benefited from. Most respondents thought that going to school was a positive aspect of life (though a few boys did state that they disliked school) because it was both a means to a desired end, and a fun process in itself. As expressed by 15 year old Temba, “Studying will be the stepping stones to give me the things I want and the process of learning...I like that”. Typical childhood and adolescent leisure pastimes, such as playing with toys, playing games and sports, and watching television were also seen positively. A number of boys stated that ‘the rugby’ was a good part of their lives. Finally, access to good and healthy food was mentioned in two groups as something that helped adolescents to feel well.

*Views on the Future: Expectations and Worries*

In spite of their illness, most adolescents were looking forward in anticipation towards the future. During focus groups, participants were asked to indicate how they felt about the future by placing stickers on faces representing various emotions (Appendix F, Item I). The results of this activity are displayed in Table 4.1.

<b>Table 4.1 – Adolescents’ feelings about the future</b>	
<b>Emotion</b>	<b>% of adolescents who felt this way about the future</b>
Happy	62
Confident	38
Relaxed	31
Uncertain	27
Nervous	23
Excited	19
Stressed	19
Depressed	15
Hopeful	15
Overwhelmed	8
Angry	8
Scared	8
Indifferent	4

Interestingly, the three most commonly chosen emotions were positive, with almost two thirds of participants indicating that they felt happy about the future. Happiness, excitement and hope stemmed from expectations about the opportunities the future held. As expressed by Amy, “The future is still to come, so that is something to be happy about”. Adolescents had dreams of leading ‘normal’ lives by finishing school, having meaningful careers and building families of their own. Several youth said that they wanted to be doctors or social workers so they could help others like the professionals who had helped them. A few respondents also felt positively about their health, as exemplified by 10 year old Vuyo, who shared that “I have hope that I will live long”. Participants who felt confident or relaxed about the future spoke about the support they received from friends, family and God. This support helped them to maintain faith in the achievability of their dreams, thus allowing them to approach the unknown with optimism.

Negative emotions about the future were also expressed. For some adolescents, these feelings stemmed from their negative perceptions about their illness. HIV made respondents feel confused, nervous and scared about what the future held. Anthony initially placed his sticker on the face representing ‘angry’, but when probed about his choice, he changed his mind:

<i>Beauty</i>	Are you angry for the future?
<i>Anthony</i>	No
<i>Mbali</i>	You're not angry? Where would you like to change it to then?
<i>Anthony</i>	Scared.
<i>Beauty</i>	Okay
<i>Rachel</i>	Why did you put it on scared?
<i>Anthony</i>	Because I have HIV. I am confused.

In addition to HIV, adolescents cited a number of other factors that made them feel negatively about the future. These issues were the same things that respondents had identified as making them feel ‘bad’ in the present, including violence in the community, and problems with peers. Negative experiences in the daily lives of adolescents thus appeared to influence the way they perceived the future. Conversely, young people who spoke positively about their current lives were more likely to do the same about their expectations of what was yet to come.



Observing the choices of individuals during this activity revealed interesting trends in young peoples' patterns of thinking. Table 4.2 shows the number of individuals who chose only negative emotions, only positive emotions and both positive and negative emotions to describe

Nature of chosen feelings	Number of respondents	% of respondents
All negative	2	8
All positive	9	35
Both positive and negative	13	50
Did not participate	2	8

the future. Some adolescents were adamant that they only wanted to place their stickers on positive feelings. Temba originally put a sticker on 'overwhelmed' but moved his sticker when he discovered that the emotion could be interpreted in the negative. Similarly, Kevin chose to put all of his stickers on 'happy', and emphasized that he didn't feel badly about life. In contrast, two adolescents placed all of their stickers on negative emotions. Both these participants were living in institutions and exhibited distress about being separated from their families. Most participants however, chose both positive and negative feelings about the future. For example, it was common for adolescents to choose both 'happy' and 'depressed' or 'confident' and 'unsure'. As participants spoke about their choices, their thought processes became clearer: positive feelings tended to derive from the expectations they held about the future, while negative feelings were prompted by uncertainty about how to achieve these goals:

I am scared because I want to finish school and you know, get a job and have a boyfriend, but I don't know how to do that as person with HIV. The happy is the positive thoughts - the things I am scared of but everything in reverse. Like finishing school, having my own job, having my own home, having my own man. -  
*Thabela, 13 years*

Thabela's statement exemplifies the tension posed by having dreams whilst not knowing how to actualize them. While her hopes were a source of happiness, they also caused fear and uncertainty.

#### *Self-Identified Needs: Being Treated with Respect*

When asked about what could be done to make life better, adolescents mentioned two additional mental health needs that should be discussed. Firstly, like most people,

adolescents wanted to be treated with respect, stating that it would be helpful if people didn't hit, stare, gossip or get angry with them. Secondly, adolescents wanted others to recognize their personal limitations. For example, Jabulani brought up his physical limitations, saying that he didn't want to be forced to eat when he didn't want to, and wanted to be allowed to go home when he felt sick at school. As aforementioned, Chantal said that others could help her by not talking about AIDS, indicating that constant reminders of her illness pushed her beyond the limits of what she was psychologically prepared to face. These self-identified needs draw attention to adolescents' desires to be listened to, and treated as capable individuals.

### Discussion: Meeting Mental Health Needs

Given the lifelong nature of HIV, seropositive adolescents need to find ways to 'live well' with their illness (Lindsey, 1996). In this study, focus group participants described a number of barriers to their health and happiness. Unsurprisingly, respondents felt badly about their serostatus, and associated the virus with feelings of anger, sadness and anxiety. However, in addition to their HIV status, respondents identified a wide range of social problems that made them feel negatively, and were also preoccupied with challenges in the family, at school, and in their communities. This study therefore offers support for the hypothesis that social context is important and may play a greater role in determining mental health than HIV status itself (Bachanas et al., 2001; Mellins et al., 2003; Donnenberg & Pao, 2005).

Conflict in the peer environment was a common theme, and merits further investigation. It remains unknown whether verbal and physical clashes are somehow related to individuals' HIV status, or whether this discord is a more general feature of young peoples' communities. However, results do fall in line with Zambian research, which observed exceptionally high rates of peer difficulties among seropositive adolescents (Menon et al., 2007). Whatever the reason for adolescents' disagreements, focus group discussions indicate that young people may need to be taught skills relating to conflict resolution, assertiveness, and peer relations.

While adolescents held negative views on HIV and the other problems in their lives, these barriers did not necessarily translate into depression or hopelessness about life in general. In contrast to the high levels of anxiety and depression observed in North American research (Ferrand, Miller & Jungmann, 2007; Johnson et al., 2003; Naar-King et al., 2006a; Mellins et al., 2006; Pao et al., 2000), most adolescents in this study conveyed a sense of personal wellbeing. Like young people with other chronic diseases, perceptions of social support enabled them to attain and preserve feelings of wellness (Berntsson et al., 2007). Respondents also found sources of health and happiness in their day-to-day routines, and enjoyed taking part in the same kinds of activities as their peers. Because they allow for societal participation and integration, it has been suggested that such pursuits help maintain a sense of normalcy in young people living with chronic illnesses (Rhem & Franck, 2000; Berntsson et al., 2007). Focus group content confirms that normalcy was important in young people's present lives, and suggests that the life of the adolescent carries on, despite the presence of the virus.

Normalcy was also an important theme running through adolescents' views on the future. Most adolescents felt positively about the future because they hoped to live 'normal' adult lives, and were excited at the prospect finishing school, working and having families of their own. However, the intersection between positive and negative perceptions, as exemplified in Thabela's comment, highlights that individuals were unsure about how to transform their dreams into reality. As they get older, and the future they envision draws nearer, young people will need help visualizing and enacting practical ways to realize their goals. For example, adolescents may need to be equipped with the knowledge and skills necessary to enter the labour market.

Given that the mental health of HIV positive adolescents seems to be dependent on many of the same factors that might affect the general adolescent population, strengthening broad-spectrum health promotion programmes and social interventions in schools and communities may be the most logical way to proceed (See Patel, V. et al. 2008 for some examples of such programs). In a province where the crime rate is the highest in the country (Leggett, 2004) and unemployment is 42% among 15-24 year olds ('Employment dynamics', 2007), patients' day to day struggles are embedded in the context of wider societal problems. However, because the possible repercussions of poor

mental health are costlier for young people living with HIV, targeted mental health services are needed for those who fall through the cracks of broader interventions.

Strategies which aim to help adolescents overcome mental health barriers should focus on strengthening the assets that individuals already possess. Focus group participants identified a wide spectrum of positive assets in their lives (see Figure 5.3 for an example). It has already been noted that support from a wide range of sources was seen as an important mediator of health and happiness. Young people mentioned the issue so frequently, that it merits a discussion of its own.



Figure 4.3 – Thabo's Message about HIV

## CHAPTER 5

# SUPPORT NETWORKS, DISCLOSURE AND STIGMA

“There are the days when the kids talk about AIDS in school and about how they would never touch or go near kids who had it. I once asked a boy what he would do if I had it, and he told me he would never go near me but that he knew that I didn’t really have it. He was wrong. I do”. - *Dawn, age 12* (Wiener, Best & Pizzo 1994:22-23 cited in Sherman et al., 2000)

### Literature Review

As was discussed in the previous chapter, social support plays an integral role in mediating the HIV positive adolescent’s mental health. Defined broadly as the “resources provided by others” (Cohen & Syme, 1985), social support has also been shown to improve the physiological, psychological and social health of HIV positive adults and adolescents with other chronic diseases (Malcolm et al., 2003; Ncama et al., 2008; Kyngas & Rissanen, 2001; La Greca et al., 1995). Support networks may involve family, friends, acquaintances, or communities, and resources can be material, instrumental, or emotional in nature (Smith, Rosetto & Peterson, 2008). Because of their proven capacity to increase quality of life, adolescents living with HIV should be encouraged to develop strong networks of support.

For vertically infected adolescents, the family unit offers the most obvious source of support. However, HIV is a family disease, which disrupts the normal parent-child relationships on which most young people depend, and a high proportion of perinatally infected adolescents have lost one or both parents to AIDS (Ferrand et al., 2007; Ferrand, Miller & Jungmann, 2007; Thorne et al., 2002). Where HAART is available, this proportion should decline in upcoming years. Yet, surviving biological parents are often HIV positive themselves, and must care for their adolescents while managing their own illness (Ledlie, 2001). Furthermore, caregivers of HIV positive children tend to experience high levels of distress (Amodei et al., 1997; Wiener, Vasquez & Battles, 2001; Steele, Nelson & Cole, 2007), which may in turn affect the child’s psychosocial functioning (Mellins et al., 2006). But despite the challenging circumstances that families face, research

has repeatedly found that the support which caregivers provide remains pivotal in helping young people stay healthy, both physically and psychologically (Naar-King et al., 2008; Bikaako-Kajura et al., 2006; Rhem & Franck, 2000).

Eliciting social support outside of the family (as well as inside the family for horizontally infected adolescents) necessitates disclosing<sup>16</sup> personal serostatus to others. However, while disclosure has been correlated with increased social support (Battles & Wiener, 2002; Smith, Rossetto & Peterson, 2008), this relationship is not universal, and disclosure also carries the risk of rejection and even greater alienation for both the adolescent and his or her family (Sherman et al., 2000). The threat of stigma<sup>17</sup>, whether experienced or perceived, continues to prevent adolescents from sharing their secret (Flicker et al., 2006; Fielden et al., 2005; Martinez et al., 2003). Furthermore, in the case of HIV, disclosure is not merely a personal act, but may also implicate a family member or a sexual partner. For example, by disclosing his or her serostatus to a friend or extended family member, a perinatally infected adolescent might inadvertently bring questions about his or her parents' sex lives to the foreground (Steele & Grauer, 2003). For sexually infected adolescents, disclosure to the family may also necessitate telling an unaware parent that they are sexually active (Steele & Grauer, 2003). Cognizant of these difficulties, many young people keep their HIV status a secret, often restricting knowledge to themselves or their immediate families, and hiding their illness from everyone else. Given that peer relationships constitute such a central part of the adolescent world, it is unsurprising that young people living with HIV feel lonely, isolated and burdened by keeping their serostatus a secret (Hefez, 2002; Flicker et al., 2005; Fielden et al., 2006).

Yet, despite these difficulties, research also suggests that disclosure to others can be a positive and beneficial experience for young people. Aside from experiencing elevated

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<sup>16</sup> Disclosure to infected children about their own HIV status was previously discussed in Chapter 3.

However, once young people become aware of their illness, they are faced with decisions about a second genre of disclosure (which is discussed in this chapter): whether or not to share their condition with others.

<sup>17</sup> According to sociologist Erving Goffman (1963), stigma is "an attribute that is deeply discrediting" that results in the devaluation and discounting of a person in the eyes of others. Stigmatized people are seen to possess a different and undesirable trait which sets them apart from the 'normal' population and hence, 'spoils' their identity (Goffman 1963). Contemporary theory has built on Goffman's work, highlighting the role that social structures and norms play in creating and perpetuating stigma. According to Parker & Aggleton (2003), stigma is a complex social process which reproduces existing patterns of power and control in society. Because of their marginal status, stigmatized groups are relatively powerless to resist their oppression; stigma is therefore seen as an expression of exclusion and exploitation of the weak by the strong (Parker & Aggleton, 2003).

levels of social support, studies have shown that adults who disclose their status to others also benefit from slower disease progression (Cole et al., 1996), safer sexual behaviour (Kalichman & Nachimson, 1999), higher levels of adherence to antiretroviral therapy (Remien et al., 2007), and better mental health outcomes (Zea et al., 2005). The small body of research that has examined the issue among HIV positive adolescents has yielded equally encouraging results. One study showed that in a group of adolescents between the ages of 8 and 18 years, those who disclosed their HIV status to friends in a one year period displayed a larger increase in CD4% than those who had yet to disclose or who had disclosed prior to the study (Sherman et al., 2000). And in a group of adolescents between the ages of 13 and 24, Wiener & Battles (2006) found that higher levels of general disclosure were correlated with lower avoidant and internalizing problems, higher self-competence in peer relationships and more frequent disclosure to sexual partners.

Research from the developed world has shown that disclosure among adolescent populations tends to be confined to a small group of trusted people. In the United States, horizontally infected adolescents are more likely to disclose to a parent than anyone else, and experience high levels of familial support after doing so (D'Angelo et al., 2001; Lam, Naar-King & Wright, 2007). Caregivers often inform schools about their child's HIV status (Thorne et al., 2002; Mialky, Vagnoni & Rutstein, 2001) and a significant minority of adolescents tell a close friend about their illness (Lam, Naar-King & Wright, 2007). Among adolescents in relationships, research has found that disclosure to a partner presents a major hurdle and occurs 48% - 68% of the time (D'Angelo et al., 2001; Ferrand, Miller & Jungmann, 2007; Rotheram-Borus et al., 2001; Wiener & Battles, 2006). This is problematic considering that at least one study has found that young people who choose not to disclose to a sexual partner are more likely to engage in unprotected sex (Sturdevant et al., 2001).

While little research on the issue has been done in the context of sub-Saharan Africa, existing evidence suggests that disclosing HIV status and generating social support present substantial challenges in the region. In many communities, stigma remains a real and salient issue and there have been reports of individuals being physically abused or losing a job or accommodation due to their HIV status (Dlamini et al., 2007; Tarwireyi, 2005; Simbayi et al., 2007). Furthermore, in some cultures, sex is a taboo topic, and communication about sex between parents and adolescents is limited or altogether non-

existent, making disclosure within the family particularly difficult (Mbugua, 2007; Oshi, Nakalema & Oshi, 2005). Qualitative research conducted in the North-West Province of South Africa revealed that fears of anger and rejection prevented 8 out of 25 adolescents from confiding their HIV status to anyone (Strydom & Raath, 2005). This proportion is significantly higher than that observed in a North American study, which found that only 3% of adolescents had not told anybody about their condition (Lam, Naar-King & Wright, 2007). In contrast to the almost universal support that North American adolescents reported receiving from their families, several of the South African young people who chose to disclose to their parents were met with reactions of hostility, rejection, fear, anger, and shame (Strydom & Raath, 2005). Given the small sample size in this study, the experiences of informants cannot be generalized to the wider population in the region. Nonetheless, findings do verify that disclosure can be a difficult experience for young people and carries real risks for seropositive individuals. In a second study, focus groups with Ugandan adolescents indicated that stigma was a major barrier to disclosing to sexual partners (Bakeera-Kitaka et al., 2008). Youth worried that others would be unable to keep their secret and that their status would become common knowledge in their communities. Some of the young people who did disclose reported that their sexual partners did not believe them because they looked healthy and lacked the physical symptoms associated with AIDS (Bakeera-Kitaka et al., 2008). Research with adult populations in the region has yielded mixed results. Whilst disclosure to friends and family has been described as positive, helpful, and a relief (Freeman et al., 2007; Greeff et al., 2008), cases of community discrimination and rejection also appear to be widespread (Freeman et al., 2007).

In light of the substantial risk of adverse outcomes, it is important to take all aspects of adolescents' environmental context into account before encouraging them to disclose their serostatus to others. While the evidence seems to favour eventual disclosure, the who, how, and when questions need to be carefully considered, especially in a context where misunderstandings about HIV are common, and the repercussions of stigma are high. The amount of time elapsed since diagnosis, and younger age at of time of disclosure (to the child) have both been correlated with higher levels of disclosure to others (D'Angelo et al., 2001; Wiener & Battles, 2006), suggesting that telling others about personal serostatus may be a natural step that occurs as adolescents adjust to their condition over time.



Whether or not an adolescent has disclosed to others, social support can also be promoted in the context of the clinic or community through participation in support groups. Support groups create a space where individuals can be open about their illness, without carrying the same risk of rejection that disclosure entails. Throughout the developed world, groups have enabled adolescents to share their secret, tell their stories, ask questions about their illness and receive input from others (Ledlie, 2001; Hefez, 2002). One controlled study has highlighted the beneficial role that such interventions can play in young peoples' lives: after two years, adolescents who participated in support groups had less negative perceptions about treatment, fewer worries about their illness, and were more likely to have an undetectable viral load than those who did not (Funck-Brentano et al., 2005). While the potential for adolescent-centred, peer-based interventions remains largely unexplored in the context of Sub-Saharan Africa, Menon et al. (2007), found that Zambian adolescents living with HIV were very receptive to the idea. While not as ideal as having firm social support networks in place for day to day activities, support groups may provide a complementary, or in some cases, alternate source of social support for seropositive adolescents.

### Networks of Support among Patients at the Adolescent Clinic

#### *Experiences of Life in the Present: Sources of Support*

Given the vast majority of patients at the adolescent clinic were infected perinatally, disclosure within the family unit was not a concern and focus group participants described a strong sense of support in the context of the home. Adolescents recognized the central role that their families played in helping them cope with both their illness and life in general. Many of the respondents had lost one or both of their biological parents to AIDS, with only 23% of adolescents living with both their mother and father, and 42% being cared for by a relative or an institution (see Table 3.1). Nonetheless, they spoke positively about their caregivers, expressing feelings of love and gratitude towards the parents, grandparents, aunts, siblings, and other carers who were raising them. For example, when asked about how he felt about HIV, Jabulani responded that he felt happy because of his family:

*Jabulani* I'm happy because I stay with my grandma. And my mom died, my father died, I was two years old. So now I stay with my sister and my mother - my grandmother.

*Beauty* And your grandfather.

*Jabulani* He's dead too.

*Beauty* So you happy.

*Jabulani* Yes.

While it is normative to link death to feelings of sadness, Jabulani described his mother, father and grandfathers' deaths as a matter of fact and associated them with feelings of happiness. Though such circumstances may hardly seem like an occasion for happiness, it is evident that the 12 year old was choosing to emphasize what he had gained rather than what he had lost. Jabulani no longer had his biological parents or his grandfather, but he was still alive and living with his sister and his grandmother, who had essentially become his new 'mother'. This was a pattern that was echoed among almost all of the young people who regarded their illness positively. Participants stated that their families helped them to take their tablets, stay healthy, and accept their situation. Fundiswa said that she was able to make peace with her HIV status because she knew that she was not the only person in her family or her immediate community who was living with the virus. Among the people closest to her, she recognized that she was not alone and this gave her the strength she needed to handle life.

Family support was not limited to the domain of HIV, but was also perceived as being instrumental in the broader aspects of life. Amy stated that family was good because "they help you get through the world" while Chantal said that her family helped her "with everything".

Others highlighted the role that their families played in providing more practical assistance such as procuring and cooking food, or paying for their school uniform and fees. In contrast, adolescents who were lacking in family support expressed feelings of anxiety and depression about their lives. Thandi, who was living in an institutional home, spoke repeatedly about her longing to be reunited with her mother. She also expressed a desire to meet her father, despite the fact that she had never known him, saying that she "missed having someone there".

Box 5.1 - Living happily with HIV with the support of family\*



"I am happy because my grandma is looking after me. Now I am healthy."  
*Imran, 13 years*



"I feel happy because there is someone behind me in this, through this HIV - it's my father." *Umar, 13 years*

\* Adolescents chose photos and quoted the accompanying passages in response to the question "Find a picture that describes how you feel about HIV". See the activity description on pages 33 to 34 for more details.

For some youth, relationships within the family appeared to replace the strong peer relationships which are typical of their developmental phase. When asked about their best friends, a number of young people replied that a family member such as a mother, father or grandfather were their best friends. Several respondents said that they did not have any friends at all. However, friendship remained important for most focus group participants, who saw their friends as a source of fun and happiness.

In many cases, family members were the only ones who knew about the adolescent's HIV status. However, a number of young people had disclosed their serostatus to others and in one case, a grandmother had told her grandson's friends about his condition. Additionally, two respondents reported that their caregivers had informed their teacher and principal of their illness. Those who had disclosed to others in this study did not report any incidents of stigma. Rather, respondents said that their decision to disclose had been easy and that their friends had responded positively, either by providing support or by not making a big deal about their illness. Chantal could enumerate her friends (she said she had exactly six), and said that all of them knew that she was ill because

she had told them herself. When asked whether it had been scary to share her status with others, she answered “No!” incredulously, as if disclosure was the most natural process in the world. The adolescents who had disclosed to others also tended to be comfortable with their status and felt like they had nothing to hide. For example, both Emile and Jabulani felt good about sharing their status with others:

<i>Rachel</i>	Is it okay that other people know?
<i>Emile</i>	Yes. Cause I told them.
<i>Beauty</i>	Is it okay to you?
<i>Jabulani</i>	Yes. Because I don't feel bad.

But despite being alright about his status, Jabulani also recognized that not everybody felt the same way as him about HIV. When asked to relay a message about the virus to the world, he wrote “If you think that HIV is bad, then you must find out”, illustrating his awareness that negative views about the virus continue to persist.

Not all youth were as comfortable disclosing their secret as Emile and Jabulani. Several participants had not told anyone about their status and said that their secret was confined to their families. For Temba, the fear of stigma motivated him to keep his condition from his peers: “I've thought about telling them, but then I stop myself because I'm afraid they'll be mean to me or they'll mistreat me or they'll avoid me”. In the absence of peer support, he had however, been resourceful in seeking other forms of support, disclosing to a Sunday school teacher and relying heavily on his faith in God. At the end of the focus group interview, he asked for the audio recorder, and declared: “people with HIV, believe in God”. As he stated repeatedly during the focus group, God was his source of hope and gave him the confidence to live positively with his illness, and remain optimistic about the future. Religion also came up as a theme for other adolescents; for example, when asked about how he was feeling, Pieter picked up a picture of Jesus on the cross and said that he felt loved by God. And in one focus group interview, participants spontaneously burst out in a hymn while talking about happiness.

Aside from their families, friends, and religion, adolescents also saw clinic support groups as a source of support. Adolescents who had been ill understood the role the hospital played in helping them to maintain their physical health. Some participants also spoke positively about the fun activities they had had the chance to participate in, such as the clinic's annual Christmas party or the adolescent HIV camp. Picture #46 (Figure 5.1)

was the most commonly chosen picture in response to the question “how do you feel today?” and focus group participants expressed satisfaction about being a part of both support and focus groups. For example, when explaining why he chose the image, Temba answered: “I’m happy to be here. I’m enjoying the camaraderie that is here. I’m enjoying being with people”. Likewise, Kevin said that he felt happy because he was playing games and holding hands like the kids in the picture. Even though Amy didn’t enjoy coming to the hospital, she shared that she was happy to see everyone and liked being a part of the groups. These positive responses suggest that patients at the infectious disease clinic saw support groups as a helpful intervention. It is also interesting to note that participants did not comment on the content of the groups but on the contentment they experienced through being around other people who were like them.



Figure 5.1 – A frequently chosen picture: Picture #46

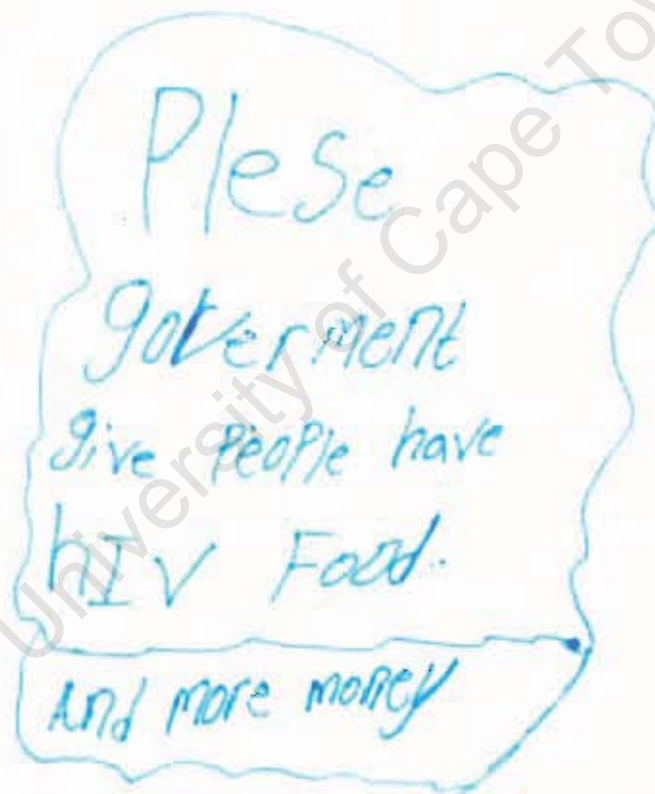
#### *Self Identified Needs: Food and Money*

Focus group respondents made references to other forms of support that they thought would benefit them. Foremost among these requests was the appeal for material support. In the youngest focus group, participants said that they wanted the clinic to provide them with more food – in particular, with fruits and vegetables. Temba also made a plea for more food, though he directed his appeal to the government. Additionally, in his message about HIV (Figure 5.2), he added that he wanted the government to make more money available to others like him. This request was also echoed by Emile and Jabulani in the following exchange:

- |                 |  |
|-----------------|--|
| <i>Rachel</i>   | What about Thabo Mbeki? What can Thabo do for you?   |
| <i>Jabulani</i> | He must give us money now. Give us money. He must give it for free. He must give us money. |
| <i>Rachel</i>   | He must give you money.  |
| <i>Jabulani</i> | Yes.   |
| <i>Rachel</i>   | What about you?  |

*Emile* Thabo. I don't want nothing to do with that man.  
*All* *Laughter.*  
*Rachel* You don't like Thabo so much.  
*Emile* Nooooooo!  
*Rachel* Why don't you like Thabo?  
*Emile* Because he doesn't want to give us money.

Both Emile and Temba were looking forward to the future because they were excited about the opportunity to earn 'good money' themselves. Temba later stated that he used to go to another support group, but had decided to frequent the clinic support group instead because he received food at the latter but not at the former. These demands for tangible support suggest that adolescents' concerns about HIV are interwoven with worries about basic needs.



Plese  
Goverment  
Give people have  
HIV Food.  
And more money

Figure 5.2 - Temba's Message about HIV

## Discussion: Meeting Support Needs

HIV positive adolescents need support in order to cope with their illness and their lives. The importance of the family context in shaping child and adolescent mental health has been widely acknowledged (Patel, V. et al., 2008), and focus group content verifies that familial support is a pivotal determinant of health and happiness in young people living with HIV. Parents, relatives, and other caregivers were repeatedly cited as sources of support for “handling life”. Notably, all of the adolescents who expressed predominantly negative feelings about the future came from challenging family circumstances, and had recently experienced parental separation, neglect, illness, and in one case, death. Strengthening families and imparting family coping skills should therefore be seen as key areas of concern. Additionally, adolescents who come from difficult family situations need to be identified and closely observed. For these individuals, alternate sources of positive support may need to be sought out.

Focus groups showed that support in the peer environment was less universal, and appeared to vary drastically from individual to individual. While friends were very important for some adolescents, others reported not having any friends at all. Some respondents had told their friends about their HIV status, and in contrast to the rejection observed in Strydom & Raath’s (2005) study of South African adolescents in the North-West Province, described disclosure as a positive event. This finding is consistent with data collected in a representative panel study of young adults in Cape Town<sup>18</sup>, in which 97% of 14 to 19 year olds reported that they would probably or definitely still be friends with someone who was HIV positive. However, according to the same survey, 18% of black and 52% of coloured respondents said that they would keep their status a secret if they were HIV positive, and only 8% of black and 26% of coloured young people indicated that they would disclose to a friend. Likewise, in this study, it was evident that many research

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<sup>18</sup> These figures were generated using wave two data of the Cape Area Panel Study (CAPS), a longitudinal and representative study of young people living in the Cape Town area, who were between the ages of 14 and 22 during the first wave of data collection. CAPS Waves one, two and three were collected between 2002 and 2005 by the University of Cape Town and the University of Michigan, with funding provided by the US National Institute for Child Health and Human Development and the Andrew W. Mellon Foundation. Given that the adolescents who participated in focus groups were all black and coloured, only data for black and coloured respondents aged 19 and younger during wave two were used in this chapter of the dissertation. Data from CAPS is publically available and additional information about the study can be found at <http://www.caps.uct.ac.za/>. See Lam, Seekings & Sparks, 2006 for more information.



participants were unwilling to share their HIV status with others. Given that a number of young people described already hostile peer environments, this hesitancy may be warranted. However, adolescents whose serostatus is confined to the family may need additional venues for social support, such as clinic support groups.

Aside from social support, focus groups revealed that adolescents may need material support. The extent of participants' poverty is unknown, but a survey of HIV positive infants at two tertiary hospitals in Cape Town revealed that half of children came from households where monthly income was below the subsistence line (as defined by the South African government) of R800 per month (Marais et al., 2008). Furthermore, it should be noted that the extra costs incurred by seropositive individuals can place an additional strain on already poor families. For instance, families at the adolescent clinic were spending up to R50 getting to and from the clinic every month. The South African government has rolled out 8.3 million child support grants (of R210 per month) since 1999 in order to help families meet the basic needs of children (Skweyiya, 2008). However, in the abovementioned study, only one third of caregivers were accessing the grant (Marais et al., 2008). Additionally, adolescents like Temba, who are older than 14 years old, are not covered by the child support grant. A foster care grant of R650/month is also offered for orphaned children up to the age of 18 years, but most children who are cared for by grannies or aunts (23% of adolescents in this study) are ineligible because their primary caregiver is not a 'legal' foster parent, as appointed by a court of law. In this study, the reasons behind adolescents' appeals to the government remained unclear. It is possible that respondents' families were ineligible or not accessing grants or adolescents may have been unaware of the support their caregivers were receiving from the government. Alternately, incoming funds simply may not have been sufficient to cover families' basic needs. The reasons for respondents' appeals should be clarified, and caregivers who are struggling to meet the basic needs of adolescents may need to work with a social worker to uncover reasons and solutions for their financial difficulties.



## CHAPTER 6

# TREATMENT MANAGEMENT

“Everyone that has a disease has stuff in common—because we all take medicine we don’t want to take—because it is hard to—especially when you’re a kid”. - *HIV positive adolescent* (quoted in Veinot et al., 2006)

### Literature Review

As children with chronic conditions become adolescents and begin to function autonomously from their caregivers, they must learn how to manage their own illness. For HIV positive adolescents, an integral part of this transition involves learning to take responsibility for their own care and treatment. Being on treatment involves a lifelong commitment to frequent clinic visits and strict compliance with a complex medication regimen that involves swallowing multiple pills at different times during the day. Anything less than 95% adherence has been associated with sub-optimal immunological and virological outcomes and the development of viral resistance (Paterson et al., 2000). Yet, when individuals take their medication faithfully, HAART has proved remarkably effective at suppressing viral replication and allowing children, adolescents and adults to live longer and healthier lives (Bangsberg et al., 2000; Watson & Farley, 1999; Flynn et al., 2004; Flynn et al, 2007; Williams et al., 2006; Martin et al., 2007). Because of its implications for virological failure and disease progression, developing treatment responsibility and adherence in HIV positive adolescents is a particularly critical challenge.

Transferring the responsibility for illness management from caregiver to child is necessary in order to prepare the adolescent for adulthood. However, decreased parental involvement has consistently been associated with poorer illness management and medication adherence in young people with chronic conditions, including those with HIV (Naar-King et al., 2008; Anderson et al., 1997; Ellis et al., 2007; Smith & Shuchman, 2005). In a study of 2088 children on treatment between the ages of 3 and 18 years, Williams et al. (2006) observed that adherence deteriorated with age and was poorest among 15 to 18 year olds. Becker et al.’s (2002) review of pharmacy records revealed poorer adherence in 18 to

24 year olds (the youngest group for which data was available) than any other age group. These findings indicate that adherence poses a particular problem for adolescents. This phenomenon is not restricted to young people living with HIV, but has also been observed in young people living with diabetes, cystic fibrosis and other long-term illnesses (Drotar & Ievers, 1994; Smith & Shuchman, 2005; Stewart & Dearmun, 2001)

A number of cross-sectional North American studies have attempted to measure adherence in both vertically and horizontally infected adolescent populations, reporting adherence rates ranging from 27% to 81% (Rao et al., 2007, Murphy et al., 2003; Murphy et al., 2001a; Steele & Grauer, 2003; Belzer et al., 1999; Farley et al., 2008; Naar-King et al., 2006a; Murphy et al., 2005; Martinez et al., 2000; Martin et al., 2007). Inconsistencies in research method and definitions of adherence account at least in part for the wide variation in figures, and make it difficult to identify trends across studies. There is however a consensus that HAART adherence among adolescents is most often sub-optimal and needs to be improved. A longitudinal study found that because of poor adherence, only half of 15 to 22 year olds who achieved an undetectable viral load were able to maintain this outcome for longer than 12 months (Murphy et al., 2005). In the same study, the median time to non-adherence was 1 year. This high rate of defection is a reason for concern and suggests that teenagers may face barriers and challenges to compliance which are particular to their developmental phase.

Three types of non-adherent adolescents have been described in the literature (Jacquin & Levine, 2008; Rianthavorn & Ettenger, 2005). *Accidental non-adherers* unintentionally miss doses of their medication, either through scheduling problems, inattentiveness, or mere forgetfulness. This form of non-adherence appears to be common among young people living with HIV; scheduling and routine disruption issues are frequently cited by adolescents as major barriers to compliance (Murphy et al., 2003; Rao et al., 2007; Veinot et al., 2002). For instance, interviews with French adolescents revealed that 19 out of 24 study participants had involuntarily missed doses of their medication (Trocmé et al., 2002b). In contrast, *invulnerable non-adherers* believe that missing doses will not have any negative effect on them. Such perceptions of invulnerability may be based on a lack of understanding about treatment (Abadia-Barrero & Castro, 2005), or a belief that that the negative consequences of non-compliance will not happen to them (Rianthavorn & Ettenger, 2005). However, at least one study has failed to find such feelings of

invulnerability in youth living with HIV (Rao et al., 2007). More often, it appears that non-compliant HIV positive adolescents are *decisive non-adherers* who are well informed about the potential consequences of their actions, but who nonetheless make a conscious and intentional choice to skip doses. There have been reports of young people lying to their physicians and hiding their medicine from caregivers in order to give the illusion of having taken their pills (Trocmé et al., 2002b; Rao et al., 2007). Adolescents who elect to stop or miss doses of their treatment cite several reasons for doing so, including side effects, stigma, the unpleasant taste of tablets, feelings of depression, and the desire to be free and autonomous like other people their age (Veinot et al., 2005; Rao et al., 2007; Trocmé et al., 2002).

Quantitative work has found a wide variety of factors which are associated with HAART adherence in adolescents. At the individual level, young people who attend school, drink less alcohol, and display higher levels of self efficacy are more likely to be adherent (Murphy et al., 2005; Naar-King et al., 2006a). On the other hand, the recent occurrence of a stressful life event, the exhibition of psychosocial distress and a diagnosis of depression have all been correlated with poorer medication compliance (Williams et al., 2006; Naar-King et al., 2006a; Murphy et al., 2001a). There is some evidence to suggest that gender also impacts on adherence, though studies have variously reported that males (Murphy et al., 2001a) and females (Williams et al., 2006) are more likely to experience adherence problems. This discrepancy may be due to the difference in population samples (Murphy et al.'s study population comprised high risk adolescents above the age of 15, while Williams et al. examined perinatally infected children with a mean age of 11.5), but more research is required to clarify the role that gender plays. The relationship between adherence and social support, though consistently reported in adult studies (Ammassari et al., 2002), also remains unclear in adolescent populations. Williams et al. (2006) found that the use of a buddy system was associated with improved adherence, suggesting that social support may play a role in promoting treatment observance. However, other studies have failed to find a similar correlation, though it has been noted that social support may indirectly affect adherence by increasing self-efficacy (Naar-King et al., 2006a; Murphy et al., 2001a).

In the case of perinatally infected adolescents, the young person's relationship with his or her primary caregiver is integral in mediating adherence. Caregivers who use drugs

or alcohol, or are HIV positive themselves are more likely to have non-adherent children, while those with a higher level of education and who are knowledgeable about their child's antiretroviral regimen tend to have more adherent children (Williams et al., 2006; Martin et al., 2007; Naar-King et al., 2006b). A North American study found that children who live with a biological parent display poorer compliance than those who live with another relative or a foster parent (Williams et al., 2006). However, research on a younger group of children in Togo observed the converse to be true (Polisset et al., 2008), while a Thai study (also with younger children) did not observe any association between the two factors (Safreed-Harmon et al., 2007).

Two recent studies have examined HAART adherence among children (including adolescents) in the context of sub-Saharan Africa. In a sample of 170 Ugandan children between the ages of 2 and 18 years, Nabukeera-Barungi et al. (2007) used multiple methods to measure the number of participants who had  $\geq 95\%$  adherence. Caregiver self-report indicated that 89.4% of children were adherent, clinic-based pill counts yielded a rate of 94.1% and unannounced pill counts at the children's homes measured 72% compliance. The study also found that when the caregiver was the only person who knew the child's HIV status, the child was more than three times more likely to be non-adherent. Additionally, children who had been hospitalized on more than two occasions exhibited better adherence than those who had not. No relationship was found between adherence and any of the other child factors, including age, gender, distance between the child's home and the hospital, orphan-status and disclosure to the child. However, a second Ugandan study did observe a relationship between disclosure and adherence. In this study, 8/12 children (aged 5-17) who knew their status had never missed a dose, compared to only 3/14 who did not know their status and 1/16 who had undergone partial disclosure (Bikaako-Kajura et al., 2006). As expressed by the caregiver of a 14 year old girl,

...[disclosure] helped because even when she gets tired of drugs then she remembers that it is good to take the drug and she takes it...I have where to start from to encourage her to take drugs because you cannot tell a child to take drugs everyday when she does not know for what reason (Bikaako-Kajura et al., 2006: S88).

While differences in adherence measures and a small sample size make it difficult to extract rates from Bikaako-Kajura et al.'s research for comparison, compliance in Nabukeera-Barungi's study was high when compared to similar studies conducted in developed countries (Reddington et al., 2000; Gibb et al., 2003; Naar King et al., 2006a;

Williams, 2006). Adherence studies among both adult (Mills et al., 2006; Attaran, 2007) and child populations (Muller et al., 2008; Wamalwa et al., 2007; Reddi et al., 2007) have revealed a similar pattern, and offer compelling evidence that despite poverty, low education levels, and under-resourced healthcare systems, HIV positive people living in sub-Saharan Africa are as, if not more capable of sustaining good adherence than individuals in other parts the world. However, there is a deficiency of research specifically concerning adherence among adolescents in the region, and it is therefore premature to speculate whether the trend holds true in this population. Clearly, more research is needed to further explore the issue.

### Treatment Perceptions at the Adolescent Clinic

I did not attempt to measure medication adherence as a part of my focus groups; doing so would have required a less exploratory and more targeted approach. However, the subject of antiretrovirals did come up in several interviews. Among adult populations, patient beliefs about treatment have been shown to correlate with adherence to both health advice and medication (Gauchet, Tarquinio & Fischer, 2007; Gonzalez et al., 2007). Though it remains unknown whether this is also true for adolescent populations, the perspectives of the young people discussed here nonetheless provide insight into the relationships they have with their treatment regimens.

#### *Experiences of Life in the Present: The Positive Role of Medication*

In general, adolescents regarded their antiretrovirals positively, recognizing that the pills were an important and beneficial part of their daily lives. For example, some participants described their tablets as “nice” or “good to me”, while others spoke about the hospital being a positive place precisely because it provided them with tablets. However, despite the general consensus that antiretrovirals were agreeable, several respondents, particularly those in the 10 to 11 year age group, were unable to explain why they liked their medicine. Among these participants, questions probing the reasons for their favour were met with uncertainty and silence. It appears that while these young adolescents had absorbed the message that their medication was good, they had yet to fully grasp the

grounds on which the value of their tablets was founded. Older adolescents exhibited a better understanding about the importance of their tablets and were aware of the role that they played in attaining and maintaining physical wellbeing. These participants recognized that antiretrovirals helped them to stay strong and healthy. A number of adolescents also demonstrated comprehension about the importance of adherence. For example, when asked about what was good in his life, Jabulani responded that his sister's phone was good because "she sets the alarm on her phone...for the tablets". Temba said that when he watched the morning and evening news, he knew it was time to take his tablets. Adolescents did not report skipping doses of their medication in any of the focus groups. Even two girls who said that they hated their pills claimed to always take them because they knew that they had to.

#### *Views on the Future: 'I am Confident the Tablets Will Work'*

Some adolescents also made reference to their medication when talking about the future, displaying an understanding that the nature of their treatment was lifelong. For these respondents, HAART gave them the confidence to feel positively about their future lives. Imran expressed an uncompromising faith in his medication, stating "I feel sure [about the future]. I feel sure because I am confident the tablets will work". Jabulani said that he felt happy about the future because the tablets were working and he was feeling strong. However he simultaneously expressed anxiety about missing doses, saying that the fact that his grandmother sometimes put his tablets away where he couldn't find them, made him feel nervous about the future.

#### *Self Identified Needs: Taking Tablets*

When asked about how life could be made better, participants in one focus group said that clinic staff could assist them by helping them take their tablets. Respondents did not however, specify how this could be done. It is possible that adolescents were referring to the role the clinic played in distributing tablets, or that they were appealing for more information about their medication. Yet, this issue was not probed and participants' expectations therefore remain unclear.

## Discussion: Meeting Treatment Needs

Given that adherence has such a profound impact on physical health, adolescents need ongoing support for taking their medication. In this study, younger focus group participants (10 and 11 year olds) displayed a lack of understanding about why their medication was important, indicating a need for basic information about how HAART works. Slightly older adolescents had a firmer grasp about the value of their tablets. However, as was evident from Jabulani's worries about missing doses, they may need instrumental support from caregivers to incorporate their medication into their daily routines. This should involve a clarification of caregiver and child roles in regards to treatment, and communication about where pills are kept and when they are to be taken (Naar-King et al., 2008).

The young people in this study were overwhelmingly positive about their medication regimens. But while their responses are a reason for optimism, it is premature to claim that medication adherence does not pose a problem in the patient population of the adolescent clinic. Through my volunteer work at clinic I was aware that several young people were having adherence problems, some of whom had even stopped treatment completely because of their poor compliance. However, the voices of these adolescents remained unheard in focus groups. In the face of strong, positive opinions about treatment, individuals who were non-compliant or who perceived their treatment negatively may have been hesitant to share their views. The silence could have also stemmed from the exploratory nature of the study. Because adolescents were asked to identify the issues most important to them, those who were more lackadaisical about their treatment may have been less inclined to raise the issue. If this were the case, more targeted questions might have been helpful in elucidating negative views. Such questions were however, beyond the scope of this particular study.

Furthermore, it is important to note that the sample population excludes the very individuals who are most likely to be experiencing adherence problems. Recruitment to the study necessitated that adolescents were in attendance at the clinic on a day where focus groups were being held. Therefore, young people who missed their clinic appointment on a research day could not be invited to participate in the study. Notably, only one of the clinic's eleven 15 to 19 year old patients participated in this study because

the others were not present on a focus group day. While I cannot comment definitively on treatment management in this older group, other studies have shown that adherence is particularly problematic in late adolescence (Williams et al., 2006; Becker et al., 2002). According to the clinic register, several of the older adolescents had missed repeated clinic appointments, and given that medication is prescribed and distributed at the hospital, it is unlikely that these patients were consistently complying with their medications.

Most of the adolescents in this study were still highly reliant on their caregivers for assistance with their medication regimens. However, as youth get older and become responsible for their own treatment, they will need support specific to this transition. It should be anticipated that adherence problems will become increasingly common during late adolescence, and older patients may need to be closely observed through case management. Targeted engagement with a social worker or other mental health professional may also be necessary to determine and address the factors influencing adherence in non-compliant individuals. Active and continual affirmation of the importance of treatment, the promotion of understanding about how HAART works, and practical support in taking tablets from an early age are necessary in order to minimize the likelihood that youth will defect as they get older. Addressing potential adherence problems before they start is easier than switching into crisis management mode once problems become manifest. The same is also true for other behaviours and this is the fifth and final issue that I investigate in this dissertation.



## CHAPTER 7

# RISKY AND HEALTHY BEHAVIOUR

“If you say HIV infected people should abstain from sex it is like condemning us to die.” – *HIV positive adolescent* (quoted in Bakeera-Kitaka, 2008)

### Literature Review

With the increased autonomy of adolescence comes the freedom to experiment and make decisions independently. Young people use this newfound freedom to try out different activities, some of which may have negative repercussions on personal health. A number of these behaviours, such as drinking alcohol and engaging in romantic or sexual relationships, are common in adult life and can be healthy when managed responsibly. Others, such as injection drug use, almost always have deleterious health effects and should be avoided completely. It is therefore important to encourage and establish patterns of behaviour which enable healthy living during this period. This task is all the more important for adolescents living with HIV, as the competent development of healthy behaviour (as opposed to behaviour which poses risks to personal health) helps maintain positive immunological and virological outcomes. Existing literature on this subject looks at two main areas: substance use and sexual behaviour. Research on each of these issues is reviewed below.

### *Substance Use*

Experimentation with drugs and alcohol is common during adolescence (Futterman, 2004). However, the use of these substances has been associated with an augmented risk of injury and death (Flisher, Ziervogel & Charlton, 1996), problems at school (Flisher et al., 2003b; Sutherland & Shepherd, 2001) and an increased probability of engaging in risky sexual behaviours (Flisher, Ziervogel & Charlton, 1996; Magnani et al., 2004; Stanton et al., 1998). For HIV positive adolescents, substance use has also been correlated with decreased medication adherence, which in turn results in poorer immunological and virological outcomes (Murphy et al., 2005). Thus, it is imperative to encourage young people living with HIV to make wise choices about drugs and alcohol.

Research indicates that substance use among horizontally infected adolescents is common in the United States (Eastwood & Birnbaum, 2007; Kadivar et al., 2006; Schwarz et al., 2001; Schneir et al., 1998). Tobacco, alcohol and marijuana are the most frequently used substances, though a small proportion of adolescents also report using harder drugs (Eastwood & Birnbaum, 2007; Murphy et al., 2001b; Naar-King et al., 2006d; Rotheram-Borus et al., 2001). Among this population, depression and health anxiety have been correlated with higher levels of alcohol and marijuana use respectively, while self efficacy and social support specific to reducing substance use have been shown to result in healthier behaviour in this area.

Although there are few studies examining the issue among perinatally infected adolescents, at least one study has found that rates are significantly lower among this group (Bernstein, Trexler & D'Angelo 2006). In contrast to findings of research conducted with high risk populations, the report showed that only 13% of the study population (consisting of vertically infected young people aged 12 to 21 years) reported substance use, which was less than a third of the comparable figure for the general adolescent population. Substance use thus appears to differ drastically in accordance with the mode of HIV transmission. As might be expected, horizontally infected adolescents are likely to engage in high risk behaviours, including substance use. Conversely, vertically infected adolescents may be insulated against these behaviours, perhaps because caregivers are more likely to be involved in their care.

To my knowledge, only one published study has examined substance use among adolescents living with HIV outside of a developed world context. The study, conducted in Thailand, measured a lifetime alcohol use rate of 70% among a group of HIV positive youth (Rongkavilit et al., 2007). This figure was comparable to findings among horizontally infected North American adolescents. However, unlike American results, experience with other drugs - including marijuana - was low in the Thai sample. Additionally, substance use was lower than in general studies conducted among Thai youth (Rongkavilit et al., 2007). The study's divergences from American research highlights the importance of context in shaping substance abuse patterns, and suggests that studies that examine substance use in local environments is necessary.

Sex is a normal part of adult life, and sexual initiation often occurs during the second decade of life. Like HIV negative teenagers, HIV positive adolescents are likely to date and may engage in sexual intercourse. However, with sexual behaviour comes the potential for unwanted pregnancy, acquisition of another sexually transmitted disease (STD), or reinfection with a different strain of HIV. Additionally, there is also the possibility of transmitting the virus to others. The potential costs of engaging in sexual activity are thus exceptionally high for both infected young people and their partners. Yet in the face of these serious consequences, there is also a danger that adolescents might become overly negative, ashamed or confused about their sexuality. For HIV positive youth, competency in the domain of sexual health must necessarily involve the development of behaviours that minimize the risk of undesired consequences resulting from sex. However, addressing sexual behaviour should go beyond risk reduction and encourage the formation of a positive sense of sexuality among young people living with HIV (Birungi, 2007).

Horizontally infected adolescents continue to have sex, even after they become aware of their serostatus. In the United States, high risk sexual behaviour is extremely prevalent in this group, with various studies reporting high rates of partner exchange (Eastwood & Birnbaum, 2007; Rotheram-Borus et al., 2001), lifetime STI infection (Kadivar et al., 2006; Johnson et al., 2003), sexual abuse (Kadivar et al., 2006), and transactional sex (Johnson et al., 2003). While unprotected intercourse is less prevalent among HIV positive adolescents than their peers (Sturdevant et al., 2001; Belzer et al., 2001), condom or contraceptive use nonetheless remains inconsistent in a significant portion of young people (Naar-King et al., 2006c; Rotheram-Borus et al., 2001; Murphy et al., 2001b). The decision whether or not to use a condom during intercourse appears to be mediated by a wide range of individual and environmental factors. Poor mental health, depression, substance use, long term relationships, and a larger age gap between partners have all been associated with higher rates of unprotected sex (Rice, Batterham & Rotheram-Borus, 2007; Murphy et al., 2001b; Naar King et al., 2006c; Sturdevant et al., 2001). Conversely, disclosure of serostatus to a sexual partner, perceived control, self efficacy, and social support particular to reducing risky sexual behaviour appear to increase

the likelihood that the adolescent will practice safe sex (Johnson & Buzducea, 2007; Rice, Batterham & Rotheram-Borus, 2007; Sturdevant et al., 2001; Naar-King et al., 2006c)

Increasingly, perinatally infected youth are also engaging in sexual behaviour, though at slightly lower rates than their uninfected peers (Wiener, Battles & Wood, 2007; Bernstein, Trexler & D'Angelo, 2006). A study of 57 vertically infected adolescents between the ages of 13 and 24 found that 79% of youth had a prior or current boyfriend or girlfriend, and 33% were sexually experienced (Ezeanolue, Wodi & Patel, 2006). Of those who had had sex, 26.3% did so before the age of 15 years. In a second group, Wiener, Battles & Wood (2007) reported that sexual initiation rates jumped from 28% to 41% over 21 months. Little is known about contraception choices in this group. While Wiener, Battles & Wood's study indicated that condom use was high, high pregnancy rates among sexually active adolescents suggest that unprotected sex is nonetheless common (Ezeanolue, Wodi & Patel, 2006; Frederick et al., 2000).

Whether planned or not, HIV positive adolescents are having children. Between 2001 and 2004, data from 28 American states indicates 1090 HIV infected women between the ages of 13 and 21 gave birth to 1183 babies (Koenig et al., 2007). This is no new phenomenon among horizontally infected youth; in fact, a large proportion of horizontally infected young people are diagnosed with HIV during pregnancy (Levin et al., 2001). However, with mounting frequency, perinatally infected adolescents are also falling pregnant (Levine, Aaron & Foster, 2006; Brogly et al., 2007; Zorilla et al., 2003; Chibber & Khurranna, 2005). Despite the low rates of sexual activity among this group, two American studies have observed that pregnancy rates among sexually active, vertically infected girls are higher than in the general adolescent population (Bernstein, Trexler & D'Angelo, 2006; Ezeanolue, Wodi & Patel, 2006). Alarming, the vast majority of pregnancies in both horizontally and vertically infected adolescents are accidental. Data on 147 American girls from the Perinatal Guidelines Evaluation Project (PGEP) found that 83% of pregnancies were unplanned (Koenig et al., 2007). The PGEP study also found high rates of sexual risk behaviour among the study sample; 67% of participants had been pregnant on a previous occasion, 89% reported inconsistent condom use before becoming pregnant, and 43% did not use any form of birth control at all. Despite knowing their status, many of the girls continued to practice unprotected sex, a finding that is consistent with other reports on pregnant HIV positive girls (Levine, Aaron & Foster, 2006).

While many pregnancies are unplanned, older adolescents may make a conscious decision to have children. Procreational intent has been studied in both adult and adolescent women and it has been shown that despite their serostatus, many individuals desire to have children and engage in unprotected sex with the aim of becoming pregnant (Chama, Morrumpa & Gashan, 2007; Ezeanolue, Wodi & Patel, 2007; Bakeera-Kitaka et al., 2008). Where prenatal monitoring and advanced prevention of mother to child transmission (PMTCT) programs are available, the risk of vertical transmission has been greatly reduced, and birth outcomes are generally favourable for both mother and child. In Chibber & Khurranna's (2006) Indian cohort of perinatally infected adolescents, all 26 girls who elected to carry their pregnancy to term had smooth pregnancies and gave birth to HIV negative children.

A recent study has looked at the reproductive health needs of adolescents in a sub-Saharan African context. The Ugandan study, which generated data through focus groups with 75 adolescents between the ages of 11 and 21 years, found that just over a quarter of participants had initiated sexual activity (Bakeera-Kitaka et al., 2008). Particularly concerning were the misconceptions that some of the adolescents held about sex. For example, a number of girls believed that they could not fall pregnant because of their infection, and others thought that the virus was only present in blood and not in semen. Hope for the future, good counselling, and fear of pregnancy were given as motivations for practicing safe sex. Conversely, environmental factors, including peer pressure, stigma, and poverty were seen as barriers to adopting preventative behaviours.

In most parts of sub-Saharan Africa, women have more children at an earlier age than in other regions of the globe. The total fertility rate in the region is 4.71 children per women, compared to 2.56 children per women globally and 1.58 children per women in the developed world (UNFPA, 2007). Though girls are getting married later than in the past, early marriage is still common in some areas of the sub-continent; for example, in West Africa, 38% of 15-19 year old girls are in marital relationships (Mensch, 2005 in Blum, 2007). In this context, it is reasonable to expect that reproductive health, which has typically been considered under the domain of the adult HIV literature, will be a more salient issue for older adolescents living with HIV in sub-Saharan Africa than in the developed world. In Bakeera-Kitaka et al.'s (2008) study, the desire to have children was

identified as a barrier to preventative behaviours among Ugandan adolescents. Reproductive health information and planning is therefore important and necessary.

### Healthy Behaviour at the Adolescent Clinic

#### *Experiences of Life in the Present: High Risk Behaviours as 'Bad'*

The adolescents in this study did not appear to be engaging in high risk behaviours. Any participants who were doing so remained silent on the issue throughout the focus groups. While they acknowledged that drugs and alcohol were common among their peers, respondents saw substance use as something negative, with which they did not want to be involved. For Temba, his determination not to engage in such behaviours led him to isolate himself from other young people in his community:

People from church are my friends and I used to have friends, but they didn't go to church and they wanted...tried to get me involved in all kinds of thing like smoking, drinking, things that I didn't want to do and I'm happy with these friends because they talk about positive things. Makes me feel good.

Rather than seeking acceptance from peers by engaging in activities he saw as detrimental, Temba chose to focus on the positive relationships in his life. However, this came with a cost – when asked about his relationships with his friends, he replied that he did not have any friends except for his mother and father. Other young people also chose to separate themselves from those who were engaging in high risk behaviours. Emile stated “I don't want to play with friends who do drugs” while Jabulani declared “I don't want to steal. I don't want to play with strangers who are stealing things from other people”. Like Temba, Jabulani also mentioned that he stayed at home, though his separation was based on his desire to stay away from all the fighting that his friends were engaging in. While Temba turned to his church, Jabulani also identified a more positive influence in his life:

*Rachel*            We have friends, hospital, playing, tablets, what else is good?  
*Jabulani*        Soccer. Soccer. Soccer keeps you away from the drugs.

None of the adolescents spoke about sexual behaviour, though questions on the issue were not specifically asked. A handful of the boys did however mention that they had girlfriends, and exhibited great curiosity about the condom display which was situated on

a desk in the room where focus groups were held. At least one adolescent was aware of the importance of using condoms, as is evident in his message about HIV (Figure 7.1).



Figure 7.1 – Emile's Message about HIV

#### Views on the Future: Procreational Intent

Study participants expressed a desire to have families of their own in the future. As is evident from this lively exchange in the youngest focus group, for some adolescents this involved having children, while for others, it didn't:

- Rachel* Do you want to have families?  
*Kids all start gesturing at once. Nodding heads, etc.*  
 Who would like to have families? Put up your hand if you would like to have a family when you grow up.  
*Everyone except for Xoliswa puts up their hand.*  
 Oh, everyone would like to have a family. Do you want children?
- Boy* NO
- Rachel* How many...who wants children?
- Boy* Not me! NO,  
*Thabo, Lindiwe, Sibongile and Vuyo all have their hands up.*
- Rachel* One, two, three four. You want children? How many?
- Lindiwe* Two
- Sibongile* And me! I want three.
- Rachel* You want three.
- Bongani* I want 1000. Giggles.

*Multiple* I want one, I want three. I want one.

Temba also expressed a desire to have children. He shared that he wanted to have a family, but felt he needed to finish his studies first, so that he could afford to feed and take care of his family. He stated that he wanted three sons, because they would be able to take care of him. But while he had clearly given the issue some thought, neither Temba nor any of the other participants who wanted children made reference to how their HIV status might impact on their decision.

#### Discussion: Meeting Healthy Behaviour Needs

This group of young people did not seem to be engaging in high risk behaviours. Perhaps because of their young age or a protective aspect of their infection, most respondents were choosing to separate themselves from their peers who practiced behaviours that they deemed as 'bad'. These findings can be explained in a number of ways. Firstly, adolescents in this study were young, averaging only 12.5 years of age. Engagement in risk behaviours becomes increasingly common as individuals get older and the fact that participants were still in early adolescence is a probable cause for the negative views on risk behaviours expressed in groups. One study of students in Cape Town found that while only 13% of males and 3% of females had made their sexual debut by the age of 14, these figures jumped to 23% and 20% by the age of 17 (Flisher et al., 2006). Combined data from waves one, two and three of CAPS<sup>19</sup> indicate that the mean age of sexual initiation is 16.1 years and 16.9 years for black and coloured adolescents respectively. Additionally, in the third wave of the study (completed in 2005), 29% of black and coloured 15-19 year olds had consumed alcohol, 35% had smoked cigarettes and 7% had used drugs in the preceding month. As the clinic population ages, it is therefore likely that views on high risk activities will change and engagement in such behaviours will increase. It should be anticipated that there will be multiple activities, both healthy and high risk, competing for adolescents' attention as they get older.

As aforementioned, the clinic's oldest adolescents did not participate in focus groups so perceptions and behaviours of HIV positive individuals in middle and late

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<sup>19</sup> For more information on the Cape Area Panel Study (CAPS), see the footnote on page 51.



adolescence cannot be confirmed. However, other studies can provide hints about what might be expected in this group. In a sample of HIV positive and negative adolescents living in a peri-urban community near Cape Town, Jaspan et al. (2006) found that 48% of seropositive 11 to 19 year olds had had sex with a mean of 1.8 partners. Of those who had experienced first intercourse, only 50% of infected males and 69% of infected females had ever used a condom (Jaspan et al., 2006). However, these findings are limited by the small sample size of infected individuals and the specificity of the community where the research took place. In the general adolescent population, data from wave two of CAPS indicate that 48% of black and 35% of coloured 14 to 19 year olds living in Cape Town have initiated sexual activity. Additionally, CAPS data show high rates of condom use, with 83% of black and 97% of coloured adolescents reporting to have used a condom at first intercourse, and 80% of sexually active black and coloured 14 to 19 year olds claiming to have always used a condom with their last partner. These figures are encouraging, indicating that young people in Cape Town are practicing safe sex. Yet, research which specifically examines how being HIV positive affects adolescent sexual behaviours is clearly needed.

Beyond age, an alternate explanation for the views expressed in focus groups may be that respondents are somehow insulated from high risk behaviours because of their HIV status. This has been observed in perinatally infected populations in other parts of the world (Lima & Pedro, 2008; Wiener, Battles & Wood, 2007; Bernstein, Trexler & D'Angelo, 2006). It is possible that caregivers are protective of HIV positive children and supervise them more closely because of their condition. Or, because of their longstanding engagement with the healthcare system, adolescents themselves may be more conscious about the consequences of high risk behaviours than their peers. A third scenario is that the physiological effects of HIV exclude young people from certain behaviours. For example, HIV positive children are often neurocognitively or intellectually delayed (Borwn, Lourie & Pao, 2000), and may therefore be less inclined to engage in high risk activities. Studies have also shown that individuals who are less developed physically are less likely to engage in sexual behaviour (Wiener, Battles & Wood, 2007), and HIV positive adolescents may experience delayed sexual debut by virtue of their physical underdevelopment.

In this study, some adolescents identified alternate activities which helped keep them away from high risk behaviours, such as sport and church involvement. Continued engagement with such pursuits should be encouraged and facilitated. As suggested for mental health interventions, it is important to create enabling family, school and community environments, as it is in these settings that risky and healthy choices are made on a day to day basis. Wild et al. (2004a & 2004b) found that in a large cohort of adolescents in Cape Town, individuals who had low self-esteem in the school and family domains and high self-esteem in the peer domain were more likely to engage in high risk behaviours. Among, girls, low body image and global self-worth were also associated with risk behaviours (Wild et al. 2004a; Wild et al., 2004b). Finding ways to increase self-esteem, particularly in the contexts of the family and school may thus be an appropriate area of focus.

Clinics can also play a role by providing relevant information about risk behaviours, giving adolescents the necessary skills to make healthy decisions, and offering a sense of belonging through support groups. Additionally, clinics constitute an appropriate venue for the promotion and monitoring of reproductive health. Like HIV positive adolescents elsewhere (Ezeanolue, Wodi & Patel, 2007; Bakeera-Kitaka et al., 2008; Funck-Brentano, Veber & Blanche, 2007), many focus group participants expressed a desire to one day have children. Funck-Brentano, Veber & Blanche (2007) observe that unlike adolescents living with cancer, young people with HIV usually feel healthy, and have the same desire for children as their peers. Health care providers can assist seropositive individuals to have children while minimizing the risk of vertical transmission, but individuals need to be informed about their options in order for this to occur. While this may not be an immediate need for all individuals, it is important that information dissemination occurs earlier, rather than later so that young people are aware that when the time comes to start a family, they have choices.

## CHAPTER 8

# CONCLUSION

This exploratory study has investigated the experiences and needs of a group of adolescents growing up with HIV in the Western Cape. The project was motivated by the rapidly increasing population of South African young people on or in need of antiretroviral therapy, and presents a preliminary analysis of the broad issues confronting this up and coming group. Like their counterparts in other parts of the world, the adolescents in this study were facing a number of challenges that are related to their HIV status. In fact, each of the five psychosocial issues that were identified in the existing literature also came up during focus groups, though this had not been my intention when originally designing the research project. Rather, these themes were raised by adolescents themselves, as subjects that concerned them in the present, affected their views on the future, and presented areas of need. Throughout the research process it was evident that in spite of differences in geographic location, social and cultural contexts, available resources, and health care systems, this group of South African adolescents was dealing with many of the same issues that are encountered by HIV positive young people from around the world.

Firstly, seropositive adolescents need to acquire knowledge and understanding about HIV and AIDS. This occurs through disclosure of serostatus to the child and ongoing communication about the virus. Young people must be given information about their condition, but beyond basic education, they must also develop a personal understanding of what it means to live with the virus. This is particularly crucial during adolescence, as individuals approach cognitive maturity and become increasingly aware of the social meanings attached to their condition. Open communication in the household and at the clinic can facilitate this process, and is desired by young people themselves.

Secondly, adolescents need to find ways to achieve and maintain mental health. Personal wellbeing is affected by HIV, and unsurprisingly, most individuals in this study felt sad, anxious and angry about their serostatus. However, the virus is not the only, or necessarily even the most important determinant of mental health. Rather, HIV positive young people are also influenced by stressors in the family, peer, school, and community

contexts. Similarly, HIV is only one consideration that focus group participants took into account when looking towards the future. Despite their status, most respondents remained hopeful and were excited about the opportunities the future held. However, it was also evident that many of these young people will require assistance developing the practical skills that will enable them to reach their future dreams.

Thirdly, young people need support, whether it is social, spiritual, or material in nature. Strong support networks enhance the ability of individuals to overcome the multiple stressors in their lives. Support from the family is particularly important, both in terms of HIV and in more general aspects of life. Mobilizing support outside of the home is facilitated by sharing personal serostatus with others. However, while disclosure can be a positive and enriching experience, it also carries the risk of rejection and discrimination. Clinic or community support groups can provide a safe place to seek support, especially for those who are not yet ready to disclose outside of the family unit.

Fourthly, because adherence to HAART is integral for attaining and sustaining positive virological and immunological outcomes, HIV positive young people need support particular to managing their treatment. During early adolescence, caregivers tend to be heavily involved in their children's day to day routines, and provide practical and instrumental help in taking tablets. However, as children grow up they must take increasing responsibility for their clinic appointments and HAART regimens. During this transition, it appears that individuals are at high risk of becoming non-adherent. Middle and older adolescents may therefore need to be targeted with interventions which enhance adherence to medication and promote responsible treatment management.

Finally, young people living with HIV need to learn how to make healthy decisions about substance use and sexual activity. Unsurprisingly, horizontally infected adolescents report high rates of risk behaviour. Conversely, young people who are infected perinatally, including those who participated in focus groups, appear to be less likely to use drugs and alcohol or engage in sexual activity than their uninfected peers. Nevertheless, because these activities can have serious health repercussions for young people and their partners, both groups need to be targeted with interventions that prevent risky behaviours and promote healthy alternatives. It should also be noted that a significant proportion of seropositive adolescents dream of having families and children of their own in the future. With advances in PMTCT, it is possible for HIV positive people

to have children with minimal risk to themselves and their babies. However, in order for this to occur, pregnancy needs to be carefully planned and monitored. Education about reproductive health options is therefore necessary.

The five themes addressed in this dissertation are unified by the fact that they constitute the lived realities of HIV positive adolescents. This study has examined these realities from a developmental perspective, highlighting adolescence as a unique phase during which seropositive individuals acquire a deeper awareness of the role that the virus plays in lives. While a small sample size and an unrepresentative study population preclude the generalization of results, findings nonetheless provide a glimpse into the world of a group of HIV infected young people, creating a knowledge base for further investigation.

Developmental stage was the only variable considered in this study; however it is both possible and probable that other variables such as race, socioeconomic status, or family structure affect the way that young people experience and understand their illness. As mentioned at the outset of this dissertation, the study was exploratory in nature, focusing more on identifying areas of need than on linking contextual factors to individual's responses. Focus groups revealed that adolescents held a spectrum of views and experiences, and pointed towards a number of environmental variables, such as family relationships and peer group dynamics, that affect adolescents' health and happiness. However, these contexts remained largely unexplored among patients at the clinic. Given that the literature concerning the psychosocial aspects of HIV in adolescents living in sub-Saharan Africa is extremely sparse, targeted research addressing any of these five issues addressed in this dissertation would be beneficial. In particular, future studies must seek to uncover reasons for divergence by examining personal and contextual correlates of adolescents' perceptions, experiences, behaviours, and needs relating to their illness. This will involve teasing out the nature of the intricate relationships that influence their knowledge and understanding about their serostatus, mental health, networks of support, treatment management and behavioural decision making. Such research is urgently needed in order to inform effective policy and practice concerning this unique and growing group.

I began this dissertation by introducing Amy, and it therefore seems appropriate that as I draw this work to a close, I might allow her to have the last word. Amy is thirteen year old South African adolescent, who is growing up with HIV. In some ways, her day to day experiences differ from those of her peers, and she has distinct needs that

are related to her serostatus. But with the help of her tablets and the people in her life, Amy can attend school, hang out with her friends, and engage in the same sorts of activities as other young people her age. Amy is finding ways to live positively with HIV. And just as she has declared to have already done herself, this young girl wants others to know that they too must learn how to “Turn HIV to HIV victory”.

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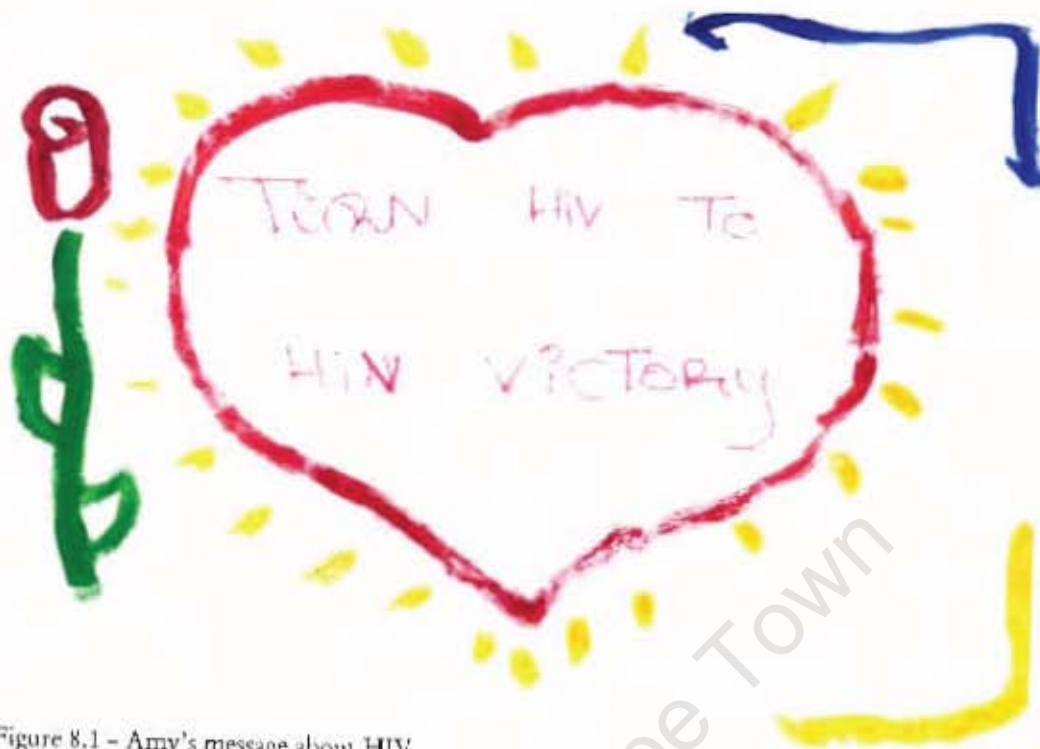


Figure 8.1 - Amy's message about HIV

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# APPENDICES

## Appendix A – Focus Group Participants

### I. Focus group participants, listed by group

<b>Group 1</b>					
Group #	Pseudonym	Gender	Year of Birth	Age	First Language
1	Pieter	Male	1994	13	Afrikaans
1	Kevin	Male	1995	13	Afrikaans
1	Grace	Female	1995	13	Afrikaans
1	Talitha	Female	1995	12	Afrikaans
1	Fundiswa	Female	1995	12	Xhosa
1	Thabela	Female	1996	12	Xhosa
1	Thandi	Female	1996	12	Xhosa

<b>Group 2</b>					
2	Temba	Male	1993	15	Xhosa
2	Chantal	Female	1994	14	Afrikaans
2	Anthony	Male	1994	14	Afrikaans
2	Amy	Female	1995	13	Afrikaans

<b>Group 3</b>					
3	Sipho	Male	1996	12	Xhosa
3	Siyabonga	Male	1996	12	Xhosa
3	Thabo	Male	1997	11	Sotho
3	Xolelwa	Female	1997	11	Xhosa
3	Lindiwe	Female	1997	11	Xhosa
3	Thokozani	Male	1997	11	Xhosa
3	Vuyo	Male	1998	10	Xhosa
3	Bongani	Male	1998	10	Xhosa
3	Sibongile	Female	1998	9	Zulu
3	Xolo	Male	2000	7*	Xhosa

<b>Group 4</b>					
4	Umar	Male	1995	13	Afrikaans
4	Emile	Male	1995	13	Afrikaans
4	Imran	Male	1995	13	Afrikaans
4	Jabulani	Male	1996	12	Xhosa
4	Jason	Male	1996	11	Afrikaans

\* Although Xolo was only 7 years, he was attending the adolescent clinic because he lived with 2 other adolescents who were attending the clinic. He was therefore allowed to participate in adolescent support groups. Because the 2 patients he lived with were participating in focus groups, and his caregiver was busy in the caregiver support group while the focus group was running (and therefore unable to watch him), he was also permitted to participate in the focus group, despite his age.

## Appendix B – Ethical Approval Letter

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UNIVERSITEIT STELLENBOSCH-UNIVERSITY  
ou kennis en hul + your knowledge partner

22 May 2008

Ms R Li  
Dept of Sociology  
University of Cape Town

Dear Ms Li

**RESEARCH PROJECT : "GROWING UP ON HAART: ASSESSING THE NEEDS OF OLDER CHILDREN AND ADOLESCENTS ON ANTIRETROVIRAL TREATMENT AT A TERTIARY SITE IN THE WESTERN CAPE"**  
**PROJECT NUMBER : N08/04/111**

It is my pleasure to inform you that the abovementioned project has been provisionally approved on 21 May 2008 for a period of one year from this date. You may start with the project, but this approval will however be submitted at the next meeting of the Committee for Human Research for ratification, after which we will contact you again.

Notwithstanding this approval, the Committee can request that work on this project be halted temporarily in anticipation of more information that they might deem necessary to make their final decision.

Please note that a progress report (obtainable on the website of our Division) should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.

I wish to remind you that patients participating in a research project at \_\_\_\_\_ will not receive their treatment free, as the PGWC does not support research financially.

The nursing staff of \_\_\_\_\_ can also not provide extensive nursing aid for research projects, due to the heavy workload that is already being placed upon them. In such instances a researcher might be expected to make use of private nurses instead.

**Please quote the abovementioned project number in all future correspondence.**

Yours faithfully

Signature removed

**FRANKLIN WEBER**  
**RESEARCH DEVELOPMENT AND SUPPORT**  
Tel: +27 21 938 9657 / E-mail: [fweb@sun.ac.za](mailto:fweb@sun.ac.za)  
Copy to Supervisor: Heather Jaspan (UCT)

1:07/04/2008 09:00:11 (1:07/04/2008 09:00:11) - PROVISIONAL APPROVAL (STUDENT PROJECT).DOC

Faculteit Gesondheidswetenskappe • Faculty of Health Sciences

Verbind tot Optimale Gesondheid • Committed to Optimal Health

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## Appendix C – Informed Consent Forms

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Forms are given here in English, but were also available in Afrikaans and Xhosa

### Form 1 – Child Assent to Participate in Research

#### Growing up on HAART: Assessing the Needs of Older Children and Adolescents on Antiretroviral Treatment

Hello, my name is Rachel. I am a student from the University of Cape Town and am doing research about HIV positive children and adolescents who are taking medicine to help keep them healthy. I am trying to find out how HIV affects their daily lives and want to learn about what can be done to help them live happily and healthily.



As part of my research, I would like to speak to young people between the ages of 10 and 21 who are on treatment for HIV. I want to hear about the things that are good and bad in their lives, listen to their concerns, and find out what would help make their lives easier.

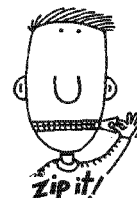
I am telling you this because I would like to invite you to be a part of this study. Being a part of this study is up to you. If you decide to participate, you can change your mind at any time. No one will be upset if you don't want to participate or if you choose to stop.

If you choose to participate, you will spend 45 minutes to 1 hour and 15 minutes doing group activities with Rachel and other young people who have HIV. We will play a game, look at some pictures, and spend some time talking with one another. The group sessions will take place at the clinic where you visit your doctor. Taking part in the group discussion will mean that everyone in the group will be aware that you are HIV positive. Likewise, you will know that the other group participants are also HIV positive.



Some of the questions that I ask might make you feel uncomfortable. However, if you do not want to answer a question, no one will make you answer it. You can decide how much information you would like to share and will not be forced to talk about a subject if you do not want to. You can say 'no' whenever you want.

I will record what we say on a tape recorder to help me remember what we did together. The tapes will be kept in a locked cabinet in my house and nobody except for the research team will be allowed to listen to them without your permission. The things that you say and do in the group will be kept confidential. I will not tell anybody that you participated in the study and your name will not be used in any reports.



You will not be paid for being in the study but you will be given a little bit of money so that you can get to the clinic and home from the clinic when the group session is over. We will also serve a snack and some drinks.



This study will help us to understand what kinds of things children and adolescents with HIV need in order to live happy and healthy lives. Once the study is finished, I will let the university, clinic and Department of Health know what was found. I hope that it will help young people living with HIV in the future but I cannot guarantee that this will happen.



I'm also going to ask your parent or guardian if he or she has any problems with you participating. But your parent and guardian will not find out what happened in the session unless you decide to tell them.



Rachel would be happy to answer any questions that you have about the study. If you have any questions or are unsure of anything, you can talk to her in person or phone her at 082-458-1532.



### Young Person's Assent

Yes, I want to take part in this study.

- The study has been explained to me.
- I understand that I do not have to participate in this study. Nobody will be upset if I do not participate.
- I understand that I can change my mind and say 'no' any time I want.
- I understand that I do not have to answer any of the questions if I do not want to.
- I understand that everything I say will be kept private and that my name will not be used in any reports.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Printed Name of Participant

\_\_\_\_\_  
Date

Form 2 – Caregiver Permission Letter

**Growing up on HAART: Assessing the Needs of Older Children and Adolescents on Antiretroviral Treatment**

Dear Parent or Guardian

My name is Rachel Li and I am a graduate student from the Department of Sociology at University of Cape Town who is working with Professor Nicoli Nattrass from the University of Cape Town and Dr. Heather Jaspan, from the HIV clinic your child attends. As a part of my Master's dissertation, I am doing research about HIV positive children and adolescents on antiretroviral therapy and would like to request permission for your child to participate in the study.

The goal of the study is to assess and understand the needs of HIV positive young people between the ages of 10 and 21, who are currently receiving treatment at the adolescent HIV clinic at [REDACTED]. We are trying to find out how HIV affects the daily lives of these children and adolescents, and want to learn about what can be done to help them live happily and healthily.

Participants in the study will spend 45 minutes to 1 hour and 15 minutes doing group activities with other young people who have HIV. We will play a game, look at some pictures and discuss some questions in a group. Questions will address the participants' experiences of living with HIV and ask about the things that should be done in order to make their lives easier. The group sessions will take place at [REDACTED], where your child visits the doctor. There will be about five participants per group and about three different groups. It should be noted that all focus group participants will be HIV positive. Therefore, everyone else in the group will be aware that your child is HIV positive. Likewise, your child will know that the other group participants are also HIV positive.

Participating in this study is entirely voluntary. Your decision whether or not to allow your child to participate will not affect the care and treatment that your child receives at [REDACTED]. Even if you give your permission, your child is free to refuse to participate and can end his or her participation at any time in the study process.

Some of the questions that I ask might be uncomfortable or difficult for your child to answer. Participants will not be forced to answer any questions. They will be able to decide how much information they would like to share and will not be forced to talk about a subject if they do not want to.

Questions and answers will be recorded on tape. Audio tapes and all documentation linking your child to the study will be kept in a locked cabinet in my house. Nobody except for the research team will be allowed to listen to the tapes without your permission and your child's assent. You will also not be able to listen to the tapes. Everything that is said and done in the group sessions will be kept confidential. Your child's identity will only be known to the research team and will not be made public.

Participants will not be paid for their involvement in the study but will be given enough money to cover the cost of getting to and from the clinic. Snacks and drinks will be provided.



This study will help us to understand what kinds of things children and adolescents with HIV want and need to help them to live fulfilling and productive lives. The findings of the study will be reported to the hospital clinic and the Western Cape Department of Health. I hope that the study will be of benefit to young people living with HIV in the future, but I cannot guarantee that this will happen.

This research study has been approved by the Committee for Human Research at the University of Stellenbosch and will be done according to internationally accepted ethical standards and guidelines. If you have any questions or would like more information about the research project, please feel free to speak to me in person or contact me:

Rachel Li  
Principal Investigator  
AIDS and Society Research Unit  
University of Cape Town  
Private Bag, Rondebosch 7701  
Phone: 082-458-1532  
Email: [rach.j.li@gmail.com](mailto:rach.j.li@gmail.com)

Sincerely,

Rachel Li

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### **Parental Permission**

Yes, I give my permission for my child to participate in this study about the needs of HIV positive children and adolescents. By signing this form, I am indicating that:

- The study has been explained to me and I understand what it involves.
- I understand that my child's participation in the study is voluntary and that neither my child nor my family will be punished if we choose not to participate.
- I understand that neither my child nor my family will be identified in the study and that my child's name will not be revealed in any reports
- I understand that even if I give my permission, my child can choose not to participate in the study.

\_\_\_\_\_  
Signature of Parent/Guardian

\_\_\_\_\_  
Printed Parent/Guardian Name

\_\_\_\_\_  
Printed Name of Child

\_\_\_\_\_  
Date

## Appendix D – Demographic Survey

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The survey is given here in English, but was also available in Afrikaans and Xhosa

### Growing up on HAART: Assessing the Needs of Older Children and Adolescents on Antiretroviral Treatment

1. I am (tick one):

Male 

Female 

2. When were you born?

\_\_\_\_\_ Day      \_\_\_\_\_ Month      \_\_\_\_\_ Year

Or if unsure, how old are you? \_\_\_\_\_ years old

3. Do you go to school?

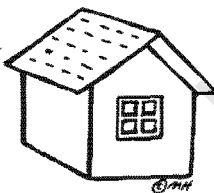
Yes       No

If yes, what grade are you in? \_\_\_\_\_ grade



4. The area where I live is called:

\_\_\_\_\_



5. Who do you live with? (tick all that apply)

Mom       Dad

Other family member       In a home

Other

6. I got HIV from (tick one):

When I was born       A sexual partner

Other       Don't know

No answer

## Appendix E – Focus Group Discussion Guide

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### **Growing up on HAART: Assessing the Needs of Older Children and Adolescents on Antiretroviral Treatment at a Tertiary site in the Western Cape**

#### **Arrival**

As participants enter, they will be invited to fill in the demographic survey.

#### **Introduction (5 minutes)**

- introduction of the investigator and the interpreter.
- explanation about the study.
- explain that we will be recording the conversation.
- ground rules:
  - o you don't have to answer the questions if you don't want to
  - o you can leave whenever you want to
  - o brief discussion about confidentiality

#### **Ice Breaker: The Smarties Game (5-10 minutes)**

- A bowl of smarties is placed in the middle of the room. Each color of smartie represents a different question. Kids are invited to choose a smartie and answer the question that correlates with the colour.
  - o Red – Pass
  - o Orange – What is your favourite TV program?
  - o Yellow – What is one thing you are good at?
  - o Green – What sports do you like to play?
  - o Blue – Who is your best friend?
  - o Purple – Who is your favourite superhero?

#### **Opening Question (5-10 minutes)**

1. Find a picture that describes how you feel today. Explain why you chose that picture.
  - \* This question makes use of *Every Picture Tells a Story*, a series of 48 pictures of different people, places and things. There will also be a 'pass' picture, which the participant may choose if he or she does not want to answer the question.

#### **Transition Question (5-10 minutes)**

2. Find a picture that describes how you feel about HIV. Explain why you chose that picture.
  - \* Again, this question makes use of *Every Picture Tells a Story*

#### **Key Questions (20-30 minutes)**

- 3a. Picture yourself in ten years. What do you see?
  - Probes: *Do you have a job? What is your job?*
  - Do you have a family?*
  - Would you like to have children?*

3b. How do you feel about the future?

\* This question makes use of a chart of faces representing 15 feelings. Each child will be given several stickers which they can place on any and as many feelings as they would like. Once they have finished placing their stickers, they will be invited to explain why they chose a particular feeling.

Answers to questions 4, 5 and 6 are to be written on a large piece of poster paper.

4. What kinds of things help you to feel good?

Probes: *What helps you to feel healthy?*  
*What helps you to feel happy?*

5. What kinds of things make you feel bad?

Probes: *When do you feel unhealthy?*  
*When do you feel unhappy?*

6. What kinds of things would make your life easier?

Probes: *Who supports you?*  
*What could doctors and nurses do to make your life easier?*  
*What could the government do to make life easier?*  
*What could people in your community do to make your life easier?*  
*What could your friends do to make your life easier?*  
*What kinds of services would be helpful for you?*

7. If you had one message you could tell everybody about HIV, what would you want to tell them? Make a sign that expresses your message. You can use words, pictures or both.

\* Paper, kokis and crayons will be provided for this task.

Probes: *What would you like to change about the way other people understand HIV?*  
*What is good and bad about HIV?*

#### **Ending Question (0-5 minutes)**

8. Is there anything else that you would like to tell us?

#### **Debriefing (5 minutes)**

7. What do you think were the most important things that we talked about today?

- Thank participants for taking part
- Restate the importance of confidentiality
- Ask whether there are any questions

## Appendix F · Focus Group Materials

### I. Feelings Chart



### II. Every Picture Tells a Story

Excerpts from the back cover of the “Every Picture Tells a Story” resource package:



A photograph frozen in time bursting with story primed to flood the soul with emotion, memories and dreams.

Here's the scoop: We scouted the planet for 48 evocative, black-and-white photos that beg for reflection and contemplation...that stir up spiritual longings, frustrations, questions...that contain layers of meaning—and a ton to say about God's story, your students' stories, your story.

We printed those photos on durable, 5 1/2-inch x 8 1/2-inch paper stock, added a 32-page leader's guide with 18 creative ways to use these photos with large or small groups, including questions that get kids talking honestly and vulnerably.

For more information on this resource, visit the following website:

[http://www.youthspecialties.com/shop/product\\_info.php?products\\_id=79](http://www.youthspecialties.com/shop/product_info.php?products_id=79)