

Quality of Life and Stigma in HIV-seropositive Adolescents

Attending Mulago Hospital, Kampala, Uganda

by

Elsabé du Plessis

A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

in partial fulfilment of the requirements of the degree of

MASTER OF SCIENCE

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## Abstract

**Introduction:** Perinatal HIV infection in adolescents could lead to psychological distress and impaired functioning, compounded by the stigma associated with HIV/AIDS. No research has investigated the effect of treatment on these problems in an African population.

**Objective:** This study aims to assess the impact of treatment on the quality of life and stigma experience of HIV seropositive adolescents attending the Paediatric Infectious Diseases Clinic (PIDC) in Kampala.

**Methodology:** 52 adolescents (ages 10 and 19) were evaluated with the Strength and Difficulties questionnaire (psychological distress), the Children's Depression Inventory (depression) and the self-report Social Adjustment scale (functioning). These measures were repeated at three-monthly intervals. A qualitative component comprising of interviews concentrated on stigma and coping.

**Results:** Psychological distress was present at baseline, with 12% experiencing difficulties and 9% depression. Functioning was not impaired. During the first year of antiretroviral treatment, psychological distress and depression improves and functioning remains stable. A low level of personal experiences with stigma was reported although half of the respondents could describe situations of stigmatization of people living with AIDS.

**Conclusion:** Psychological distress is present and improves through the first year of treatment with antiretroviral therapy. Social functioning shows little variation over time.

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## Chapter 1: Introduction and Background

"HIV/AIDS is most profoundly reflected in the lives of children, whose very survival and development are at stake."

UNICEF2004

The first HIV cases were reported more than 25 years ago and the past 2 decades have seen many changes in the face of the epidemic. Initially associated with men who have sex with men (MSM) in the United States, more women than men are now infected in Sub Saharan Africa, the worst affected region of the world. An estimated 38.6 million people are infected with HIV worldwide, 64% or 24 million people Sub Saharan Africans (UNAIDS, 2006). In many countries the epidemics are thought to have peaked, stabilizing now albeit at higher prevalence than in the developed world (UNAIDS, 2006). Hailed as an African success story, prevalence rates in Uganda have declined steadily. The Ugandan Ministry of Health Surveillance Unit in 2004 estimated the prevalence in urban areas at 6.4% (UAC, 2006), compared to 30% ten years earlier (UNAIDS/WHO, 2003). Young people (15-24) also constitute nearly half of the HIV infected population in Uganda (Neema, Musisi & Kibombo, 2004). Despite the reduction in overall prevalence rates, HIV/AIDS still threatens the health and well-being of both HIV infected and uninfected Ugandan children and youth (Neema et al., 2004) through parental loss, stigmatization and poverty. Previous research documented high levels of psychological distress and impairment of social functioning in HIV-seropositive adolescents in Uganda (Bakeera Kitaka et al., 2004; Musisi and Kinyanda, 2003).

The survival of perinatally infected children into adolescence is a relatively new development in the HIV/AIDS epidemic in Africa. According to a study conducted at an antenatal clinic in Kampala 61.6% of HIV infected children recruited from 1989 to 1993

died before their fourth year (Bagenda et al., 2006). Data from Rwanda suggest that two thirds of HIV infected children pass away before their fifth birthday (Spira et al., 1999). Ten percent of children appear to be 'long-term slow-progressors' however, and do not develop AIDS before age 10 (Spira et al., 1999). Recent improvements and advances in treatment and care increase the likelihood of people with HIV living longer. Researchers have reported delayed growth and pubertal delay in surviving children due to their illness (Bakeera Kitaka et al, 2004; Nathan et al., 2003; Newell, Borja, Peckham & European Collaborative study, 2003). A needs analysis of 58 adolescents attending the Paediatric Infectious Disease clinic (PIDC) in Kampala found that 45% had stunted growth and delayed puberty depending on the severity of the disease (Bakeera Kitaka et al., 2004). The same study reported significant improvements in the physiological status of adolescents receiving antiretroviral treatment but documented high levels of psychological distress and social impairment in HIV-seropositive adolescents (Bakeera Kitaka et al., 2005).

This thesis is part of a larger project examining the impact of antiretroviral treatment over time in a larger sample of adolescents attending the PIDC at Mulago hospital. The study entitled *A prospective study of HIV-infected adolescents: monitoring growth, development and recovery while on ART* (referred to as the Prospective Adolescent Study) was funded by the Bill and Melinda Gates foundation. It followed 125 patients starting antiretroviral treatment through an 18-month period. Pubertal development was recorded during a baseline physical exam, followed by a laboratory evaluation. Bone age was determined from X-rays of the left hand. Physical examinations were conducted on a monthly basis with laboratory testing repeated at three monthly intervals. Follow up x-rays were taken for 58 adolescents after one year of antiretroviral treatment. Preliminary results showed increased CD4 counts within three



months (IDI annual report, 2005) and adolescents caught up to their peers in growth and weight.

The prospective adolescent study focused primarily on the physiological and clinical impact of treatment, while my own research study concentrated on the effect of antiretroviral treatment on the levels of psychological distress experienced by these adolescents, as well as improvements on their quality of life and social adjustment. The specific objectives are:

1. To describe and follow up on changes in the psychological wellbeing of HIV-seropositive adolescents receiving treatment at the PIDC.
2. To describe and follow up on changes in the social functioning of HIV-seropositive adolescents receiving treatment at the PIDC.
3. To assess the impact of treatment and care on perceived stigma, including self-stigmatization and discrimination of HIV-seropositive adolescents receiving treatment at the PIDC.

The remainder of this chapter will provide a description of the study setting as well as an overview of the literature pertaining to the subject.

### **Description of study setting: the Paediatric Infectious Diseases Clinic**

The research was conducted during a two year period at the Paediatric Infectious Diseases Clinic (PIDC) at Mulago Hospital in Kampala. Mulago Hospital is a 1500 bed national referral hospital as well as the teaching hospital for Makerere University Medical School. The PIDC is located in Upper Mulago and delivers care to children and adolescents with HIV/AIDS. It started in 1988 under the administration of the Child Health and Development Centre of Makerere University as a weekly clinic delivering

care to approximately 60 HIV positive children under the age of 12. The number of patients increased steadily and the clinic was relocated to its current ward in 2003, renovated for the clinic by the US Centre for Disease Control and prevention (CDC). Physician visits as well as medications are provided free of charge at the clinic and basic laboratory testing is available on site. Tuberculosis screening and treatment, treatment of opportunistic infections and other HIV-related complications are available. Counsellors provide support, facilitate disclosure and offer adherence counselling. Home care workers follow up on patients receiving antiretroviral treatment from the clinic. A family based care model now piloted at the clinic in cooperation with the Adult Infectious Disease Clinic could lessen the burden on families with multiple HIV positive generations. In addition to the medical services, patients are also supported in other ways. Nutritional assistance is available and patients receive breakfast while waiting for their doctor's appointments.

The PIDC operates five days a week. On Mondays, Wednesdays and Fridays infants and children younger than 12 are seen, Tuesdays are dedicated to adolescents between the ages of 12 and 18 and a family clinic takes place on Thursdays.

The clinic has grown exponentially: statistics for December 2005 (IDI Annual report) report an average of 144 adolescents seen every Tuesday, up from an average of 40 when the proposal for this research was written in early 2004. The Infectious Disease Institute's 2005 annual report puts the total number of patients registered up to December of that year at 6,725 (children and adolescents). Only six months later, at the 2006 PEPFAR conference in Durban, South Africa, Dr. Addy Kekitiinwa, Director of the PIDC, reported 8,211 registered patients. The clinic has again outgrown its premises and the groundbreaking for a Children' Centre of Excellence (in cooperation with Baylor Pediatric AIDS Initiative and supported by the Bristol-Myers Squibb foundation) took place in 2006 (IDI Annual report, 2006).

One of the reasons the PIDC has been so successful is the number of partnerships it has with various institutions and the funding received from these organizations. The combined efforts of the Infectious Disease Institute, Department of Medicine and Paediatrics at Makerere University, the Ugandan Ministry of Health, CDC and other non-profit organizations, enables the clinic to provide medical and other services free of charge.

The clinic first started prescribing antiretroviral (ARV) treatment in December 2002, supported by a private donor until Paediatric AIDS Canada agreed to provide funding. This allowed 232 patients to be placed on treatment between September 2003 and December 2004 (Kekitiinwa et al., 2006). In December 2004, the President's Emergency Plan for AIDS Relief (PEPFAR) began providing support to the clinic and treatment became more readily accessible to patients. In June 2006, the PIDC was dispensing ARVs to 1,484 patients, (IDI Annual report, 2006). At the PIDC, the medications prescribed are generic fixed-dose combinations. Controversy still surrounds the use of generic ARVs, but recent research has proven the drugs safe, effective and of good quality (Laurent et al., 2004).

This was an interesting time to be involved with the PIDC. The clinic had only moved to the premises it now occupies in 2003 and while staff and patients were still acquainting themselves with the new surroundings, the clinic had already outgrown its space. They were also about to receive PEPFAR funding and preparing for this. Funding for antiretroviral treatment was not included in the Adolescent Study and treatment was provided by the clinic, through PEPFAR funding. This reliance on outside funding delayed the recruitment of adolescents. Recruitment started in November 2004, but it was not until early 2005 that ARVs were readily accessible and more participants could be recruited. This influenced the number of adolescents recruited into the prospective adolescent study as well as mine.

The Baylor International Paediatric AIDS Initiative (BIPAI) is not only involved in developing a comprehensive treatment program in the clinic in cooperation with Makerere medical school, but also aids in training the staff. Trainees attending the Infectious Disease Institute (IDI) training program also visit the PIDC and numerous students from universities in North America, Canada and Japan were involved with the clinic. It has also become the focal point of research supported by organisations such as the Infectious Disease Institute and BIPAI.

### ***Adolescent clinic***

The adolescent clinic at the PIDC started in 2003. Prior to 2003 the PIDC, as a purely paediatric clinic, only accepted patients under the age of 12 and HIV positive adolescents had to attend the adult clinic. In 2003, the adult clinic had around 40 registered adolescent patients. It became clear that the adult clinic and the services delivered there was not appropriate for the adolescents and adolescents themselves did not feel comfortable in this setting. As the PIDC moved to its new premises in 2003, the adolescent clinic was incorporated into its existing services.

Initiated in 2003, a monthly support group for adolescents takes place on the second Saturday of every month. Initially funded by the Bill and Melinda Gates foundation it now relies on other donors and is known as the Mulago Teens Club. Adolescents older than 10 and aware of their HIV positive status are informed of the meetings by doctors or counsellors and encouraged to attend. The support group aims at providing adolescents with social support, educating them about their illness and equipping them with skills to cope with the challenges they face. Group discussions allow adolescents to share their experiences with others who may face many of the same challenges and have similar experiences, creating a system of peer support.

The time I spent waiting for ethics approval and for the recruitment process to get underway gave me the opportunity to familiarize myself with the clinic, staff and adolescents. I attended the monthly peer support group meetings and through group discussions there and in talking with them individually I gained a better understanding of their lives. I heard many adolescents talking about stigma and being discriminated against. Determining what stigma meant in the experience of these adolescents became a key goal of the research and these discussions informed the questions asked during their interviews.

### **Literature review**

The visibility of HIV positive adolescents in HIV/AIDS research has improved over recent years, but research in sub-Saharan Africa still focuses mainly on either children or adults (Save the Children South Africa, 2001). Until recently HIV positive adolescents were rarely treated as a separate category but included in adult population studies or regarded as older children. This ignores the unique developmental situation of, and issues faced by adolescents. The perinatal transmission adds to the distinctiveness of the study population, as disease progression is unique. Little is known about the progression of HIV/AIDS in perinatally infected adolescents. The interaction of adolescence with a chronic, stigmatized disease could influence treatment experience and adherence as well as the psychological, social and emotional well being of adolescents. Effects of the disease such as stunted growth and delayed puberty could also affect the adolescent's quality of life negatively (Newell et al., 2003).

There is still no cure for HIV but advances in HIV management with ARV therapy combined with the use of antibiotics in treating secondary infection (Armstrong, Willen & Sorgen, 2003; de Martino et al. 2000; Thorne et al. 2002) has improved the prognosis of

HIV-seropositive individuals, including adolescents. This increases the importance of understanding factors that may have an effect on quality of life.

### ***HIV/AIDS***

The mode of HIV transmission influences the disease progression. Adolescents who contract HIV sexually during adolescence experience disease progression similar to adults. The disease course for those infected perinatally is different, even compared to those infected through breastfeeding (Newell et al., 2004b). Without treatment, about two thirds of children vertically infected by their mothers die before age 5. (Bagenda et al., 2006; Newell et al., 2004b; Spira et al., 1999). Newell and colleagues (2004a, 2004b) obtained data from seven mother-to-child transmission trials in sub-Saharan Africa. They reported a mortality rate among HIV positive children of 35.2% before age 1 and 52.5% at age 2, after which point disease progression appears to slow down. They also found children with late infection (after 4 weeks of age, presumably through breastfeeding) to be 60% less likely to have died compared to those infected within the first 4 weeks.

In the above study, the median survival age for ARV naive children reported was 3 years (Newell, Brahmbatt & Ghys, 2004a). Even in the absence of ARV treatment, however, ten percent of children appear to be 'long-term slow-progressors' and do not develop AIDS before age 10 (Spira et al., 1999). These children experience stunted growth and pubertal delays due to their illness (Bakeera Kitaka et al, 2004; Nathan et al., 2003) and early research reported cognitive delays and psychiatric disorders (Boivin, 1995; Cooper 1988). Evidence from a European multi-centre study of 184 infected and 1403 uninfected children found HIV positive children born to HIV positive mothers to grow significantly slower than the uninfected control group (Newell et al., 2003). A retrospective chart review of 138 adolescents treated at the adult and paediatric infectious disease clinics in Kampala reported similar findings (McKellar et al., 2004). In

their sample, the growth of 62% of the adolescents was stunted and 43% were underweight. The difference between infected and uninfected children increased with age. In the European study, differences in growth patterns increased after age 2 (Newell et al., 2003). In a South African study, the infected children were no different from uninfected children at birth but the difference in growth increased with age (Bobat, Coovadia, Moodley, Coutsooudis & Gouws, 2001). Delayed pubertal development associated with perinatal HIV has been reported in North America (Buchacz et al., 2003) and in Europe (de Martino et al., 2001). In the study of 58 adolescents attending the PIDC (Bakeera Kitaka et al., 2004), Tanner staging was used to assess sexual maturation. Sexual maturation can be classified as stage 1 through 5, with 1 representing no sexual characteristics and 5 full adult development. According to their results, 50% of adolescents with AIDS experienced Tanner staging delay of two to three stages. A study conducted in Zaire found cognitive deficits among infants and preschoolers with HIV (Boivin, 1995), while Cooper and colleagues reported neurological impairment in half of HIV infected children as early as 1988. Research into the development of HIV infected children found delays in specific areas of language development, with some researchers reporting improvements in these delays with antiretroviral treatment (reported in Armstrong et al., 2003). Similar improvements in growth and pubertal development have also been reported (de Martino et al., 2001; Nachman et al., 2005; Newell et al., 2003).

A recent study from Uganda did not find significantly more neurological impairment in HIV positive children than in HIV negative children or seroreverters<sup>1</sup> (Bagenda et al., 2006). Psychiatric disorders, especially severe depression (40%) were

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<sup>1</sup> Seroreverter are babies born to HIV positive mothers and who initially have HIV antibodies and thus test positive. When the antibodies they had from their mother disappeared and they are established as HIV negative, they are referred to as seroreverters.

reported to be common among HIV adolescents attending Mildmay (Musisi & Kinyanda, 2003).

### ***Adolescence***

According to the World Health Organization, adolescents are individuals between the ages of 10 and 19 years of age (WHO, 2004). Adolescence is a time of change in all aspects of an individual's life. Puberty bring with it physical changes while they are also emotionally and socially adapting to the roles expected from them in adulthood. In attempts to develop an individual identity, adolescents experiment and are more prone to risky behaviour. According to development theories, experimentation with risk-taking behaviours is typical of adolescence (Tolpolski et al., 2001) and a necessary step in the development of a self-identity.

In Uganda, adolescents constitute 24% of the country's total population, increasing the importance of this age group. Here adolescence is considered a period of transition from childhood to adulthood (Neema et al., 2004) but legally and culturally, they are still regarded as minors in need of guidance. In a survey conducted by Neema et al. (2004) reference were made to their "unruly" and "stubborn" behaviour. During adolescence individuals familiarize themselves with cultural and social norms that will govern their adult roles.

Peers are a major influence on the development of the adolescent, and increase in importance in the absence of parents (Neema et al., 2004). In Uganda, the increasing number of AIDS orphans would therefore increase the importance of peers in the adolescent's life. Another factor contributing to the importance of peers in Ugandan adolescents' lives is the cultural restriction on the discussion of sex between adults (including parents/caretakers and adult health workers) and children (Neema et al.,



2004, Musisi & Kinyanda, 2003). This suggests that peers are the most important source of information about sex and HIV/AIDS for adolescents.

### ***Quality of Life: the impact of HIV and Adolescence***

The World Health Organization defines quality of life as 'the individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns' (quoted from Bullinger, Schmidt, Petersen & The DISABKIDS Group, 2002). This is a broad definition and previous research (e.g. Bullinger et al., 2002) has conceptualized it as an individual's subjective evaluation of their well-being and functioning in various domains, including physical, psychological, social and behavioural. The impact of disease and treatment on these domains is especially important in childhood and adolescence as it may negatively affect development. Quality of life in adolescence is also the foundation for health and quality of life in adulthood (Bisegger et al., 2005).

Including measures of quality of life assessment in health research creates a more inclusive picture of the illness experience by incorporating internal (e.g. self-esteem) and external (e.g. family, stigma) factors. It can be useful in evaluating the effectiveness and net benefit of new therapies and interventions. Improvements in quality of life, such as symptomatic relief, can influence the effectiveness of an intervention regardless of the medical outcome. This is especially true with children and adolescents more prone to concrete thinking. Previous studies found psychological and social dimensions of quality of life to account for much of the variance in treatment experience: Bullinger and colleagues (2002) assert that for chronically ill children the amount of variance in treatment experience explained by psychosocial variables is greater than that explained by clinical variables. Zullig, Vlois and Drane (2005) further found mental health to contribute more to healthy adolescents' self-rated health than

physical health, underscoring the importance of psychological and social variables in adolescents' perception of their health and consequently treatment. Combining measures of psychosocial quality of life with clinical data should thus create a more inclusive view of the effectiveness of treatment. In a resource-limited setting, it could serve as an indicator for the effectiveness of therapy in the absence of expensive medical tests such as viral load.

### ***Psychological distress***

The risk of developing depression may increase with an HIV positive diagnosis (Hosek, Harper and Domanico, 2000; Johnson et al., 2001), a risk further amplified by decreasing self-esteem and changes in clinical or social situation (Lichtenstein, Laksa and Clair, 2001). Chronically ill adolescents can experience depression and anxiety as a result of 'being different' from their peers at a time in their development that peer conformity and social acceptance is particularly important (Boice, 1998). Stunted growth, delayed puberty and frequent absence from school (or not attending at all) all contribute to perception of being different (de Martino et al., 2001; Musisi & Kinyanda, 2003). The stigmatized nature of HIV/AIDS further isolates and alienates HIV positive adolescents (Bronheim, 1987). A South African study exploring the psychosocial needs of HIV infected adolescents as well as the adolescent children of HIV positive parents, reports feelings of anxiousness, fear, sadness, and hopelessness among the adolescents. In their sample, some adolescents exhibited aggression and anger and two had considered suicide. Almost all respondents felt their illness was hampering their social functioning (Strydom & Raath, 2005). The sample also included adolescents who had no feelings about their illness, whether positive or negative. This illuminates to some extent the heterogeneity of this population and the wide range of feelings and emotions experienced.

The pilot study conducted at the PIDC (Kampala) in September 2003 found HIV to impact significantly on the lives of infected adolescents (58 patients participated) and their families. Almost 80% of respondents had lost at least one parent. Social isolation and psychological distress was reported by 52% who felt the need to discuss their feelings about their HIV disease with others. Feelings of sadness/depression were reported by 40%. The survey included a question on the experience of stigma (Do you ever feel that people treat you differently because you have HIV/AIDS?) to which 43% replied "yes". Musisi and Kinyanda in 2003 explored the 'psychological and social problems' of 82 adolescents attending the Mildmay Centre's<sup>2</sup> Child and adolescent clinic. They used a combination of methods, including questionnaires, interviews and focus group discussions. This population exhibited high levels of psychological distress. More specifically, they reported high levels of depression (41.5%) and anxiety (58.5%), and 19.5% of the adolescents had attempted suicide (Musisi & Kinyanda, 2003). The researchers found age, not attending school, inability to participate in sports and caretaker's HIV-serostatus to be significantly correlated with psychological distress in the adolescents. Their results also indicated poor coping and stigmatization. The latter addressed during the qualitative phase of their research. The findings from the Mildmay study suggest that the stigmatized nature of the disease, poverty as well as the multi-generational aspect of the disease, which left many adolescents orphaned (53.7 % had lost both parents) all contribute to HIV positive adolescents' experience of their illness.

### ***Coping***

Effective coping mechanisms are significantly correlated with social and mental health in HIV-positive adolescents (Murphy, Moscicki, Vermund, Muenz and the Adolescent Medicine HIV/AIDS research network, 2000). Gender (Sawyer, Rosier,

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<sup>2</sup> A Mildmay International centre on the outskirts of Kampala providing outpatient care to HIV positive patients, a research centre and training to local staff.

Phelan & Bowes, 1995), age, and time since diagnosis (Bauld, Anderson & Arnold, 1998) all influence the coping mechanisms used. Avoidance coping mechanisms such as denial and avoidance have been associated with higher psychiatric distress and depression (Vosvick et al., 2002).

In the Mildmay study, adolescents reportedly scored themselves at or below 50% on the Social Adjustment Scale (SAS), pointing to poor coping with their illness, especially in the domains of school work, home functioning, social and leisure activities (Musisi & Kinyanda, 2003).

### ***Orphan Status***

Twenty three million AIDS related deaths have occurred since the 1970's (UNICEF, 2003a) and more than 14 million children under the age of 14 have lost one or both parents: a number expected to rise to 25 million by 2010 (USAID/UNICEF/UNAIDS, 2002). Eighty percent of all AIDS orphans are African, many of them HIV infected themselves. In Uganda, an estimated 14.6% of all children were orphans in 2001 (USAID/UNICEF/UNAIDS, 2002). The country also has a mother to child transmission rate of 14% (Ministry of Health, 2003), suggesting that a number of orphans will be HIV infected.

Losing a parent poses its own threats to quality of life. Orphans are more vulnerable to abuse, malnutrition and illness (UNICEF, 2004). Poverty, lack of support and affection from a parent, limited access to school, and psychological distress (Neema et al., 2004; Sarker, Neckerman & Müller, 2005; UNICEF, 2004) all contribute to the increased vulnerability of orphans. A study of Ugandan street children (Sarker et al., 2005) found orphans to have limited access to school and that they were in worse health than non-orphans. A study of AIDS orphans in a rural area of Uganda (Atwine, Cantor-Graae & Bajunirwe, 2005) report orphans to be at greater risk of anxiety, depression and

anger. This is not taking into account the orphan him or herself may also be HIV positive, which further complicates their lives.

### ***Stigma***

In classical Greece, groups exiled from the mainstream community were branded to remind them and others of their outcast status (Aggleton, Parker & Maluwa, 2003). More recently, Erving Goffman defined stigma as an individual characteristic or trait "significantly discrediting" to the individual (as quoted in Aggleton et al. 2003). In their social setting this characteristic deviates from the accepted norm and diminishes the worth ascribed to the individual. The stigmatized nature of HIV in present day society stems from its deviation from many of our societal norms: those regarding cleanliness, illness and infection as well as what constitutes moral and immoral behaviour (sex and drug use).

The impact of stigma on the lives of HIV positive adults has been shown in various research studies. In 2001, Save the Children published a report on the stigma experience of HIV/AIDS infected and affected children in South Africa. It revealed the high level of stigmatization and resulting discrimination experienced at all levels of society. Musisi and Kinyanda (2003) also found stigma to be a significant problem for HIV positive adolescents attending Mildmay Center in Kampala, as did the needs analysis conducted at the PIDC (Bakeera Kitaka et al., 2004).

The main forms of HIV/AIDS discrimination described by children in both South Africa and Uganda (Gilborn, Nyonyintono, Kabumbuli & Jagwe-Wadda, 2001; Musisi and Kinyanda, 2003; Save the Children, 2001) are social ostracization and teasing. Both represent risks to the physical health, self-esteem and emotional well-being of adolescents. Many children experience poverty, often as a direct result of their connection with HIV. Poverty significantly decreases access to resources and adds

another dimension of shame to their experiences. Participating children also referred to the gendered nature of stigma, with girls facing more stigma than boys do. This gender imbalance has been reported across Africa (Foster & Williamson, 2000), and was a key finding of stigma research conducted with HIV positive adults in Uganda (UNAIDS, 2001). In Strydom and Raath's (2004) study of HIV infected adolescents in South Africa, more than half (17 out of 25) of their HIV infected participants had disclosed their status to someone. Almost all (14 out of 17) consequently experienced discrimination from family, friends and/or at school. Participants who had not disclosed their status reported fear of rejection as a motivating factor. A high level of internalized stigma was also present in this sample, as most respondents were actively considering suicide or believed they deserved to die. In a 2004 documentary, *Living with Slim* six HIV positive Ugandan children and adolescents discuss the uncertainty, stigma, discrimination and abuse they face as a result of their status.

Antiretroviral treatment could alleviate some of the stigma experience by altering the perception of AIDS as a fatal illness to a manageable illness. According to the UNAIDS report released in 2006, research evidence from Brazil indicate that access to treatment, both antiretroviral and other treatments for opportunistic infections, could be "the most powerful anti-stigma interventions" (UNAIDS, 2006).

Losing a parent to AIDS is stigmatizing in itself and adds another dimension to the stigma experience of HIV positive adolescents (Musisi, Kinyanda et al., 2004). Extended family remains the main source of care for orphans in Uganda (Neema et al., 2004; Sarker et al., 2005) even though resources may not be available. This may be more difficult in the case of AIDS orphans as UNICEF (2004) asserts that children orphaned by AIDS are more likely to be turned away or treated badly by their extended family than children orphaned from other causes.

### ***Anti-Retroviral Therapy***

In 2005 the number of HIV infected people receiving antiretroviral treatment in Sub-Saharan Africa doubled, but still only reached one in six people in need of treatment (UNAIDS, 2006). In Uganda, 75,000 individuals were receiving antiretroviral treatment in 2006 but 208,000 were in need of treatment (Kekitiinwa, Chang Pitter, Kline & Bakeera-Kitaka, 2006).

Administration of treatment to children is primarily the responsibility of the parent/guardian, but adolescent patients take on more of this responsibility and are also more able to refuse treatment. The developmental characteristics of adolescence, such as concrete thinking, egocentrism (Boice, 1998) and the desire for peer conformity, can complicate adherence to antiretroviral and other therapies and affects the illness experience itself, as found with other chronic illnesses (Thorne et al., 2002). Concrete thinking may be further exacerbated by cognitive deficits in children perinatally infected with HIV (Mellins, 2004). Adolescents experiencing adverse side effects of the drugs or immune reconstitution syndrome could doubt the treatment's efficacy. If the adverse effect of therapy is seen as overshadowing a positive overall outcome, (Mellins, 2004) adherence could be negatively influenced. These are important considerations in planning treatment for adolescents as non-compliance could lead to drug resistance. Few studies have looked at the impact of HIV and antiretroviral therapy on the quality of life of adolescents. Side effects of antiretroviral treatment can confuse quality of life outcomes however. Disturbances in eating or sleeping patterns or concentration are side effect of ARVs but also considered signs of depression. Their presence could influence outcome measures as it may be difficult to separate the two (Armstrong et al., 2003).

The increasing global availability of ARV treatment increases the importance of medications' impact on quality of life. Studies conducted by Lee and colleagues (2006)

and Storm et al. (2005) looked at different antiretroviral treatments and their impact on quality of life of North American adolescents. Only one of these studies (Lee et al., 2006) focused on perinatally infected children and adolescents (12 to 21 year olds in their definition). They found only two significant differences between participants receiving antiretroviral therapy and those not receiving treatment. Older children (5-11 years) not receiving antiretroviral therapy viewed their health more negatively than children receiving treatment did. Adolescents not receiving ARV therapy not only had worse health perceptions, like older children, but also more physical symptoms than adolescents receiving treatment. Storm et al. (2005) found children in more advanced stages of AIDS to have increased difficulty in some aspects of functioning and perceived health status. Neither study found any difference in quality of life between groups receiving different treatment regimens including protease inhibitors, NRTIs or NNRTIs. Both studies were conducted in metropolitan areas in the United States, where the social context of the disease is very different to that of Uganda and both studies relied on cross-sectional data. This does not allow exploration of changes in quality of life over time and in relation to therapy.

## **Conclusion**

HIV positive adolescents face many factors that could potentially affect their quality of life. Difficulties associated with the illness, including stunted growth, delayed pubertal development, impairments in cognitive development and chronic opportunistic infections are compounded by social factors such as stigma and orphanhood. Some evidence suggests antiretroviral treatment not only improves physical health but could also reduce the stigma attached to HIV. Antiretroviral therapy could therefore also have a significant impact on the quality of life of HIV seropositive adolescents.



Literature reviews regarding quality of life revealed depression, social support, coping, social adjustment and school attendance and achievement as key concepts determining psychosocial quality of life (Musisi and Kinyanda, 2003; Huurre and Aro, 2002; Murphy et al., 2000; Pakenham and Rinaldis, 2002; Gilborn et al., 2001; Bronheim, 1987). Physical health is recognized as an important component of quality of life and included although the main focus of this research was on those aspects of quality life not directly related to physical health. Stigmatization was additionally identified as an important factor in the lived experience of HIV positive people and with significant impact on their well-being (Save the Children, South Africa, 2001).

## Chapter 2: Methodology

This chapter will provide an overview of the quantitative and qualitative methods employed in this study. It will describe the instruments used and describe the steps taken throughout the research project.

### Study Population and Sample

The study population comprised adolescents attending the PIDC who met the clinic criteria for initiating antiretroviral therapy and were enrolled in the prospective adolescent study. The selection criteria are displayed in table 2.1.

Table 2.1

#### Selection Criteria

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##### *Clinic criteria for antiretroviral therapy:*

CD4 count less than 200 or less than 15% of total lymphocytes

Social Support

Live within a 50 kilometre radius of the clinic

##### *Adolescent study criteria:*

Meet clinic criteria for antiretroviral therapy

Antiretroviral naïve

Able to communicate with study staff

Between the ages of 10 and 19 years

Written informed consent from a parent/guardian and assent from adolescent (if younger than 18).

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The definition of adolescence guiding the prospective adolescent study and therefore this study, identified adolescents as persons between the ages of 10 and 19 years of age. This definition was set forth by the World Health Organization in 1986 and has subsequently been adopted by the majority of United Nations organizations, including UNICEF (2002a).

Sample size was informed by practical considerations, including the time and financial constraints of the investigator. As this portion of the research was exploratory in nature and did not aim to test a hypothesis, this was considered acceptable. The research team for the prospective adolescent study planned to recruit six adolescents weekly. If all six also agreed to participate in this quality of life study, 100 adolescents would have been recruited in five months, using a consecutive sampling method. Recruitment commenced in November 2004 but five months later, by March 2005 only 52 adolescents (52% of the expected 100) had been recruited. The problem was that ARV drugs were not included in the prospective adolescent study budget and was dependent on outside sources such as PEPFAR. As a result, enrolment was slow until drugs became more widely available at the beginning of 2005. Obtaining consent was also a problem. In Uganda, adolescents under the age of 18 are considered minors and parental consent is needed in addition to the adolescent's assent. Many adolescents attended the clinic unaccompanied and getting in touch with their parents or guardians proved problematic. Four adolescents were 18 and could sign their own consent. Three adolescents were approached and assented but were excluded from the sample. No formal consent from a parent or guardian could be obtained for one adolescent, another was known to be sexually infected and the third had been receiving antiretroviral therapy from another clinic for over a month.

There was a high rate of sample attrition with 46 adolescents followed to three months, 45 to six months and 40 (80%) to nine months. Initially, participants were only to be followed for nine months but as enrolment took place over five months some participants had reached their 12 month follow up before others completed nine months. A further 36 adolescents (70% of original sample) were followed to 12 months. Three adolescents passed away during the course of the study.

Many adolescents missed follow up appointments and data from all time points were only available for 32 of the 40 adolescents at nine months and 28 (of 36) at 12 months. Many factors contributed to this. One reason was the inconsistency between the study definition of adolescence and the definition adopted by the clinic. According to clinic definitions, those younger than 12 were children and did not attend the adolescent clinic but the paediatric clinic on Mondays, Wednesdays and Fridays. One of these days was also adopted as a research day to reach the youngest adolescents and their follow-up appointments were scheduled on these days as well. They did not always attend on those days but came earlier or later in the week. Adolescents also fell ill in the time between follow up visits and attend the clinic for an acute care visit or be hospitalized. On such occasions, they would receive their medication and not return for their scheduled appointments. In-school adolescents have to fit their clinic visits in with their school agendas and could not wait for an interview or fill out a questionnaire. School holidays also posed problems as many children went to the villages for holidays and missed follow up appointments. In one instance, an adolescent had traveled to Rwanda for a funeral and remained there for two months before returning to Kampala.

The decline in sample size was even more pronounced in the qualitative portion of the research. At baseline, 46 adolescents were interviewed and at the conclusion of the research 33. The reasons for the decline in sample size described above were also factors in this decline. The setting also imposed its own restrictions. The clinic had

experienced rapid growth during the study period and space was becoming an issue, not only for the research but for clinic functioning as well. There was no room to conduct interviews during the adolescent clinic. The first round of interviews could also not all be conducted at the clinic during adolescent days, but could be scheduled to occur on a Thursday, as the clinic was closed on this day. During the year, however, a pilot family clinic was initiated on this day and space again was an issue. As a result, not all adolescents could be scheduled for second interviews before the conclusion of the research.

### ***Research Assistant***

A research assistant was hired during the planning stages of the research. He worked as a research assistant and counsellor on other HIV/AIDS research projects and was the research counsellor/assistant in the prospective adolescent study. He was already involved with the adolescents as a facilitator at the monthly peer support groups. Adolescents knew him, and trusted him. He was involved with the adolescents through the work he did on the overall prospective adolescent study as well.

### **Design**

Multiple data collection methods, both quantitative and qualitative, were used in order to gain a more comprehensive overview of the adolescents and their situation. Adolescents were asked to fill out questionnaires at three monthly intervals to gather the quantitative data. The qualitative portion consisted of interviews conducted at baseline and the conclusion of the study.

### **Instruments**

Participants completed questionnaires at baseline, three months, six months, nine months and 12 months after the initiation of therapy. All questionnaires consisted of

separate sections regarding demographics, psychological distress, depression and social functioning. A few quality of life instruments for adolescents exist and were considered for the research. None of these had however been used in research with HIV positive adolescents or in East Africa. Quality of life instrument for HIV positive adults (such as the World Health Organization's health related quality of life for HIV positive people) were also considered, but as the research had its foundation in the belief that the developmental phase of adolescence creates unique complications for HIV-seropositive adolescents, they were also considered inappropriate. It was therefore decided to employ three existing, standardized instruments to measure the key aspects of quality of life identified from the literature. measured psychological distress, depression and social functioning. The Strength and Difficulties Questionnaire (Appendix C) developed by Robert Goodman (1997, 2001), was included to measure general psychological distress, the Children's Depression Inventory (Kovacs, 1992) for the presence of depression (Appendix D) and the Social Adjustment Scale Self report (Cooper & Osborne, 1982) to measure social functioning (Appendix E). These measures were chosen for their suitability to the research objectives and their use in Uganda in recent years.

At baseline, demographic questions included age, sex and family situation (Appendix A). In follow up questionnaires participants were asked whether they had moved in the previous three months (stability of social support), whether they had attended a peer support group and if they had participated in sexual activity (Appendix B). Participants were also asked to rate their physical health on a four point scale (very good, good but not perfect, somewhat poor and very poor) at all months. This question was included in the questionnaires, adapted from the health and nutrition section of the Horizons program study "Refining interventions to improve the well-being of AIDS-affected children" conducted in Uganda during 1999 to 2001 (Gilborn et al., 2001). Child

and adult version of the questionnaire for the Horizons study were developed in partnership with the Department of Sociology at Makerere University (Kampala, Uganda) and Plan International. The study included 1,047 participants at baseline of whom 728 were children between the ages of five and 17 years.

### ***Translation***

Few adolescents' grasp of English allowed them to complete questionnaires or interviews in English. Consent forms and questionnaires were translated from English into Luganda by a local advisor and administered by the research assistant.

### ***Psychological Distress: Strengths and Difficulties Questionnaire***

The Strength and Difficulties Questionnaire (SDQ) is a brief instrument (25 items) designed as a screening tool for use with children and adolescents between three and 16 years old (Appendix C). The questionnaire is available in 51 languages on the internet (<http://www.sdqinfo.com/>) and may be used for free. It is easy to administer and no extensive training in psychometrics is necessary.

Two versions of the questionnaire exist: a version for completion by parents or teachers and a self-report version that can be administered directly to adolescents older than 11 (Goodman, Meltzer & Bailey, 2003). A follow up version of the questionnaire is also available and the questionnaire is considered sensitive to changes in psychological distress (<http://www.sdqinfo.com/>).

The SDQ has five subscales of five items each. Four scales focus on the "difficulties": emotional symptoms, conduct problems, hyperactivity and peer problems. The scores achieved on these scales can be used individually or summed for a total difficulties score, with higher mean scores indicating higher levels of distress. The fifth subscale focuses on prosocial behaviour (their "strength"). This refers to behaviour that

helps other but has no direct benefit to the person doing it (Baron & Byrne, 1997). On this scale, a lower mean score indicates less prosocial behaviour and more distress.

The items of the SDQ consist of statements that participants are asked to rate as “not true”, somewhat true” or “certainly true”. Apart from a handful of categories scored in reverse, “not true” is then scored as 0, “somewhat true” as 1 and “certainly true” as 2. Subscale scores are calculated by summing item scores in that category and total difficulties by summing the scores of the four difficulty scales. Subscale scores can range from 0 – 10 and the Total Difficulties score from 0 to 40. Scores can be used as continuous variables or classified as normal, borderline (based on the 80<sup>th</sup> percentile) and abnormal – based on the 90<sup>th</sup> percentile. In this study, less emphasis was placed on the latter.

An additional measure of the level of distress experienced is also available and was included in this research. The impact supplement asks respondents to rate the impact on of the difficulties they experience on their home life, friendships, classroom learning and leisure activities. Not all adolescents attended school however and asking them to rate the level of interference with their classroom learning could lead to bias. Non-attending participants could rate the impact on classroom learning high as they could not attend to school, especially since many adolescents cited illness as their reason for not attending school. In an attempt to minimize this, “classroom learning’ was rather seen as referring to their daily activities.

The SDQ has proven validity internationally, including a number of developing countries. Psychometric evaluations (for instance by Goodman et al., 2003) report good internal consistency for the subscales with Chronbach’s alpha of 0.73. SDQ results were also highly correlated to the Rutter Child Behaviour Questionnaire scale and comparable or even better than the widely used Achenbach Child Behaviour Checklist (Goodman & Scott, 1999). Parent-Teacher correlation on the two



instruments (Achenbach and SDQ) was comparable or favoured the SDQ. It has also been suggested that a total difficulties score of 16 and above is a good predictor of mental disorder.

In Britain, the instrument has been successfully used in assessing psychological disturbance in 101 refugee children from various ethnicities (Fazel & Stein, 2003). The study successfully used British norms though refugee children were from developing countries. No specific psychometric is available for Africa. The questionnaire has been used in South Africa (Cluver & Gardner, 2006) with 60 African children and adolescents between the ages of 6 and 19. The authors of this study suggest that, though norms are not available, the established British norms (available on website) can be useful in indicating greater need.

In Uganda, Kizza employed the SDQ in examining the prevalence of mental disorders among hospitalized children (unpublished thesis). She also used it in UNICEF sponsored community surveys in different regions of Uganda to assess the level of emotional and behavioural disorders among children (ongoing, personal communication). She used the British norms.

In the present study, scores were predominantly used as continuous variables. This was better suited to the objective of determining change over time.

### ***Depression and Anxiety***

The Children's Depression Inventory (CDI) designed by Kovacs (Kovacs, 1981) is a children's version of the Beck Depression scale for use with children between the ages of 7 and 17 (appendix D). Two forms of the self report instrument exist, a longer (27 items) and shorter version (10 items). The longer version was used in this research as scores can be calculated and analysed for the different subscales, not just a total depression score.

CDI items consist of three statements describing a situation or feeling in varying degrees of severity. Participants are asked to select the statement that most accurately reflects their feelings over the past two weeks. The instrument has five subscales focusing on negative mood (6 items), problems in relationships (4 items), feelings of ineffectiveness (4 items), anhedonia – the inability to experience pleasure (8 items) and negative self-esteem (5 items).

Items are scored from 0-2, according to severity. Scores can be added for a total depression score ranging between 0-52 with higher scores indicating greater severity of symptoms. Scores for the five sub-scales can also be calculated individually. The scores calculated are converted to t scores, (scores with a mean of 50 and a standard deviation of 10), according to established norms for age and gender. T scores are provided on a profile sheet attached to the instrument. Scores can be used as a continuous variable, but cut off scores are available for use in identifying adolescents with depression. The author of the instrument recommends various cut off scores depending on the population (as reported in Matthey & Petrovski, 2002). In this study, a t score below 50 was associated with no depression symptoms, 50-65 with mild depression, 65-85 with moderate depression and above 85 with severe depression as set out in the norms accompanying the CDI. Only the latter two categories were considered as indicative of difficulties.

The CDI has shown good psychometric properties in many international settings and cultures. Internal consistency alpha coefficients reportedly range between 0.71-0.89. In Africa, the CDI has been used in South Africa and versions of the CDI are available in two South African languages. The instrument is also used in Uganda, both as a diagnostic and research tool.

The use of this instrument as a screening tool for depression has been criticised by Matthey and Petrovski (2002). It is considered better suited to monitoring changes in

mood. The current study was more interested in measuring changes in mood and this did not affect its use here. The choice of this instrument was further supported by the first grade reading level required by the CDI. In this study setting, where education levels were not known during the planning stages, this was an asset.

### ***Social adjustment***

The Self Report Measure of Social Adjustment (self report SAS-M) was modified for use in Britain by Cooper and Osborne (1982) from a scale developed in the United States by Weissman and Bothwell (1976). In its original form the scale consists of 42 items measuring functioning in six role areas: job or house work, social and leisure activities, relationships with extended family, relationship with spouse, functioning as parent, and functioning in the family unit. Each item consists of a statement with five response categories (all the time, most of the time, about half the time, occasionally, not at all) corresponding to varying levels of functioning. According to the methods set out by Weisman and Bothwell (1976) items are scored from 1-5 with higher scores indicating more problems with functioning. A mean score is calculated for each role area by summing the item scores within the category. A mean score for overall adjustment is calculated by totalling all item scores and dividing this by the number of items answered.

The self report SAS-M was modified for use with adolescents by Musisi and Kinyanda in their 2003 study of HIV positive adolescents attending Mildmay clinic. In their version the scales included were school work and work at home/chores, social and leisure activities, relationship with extended family, relationship with siblings and their relationship with members of their current family. Not all subscales were relevant to HIV positive adolescents in Uganda: In both the Mildmay and this study, not all adolescents attended school, for example, and participants were instructed to fill out only those sections pertaining to them. The scale was chosen as it had been used by Musisi and

Kinyanda in similar research and measured one of the core concepts of the research. It is also sensitive to change in social adjustment over time.

The remaining aspects of quality of life were addressed in interviews conducted at baseline and at the conclusion of the research. Interviews asked questions relating to stigma experience, social support, coping strategies and risk behaviours (sex, drugs and alcohol use). Questions asked during the second interview were based on those in the first interviews but focused more on changes adolescents may have experienced in these domains. Risk behaviours were added to the interview guide after discussions with clinic staff (see Appendix F for complete interview guides).

### **Stigma**

Understanding the nature of stigma experienced by the adolescents at the clinic was an important objective of the study. Stigma was not defined prior to the study, although a working definition had to be adopted as a guideline for developing questions. The definition adopted to this end was that of the 2001 Save the Children study in South Africa where stigma is conceptualized as:

*The imposition of a special, discrediting and unwanted mark on a person or a specific category of persons in such a way that in their interactions with others they are looked at as fundamentally and "shamefully different" by themselves and others.*

In the planning stages of the research, few HIV/AIDS stigma scales exist and those that could be found (e.g. Berger, Ferrans & Lashley, 2001) focused on adult populations in North America. These measures were not appropriate, as stigma is a social construct shaped by our social environment. An adolescent in an African country

would experience stigma differently than an adult in the United States. Questions regarding stigma were therefore included in the interviews, aimed at exploring not only the level of stigma but also the meaning attached to the concept in this specific environment. All stigma questions were open-ended.

Literature reviews, the Berger stigma scale, conversations with clinic staff and adolescents and the Horizons study of AIDS affected children (1991) in Kampala informed the stigma questions included in the interview guide (Appendix F). In the Horizons study, HIV positive parents or guardians were asked if their children had “ever been treated differently or badly because of your health situation?”. The question was reworded to reflect first person perspective and included in the interviews. No appropriate items about disclosure or the feelings stigmatization evoked were found in the literature or existing instrument. These items were developed.

### ***Coping and Social Support***

Interviews also included questions related to social support and coping strategies. Coping mechanisms were assessed by asking adolescents about their actions when faced with emotional difficulties and problems, as well as what help they needed from others. Questions were based on questions from the Fleischman and Fogel scale for coping with HIV/AIDS (1994) as well as the ACOPE (Carver, 1997).

Both the Social support for adolescents scale (Seidman et al., 1995) and the Horizons questionnaire (2001) shaped the social support questions included in the interview guide. The Social Support scale asks participants to rate seven individuals (categories are given) in their lives in terms of emotional and instrumental support provided. An additional question (“how much fun do you have with this person”) assesses satisfaction with the support provided by the mentioned individual. The categories of individuals listed in the instrument would not necessarily have been

appropriate for this research. From the pilot study it was clear that many participants in the study would be orphans and the nature of their social support system was not clear. Asking participants to rate seven people would also have made it too time consuming in the context of this research.

In the interviews participants were first asked to identify who they spent most of their time with and how much they could confide in this person (from Horizons study). They were then asked how helpful that person was in terms of emotional and instrumental support and how much fun they had with said person. If the participant felt they were not helpful in such situations, they were asked if there was anyone else they could rely on in such situations. In this way we attempted to gain information not only about the level of different types of support but who constituted the social support networks for these adolescents.

### **Demographic Information**

Adolescents' gender were recorded during their first contact with the research team and included in analysis.

Ages ranged between 10 and 19 and to simplify analyses, age groups were constructed. This was done in two ways: In the first instance, ages were divided according to the three age groups used in the peer support group meetings: 10-12 year olds, 13-15 year olds and 16-18 year olds. It was also used as dichotomous variable classifying participants as young adolescents, aged 10-12 years, and older adolescents aged 13-18 years. The definition of adolescence used here is that of the World Health Organization, but other definitions of adolescence exist. In many other studies, 10-12 year olds are regarded as children and adolescence seen as starting at 12 years (see for instance Bisegger et al., 2005). Classifying adolescents as those younger than 12 and those older than 12, would expose any differences between the young adolescents and

older adolescents as well. The CDI is considered appropriate for adolescents 17 or younger and 18 year olds were excluded from analysis. Expanded age categories (three age groups) were therefore not used and 10-12 year olds were compared to 13-17 year olds. In all other instances analyses was run with both categorizations.

A short survey conducted during the interviews focused on Academic performance (self-report and report cards), self-reported school attendance and participation in extra-curricular activities (sports, leadership positions). These criteria were adopted from Musisi and Kinyanda (2003) and their study of HIV seropositive adolescents.

To determine who was attending school at 9 months, responses to the self report SAS-M were consulted. The schoolwork section of the instrument was only completed by those attending school at the time. If this section was completed at nine months, adolescents were considered to be in school. Responses to this section of the SAS-M were compared to available school information to determine if only school-attending adolescents had completed the section. Good correspondence between the two sources suggests that school attendance obtained in this way was reliable.

Including school attendance in the longitudinal analyses proved problematic as the adolescents moved in and out of school attendance depending partly on their health and partly on whether they had the resources necessary to continue. Categorizing participants according to school attendance at the end of the research period did not take into account the change that may have occurred during the research period. A school attending adolescent, therefore, was not necessarily attending school at baseline, three months or six months. In response to this problem, data was only analysed regarding 9 and 12 months with respect to baseline. Taking into account changes in school attendance during the study period can also counteract this and participants were

also categorized according to change in school attendance to supplement the discussion.

Two approaches were taken to the analysis of data on parental loss. Firstly, double orphans (those who had lost both parents) were compared to participants with a living birthparent. In the second instance, double orphans were compared to those who had not lost either parent, who had lost only their mother and who had lost only their father. UNICEF definition of orphans states that all adolescents who had lost their mother were considered maternal orphans – this would include the double orphans. The same applies to paternal orphans (lost their father). In this study, however, double orphans were not included in the maternal and paternal orphan category but included as separate groups. It allows for comparison between those with no parents, a single parent and both parents.

Peer support group attendance for 2005 was available. According to their attendance adolescents were considered to attend regularly if they missed three or less sessions during the year. Attending fewer than 9 sessions was considered occasional attendance. There was also a category of adolescents who never attended.

## **Implementation**

Questionnaires were tested with five adolescents already receiving antiretroviral therapy and therefore ineligible for the study. After completing the questionnaire they discussed it either with myself or the research assistant and were asked if any questions were unclear, confusing or otherwise problematic. Questions identified as potentially problematic by research staff or other interested parties were discussed with them and we repeated certain questions verbally with them, to ensure their comprehension of the questions. No problems with the instrument were identified and everyone completed the



questionnaire in less than 30 minutes. The minimal testing of the questionnaire was considered sufficient, as all instruments had recently been used in similar populations in Uganda.

The research assistant translated the interview guides for his use in the interviews. Interview guides were tested with only a couple of people, as the same research assistant would conduct all interviews. A more thorough testing would have been prudent, however, especially since the interviews dealt with abstract concepts such as "stigma".

The investigator and research assistant discussed all instrument, including the interview guides, to ensure similar understanding of the questions and uniform administration.

The research team attended the clinic on Mondays and Tuesdays. The adolescent clinic takes place on Tuesdays, and Mondays were added to ensure 10-12 year olds were included. A research nurse stationed at reception screened patient files as adolescents reported to the clinic. Candidates meeting the criteria for antiretroviral therapy and the prospective adolescent study were identified. The study nurse or counsellor would approach those identified, explain the study to them and inquire whether they were interested in participating. If an adolescent agreed to participate in the prospective adolescent study, the research assistant would also invite them to participate in the quality of life study. No adolescents refused participation but three were ineligible due to inability to procure consent, known sexual infection and one was already receiving antiretroviral therapy from another clinic.

Questionnaires were administered at the clinic on the day of an adolescent's scheduled appointment and took around 45 minutes to complete. Where possible, interviews were also conducted on days of regularly scheduled clinic appointments and averaged 30 minutes each. Questionnaires and interviews were rarely done together as

it was too time-consuming. Adolescents whose interviews had to be scheduled on days other than their clinic appointments received a transport reimbursement.

### **Data Management and Analysis**

Completed questionnaires and interview guides were collected weekly. A scoring guide was developed for the questionnaires based on the guides available for the existing instruments. Questionnaires were scored accordingly and the data entered into an Excel database where they were checked for completeness and accuracy. Participants would have been excluded from analysis if they missed more than half of data collection sessions, but this did not happen.

Quantitative data was analysed using SPSS (version 10) according to the objectives set out. The alpha level was set at 0.05, and any p value smaller than 0.05 was considered significant. Analysis of the sample at baseline included descriptive statistics and independent-samples t-tests, as well as chi square analysis to determine if significant differences existed between groups according to the demographic variables.

In longitudinal analysis, paired sample t-tests assessed changes in psychological distress, depression and social functioning over time. This test was considered most appropriate as it only included participants if data was available at both baseline and the later time point. Missing data could therefore be excluded on a case-by-case basis. Independent-samples T tests were also used to determine if there were significant differences between groups according to gender, age, parental loss and school attendance. In variables that had more than two categories one-way ANOVA tests were used to the same end.

In ordinal variables, Wilcoxon signed ranks tests was used to indicate significant changes in health ratings and depression groups. Mann-Whitney and Kruskal-Wallis tests determined if there were group differences in the ordinal variables over time.

Statistics were reported to two decimal places, although this does not suggest that the small sample size allows for that level of precision.

Interviews were taped, transcribed and translated. Only two adolescents refused to have their second interviews taped. Transcripts were analysed thematically.

## **Ethics**

Approval for the research was obtained from the Health Research Ethics Board at the investigator's home institution of the University of Manitoba. Local approval was obtained from the departments of Paediatrics and Psychiatry at Mulago Hospital and the Makerere University Medical School ethics review board. Approval from the University of Manitoba was received in August 2004 and from Makerere medical school in November 2004. This research was included in the proposal submitted to the Uganda National Council for Science and Technology by the larger adolescent study and not submitted independently. The research took longer than one year and ethics approval from the University of Manitoba was renewed in October 2005.

During the planning of the research, the *Interim Statement of Intent*, which informed Save the Children's South African study, was consulted as ethical guidelines. UNICEF's *Children Participating in Research, Monitoring and Evaluation (M&E) – Ethics and your responsibility as a Manager* (UNICEF, 2002b) was also consulted and these two guidelines were adhered to.

In a 2003 survey conducted with adolescents at the clinic more than half of the adolescents stated they had no one with whom to discuss their illness. It was expected that the research interviews themselves might be beneficial to participants as talking

about experienced difficulties have been shown to be therapeutic (Barnett, 2001). One study participant did comment to this effect: "Thank you, coz (because) the more I express my feeling at least am relieved".

The research posed minimal risk but interviews did evoke emotional responses for some. They were asked if they wanted to stop the interview and one adolescent did choose to suspend the interview. They were also advised to speak to a counsellor immediately or at their next visit. We could not force adolescents to talk to a counsellor, but clinic patients see counsellors regularly and the research assistant followed up to ensure that these adolescents did see a counsellor. Out of respect for clinic procedures, study participants were not directly referred to the psychiatrist but referred to a clinic physician or counsellor who would then refer them to the psychiatrist. In the event of high depression scores, suicidal tendencies or distress expressed during sessions, a study team member would approach a physician or counsellor and request an appointment for the adolescent. Specifics regarding the situation were not shared, only that the adolescent was in need of help.

Stigmatization is a concern when dealing with HIV/AIDS. Involvement in this research did not expose participants to increased stigmatization. Adolescents were attending the clinic before the study and continued to do so regardless of participation in the research. Participant's identities were protected. They were assigned a study number upon enrolment into the prospective cohort study and the same number was used for this study. Two lists existed linking the names and study number of participants. Both were kept in locked filing cabinets.

The level of independence of this research to clinic activities and treatment were emphasized and in no way influence the regular treatment received. Every effort was made to protect participants' identity.

### Chapter 3: Baseline Description

Little is known about this particular population and creating a profile of these adolescents before the start of antiretroviral therapy was an important objective of the study. This chapter will describe the demographic characteristics as well as the psychosocial profile of this sample.

#### Demographic Characteristics of sample

Baseline information was available for 52 adolescents and demographic information is displayed in table 3.1. The mean age of participants was 14.15 years ( $SD=2.02$ , range 10-18), with more than half of participants being 13–15 years old. There were slightly more girls in the sample than boys with even distribution across age groups.

Forty-three adolescents (83%) had suffered a parental loss with double orphans accounting for a third of the sample. Single orphans made up just under half of the sample and maternal orphans were only slightly more than paternal orphans. Only eight adolescents had not lost a birthparent. Nineteen orphaned adolescents did not know how old they were at their parents' passing. Of the remaining orphans, 54.5% had been younger than 10 at the time of their mother's death and 46.7% at their father's death. Mean age at mother's death (7.65,  $SD=3.57$ ) was also younger than mean age at paternal death (8.55,  $SD=4.83$ ). The majority of participants were living with a birthparent or extended family. Single parent families dominated (19 families, 36.5%) followed by monogamous families and families headed by grandparents, both reported by 11 families or 22.4% of respondents. Sibling families accounted for 10% of living arrangements. The median number of other children in participant's households was three ranging from zero to nine. The range for the number of siblings in the household

was also zero to nine but on average, only one (out of the above-mentioned 3) was a sibling. Number of total siblings ranged between none and 12 with a mean of two.

Table 3.1.

Demographic Characteristics

	n (%)
Gender ( <i>n</i> =52)	
Male	23 (44.2)
Female	29 (55.8)
Age distribution ( <i>n</i> =52)	
10-12 years	12 (23.1)
13-15 years	28 (53.8)
16-18 years	12 (23.1)
Parental Loss ( <i>n</i> =51)	
None - Both Parents alive	8 (15.7)
Maternal Orphan	13 (25.5)
Paternal Orphan	11 (21.6)
Double Orphan	19 (37.3)
Current living Arrangements ( <i>n</i> =51)	
Birthparent	19 (37.2)
Stepparent	3 (5.9)
Grandparent	9 (17.6)
Extended family	11 (21.6)
Sibling family	5 (9.8)
Orphanage	2 (3.9)
Other	3 (5.9)

## Disclosure

Adolescents had to be aware of their HIV status to qualify for the study. During the interviews, however, two adolescents claimed never being officially disclosed to. One respondent had deduced her status from clinic visits but the other was under the impression she was receiving TB treatment when first recruited into the adolescent study. The majority of participants were disclosed to within the past year with only three having known for 3 years (table 3.2).

Most adolescents were disclosed to by counsellors and family members. Fourteen adolescents had been disclosed to at the study site (PIDC), although not all by counsellors. In some instances caretakers disclosed to adolescents at the clinic, within the support system of the counsellors and staff.

## Source of Infection

A question regarding the suspected origin of infection was included in the interviews. It was an open ended question and response categories were constructed after the fact from the 33 responses (table 3.2).

The majority of adolescents had an idea as to the source of infection, and only six indicated not knowing. The overwhelming majority thought they had contracted it from their parents with only two listing causes not related to their mothers. Mothers were only named explicitly by a few adolescents but categories such as 'breastfeeding' or 'during birth/born with it' all referred back to the mother.

Table 3.2

## Disclosure and suspected origin of infection

	n (%)
Time since disclosure ( <i>n</i> =40)	
Less than a year	14 (35)
Previous year	13 (33)
Two years	1 (3)
Three years	3 (8)
Not disclosed to before study	2 (5)
Does not remember	7 (17)
Disclosed to by ( <i>n</i> =33)	
Counsellor	15 (46)
Family/caretakers	14 (42)
Doctor	2 (6)
Nurse	1 (3)
House matron	1 (3)
Suspected source of Infection ( <i>n</i> =33)	
Parents/Mother	18 (55)
Born with it	5 (15)
During birth	1 (3)
Breastfeeding	1 (3)
Teeth extraction	1 (3)
Forced sex	1 (3)
Does not know	6 (18)

Note: Percentages were rounded and may not calculate to 100.



## School

School attendance was only 51.9 %, or 27 participants attending school (table 3.3). There was no significant gender difference ( $\chi^2 = .001$ ,  $df=2$ ,  $p > .05$ ) but school attendance significantly decreased with increased age ( $\chi^2 = 10.749$ ,  $df=2$ ,  $p < .05$ ). In the youngest age group school attendance was 83.3% compared to 53.6% in the middle age group and 16.7% in the oldest age group. The difference in the mean ages of adolescents attending school (13.4,  $SD=1.69$ , range 11-18) and adolescents not attending school (14.96,  $SD=2.07$ , range 10-18) was also significant ( $t = 2.969$ ,  $df=50$ ,  $p=0.005$ ).

The attendance rate of double orphans was half that of adolescents with both parents. Maternal orphans had an attendance rate of 53.8%, while paternal orphans had the highest attendance with 72.7%. The differences between the four groups were not significant. Combining categories revealed a significant difference between double orphans and those participants with a living birthparent ( $\chi^2 = 4.561$ ,  $df = 1$ ,  $p = 0.03$ ).

All participants in this study had some schooling, even if not currently attending school. In interviews, the main reason for not attending school was illness, reported by 17 of the 25 adolescents. This was followed by lack of school funds (4) and a combination of lack of funds and illness (2). One adolescent did not know why she was not attending school and another stated holiday as the reason for absence.

Information about the last year completed was available for 46 participants. Of these, 14 (30.4%) had advanced to a senior level (high school) and 32 (69.6%) were in primary school. The last year completed by those not attending school ranged from P1 (first grade) to S4 (11<sup>th</sup> grade) with the majority having a P6 education. Eight had advanced to a senior year. The median grade completed for those attending school was P6 as well. Seven had advanced to a senior level while 16 were in primary school.

Table 3.3

School attending adolescents compared to adolescents not attending school

	Attending School (n=27)	Not Attending School (n=25)
	n (%)	n (%)
Gender		
Male	12 (44.4)	11 (44)
Female	15 (55.6)	14 (56)
Age group		
10-12 years	10 (37.04)	2 (8)
13-15 years	15 (55.56)	13 (52)
16-18 years	2 (7.41)	10 (40)
Parental Loss		
None	5 (18.5)	3 (12)
Maternal Orphan	7 (26)	6 (24)
Paternal Orphan	8 (29.6)	3 (12)
Double Orphan	6 (22.2)	13 (52)
Unknown	1 (3.7)	
Self-evaluated attendance		
Every day	4 (14.8)	
Most of the time	13 (48.1)	
Some of the time	5 (18.5)	
Very irregularly	4 (14.8)	
Unknown	1 (3.7)	

Adolescents attending school were asked to rate both their school attendance and performance. They were also asked to bring report cards for the last term completed as independent measure of both attendance and performance. While the report cards did provide valuable information regarding performance, it unfortunately did not provide any indication of attendance and self-evaluation is the only available information. More than half of the adolescents reported going to school most of the time with only four reporting irregular attendance (table 3.3).

Performance self-evaluation ranged from poor (1 adolescent) to excellent, with most adolescents feeling their academic year had gone 'fair' to 'well'. We obtained 18 report cards (from 27). One report card was incomplete, as the individual had fallen sick during the examination period and had not completed his exams. Average grades were available for 16 adolescents. Eleven (68.75%) of these adolescents had an average of 50% or lower with 5 having an average between 21-30%. Position in class was also taken into consideration as this measure would allow for comparison to classmates. Five adolescents were in the top 25 % of their class and of these 2 were in the top 10%. The majority of students (55.5%) were however, in the bottom half of their classes with 2 placed in the bottom 25% of their class.

Participation in extra curricular activities was also recorded during the interviews and nine adolescents (one third, 33.3%) indicated participation in some activity. During the interviews, many participants listed sports such as football and athletics as favourite activities but only three (or 11.1%) participated in any sports at school. Of these, two (7%) were in school teams. More adolescents participated in non-physical activities with singing being most popular (three participants, 11.1%) followed by debate and drama club (both reported by one adolescent). Two adolescents held leadership positions as a timekeeper and a class prefect.

Primary school education is offered free in Uganda through the Government's Universal Primary school education initiative (UPE). There are still many costs involved in schooling, as most schools require children to wear uniforms and acquire their own books and other supplies. Primary school students also needed financial support, albeit not as much as secondary school pupils who needed to pay school fees. In this sample, one student named UPE as supporting his/her education. Parents (37%) or other family members (33.3%) supported the majority. Additional sources of funding included stepparents, the clinic's school support fund and other charitable organizations.

### **Risk behaviours**

The interviews included questions on risk behaviours teenagers may engage in. The reported use of both alcohol and drugs were low. Only one adolescent reported current alcohol use and forty-one (of 46) had never used alcohol (89.1%). Drug abuse was as uncommon with none reporting current drug use and only one adolescent admitted trying any drug before.

Participants were asked about the presence of a boyfriend or girlfriend in their lives and two admitted being in relationships. One girl ended her relationship when she found out she was HIV positive. The remaining 43 were not involved in relationships. Five adolescents (three female and two male) reported sexual encounters in the past and one male engaged in 'romance' but stopped short of penetrative sex. For the purpose of this study, 'sex' was defined as penetration of the vagina and this last boy was excluded. Three of the five adolescents with sexual experience had participated in consensual sex while two had been forced. All adolescents reported these initial sexual encounters as their only experience.

The victims of rape were both female and had both been forced by male extended family members. Both girls were nine years old at the time. In one case the

perpetrator was an adolescent himself (12 years old) but the other was in his early twenties. The older male's victim believes he is the source of her HIV infection, describing him as "the one who gave me the HIV infection".

Those who participated in consensual sex had done so with friends. All respondents had been 9 or 10 years old at the time of the sexual experience with a mean age of 9.4. Ages for the other party involved ranged between 10 and 20 with a mean age of 12.6 years.

Table 3.4

Sexual Experience

	n (%)
Sexual experience	5 (10.8)
consensual sex	3 (60)
forced sex	2 (40)
Age at first sexual experience	
9	3 (60)
10	2 (40)
Who first experience was with	
Uncle or other family member	2 (40)
Neighbour	2 (40)
Friend	1 (20)

## Health rating

Adolescents were asked to rate their health on a four-point scale as very good, good but not perfect, somewhat poor or very poor. Two thirds of the participants described their health as quite good and an additional 20% as very good (table 3.5). Seven adolescents felt their health was suffering to some extent. No significant difference in health rating was found by gender ( $\chi^2=1.630$ ,  $df=3$ ,  $p=0.653$ ) or age group ( $\chi^2=3.815$ ,  $df=6$ ,  $p=0.702$ ). In-school adolescents were more likely to rate their health as “very good” compared to participants not attending school (23.1% versus 16.7%). The difference between these groups ( $\chi^2=2.26$ ,  $df=3$ ,  $p=0.52$ ) was not significant.

A quarter of adolescents with both parents rated their health as ‘very good’ followed by double orphans (21.1%). Paternal orphans rated their health more negatively than maternal orphans, adolescents with both parents or double orphans (10.5%). Paternal orphans were also the only group with a rating in the ‘very poor’ category – in the other groups negative scores were all in the ‘somewhat poor’ category. None of these differences were significant ( $\chi^2=4.961$ ,  $df=9$ ,  $p=0.838$ ).

Table 3.5.

## Subjective Rating of Health

	Very Good	Good*	Poor**	Very Poor
	n (%)	n (%)	n (%)	n (%)
Baseline Health rating	10 (20)	33 (66)	6 (12)	1 (2)
Gender				
Male ( <i>n</i> =23)	5 (50)	15 (45.45)	2 (33.33)	1 (100)
Female ( <i>n</i> =27)	5 (50)	18 (54.54)	4 (66.67)	
Age Group				
10 -12 years ( <i>n</i> =12)	2 (20)	7 (21.21)	2 (33.33)	1 (100)
13-15 years ( <i>n</i> =27)	6 (60)	18 (54.54)	3 (50)	
16-18 years ( <i>n</i> =11)	2 (20)	8 (24.24)	1 (16.67)	
School Attendance				
Attending school ( <i>n</i> =26)	6 (60)	15 (45.45)	4 (66.67)	1 (100)
Not attending school ( <i>n</i> =24)	4 (40)	18 (54.54)	2 (33.33)	
Parental Loss				
None ( <i>n</i> =8)	2 (20)	5 (15.15)	1 (16.67)	
Maternal orphan ( <i>n</i> =13)	3 (30)	8 (24.24)	2 (33.33)	
Paternal Orphan ( <i>n</i> =10)	1 (10)	7 (21.21)	1 (16.67)	1 (100)
Double orphan ( <i>n</i> =19)	4 (40)	13 (39.39)	2 (33.33)	

\* Good, but not perfect

\*\* Somewhat poor

## Psychological Distress: Emotional and Behavioural Difficulties

The Strength and Difficulties Questionnaire (SDQ) was used to determine the level of emotional and behavioural distress adolescents experienced. The Questionnaire consists of five subscales. Four of these focuses on difficulties respondents may experience with higher scores indicating increased difficulty. The fifth scale measures respondents' prosocial behaviour and is the only 'strength' scale. Prosocial behaviour refers to helping behaviour towards society as a whole – younger and older, not only their peers. Unlike the difficulty scores, a higher prosocial score indicates improved functioning. An optional Impact supplement measures adolescents' perceptions of the overall level of distress and resultant impairment in various areas of life experienced.

All scores can also be classified as normal, borderline and abnormal according to given norms and table 3.6 displays the distribution of difficulties across categories. The greatest percentage of scores falls within the normal range, with frequencies of above 80% in all but two categories. The greatest problems were reported in peer relations and emotional symptoms. The emotional symptom scale had the highest number of scores in the abnormal range. If the low cut off was employed, however, and difficulties of all severity included (anybody with a borderline or abnormal scores), it seems that the adolescents struggled most with peer problems, as 43.1% experienced some degree of difficulty in this area.



Table 3.6

Distribution of difficulties scores across categories (n=51)

	Normal	Borderline	Abnormal
	n (%)	n (%)	n (%)
Total Difficulties	44 (86.3)	1 (2)	6 (11.8)
Emotional Symptoms	38 (74.5)	5 (9.8)	8 (15.7)
Conduct Problems	45 (88.2)	4 (7.8)	2 (3.9)
Hyperactivity	45 (88.2)	3 (5.9)	3 (5.9)
Peer Problems	29 (56.9)	15 (29.4)	7 (13.7)

Scores can also be used as continuous variables (all difficulties means are displayed in table 3.7). Means all fell in the normal range except for peer problems, which fell in the borderline range. All difficulties scores were also compared across groups (table 3.7). Male participants showed more distress on all but the emotional problems and prosocial scale. On the conduct problems subscale the difference is significant with the mean for male participant being more than double that of female participants ( $t=1.983$ ,  $df=49$ ,  $p=0.053$ ). None of the other differences was significant. There was also no significant difference in the percentage of boys and girls classified as normal, borderline or abnormal on any scale.

Age, school attendance and parental loss were not associated with any significant differences in means or in distribution across categories. Older adolescents (aged 16–18) had the highest mean total difficulties score, emotional symptoms, hyperactivity and peer problems. School attendance was associated with lower mean scores for total difficulties, emotional symptoms, and conduct problems. Paternal orphans had the highest mean total difficulties scores, emotional symptoms and

hyperactivity scores. The highest scores on the remaining scales (conduct and peer problems) were both for adolescents who had not lost a parent.

Table 3.7

Distribution of Difficulties scores

	Total Difficulties		Emotional Symptoms		Conduct Problems		Hyperactivity		Peer Problems	
	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range
Overall	10.76 (6.17)	0-29	3.29 (2.62)	0-10	1.24 (1.69)	0-8	2.63 (2.32)	0-9	3.04 (2.23)	0-8
Gender										
Male ( <i>n</i> =23)	11.17 (5.94)	1-29	3.61 (2.44)	0-10	1.74 (1.98)	0-8	2.7 (2.58)	0-8	3.22 (1.91)	0-7
Female ( <i>n</i> =28)	10.43 (6.44)	0-24	4.18 (2.78)	0-10	0.82 (1.31)	0-9	2.57 (2.13)	0-9	2.89 (2.23)	0-8
Age Group										
10-12 years ( <i>n</i> =12)	10.75 (7.37)	1-29	3.75 (2.09)	0-8	1.33 (2.5)	0-8	2.50 (2.65)	0-8	3.17 (2.21)	0-7
13-15 years ( <i>n</i> =27)	10.33 (5.23)	1-22	3.96 (2.53)	0-10	1.19 (1.33)	0-8	2.44 (2.01)	0-8	2.85 (2.01)	0-8
16-18 years ( <i>n</i> =12)	11.75 (7.24)	0-24	4.00 (3.41)	0-10	1.25 (1.6)	0-9	3.17 (2.76)	0-9	3.33 (2.23)	0-7
School Attendance										
Attending ( <i>n</i> =27)	10.37 (5.1)	1-22	3.74 (2.28)	0-8	1.07 (1.49)	0-8	2.67 (2.58)	0-8	3.07 (1.98)	0-8
Not attending ( <i>n</i> =25)	11.21 (7.28)	0-29	4.13 (3.00)	0-10	1.42 (1.91)	0-9	2.59 (2.12)	0-9	3.00 (2.23)	0-7
Parental Loss										
None ( <i>n</i> =8)	11.75 (9.56)	2-29	3.5 (3.3)	0-10	2.00 (3.02)	0-8	2.88 (2.9)	0-8	3.38 (2.00)	1-7
Maternal Orphan ( <i>n</i> =12)	10.08 (3.63)	1-15	3.83 (1.53)	1-6	0.67 (0.98)	0-4	2.83 (1.53)	0-4	2.92 (2.19)	0-7
Paternal Orphan ( <i>n</i> =11)	12.27 (5.41)	7-24	4.55 (2.81)	2-10	1.27 (1.1)	0-9	3.64 (2.84)	0-9	2.82 (1.78)	0-6
Double Orphan ( <i>n</i> =19)	9.42 (6.09)	0-22	3.84 (2.95)	0-10	1.11 (1.49)	0-6	1.6	0-6	2.84 (2.06)	0-6

The mean for the prosocial scale was in the normal range and the majority (92%) of adolescents scored in the normal range (table 3.8). There were no significant differences regarding gender, age, school attendance or parental loss.

Table 3.8

## Distribution of Prosocial Scores

	Mean (SD)	Range	n (%)
Overall distribution	7.9 (2.23)	1-10	
Normal			46 (92)
Borderline			1 (2)
Abnormal			3 (6)
Gender			
Male	7.91 (2.02)	3-10	23
Female	7.89 (2.42)	1-10	28
Age group			
10-12 years	8.67 (1.92)	4-10	12
13-15 years	7.65 (2.15)	1-10	27
16-18 years	7.67 (2.67)	2-10	12
School Attendance			
Attending	8.08 (2.17)	2-10	27
Not attending	7.71 (2.33)	1-10	25
Parental Loss			
None	8.5 (2.62)	3-10	8
Maternal Orphan	8.36 (1.69)	6-10	12
Paternal Orphan	6.91 (2.62)	2-10	11
Double Orphan	8.05 (2.09)	1-10	19

The Impact scale of the SDQ asks adolescent to rate the effect of emotional and behavioural difficulties on their functioning in the areas of home life, friendships, classroom learning and leisure activities. An overall impact score is calculated by summing all answer. As with the other scores on this scale, the impact score can be used as a continuous variable or categorized as normal, borderline or abnormal. A normal score can only be obtained if the respondent reported no difficulties. In this sample, the mean impact score was 1.18 (SD=2.35) and scores ranged between zero and nine (table 3.9). Seventy percent (36 adolescents) reported having no disruptive difficulties, but a quarter of the adolescents felt the difficulties were severely affecting their lives. There were no significant differences according to gender, age, school attendance or parental loss.

Table 3.9

## Distribution of Impact Scores

	Mean (SD)	Range	n (%)
Overall distribution	1.18 (2.35)	0-9	
Normal			36 (70.59)
Borderline			2 (3.92)
Abnormal			13 (25.5)
Gender			
Male	1.22 (2.21)	0-9	23
Female	1.14 (2.49)	0-9	28
Age group			
10-12 years	1 (1.65)	0-5	12
13-15 years	1.26 (2.54)	0-9	27
16-18 years	1.17 (2.66)	0-9	12
School Attendance			
Attending	0.75 (1.94)	0-9	27
Not attending	1.56 (2.64)	0-9	25
Parental Loss			
None	1.5 (3.21)	0-9	8
Maternal Orphan	0.5 (1)	0-3	12
Paternal Orphan	1.09 (2.02)	0-5	11
Double Orphan	1.16 (2.34)	0-9	19

### Psychological Distress: Depressive symptoms

The Children's Depression Inventory (CDI) was used to examine the level of depressive symptoms experienced. The CDI is only appropriate for use with adolescents 17 years of age and younger, and 18 year olds had to be excluded from analysis. CDI data was available for 45 adolescents. The CDI has five subscales focused on different aspects of depression. Scores can be calculated for each of the scales and summed for an overall depression score. Raw scores were converted to t scores according to age and gender. A t score below 50 indicates an absence of significant depression symptoms. Above 50, adolescents' scores can be categorized as mild (t scores between 50 and 64), moderate (between 65 and 84) or severe (above 85) depression. Table 3.10 displays the distribution across categories. No participant had severe depression and 8.9% of the participants had a t score in the moderate range. The mean total t score for this sample was 51.47 and the majority of the participants had t scores below 50.

Female participants had a higher total CDI score and higher mean scores on all but the negative self-esteem scale (table 3.11). On the Ineffectiveness subscale, the mean for female participants was significantly higher ( $t=-2.37$ ,  $df=43$ ,  $p=0.02$ ). There was no significant gender difference in the percentage of male and female participants in the different categories. Four female participants were in the moderate depression range but no male participants scored that high.

Table 3.10

## Distribution of Total Depression scores

	Mean (SD)	Range	n (%)
Overall distribution	51.47 (9.8)	34-82	
No Depression			21 (46.67)
Mild Depression			20 (44.44)
Moderate Depression			4 (8.89)
Gender			
Male (n=23)	49.19 (6.59)	40-62	23
Female (n=28)	53.46 (11.7)	36-82	28
Age group			
10-12 years (n=11)	49.09 (7.03)	39-61	22
13-17 years (n=34)	52.25 (10.51)	34-82	34
School Attendance			
Attending (n=25)	50.54 (9.75)	39-78	25
Not attending (n=24)	52.52 (9.98)	34-82	24
Parental Loss			
None (n=7)	48.29 (6.45)	40-57	7
Maternal Orphan (n=11)	49.18 (6.16)	39-62	11
Paternal Orphan (n=10)	55.18 (11.72)	40-82	10
Double Orphan (n=19)	51.42 (10.55)	34-78	19



Participants in the youngest age group had the lowest mean total and the lowest means on the ineffectiveness, anhedonia and negative self-esteem subscales. None of the participants in this age group were in the moderate depression category either. The older adolescents had 4 participants in the moderate category and 14 classified as mild. There were no significant differences between the age groups, however.

Paternal orphans had the highest mean score (55.5) followed by double orphans, maternal orphans and children with both parents alive (table 25d). They also scored consistently higher across subscales with the highest mean scores on four of the five subscales. Maternal orphans scored higher only on ineffectiveness. Adolescent who had not lost a parent not only had the lowest total mean but also had the lowest means on three of the subscales (Interpersonal problems, Ineffectiveness and Negative self-esteem). No differences between the means were significant (table 25d). There was no significant difference in the number of participants in each category. There were no significant difference between participants in school and those not attending school although the latter had the highest total CDI and the highest mean on three of the subscales. In school adolescents higher mean score only on the interpersonal problem scale and this was also the only difference to approach significance (table 25c). Groups were almost identical in terms of percentage of respondents scoring in the different categories.

Table 3.11

Distribution of Depression Subscale scores

	Negative Mood		Interpersonal		Ineffectiveness		Anhedonia		Negative self-esteem	
	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range
Overall	49.53(10.47)	37-81	45.98 (4.85)	42-64	51.82 (10.76)	38-81	56.07 (11.5)	37-81	47.84 (9.21)	39-76
Gender										
Male ( <i>n</i> =21)	48.12 (8.53)	39-66	45.36 (3.71)	42-57	47.95 (7.81)	38-64	54.48(10.05)	37-73	47.9 (8.88)	39-76
Female ( <i>n</i> =24)	50.67(12.54)	37-81	46.5 (5.7)	43-64	55.21 (11.95)	38-81	57.46(12.68)	38-81	47.79 (9.68)	39-70
Age Group										
10-12 years ( <i>n</i> =11)	49.91 (6.58)	40-64	46.64 (5.28)	42-57	49 (8.02)	41-64	53 (12.14)	42-81	45.9 (8.56)	40-62
13-17 years ( <i>n</i> =34)	49.41(11.86)	37-81	45.67 (4.77)	43-64	52.74 (11.46)	38-81	57.06(11.29)	37-78	48.47 (9.45)	39-76
School Attendance										
Attending ( <i>n</i> =25)	49.67 (9.75)	37-76	47.25 (5.8)	42-64	49.58 (10.3)	38-81	54.42(10.95)	37-78	47.33 (8.06)	40-64
Not attending ( <i>n</i> =24)	49.38(11.28)	37-81	44.53 (3.01)	42-54	54.38 (10.94)	38-81	57.95(12.09)	38-81	48.43 (10.55)	39-74
Parental Loss										
None ( <i>n</i> =87)	49.17(12.11)	37-66	44.43 (2.23)	42-49	46.29 (3.9)	43-54	54 (9.5)	42-67	44.43 (6.65)	39-56
Maternal Orphan ( <i>n</i> =11)	45.36 (4.72)	37-50	46.27 (4.8)	43-56	53.35 (9.67)	41-74	53.45 (8.38)	41-66	46.09 (10.64)	39-76
Paternal Orphan ( <i>n</i> =10)	54.1 (13.8)	37-81	47.2 (5.22)	42-57	52.9 (13.03)	38-81	60.2 (15.59)	37-81	50.9 (7.8)	40-64
Double Orphan ( <i>n</i> =16)	48.88(10.84)	37-75	44.56 (3.08)	42-54	51.63 (11.79)	38-81	55.94(11.82)	38-78	47.63 (9.37)	39-70

### Psychological Distress: Social Functioning

Social functioning in seven domains (table 3.12) was assessed with the self-report Social Adjustment scale (self report SAS-M) with higher means indicating more difficulties functioning in the specific area. The instrument design expects adolescents to fill out only those sections applicable to them, i.e. on sections such as schoolwork, only those adolescents attending school will respond. The sample sizes for the different subscales vary therefore, as summarized in table 3.12.

Table 3.12

Sample Sizes and means of self report SAS-M Subscales

	n	Mean	SD	Range
Overall	51	2.28	0.37	1.6-3.4
School work	26	2.17	0.63	1.16 -3.5
Work at home	51	1.98	0.68	1-3.83
Social and leisure activities	51	2.56	0.61	1.56 – 4.11
Extended family	51	2.42	0.56	1 - 3.74
Parents/guardians	38	2.13	0.49	1 - 3
Siblings	41	2.24	0.79	1 - 4.25
Family unit	37	1.98	0.82	1 - 4.67

Adolescents rated themselves at or above 50 % on all scales. Comparison of mean scores by gender revealed no significant difference in any area or in overall functioning although male participants had the highest mean score on only one of the scales. Parental loss also had no significant affect on any self report SAS-M scores.

The youngest age group (10-12 years) had the lowest mean scores on all but the family unit ( $F_{0.05}(2,23) = 2.42$ ) subscale while the oldest age group (16-18 years) had the highest mean score on four of the seven scales (table 3.13). The age differences in overall adjustment approached significance ( $F_{0.05}(2,48) = 2.64$ ). The difference between the groups was significant on the parent/guardian subscale ( $p=0.05$ ), with both categories of older adolescents scoring significantly higher. Grouped together, older adolescents (13-18 years) had an even higher parent/guardian mean ( $t(24) = 2.53$ ,  $p=0.02$ ). The age groups were also significantly different in terms of schoolwork ( $t(24) = 2.24$ ,  $p=0.03$ ).

Comparison of adolescents attending and not attending school showed a significant difference between the groups regarding parent/guardian relationship with a significantly higher mean score for those not attending school ( $t(36) = 2.05$ ,  $p=0.05$ ). No other differences were significant. As school attendance was the factor here, the first scale, schoolwork, was not included in analysis.

Table 3.13

Age Differences in self report SAS-M scores.

	Age groups	n	Mean	SD
Overall Adjustment (n=51)	10–12 years	12	2.07	0.37
	13-15 years	27	2.33	0.37
	16-18 years	12	2.36	0.32
School work* (n=26)	10–12 years	9	1.81	0.54
	13-15 years	15	2.34	0.64
	16-18 years	2	2.42	0.36
Housework (n=51)	10–12 years	12	1.85	0.63
	13-15 years	27	2.02	0.71
	16-18 years	12	2.01	0.70
Social and leisure (n=51)	10–12 years	12	2.45	0.66
	13-15 years	27	2.50	0.53
	16-18 years	12	2.79	0.72
Extended family (n=51)	10–12 years	12	2.21	0.36
	13-15 years	27	2.46	0.62
	16-18 years	12	2.54	0.58
Parents/Guardians* (n=38)	10–12 years	9	1.80	0.35
	13-15 years	23	2.21	0.46
	16-18 years	6	2.33	0.58
Family Unit (n=37)	10–12 years	9	2.00	0.62
	13-15 years	18	2.02	1.03
	16-18 years	10	1.90	0.55

\* Group Differences are significant (two-tailed) at 9 and 12 months,  $p < 0.05$

## Discussion

A convenience sample was recruited for this study and there was no control over the gender and age characteristics of the sample. In this sample the sex distribution was almost equal with only slightly more females than males (ratio of 1:1.3). This distribution mirrors that of Musisi and Kinyanda's study at Mildmay (2003) but is not representative of the AIDS picture in Uganda as the infection rate for female adolescents is almost four times higher than that of male adolescents (Neema et al, 2004). This difference declines as adolescents reach adulthood.

The age distribution of the sample is reasonably representative of the age distribution in the clinic as illustrated by peer support group attendance. As of December 2005, 130 adolescents between the ages of 13 and 15 attended (46.4%), 95 (33.93%) 10 to 12 years olds and 55 (19.64%) 16 to 18 year olds. This sample may therefore slightly under represent the youngest adolescents, as they comprise only 23% of the sample, equal to the number of 16 to 18 year olds.

All adolescents were aware of their HIV status at baseline measurements. This sample is assumed to be perinatally infected. This assumption is supported by the high proportion of participants who considered their mothers/parents as the source of their infection as well as the fact that more than a third of the sample was double orphans..

The majority of the adolescents were double or single orphans with most adolescents (37%) having lost both parents. This is consistent with a population considered to be predominantly perinatally infected where the mother and probably the father would be infected. Sarker and colleagues (2005) had found the same tendency towards double orphans among AIDS orphans living on the street in Kampala. In the Mildmay study (Musisi and Kinyanda, 2003) the number of adolescent who had suffered the loss of a parent was much higher (97.6%) than in this sample. The number of

adolescents having lost both parents was almost double the rate in this study. It is not surprising then, that more adolescents from Mildmay were living with extended family members (24.4% with their grandparents and 43.9% with other family members) than in our sample. This study found most adolescents living with a birthparent. Only 17.6% were living with a grandparent and 21.25% with extended family members, not including the 9.8% living in sibling families.

Overall, school attendance was significantly lower than the 75.6% reported by Musisi and Kinyanda. No gender difference was found in school attendance. This corresponds with statistics from the Uganda Ministry of education and sport. According to their 2004 report, 49-50% of the pupils attending urban schools are female (Uganda Ministry of education, 2004).

School attendance declined significantly as age increased, with an 83.3 % attendance rate among adolescents aged 10 to 12 and only 16% attendance in the oldest age group. The Universal primary education policy (UPE) instituted by the Ugandan government in 1997 surely affects this decline. According to UPE, primary school fees are waived for four children per family. Most children younger than 12 are in primary school and would benefit from UPE. Adolescents older than 16, however, will most likely have moved on to senior years and be expected to pay school fees. In a resource poor setting, this will have a significant impact on school attendance. The role of UPE in school attendance is further illustrated by the Ugandan Ministry of education's 2004 report, calculating net primary school enrolment rate at 81.4% compared to the net secondary school enrolment rate of 14.6% (Uganda ministry of Education, 2004). The mean age of Musisi and Kinyanda's sample was 13.4, 35.8% of the adolescents were younger than 12 (compared to 23.1% in this study) and only 11.1% were older than 16 (again compared to 23.1%). The greater representation of the younger age group could explain the higher rate of school attendance reported. Their sample also had a higher

number of double orphans who, in this study at least, had half the attendance rate of those with both parents. In our sample, school attendance was significantly associated with parental loss. The attendance rate of double orphans was significantly lower than that of adolescents with a living birthparent. If single orphans were included as separate categories, however, there was no significant difference. Paternal orphans had the highest attendance rate with 72.7%, followed by adolescents who had not lost a parent (62.5%), maternal orphans (53.8%) and double orphans (31.6%). These numbers suggest that maternal presence plays an important role in the school attendance of adolescents.

Illness accounted for more than two thirds of the reasons offered for not being in school and lack of financial support accounted for the remaining third. These echo the findings by Musisi and Kinyanda at Mildmay where illness accounted for 40% of non-attendance and financial insecurity for 30%. More adolescents in our study cited illness as the reason for their absence. This could imply that the physical health of adolescents in this study was worse than that of the Mildmay sample. As Mildmay participants were not receiving antiretroviral treatment it is possible that the adolescents were in less advanced stages of the disease.

The only measure of school absence was self-report. Reliability is therefore an issue. Further doubt was cast on reliability by the fact that adolescents could not seem to remember how many school days they had missed in the preceding month. It could be that a month was too long a period to remember and confused adolescents. Nevertheless, the high rates of self-reported attendance are supported by almost equal attendance rates reported by Musisi and Kinyanda (2003). In their sample, 26.8% reported not missing any days and a further 25.5% missed less than one week of school in the preceding three months.



Few adolescents performed well at school and the majority's achievement was below average compared to their peers. Their participation in extra curricular activities was low with slightly higher participation in non-physical activities. At 22.2% their participation was less than half that of adolescents at Mildmay. They were not asked to explain why they were not participating and it is difficult to determine why their participation would be so much lower. It could again be due to greater severity in illness, especially considering the lower rate of physical activity.

Reported risk behaviours were low and although none reported current sexual activity, 10.8% reported previous sexual encounters. Of these two were forced into sex by male members of their extended family. In the Mildmay sample, 6.1% had sexual experience and the first sexual encounter for all of them was related to forced sex: four had been forced and one raped younger girls in his village. Only one of them was not engaging in sex anymore.

Psychological quality of life was moderately impaired at baseline. On the SDQ, mean scores were all within the normal range, the only exception being peer problems. The percentage of total difficulty scores falling within the abnormal range was 11.8% although 25.5% of adolescents felt their difficulties were affecting their lives negatively. This is still a significant number of adolescents feeling the impact of their difficulties. On the CDI 8.9% reported moderate depression and none severe depression. Social functioning was generally above average with only housework and extended family scales showing difficulty compared to the group mean. In combination, these results suggest that the overall psychological distress and functional impairment was lower than expected, based on Musisi and Kinyanda's study (2003) of HIV positive adolescents in Uganda. They reported more functional impairment and higher levels of psychological distress (51.2%) with depression at 41.3%. The instruments used were different and a conclusive comparison cannot be made. The self report SAS-M was used in both

studies. In this study, functioning seemed to be above average while below average rates were reported for the Mildmay sample on almost all scales, especially in relationships with siblings and schoolwork. The sample from our study reported a lower depression rate than that of Musisi and Kinyanda but 8.6% is higher than the 2.7% (combined depression and dysthymia) Nalugya (2004) found. Her study population was schoolchildren in a district on the outskirts of Kampala and she found depression to be associated with the loss of a parent to HIV/AIDS. The adolescents attending the PIDC seem to experience better mental health than those attending Mildmay, but they are still experiencing more problems than the general population.

The high level of functioning reported is supported by findings from studies of the health related quality of life of HIV infected adolescents and children. An American study of 33 HIV positive children and adolescents receiving antiretroviral therapy asked parents or guardians to complete a quality of life questionnaire for their child (Byrne and Honig, 2006). They reported normal social role functioning, behavioural problems, emotional problems and functioning (established norms for the United States are available).

Gender did not affect psychological distress or functioning significantly. The only difference to approach significance was conduct problems (SDQ) with male adolescents reporting a mean more than double that of female adolescents. On the SDQ, male participants had the highest mean on total difficulties, hyperactivity and peer problems. On the CDI, however, the only scale with a higher mean for male participants was negative self-esteem. These scores suggest that males were more prone to behavioural difficulties than female participants who showed more emotional distress and less prosocial behaviour. Their higher mean scores on the negative mood and interpersonal problem scales of the CDI provides further support for the idea that female adolescents may internalize their distress more and experience problems in their interpersonal

relationships. Male adolescents were more prone to 'acting-out' behaviour. Our results were not significant, but illustrate the same trend Bisegger and colleagues (2005) found in their study of 3710 European adolescents (aged 9 to 17) from seven European countries. They reported marked gender differences in health related quality of life for adolescents older than 12. The European study also found lower quality of life to be associated with increasing age.

Younger adolescents (10-12 years) seem to experience the lowest degree of difficulties overall. On no measure did they have the highest total mean; on the CDI they had the lowest total mean and the lowest mean scores on all but one category. The only areas they reported some degree of difficulty in is conduct problems, problems with schoolwork and relationships within the family unit. The oldest age group had the highest mean scores on total difficulties as well as emotional symptoms, hyperactivity and peer problems – three of the five SDQ subscales. The same pattern was seen for the CDI with highest mean scores on three of the five subscales, though they did not have the highest mean for total depression. Higher mean scores on half of the self report SAS-M subscales further suggests higher levels of psychological distress in this age group. The link between age and distress is supported by evidence from Africa and Europe. In Europe, Bisegger and colleagues (2005) reported higher health related quality of life in children younger than 12 compared to adolescents older than 12. In Uganda, Musisi and Kinyanda found the same inverse relationship between age and psychological distress with 88.9% of the adolescents between the 16 and 18 years experienced psychological distress compared to 34.5% of 10 to 12 year olds. In Uganda, Musisi and Kinyanda (2003) also found a significant relationship between older age and increased distress

Adolescent's relationships with their parent or guardian were significantly different for the different age groups, increasing age again associated with increased

difficulty. The difference in relationship to parents/guardians could be due to the increased number of older adolescents having lost both parents: Double orphans accounted for 58.3% of the oldest age group compared to 16.7% in the youngest age group and 37% for adolescents 13-15 years. Double orphans would be living in extended families and not with their birthparents, which could lead to problems with guardians. This argument is seemingly supported by the fact that oldest adolescents also showed the worst functioning in relationship with their extended family. The same was true for double orphans.

Adolescents not in school reported significantly worse relationships with their parent/guardian than adolescents attending school. This difference may be related to the difference observed for the age groups, as the average age of participants attending school was younger than that of out of school adolescents (13.4 compared to 14.24 years). The difference in age becomes more apparent when it is taken into account that 83.3% of adolescent between the ages of 16-19 were not attending school and 83.3% of adolescents 10-12 years old were attending school. Parental loss may also be an influence here as more than half (52%) of the adolescents not attending school were double orphans. No other differences based on school attendance were significant although those not attending school reported more difficulties and distress overall.

In initial analysis, all adolescents who had lost a parent were grouped together into a 'single orphan' category. It became apparent however, that differences between maternal and paternal orphans were lost when grouped in this way. Paternal orphans demonstrate more emotional, behavioural and functioning problems than any other group. Paternal orphans scored consistently higher across all instruments, although differences were not significant. They had the highest mean difficulties score and the highest CDI total. They also had the highest mean scores on half of the SDQ difficulties

subscales, the lowest prosocial mean and the highest mean scores on four of the CDI subscales.

## **Conclusion**

More than a third of the participants were double orphans, consistent with the belief that these adolescents were perinatally infected. This was still fewer orphans than reported in Musisi and Kinyanda (2003) but only slightly lower than the 40% double orphans reported by the PIDC (Kekitiinwa et al., 2006).

The results indicate moderate levels of psychological distress, especially depression, and high levels of functioning in this sample of adolescents. Gender did not account for any significant difference, but female participants generally scored higher on scales related to emotions and mood. The variables accounting for the most differences were age and school attendance.

## Chapter 4: Longitudinal data

The measures of psychological distress, the Strength and Difficulties Questionnaire (SDQ), Children's Depression Inventory (CDI) and Self Report Social adjustment scale (self report SAS-M), were repeated at three monthly intervals to determine changes in quality of life ( see appendices C,D and E for full versions of instruments). This chapter summarizes the findings of the longitudinal investigation, highlighting the more significant changes that occurred in well-being and adjustment. The first section of the chapter will describe changes in overall distress, depression, social adjustment and physical well-being, as well as changes in different dimensions as measured by the various instrument subscales. The final section of the chapter will outline differences in quality of life attributable to gender, age, parental loss, school attendance and peer support group attendance.

### Sample Description

There was attrition in the sample size across time and 40 (of 52) were followed to 9 months (77% of baseline sample) and 36 to 12 months (69%). Not all adolescents were followed up at all months either and of those followed to nine months, data was only available for 32 of the 40. At 12 months, only 28 of 36 had filled out questionnaires at all follow up appointments. Three adolescents passed away.

To determine whether the adolescents lost were different from those followed, chi square analyses and independent t-tests were conducted with the samples at 9 and 12 months. Table 4.1 presents a comparison of those adolescents followed to 12 months compared to those not followed and those who passed away. No significant differences were found at nine or 12 months.

Table 4.1

Characteristics of participants retained to 12 months and participants lost to follow up

	Retained (n=36)		Lost (n=13)		Deceased (n=3)	
	n (%)	Mean	n (%)	Mean	n (%)	Mean
Gender						
Male	16 (44)		7 (54)			
Female	20 (56)		6 (46)		3 (100)	
Age Group						
10-12 year olds	6 (17)		5 (38)		1 (33)	
13-15 year olds	20 (55)		7 (54)		1 (33)	
16-18 year olds	10 (28)		1 (8)		1 (33)	
Parental Loss						
None	4 (11)		2 (15)		2 (67)	
Maternal orphan	10 (28)		3 (23)			
Paternal orphan	7 (19)		3 (23)		1 (33)	
Double Orphan	14 (39)		5 (38)			
Missing	1 (3)					
School attendance						
Not attending school	12 (33)		7 (54)			
Attending school	24 (67)		6 (46)			
Peer Support group Attendance						
Never Attended	9 (25)		5 (38)			
Irregular attendance	14 (39)		7 (54)			
Regular attendance	13 (36)		1 (8)			

## Emotional and Behavioural distress

Strength and difficulties (SDQ) data was available for 51 adolescents at baseline, 46 at three months, 45 at six months and 40 at nine months. One participant did not complete the SDQ at 12 months, and data was available for only 35 adolescents.

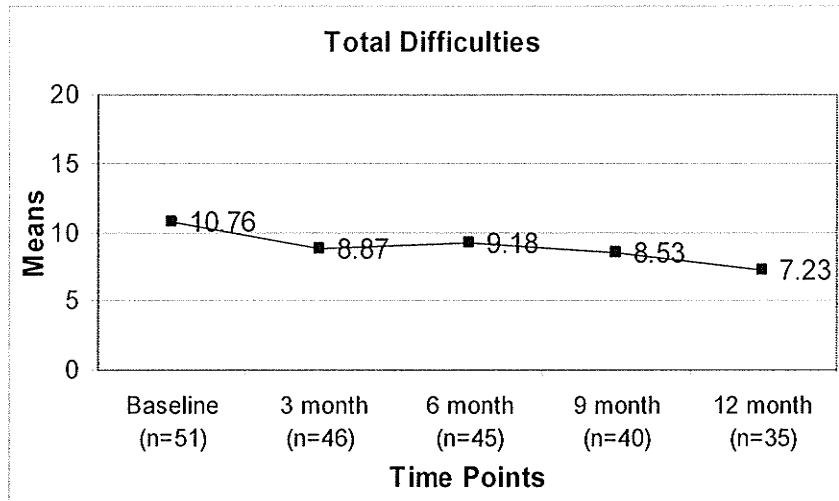
The SDQ (Goodman, 1997; see appendix C for full instrument) consists of five subscales. Four of these focus on difficulties respondents may experience in the area of emotional symptoms, hyperactivity, conduct problems and peer problems. Higher scores on these scales indicate greater difficulty. The fifth scale measures prosocial behaviour and is the only 'strength' scale. Prosocial behaviour refers to helping behaviour towards others that have no direct benefit to the adolescent him, or herself (Baron and Byrne, 1997). Unlike the difficulty scores, a higher prosocial score indicates improved functioning. An optional impact supplement measures adolescents' perceptions of their overall level of distress and the resultant impairment experienced in various areas of life.

The Total Difficulties score was calculated by totalling the score of the four difficulties scales. As with the subscales, higher scores indicate greater distress. Total Difficulties declined across all months (fig 4.1). The initial decline to three months was significant ( $t=2.13$ ,  $df=44$ ,  $p=0.04$ ) and the largest decline between two time points. The decline from baseline to nine months was significant ( $t=2.42$ ,  $df=38$ ,  $p=0.02$ ) as was the decline from baseline to 12 months ( $t=3.36$ ,  $df=33$ ,  $p=0.002$ ).

Emotional difficulties, hyperactivity and peer problem scores improved significantly during the course of the research. Conduct Problems - referring to behavioural problems such as fighting, disobedience, lying and cheating – did not change significantly and prosocial behaviour also remained stable: a slight improvement from baseline to 12 months was not significant.



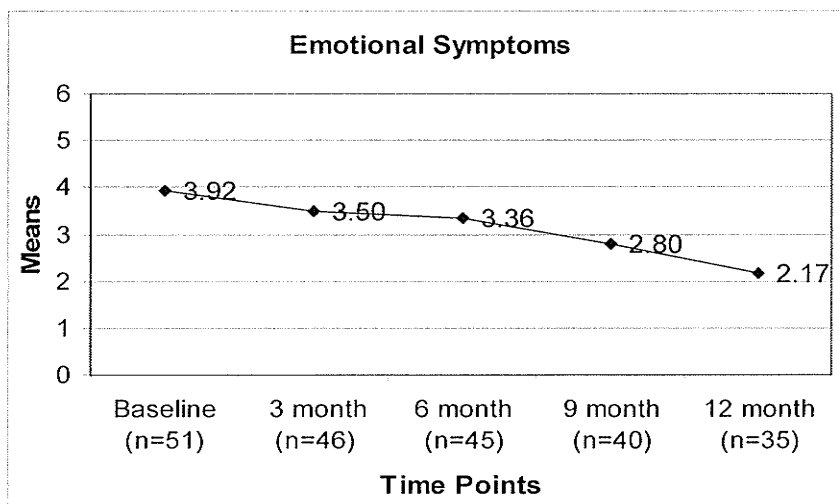
Fig 4.1 Total Difficulties scores over time



*Decrease to 9 months and 12 months are significant (two-tailed)  $p < 0.05$*

The emotional symptoms scale includes questions regarding worrying, feelings of unhappiness, fears and physical symptoms such as headaches and stomach aches. Emotional symptoms scores significantly declined to both nine months ( $t=2.06$ ,  $df=33$ ,  $p=0.05$ ) and to 12 months ( $t=4.23$ ,  $df=33$ ,  $p=0.00$ ).

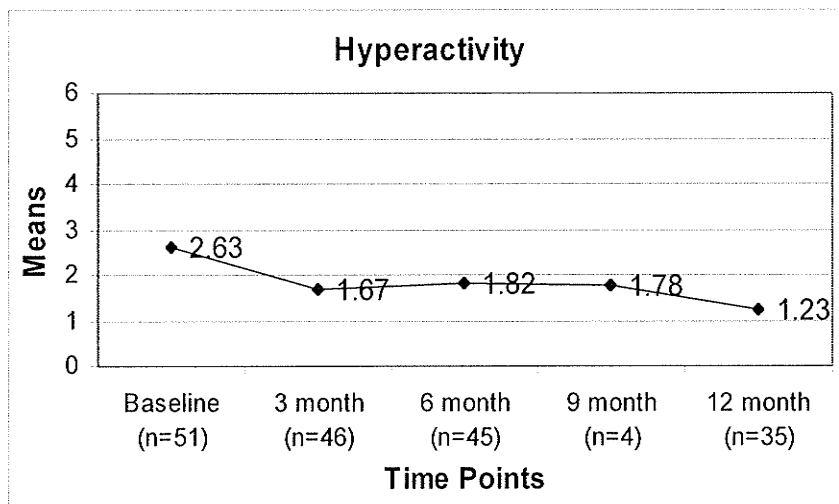
Fig 4.2 Emotional Symptoms Scale



*Decrease to 9 months and 12 months are significant (two-tailed),  $p < 0.05$*

Hyperactivity means (regarding problems with attention span, concentration and focus) declined significantly to nine months ( $t=2.3$ ,  $df=38$ ,  $p=0.03$ ) and more to 12 months ( $t=3.88$ ,  $df=33$ ,  $p=0.00$ ).

Fig 4.3 Hyperactivity Scale



*Decrease to 9 months and 12 months are significant (two-tailed),  $p < 0.05$*

Peer problems decreased during the study period. The resultant decline was not significant at nine months ( $t=1.23$ ,  $df=38$ ,  $p=0.22$ ) but from baseline to 12 months the incidence of reported peer problems declined significantly ( $t=2.75$ ,  $df=33$ ,  $p=0.01$ ).

Mean impact scores remained relatively stable. During the first three months, mean scores declined significantly ( $t=2.08$ ,  $df=44$ ,  $p=0.04$ ), dipping below one. After this initial improvement, it increased to its original level at six months and continued its increase to nine and 12 months. This increase was not significant.

## Depression

CDI scores were available for 45 adolescents at baseline, 42 at 3 month, 41 at 6 month, 37 at 9 months and 32 at 12 months. Adolescents older than 17 were excluded from the analysis as the instrument is only appropriate for those 17 years and younger.

The CDI (Kovacs, 1992; see appendix D for full instrument) has five subscales focused on different aspects of depression. The scales are negative mood, interpersonal problems, ineffectiveness, anhedonia and negative self-esteem. Scores can be calculated for each of the scales individually, and summed to reach an overall depression score. In this study, raw scores were converted to t scores according to age and gender. A t score below 50 indicates an absence of significant depression symptoms. Above 50, adolescents' scores can be categorized as mild (t scores between 50 and 64), moderate (between 65 and 84) or severe (above 85) depression.

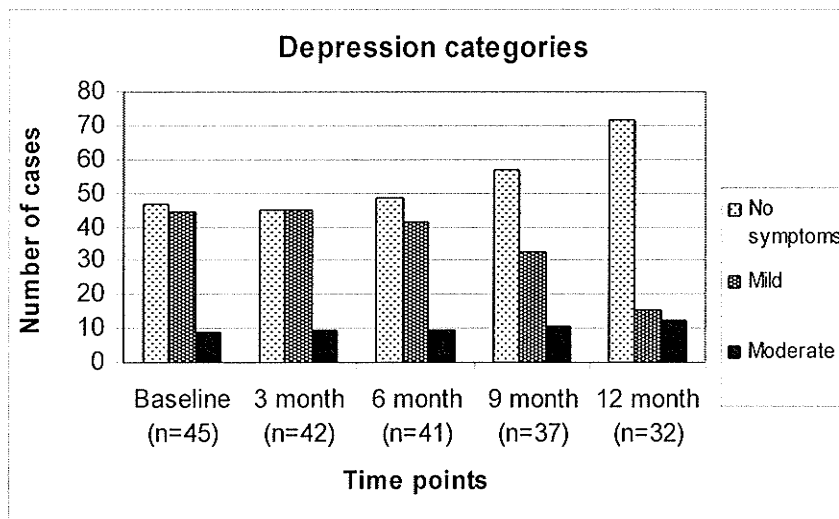
No participant reported severe depression during the study and rates of moderate depression ranged between 9% and 13%. Table 4.2 displays the distribution of depression across all months. At baseline 24 adolescents (53%) showed some depression symptoms, whether mild or moderate, 23 (55%) at three months, 21 (51%) at six months, 16 (43%) at nine months and nine (29%) at 12 months. Wilcoxon Ranks tests revealed that movement between categories was not significant although it approached significance at 12 months ( $z=-1.706$ ,  $p=.09$ ). As illustrated in fig 4.4, the group of participants with no depression symptoms increased to 12 months, mild declined considerably but moderate remained stable.

Table 4.2

Depression prevalence at all months

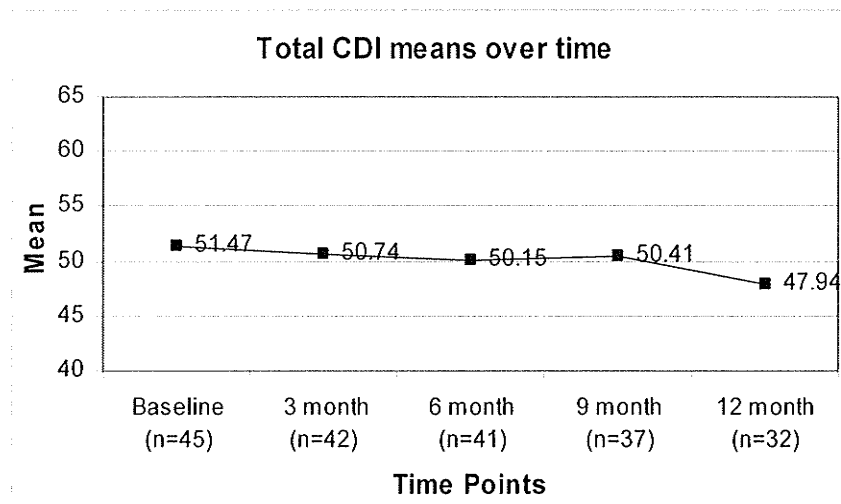
	Baseline (n=45)	3 month (n=42)	6 month (n=41)	9 month (n=37)	12 month (n=32)
	N (%)	N (%)	N (%)	N (%)	N (%)
No depressive symptoms	21 (47)	19 (45)	20 (49)	21 (57)	23 (72)
Mild Depression	20 (44)	19 (45)	17 (41)	12 (32)	5 (16)
Moderate Depression	4 (9)	4 (10)	4 (10)	4 (11)	4 (13)

Fig.4.4. Distribution of Depression over time



As continuous variables, total CDI scores declined during the study period (Fig 4.5). The decline was not significant to nine months ( $t=1.46$ ,  $df=34$ ,  $p=0.15$ ) and only nears significance at 12 months ( $t=1.82$ ,  $df=29$ ,  $p=0.08$ ). The general decline corresponds with the trend seen above, suggesting a decline in depressive symptoms during the study period.

Fig. 4.5. Distribution of Total CDI means over time



*Difference in means is not significant (two-tailed),  $p < 0.05$*

Twenty adolescents followed to nine months (out of 37) remained at the same level of depression (in the same category) throughout. Ten participants showed no signs of depression, with scores below 50 at all time points: five were followed to 12 months where their scores remained below 50. In other words, of the 23 participants reporting no depression symptoms at 12 months, five had not experienced any depression symptoms during the year. Six adolescents consistently scored within the mildly depressed category to nine months and two followed further to 12 months remained in the mild category. Two girls (13 and 15 years) had moderate depression throughout – both to nine and 12 months. One girl was ill at enrolment into the study and had not completed the CDI at this time. She therefore had no baseline score, but scored in the moderate depression range from 3 months on. This means that three out of the four adolescents reporting moderate depression at both nine and 12 months never showed any decrease (or increase) in their depression symptoms.

Three adolescents (all female) passed away during the course of the research and limited data is available for them. The first adolescent had both baseline and three-

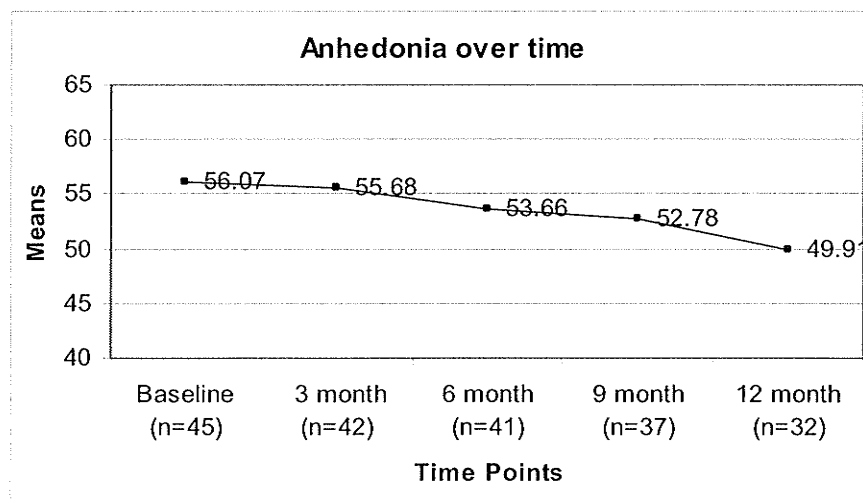
month scores below 50, indicating no signs of depression. Both the other girls have only one available data point: At 82 and 79 both these scores fall within the upper limits of the moderate range.

Scores obtained on each of the individual scales were also analysed separately (Table 4.3). The most significant change was observed in anhedonia means. Anhedonia refers to the inability to experience pleasure from daily activities considered pleasurable, including eating, sleeping and interactions with others. Overall anhedonia means declined to both nine ( $p=0.01$ ) and 12 months ( $p=0.01$ ) (fig 4.6).

Negative Mood (feelings of sadness and indecisiveness) means also showed decline to nine months and 12 months but the decline was not significant. Negative self-esteem scores remained stable throughout the research period. Ineffectiveness scores increased to nine months, not significantly, returning to baseline levels at 12 months.

Relating to other people seemingly became more problematic as Interpersonal problems scores showed a significant increase to nine months ( $t=-2.4$ ,  $df=34$ ,  $p=0.02$ ) but to 12 months the mean decreases back to baseline level.

Fig 4.6. Distribution of Anhedonia means over time



*Difference in means significant (two-tailed) at 9 and 12 months,  $p<0.05$*

Table 4.3

Change in subscale means from baseline to 9 and 12 months

	9 months			12 months		
	Mean	SEM	CI	Mean	SEM	CI
Negative Mood	0.86	1.58	-2.36 - 4.07	3.27	2.25	-1.34 - 7.87
Interpersonal Problems	-2.17	0.91	-4.01 - -0.33	0.10	1.23	-2.42 - 2.62
Ineffectiveness	-0.69	1.92	-4.59 - 3.22	-1.47	2.25	-6.06 - 3.13
Anhedonia	4.63	1.80	0.97 - 8.29	5.77	2.13	1.41 - 10.12
Negative self esteem	1.40	1.57	-1.8 - 4.6	1.77	1.30	-0.90 - 4.43
Mean: mean change from baseline						
SEM: Standard Error of the mean,						
CI: 95% Confidence interval of the difference						
* Significant change from baseline ( $p < 0.05$ )						

### Social Adjustment and coping

At baseline, 51 adolescents completed the Social Adjustment Scale (self report SAS-M), 47 at 3 month, 44 at 6 month, 40 at 9 months and 35 at 12 months. The instrument has seven sections (Cooper et al., 1982; see appendix E for the full instrument), but the design, however, meant that not all individuals filled out all sections. On sections such as Schoolwork, for instance, only those adolescents attending school responded to the questions. The sample sizes for the different subscales vary therefore, and are summarized in table 4.4.

Table 4.4

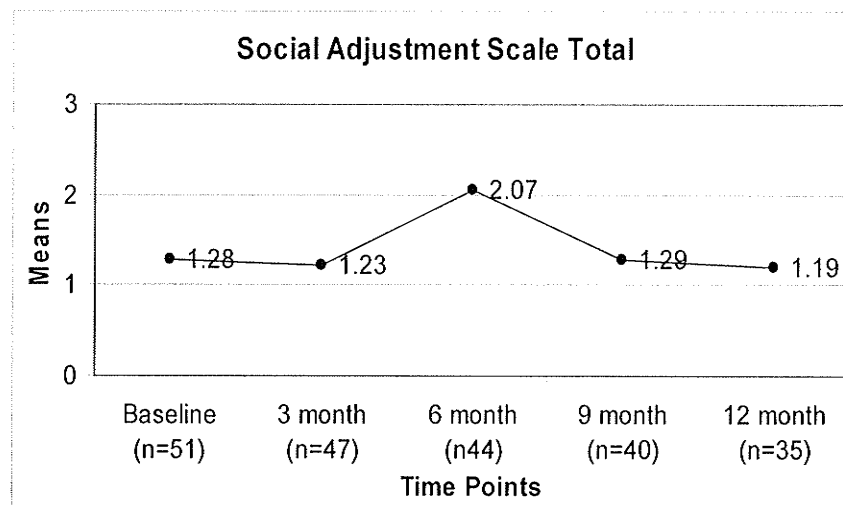
Social Adjustment Scales Sample Size and means

	Baseline		3 month		6 month		9 month		12 month	
	n	Mean	n	Mean	n	Mean	n	Mean	n	Mean
Total	51	1.28	47	1.23	44	2.07	40	1.29	35	1.19
Schoolwork	32	1.20	30	1.23	30	0.98	26	1.17	25	0.88
Housework	51	0.98	47	0.87	44	0.89	39	1.08	35	0.90
Social & Leisure	51	1.56	47	1.49	44	1.37	40	1.41	35	1.47
Extended family	51	1.42	47	1.41	44	1.45	39	1.53	34	1.59
Parents/Guardian	38	1.13	36	1.00	36	1.16	30	1.05	25	1.04
Siblings	41	1.24	35	1.21	29	1.06	27	1.51	22	1.23
Family Unit	37	0.98	42	1.17	41	1.25	38	1.05	34	0.97

Overall, self-report SAS-M means did not change significantly during the study period (table 4.5). Total means increased to six months but returned to baseline levels at nine months (fig 4.7), decreasing further to 12 months. The decline was not significant ( $t=0.87$ ,  $df=33$ ,  $p=0.39$ ).



Fig 4.7. Distribution of self-report SAS-M Total means.



*Decreases to 9 months and 12 months not significant (two-tailed),  $p > 0.05$*

No significant changes occurred to 9 or 12 months on any of the subscales. Schoolwork scores at baseline and nine months are almost equal ( $t = -0.1$ ,  $df = 21$ ,  $p = 0.92$ ). The scores for those followed to 12 months declined from nine months and the difference from baseline is closer to significance here ( $t = 1.77$ ,  $df = 19$ ,  $p = 0.09$ ).

All adolescents filled out the social and leisure section of the instrument. While means declined significantly to six months ( $t = 2.27$ ,  $df = 42$ ,  $p = 0.03$ ) it increased again and neither the nine nor 12 month means are significantly different from baseline.

Means for the Extended family scale increase to nine months and even more so to 12 months. The increase is almost significant at 12 months ( $t = -1.98$ ,  $df = 32$ ,  $p = 0.06$ ) but not at nine months.

Table 4.5.

Mean Difference from Baseline

	9 months			12 months		
	Mean	SEM	CI	Mean	SEM	CI
Total	0.03	0.07	-0.11 – 0.16	0.08	0.09	-0.11 – 0.27
School Work	-0.01	0.16	-0.34 – 0.31	0.37	0.21	-0.07 – 0.80
Chores	-0.10	0.13	-0.36 – 0.16	0.19	0.16	-0.14 – 0.51
Social and Leisure activities	0.18	0.11	-0.04 – 0.40	0.11	0.12	-0.13 – 0.35
Extended Family	-0.08	0.12	-0.32 – 0.16	-0.21	0.11	-0.43 – 0.01
Parents/Guardians	0.15	0.11	-0.07 – 0.37	0.17	0.13	-0.11 – 0.45
Siblings	-0.24	0.21	-0.67 – 0.19	0.09	0.20	-0.33 – 0.51
Family Unit	0.03	0.15	-0.29 – 0.34	0.01	0.22	-0.44 – 0.46

Mean: mean change from baseline

SEM: Standard Error of the mean,

CI: 95% Confidence interval of the difference

\* Significant change from baseline ( $p < 0.05$ )

### Physical Well-being

Questionnaires included a question asking participants to rate their physical health on a four-point scale: 'very good', 'good but not perfect', 'somewhat poor' and 'very poor'. Items were scored one through four with increased scores indicating worse perceptions of their health. This question was answered by 50 adolescents at baseline, 45 adolescents at three months, 43 at six months, 38 at nine months and 33 at 12 months.

The overall rating of physical health was good at baseline and improved during the research period. At baseline, 86% (43) of the adolescents rated their health as 'good, but not perfect' or 'very good' and only one rated his health as 'very poor' (table 4.7). Three girls passed away during the study period. Of these, one did not rate her health at all, and both the others rated theirs as 'good but not perfect' at baseline and three months.

Table 4.6.

#### Rating of physical health

	Baseline		3 months		6 months		9 months		12 months	
	n	%	n	%	n	%	n	%	n	%
Very good	10	20	21	47	24	52	25	64	19	56
Good, but not perfect	33	66	22	49	17	37	9	23	12	35
Somewhat poor	6	12	2	4	5	11	5	13	1	3
Very poor	1	2							2	6

*Difference to 3 months, 6 months, 9 months and 12 months significant (Two-tailed)*

*p<0.05*

Analyses with Wilcoxon ranks tests show significant differences between health ratings from baseline to all months. Health ratings improved most to nine months before declining back to the values it had at three and six months. The biggest gains occurred from baseline to three months ( $Z=-2.83$ ,  $p=0.005$ ), and baseline to nine months ( $Z=-2.64$ ,  $p=0.008$ ). Looking at table 4.7, 25 adolescents (64%) rated their health as 'very good' and a further nine (23%) as 'good but not perfect' at nine months. At 12 months health ratings are not quite as positive but the difference from baseline is still significant ( $Z=-2.02$ ,  $p=0.04$ ). Although less adolescents rate their health as 'very good' at 12 months (19 or 56%), the total portion of adolescents who rate their health as 'very good' or 'good' is the largest of all months. Two adolescents also rated their health as 'very poor', however, the only month other than baseline to have such a rating.

At nine months, 11 adolescents still rated their health in the same category as baseline, 21 rated their health as improved and six rated their health worse. All the adolescents who remained the same rated their health as good. No adolescent viewed their health very poorly at nine months but five adolescents rated their health as somewhat poor. None of the five had rated their health this poorly at baseline: Four of them had rated it as 'good, but not perfect' and one as 'very good'.

At 12 months, 13 adolescents rated their health the same as at baseline, 16 felt their health had improved and four rated their health worse. The majority of the adolescent who remained the same were in one of the 'good' categories. One participant rated her health as 'somewhat poor' at both baseline and 12 months although she had rated her health as 'good, but not perfect' at nine months. Two adolescents rated their health very poorly at 12 months having both rated their health as 'good, but not perfect' at baseline.

## Demographic Variables

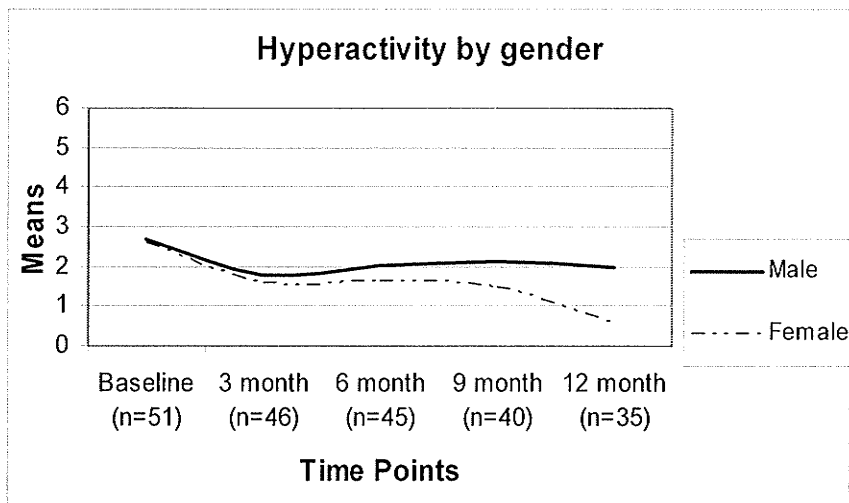
In addition to the overall analysis discussed above, demographic variables were included in the analysis to investigate their impact on treatment experience. In this section, the effects of gender, age, parental loss, school attendance and peer support group attendance are described.

### *Gender*

Gender did not have an effect on Total Difficulties or overall self-report SAS-M scores but did affect Total Depression scores. The total depression mean for female participants was significantly higher than that of their male counterparts at nine months ( $t=-2.05$ ,  $df=35$ ,  $p=0.05$ ). To 12 months both groups declined and while the female participants' mean was still higher (50.18 compared to 45.4) the gap was not significant anymore ( $t=-1.25$ ,  $df=30$ ,  $p=0.22$ ).

On the SDQ subscales, gender had no effect on emotional symptoms, conduct problems, peer problems, prosocial behaviour or the perceived impact of their difficulties. Male participants reported significantly more conduct problems ( $t=1.98$ ,  $df=49$ ,  $p=0.05$ ) at baseline, but this difference disappears during the study period and at nine months the group means are identical. Hyperactivity scores for both genders decline (fig 4.10) although the mean for female participants decreases more, increasing the difference between the groups. There is no significant difference at nine months, but at 12 months girls have significantly lower mean scores ( $t=2.5$ ,  $df=33$ ,  $p=0.02$ ).

Fig 4.8 Hyperactivity means by gender

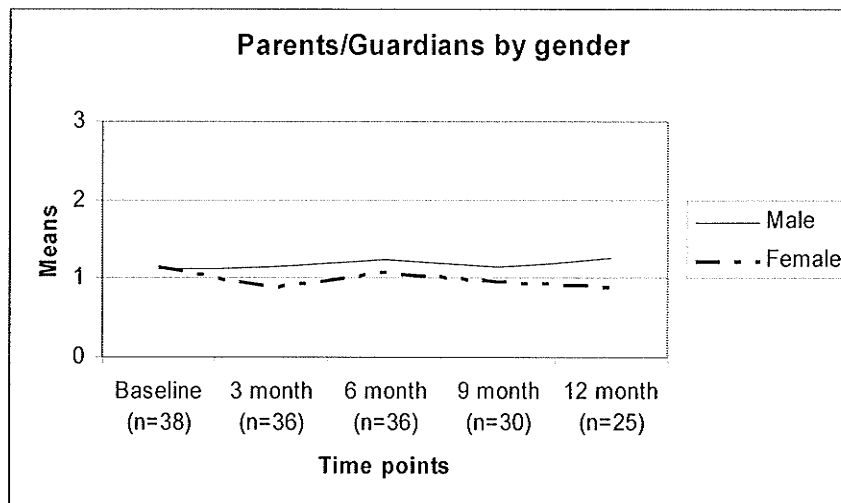


*Difference between groups at 12 months is significant (two-tailed),  $p < 0.05$*

Gender did not influence scores on any of the individual depression scales even though it had an effect on total depression scores. Female participants had consistently higher means on the ineffectiveness and anhedonia (loss of pleasure) scales. At nine months the female anhedonia mean was almost significantly higher than that of male participants ( $t = -1.92$ ,  $df = 35$ ,  $p = 0.06$ ).

In terms of adjustment, gender only had a significant effect on relationships with parents/guardians and with siblings. Male adolescents seemingly experienced more problems in their relationships with their parents/guardians: although the genders had the same mean at baseline, male participants consistently had higher means during the study period (fig 4.11). The mean difference scores were significantly different from baseline to 3 months ( $t = -2.72$ ,  $df = 28$ ,  $p = 0.01$ ) and from baseline to 12 months ( $t = 2.72$ ,  $df = 18$ ,  $p = 0.01$ ).

Fig. 4.9. Distribution of Parents/Guardians relations means.



*Changes to 3 months and 12 months are significantly different (two-tailed),  $p < 0.05$*

The means for sibling relations remain stable through the first six months of the research period with female participants having consistently lower means than the males. The means for both genders increase to nine months but more so for the male participants' mean. At 12 months, the difference between the group means for the genders are significant ( $t=2.05$ ,  $df=20$ ,  $p=0.05$ ).

Perceived physical health was not significantly impacted by gender, although female participants generally rated their health better than male participants did.

### Age

As discussed in chapter two, age was categorized and used in two ways: in two categories of young adolescents (10-12 years) and older adolescents (13-18 years) and with three categories, splitting the older adolescents into 13-15 year olds and 16-18 years olds. Only in the analyses of depression scores were the expanded categories not used as 18 year olds were not included in analysis. Here age was used only in two categories: 10-12 year olds and 13-17 year olds.

Age did not account for significant differences in Total Difficulties, Total Depression scores or overall self-report SAS-M scores.

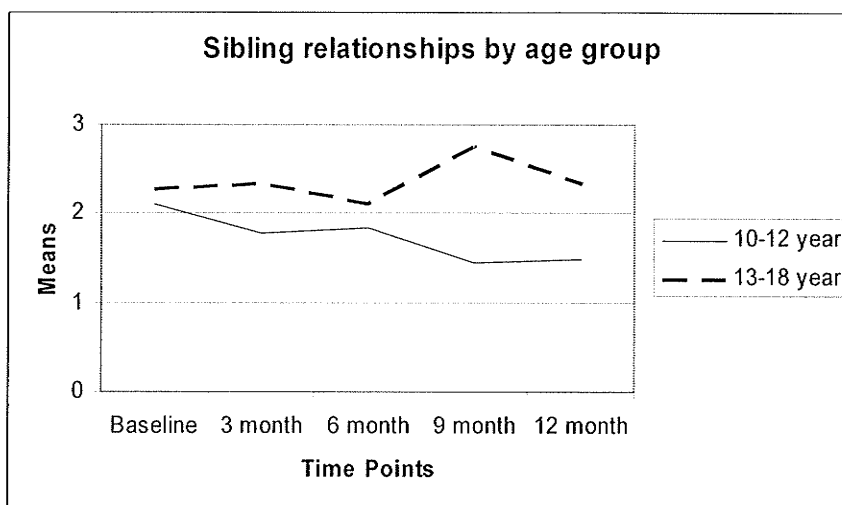
Focusing on individual SDQ scales, age had no effect on emotional symptoms, hyperactivity, peer problems, prosocial behaviour or impact means at nine or 12 months but influenced conduct problems. At baseline, the mean conduct problem score for young adolescents is slightly higher than that of older adolescents (13-18 years). During the study period, the mean for the youngest group steadily decline while that of the older group increases. The difference between group means (for two age groups) are almost significant at nine months ( $t=-1.72$ ,  $df=38$ ,  $p=0.09$ ) as well as 12 months ( $t=-1.85$ ,  $df=33$ ,  $p=0.07$ ). The difference between the three age groups is significant at 12 months, ( $f=3.78$ ,  $p=0.03$ ) with 13-15 year old participants having a significantly higher mean.

There were no significant differences in age groups regarding any of the dimensions of depression as measured by the subscales of the CDI.

Age has a limited effect on adjustment as only relationships with siblings and extended family members showed any variation according to age. Young adolescents (10-12 years) reported better relationships with their siblings at baseline and throughout the study period (Fig. 4.12). The difference between group means was significant at nine months ( $t=-3.09$ ,  $df=25$ ,  $p=0.0005$ ) but not at 12 months ( $t=-1.53$ ,  $df=20$ ,  $p=0.14$ ). The significant difference at nine months was still present after categories were expanded to separate 13-15 year olds from 16-18 year olds ( $f=4.86$ ,  $df=2,24$ ,  $p=0.02$ ). The youngest adolescents had the lowest mean throughout while the mean for 13-15 year olds increased. They had the highest mean of all groups at 12 months.



Fig. 4.10. Sibling relationships and age.



*Difference between means at 9 months is significant (two-tailed),  $p < 0.05$*

Means for the youngest adolescents were also consistently lower on the extended family scale and at nine months the mean for 10-12 year olds was almost significantly lower than that of 13-18 year olds ( $t = -1.95$ ,  $df = 37$ ,  $p = 0.06$ ). The difference between the means of the three age groups was significantly different at nine months ( $F = 3.25$ ,  $df = 2, 36$ ,  $p = 0.05$ ). The 13-15 year olds had a much higher mean than that of the 10-12 year olds or 16-18 year olds.

Age had a significant influence on self-perceived physical health. Differences between the health ratings of 10-12 year olds and 13-18 year olds were significant at six months ( $Z = -2.08$ ,  $p = 0.004$ ) and 12 months ( $Z = -2.3$ ,  $p = 0.02$ ). The youngest adolescents rated their health the worst at baseline but by six months had surpassed the other age group and rated their physical health the best. Their health rating continued to improve to nine and 12 months while the health ratings of older adolescents remained stable. The difference in the amount of change in rating was significant from baseline to nine months ( $Z = -1.98$ ,  $p = 0.05$ ) and baseline to 12 months ( $Z = -2.13$ ,  $p = 0.03$ ). The difference between the age groups was still present after older adolescents were separated into

13-15 year olds and 16-18 year olds, with 10-12 year olds still rating their health significantly better than either of the other age groups. The group means were significantly different at six months ( $X^2=6.35$ ,  $p=0.04$ ) and approached significance at 12 months ( $X^2=5.55$ ,  $p=0.06$ ).

### ***Parental Loss***

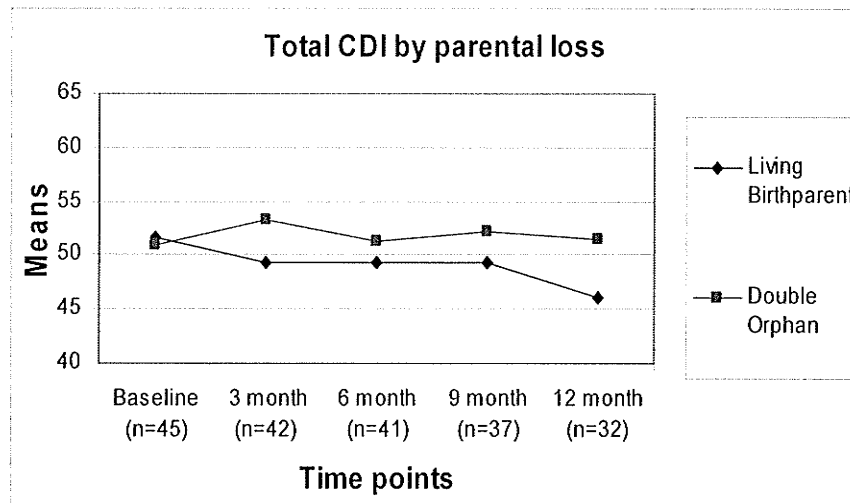
Similar to age, analyses regarding parental loss considered it in two ways. In the first instance, double orphans (those who had lost both parents) were compared to participants with a living birthparent. The latter category was then expanded to separate paternal orphans, maternal orphans and participants who had not lost either birthparent.

Parental loss did not significantly affect Total Difficulties scores although the mean for participants with a living birthparent declined significantly more to 12 months than that of double orphans ( $t=-2.11$ ,  $df=32$ ,  $p=0.04$ ).

Parental loss significantly influenced depression scores and social adjustment. The depression scores for double orphans and participants with a parent were never significantly different, but the change in means to nine months was significant ( $t=2.15$ ,  $df=33$ ,  $p=0.04$ ). Although the mean for adolescents with a birthparent continued its decline to 12 months, the difference here was not significant (fig 4.13).

Expanding the categories, groups showed significantly different amounts of change in total depression scores to six months ( $F=3.034$ ,  $df=3,30$ ,  $p=0.04$ ) and to 12 months ( $F=3.09$ ,  $df=3,25$ ,  $p=0.05$ ). At nine months, the difference is almost significant ( $f=2.76$ ,  $df=3,30$ ,  $p=0.06$ ). The means for maternal and double orphans remained stable during the course of the research while means for paternal orphans and adolescents with both parents declined to both 9 and 12 months. The mean for paternal orphans declined the most.

Fig. 4.11. Total CDI Means and Parental Loss.



*Difference between means is not significant (two-tailed),  $p < 0.05$*

The overall adjustment scores of participants with a living birthparent was stable throughout the research period and consistently lower (indicating fewer problems with adjustment) than that of double orphans. The difference in the amount of change experienced from baseline to nine months was significantly different, with double orphans' mean increasing while the other decreased ( $t=2.38$ ,  $df=37$ ,  $p=0.02$ ).

Focusing on individual subscales, parental loss had no effect on any of the difficulty scales of the SDQ, prosocial behaviour or impact of difficulties on daily life. Similarly, parental loss did not have a significant effect on any of the depression subscales. On Negative Mood, Ineffectiveness, Anhedonia and Negative self-esteem, double orphans had higher means at almost all months, even if they started out with similar means at baseline. On the Anhedonia scale the difference between the group means increase during the research period and at 12 months, it was almost significant ( $t=-1.75$ ,  $df=30$ ,  $p=0.09$ ).

Only adjustment to schoolwork was significantly impacted by parental loss.

There was no significant difference in schoolwork means for those with a living birthparent compared to double orphans. Expanding the categories revealed a significant difference in the change from baseline to nine months ( $f=3.2$ ,  $df=3,17$ ,  $sig=0.05$ ). Double orphans remained stable, means for participants with both parents and paternal orphans declined and the mean for maternal orphans increased, indicating an increase in severity of problems. To 12 months, the difference between groups decreased again.

Parental loss did not have a significant affect on self-perceived physical health.

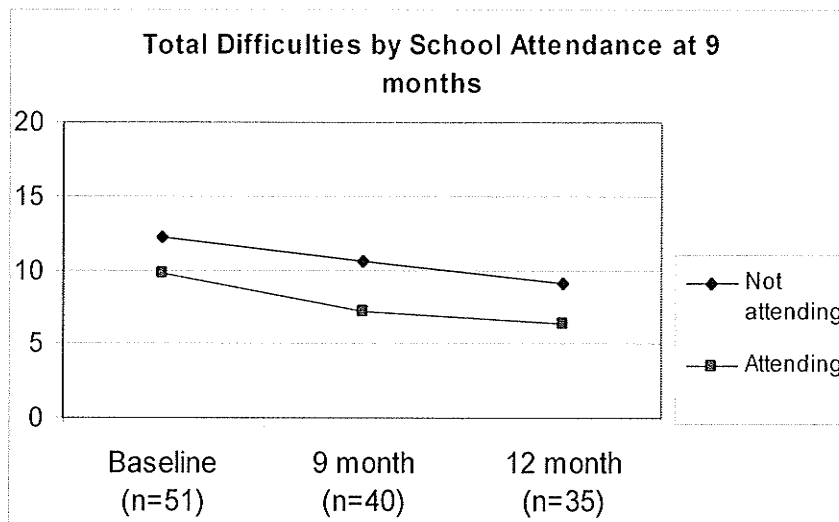
### ***School Attendance***

The difficulty with including this variable in the longitudinal analysis was mentioned above. In response, categories based on change in school attendance during the research period were included in the analysis. Analysis also included only the time points baseline, 9 months and 12 months. As school attendance information was collected again at the conclusion of the research period, which strictly speaking was 9 months, attendance data was felt to be valid for these time periods. Including school attendance in the longitudinal analyses proved problematic.

School attendance did not have a significant impact on total difficulties or overall adjustment. It did significantly influence total depression scores.

Adolescents attending school at 9 months had lower total difficulty scores than those not attending (fig 4.14) and the difference in the amount and direction of change approached significance at nine months ( $t=1.89$ ,  $df=38$ ,  $p=0.07$ ). The two groups responded similarly, with those not attending laying a few points higher (indicating more difficulties). Taking into account changes in school attendance still revealed no significant differences.

Fig 4.12. Total Difficulties and School Attendance



*Difference between groups are never significant (two-tailed),  $p < 0.05$*

School attendance significantly impacted on total depression scores. Comparing those in school (at conclusion of research) to those not attending school, there are significant differences in scores at nine months ( $t=2.21$ ,  $df=35$ ,  $p=0.03$ ) as well as 12 months ( $t=2.55$ ,  $df=30$ ,  $p=0.02$ ). Taking into account changes that occurred in school attendance reveals that the group who attended school throughout the research period not only had lower means throughout but their means also declined the most. Differences between the group means are significant at nine months ( $F=2.84$ ,  $df=3,33$ ,  $p=0.05$ ) and 12 months ( $F=3.63$ ,  $df=3, 28$ ,  $p=0.03$ ).

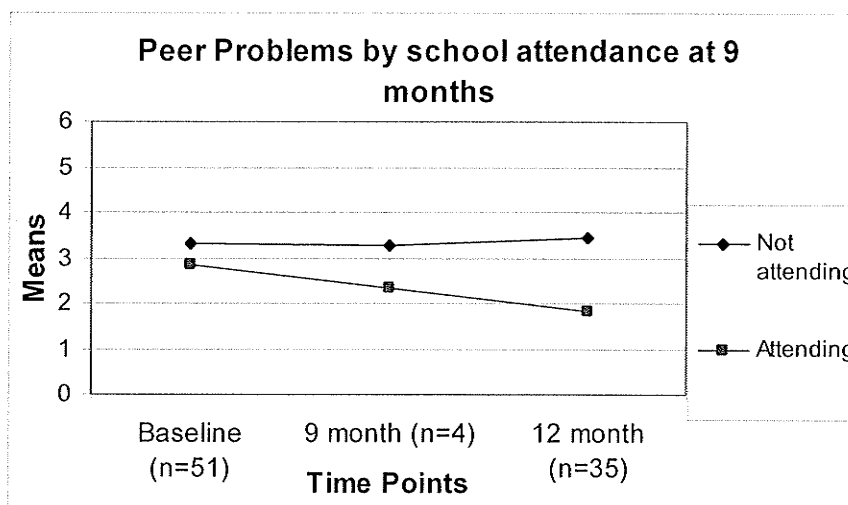
The effect of school attendance on overall adjustment scores was not significant although participants attending school had almost significantly lower mean scores at nine months ( $t=1.88$ ,  $df=38$ ,  $p=0.07$ ). Separating groups according to change in school attendance did not yield significant results either.

Focusing on the subscales constituting the SDQ, only peer problems were significantly influenced by school attendance, even taking into account changes in

school attendance. All the other subscales showed the same general trend (illustrated in figs 4.13 and 4.14) with adolescents attending school consistently reporting fewer problems. Only the hyperactivity scale did not fit this trend and school attending and non-attending groups were almost identical both in means and response.

At baseline, peer problem means for those attending and not attending showed little difference although the mean of those not attending was slightly higher (fig. 4.15). Scores for those not attending school remain stable throughout the study period while the scores for those attending decrease, indicating improvement. At 12 months the difference between the group means are significant ( $t=2.7$ ,  $df=33$ ,  $p=0.01$ ).

Fig 4.13. Peer Problem means and School Attendance



*Difference between groups at 12 months is significant (two-tailed),  $p<0.05$*

The Anhedonia, Ineffectiveness and negative mood dimensions of depression were influenced by school attendance, although the variance in negative mood only became clear after expanding the categories.

Mean anhedonia scores for those attending school was significantly lower at both nine ( $t=2.22$ ,  $df=35$ ,  $p=0.03$ ) and 12 months ( $t=2.86$ ,  $df=30$ ,  $p=0.01$ ). Adolescents

attending school had significantly lower Ineffectiveness means at 12 months ( $t=2.11$ ,  $df=30$ ,  $p=0.04$ ) but not at nine months ( $t=1.7$ ,  $df=35$ ,  $p=0.1$ ). Expanding the categories to reflect changes in school attendance the scores for those attending school throughout was consistently lower. The difference in group means approached significance ( $F=2.32$ ,  $df=3,33$ ,  $p=0.09$ ) at nine months and was significant at 12 months ( $F=3.25$ ,  $df=3, 28$ ,  $p=0.04$ ). This same pattern of lower means and greater improvement in the group attending school throughout was seen in Negative mood scores as well. Negative mood means are significantly different at nine months ( $F=3.24$ ,  $df=3,33$ ,  $p=0.03$ ) and 12 months ( $F=3.37$ ,  $df=3, 28$ ,  $p=0.03$ ),

School attendance had significant impact on only two of the dimensions of social adjustment: sibling relations, and family unit. Means for sibling relationships were identical at baseline but to nine months the mean for out-of-school participants increased while in-school participants remained stable. The means themselves are not significantly different at nine months, but the groups experienced significantly different change from baseline ( $t=-2.09$ ,  $df=22$ ,  $p=0.05$ ). If scores are categorized according to change in school attendance, the difference in the amount of change shown to nine months is still significant ( $f=4.93$ ,  $df=3,20$ ,  $p=0.01$ ). Those who attended throughout constantly had the lowest mean score. At nine months the difference between group means approaches significance ( $f=2.45$ ,  $df=3,23$ ,  $p=0.09$ ).

Mean scores for adjustment within the family unit were identical for all groups at baseline. To nine months, however, the mean score of participants not attending school increased while the mean for those attending school decreased. The resultant difference between the means were significant at nine months ( $t=1.98$ ,  $df=36$ ,  $p=0.05$ ). The mean for those not attending is still higher at 12 months but the difference is not significant. Considering change in school attendance, the mean scores for those

attending school throughout decrease steadily to nine and 12 months but there are no significant differences.

Perceived physical health was not influenced significantly by school attendance or change in school attendance.

### ***Peer Support group Attendance***

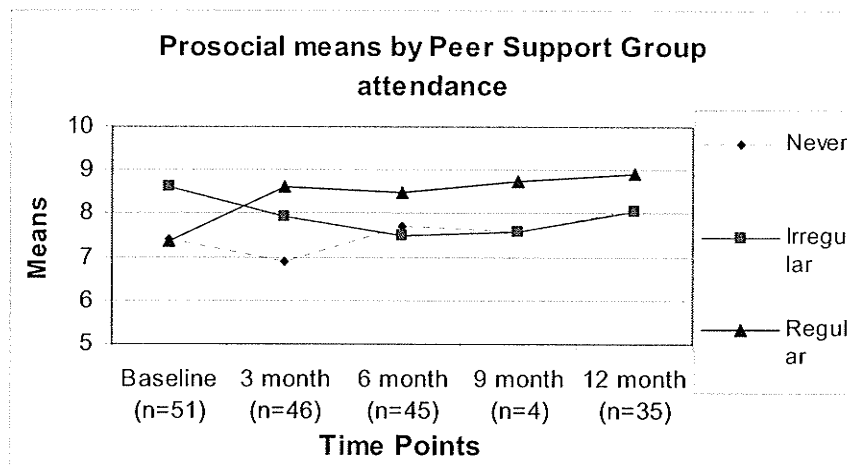
Peer support groups attendance did not significantly influence total difficulties scores, total depression scores or overall adjustment and had little impact on individual subscales.

On the SDQ, the only effects were on the peer problem and prosocial scales. Attending peer support groups influenced Peer Problem scores. All groups started out with similar means but scores for the groups who attended peer support groups, whether regularly or not, decreased to nine months while the mean score for those who never attended increased. The resulting difference between the group means were significant ( $f=3.26$ ;  $df=2, 37$ ;  $p=0.05$ ). To 12 months the mean for the group who had never attended also declined to a lower level than baseline and there was no significant difference between groups.

Peer support group attendance influenced prosocial scores. Those with regular attendance showed an increase in prosocial scores (increased prosocial behaviour and 'strength') and they had the highest mean at this point (Fig 4.15). While the difference between group means was not significant at nine or 12 months, the difference in the direction and amount of change was significant at six months ( $f=42.8$ ;  $df=2,40$ ;  $p=0.02$ ), nine months ( $f=3.27$ ,  $df=2, 35$ ;  $p=0.05$ ) and 12 months ( $f=3.69$ ;  $df=2,30$ ;  $p=0.04$ )



Fig 4.14. Prosocial means and Peer Support Group attendance



*Difference in means is not significant (two-tailed),  $p < 0.05$*

Peer support group did not have a significant influence on overall adjustment or on the housework, social and leisure activities, parents/guardians relationships or sibling relationship scales.

In the first three months of the study there was a significant difference between the groups in terms of school work and the difference between the group means were significant at three months ( $f=5.81$ ,  $df=2,25$ ,  $p=0.01$ ) as is the difference in change from baseline ( $f=4.57$ ,  $df=2,20$ ,  $p=0.02$ ). During the study period the mean for those who never attended is consistently lower (indicating better adjustment). At 12 months the difference between the group means are again significant ( $f=3.55$ ,  $df=2,22$ ,  $p=0.05$ ) with the mean of those who never attended the lowest.

Family relationships, both within extended family and the family unit were influenced by peer support group attendance. The extended family means for the group who never attended and those who regularly attended increase from baseline to nine months and to 12 months, while the means for the group who attended occasionally remained steady. At nine months, group means are significantly different ( $f=3.44$ ,

$df=2,36$ ,  $p=0.04$ ), the mean for those who never attended being significantly higher than the others. This difference disappears to 12 months ( $f=0.89$ ,  $df=2,31$ ,  $p=0.42$ ).

On the family unit scale, change from baseline to nine months ( $f=5.99$ ,  $d=2,23$ ,  $p=0.01$ ) as well as to 12 months ( $f=5.4$ ,  $df=2,22$ ,  $p=0.01$ ) were significantly different for the groups. At baseline, those attending regularly had a higher mean score than the other groups, who were closer together. To nine months the mean for those who regularly attended decreased and group means were now similar. At 12 months, there are bigger differences between the means than at nine months, but it's still not significant ( $f=2.65$ ,  $df=2,31$ ,  $p=0.09$ ).

Peer support group attendance had no lasting effect on health ratings. The significant difference in change from baseline to six months ( $X^2=6.6$ ,  $p=0.04$ ) - with those attending occasionally reporting less improvement than the other groups - disappears to nine months and there are no further significant differences.

## Discussion

The psychological health of participating adolescents improved during the study period. Although only the improvement in total difficulty scores was significant, mean depression scores improved steadily. Three of the Strength and Difficulties subscales - emotional symptoms, hyperactivity and peer problems - all improved significantly as did scores on the anhedonia subscale of the CDI. The interpersonal problems scale of the CDI was the only scale that significantly deteriorated with nine-month scores indicating significantly more problems than at baseline: Scores steadily increased to nine months, suggesting the increase was not a random occurrence. It does however decrease steeply to 12 months, returning to baseline levels. The SDQ has two scales measuring aspects of interpersonal relationships and none shows the same trend as the interpersonal scale. Peer problems improved significantly and while prosocial behaviour

did not improve significantly, it remained steady showing a slight improvement to 12 months. The increase in interpersonal problems also did not seem to be attributable to any of the independent variables included in analysis. Despite the increase in interpersonal problems, quality of life improved during the study period. A study of 117 HIV positive adults receiving ARV treatment in Cape Town, South Africa (Jelsma et al, 2005) reported similar gains in quality of life. Participating adults completed a measure of health-related quality of life (EQ-5D) at baseline, 1 month, 3 months, 6 months and 12 months. The dimensions measured (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) differs from those measured in this study, but the reported increase in overall health-related quality of life does provide support for the findings reported here.

The percentage of adolescents reporting moderate depression symptoms increases from baseline to 9 months and 12 months and would indicate an increase in the number of adolescents with depression. This was, however, not the case. The increased percentage is due to the declining sample size: the number of adolescents in the category remains four. ARV treatment might have affected mild depression symptoms, but could not lower the overall depression rate.

The most significant gains in quality of life occur during the first three months of treatment and it seems to be a long-term effect as scores do not return to baseline level. In the South African study conducted by Jelsma and colleagues (2005), the greatest improvement in health-related quality of life also occurred within the first three months and did not return to baseline level but continued improving. They included a measurement one month into therapy and the results indicate that much of the improvement occurs within this month. In both the current and the South African study, data was gathered by self-report questionnaires. It is possible that the initiation of antiretroviral therapy is accompanied by increased optimism and hope for the future.

This sense of euphoria would explain the greater improvement directly following the start of therapy and as emotional health is more subjective it may be more susceptible to the influence of mood.

In this study, a second marked decrease in scores occurred from nine to 12 months. This was not reported for the South African study. They did not include a nine month measure, but the increase in the percentage of people with no problems was not that marked between 6 and 12 months (Jelsma et al., 2005). A decrease in sample size could be partially responsible for the decrease seen in the data reported here as only 36 adolescents (70% of the original sample) were followed to 12 months. There were, however, no significant differences between retained participants and those not followed to 12 months.

Social adjustment scores did improve but was high at baseline and throughout research period. This supports findings from other studies of the health related quality of life of HIV infected adolescents and children. In a study of 33 HIV positive children and adolescents receiving antiretroviral therapy from an academic health centre in the United States, Byrne and Honig (2006) reported normal social role functioning, behavioural problems, emotional problems and functioning (established norms for the United States are available). In their study of HIV positive adolescents in Uganda, however, Musisi and Kinyanda (2003) reported more problems with functioning. The sample had a much higher percentage double orphans and the results reported here indicate a significant link between the loss of parents (especially the mother) and impaired functioning which may account for the lower reported functioning in Musisi and Kinyanda's study.

Inclusion criteria for the study were contingent on the criteria used at the study site to determine eligibility for antiretroviral treatment. The PIDC's criteria specified that patients had to have a source of social support (to facilitate adherence). Seeking social support is an important source of comfort and a coping strategy reported by many. The

social situation of this sample of adolescents was therefore more favourable from the outset as they had someone to support them. This may also account for their high level of functioning and psychological health reported.

Depression scores were the most easily affected by the independent variables, with gender, parental loss and school attendance all influencing total depression scores. Total difficulty and adjustment scores, on the other hand, was only influenced by one variable each: school attendance influenced difficulty scores and parental loss influenced adjustment. The greater number of variables affecting the depression scores implies that depression scores are more vulnerable to external influences and other problems not directly related to being HIV positive. In the qualitative responses from the coping section and emotional health sections, adolescents mentioned having other 'worries' not related to their health. Many of these worries, however, are still indirectly linked to their HIV status, such as being orphaned and resultant poverty or abuse by unwilling caretakers. If depression scores were more vulnerable to these worries, they would not change as much in relation to only one worry – their health. Effective interventions aimed at improving the quality of life of HIV positive adolescents would have to take into account the other factors.

The independent variable affecting the greatest number of scales was school attendance. School attendance was associated with significantly lower difficulties and depression scores. In-school adolescents also reported less peer problems, lower scores on negative mood, ineffectiveness, anhedonia and increased functioning regarding their sibling and family unit. The same trend emerged across the majority of scales, even those not significantly affected by school attendance: the two groups responded in parallel fashion, with in-school adolescents scoring better than those not attending throughout. Adolescents who attended school throughout had the lowest scores and showed the most improvement across the board. Musisi and Kinyanda

(2003) also found school attendance to be significantly associated with psychological distress. School attendance significantly improves adolescents' quality of life.

Peer contact at school and hope for a future may be two factors involved in the role of school attendance, but adolescents not in school are also younger and less likely to be double or maternal orphans, as discussed previously. Both parental loss and age influence quality of life independently. In this setting, school attendance overlaps and interacts with many other important variables that influence quality of life. The significance of school attendance could be attributable to these variables.

Parental loss significantly affected total depression and overall adjustment scores as well as schoolwork but there was no significant influence on SDQ scores. A South African study using the SDQ compared 30 children (ages 6-19) orphaned by AIDS (HIV status unknown) with a matched control group and found no differences (Cluver and Gardner, 2006). They did not separate double orphans from paternal or maternal orphans, however. In our sample, double orphans consistently reported more problems than adolescents with at least one living birthparent. Separating double orphans, maternal orphans and paternal orphans from those with both living birthparents, revealed that trends in paternal orphans' scores were most similar to that of adolescents with both parents. Maternal orphans and double orphans, on the other hand, were more similar and reported higher depression rates and more impaired functioning. The results suggest that the loss of their mother most negatively affects adolescents' quality of life. The social milieu of the maternal orphans in this sample may be more similar to that of double orphans than that of paternal orphans as they were more likely to be living with their remaining birthparent than maternal orphans were. Of the 13 maternal orphans, four lived with their father compared to eight of the 11 paternal orphans living with their mothers.

The effect of age was especially clear in terms of conduct problems and relationships with siblings and extended families. Younger adolescents seem to experience fewer difficulties on all three these scales. Adolescents between the ages of 13 and 15 had the highest conduct problems and consistently scored higher on the siblings and extended family scales –indicating poorer adjustment in these areas. The effect of age on quality of life has been shown in prior studies. In a study of 3 710 healthy children and adolescents (aged 9 to17) from seven European countries, Bisegger and colleagues (2005) found significantly higher quality of life for children younger than 12 than for the adolescents older than 12. In Uganda, Musisi and Kinyanda (2003) found the same inverse relationship between age and psychological distress.

Gender had limited affect. The only significant difference was seen in depression scores, with girls reporting higher depression rates than male participants. The means for boys also declined steadily throughout the research period while the girls' mean remained stable. This is consistent with existing reports of higher depression rates for female adolescents (Bisegger et al., 2005). One explanation given for this is that females are more likely to internalize distress than their male counterparts. The higher level of depression in the female population needs to be addressed, however and the difference in response taken into account in planning interventions or counselling.

Peer support group attendance had no effect on any of the overall scores and influenced the scales related to family relationships, peer problems and prosocial behaviour. This was the only variable to have any effect on prosocial behaviour. Regular attendance at peer support groups was associated with better scores on all these subscales. Regular contact with peers appears to help adolescents hone their relationship skills as they learn how to interact with others. This is an important skill for adolescents' functioning in society.

## Conclusion

Participating adolescents' quality of life improved during the first year of treatment with antiretroviral treatment. Potential side effects of the treatment do not seem to influence quality of life. The psychological and physical well-being of participating adolescents improved markedly during the study period while functioning remained at a high level. The higher level of functioning reported at baseline means that a ceiling effect decreases the possibility of significant improvement in functioning scores. The maintenance of a high level of functioning is therefore an acceptable outcome.

The gains in quality of life predominantly occurred during the first three months of the study, especially in the psychological and physical domains of well-being. The results seem to be sustained for the first year but future research is needed to determine if it remains at this level. A second decrease from nine to 12 months also warrants further investigation.



## **Chapter 5: The social context of quality of life.**

*"When the public knows that you're HIV+ they treat you differently"*

Quality of life is not only informed by their physical health but is influenced and shaped by the social context in which the adolescent lives and functions. If services are to be effective it is important to understand the adolescents' experience of being HIV positive and their needs from their own point of view and in their own words.

Interviews were conducted with adolescents during the course of the research and qualitative information gathered provided valuable insight into the lived experience of the adolescents and enriches the quantitative data described in previous chapters.

This chapter describes the feelings reported by adolescents regarding changes in their physical and emotional health and coping before addressing adolescents' understanding and experience of stigma. The following discussion attempts to illuminate issues of importance to the adolescents but is not meant to be an in-depth exploration of coping or stigma in this population. It does however present an overview that can serve as an important guide to future research.

### **Self perceived changes in physical and emotional health**

The second interview conducted at the end of the research included two questions asking adolescents to compare their physical and emotional health to that at baseline (prior to starting ARV therapy). They could rate their health on a closed response set as much worse, bit worse, about the same, bit better or much better. An additional open-ended question asked them to support their response ("why do you say that?"). Twenty-one participants answered these questions.

### ***Physical health***

Asked to compare their physical health to that at baseline, most adolescents reported their health as “much better” and a third rated their health as “a bit better”. No participant rated his or her physical health as worse.

Seven adolescents specifically mentioned the role of antiretroviral therapy in their health improvement while another felt clinic attendance and overall care had made the difference, saying “life has changed. There's a difference between now and before I had started coming here”.

Increased strength improved adolescents’ ability to function in their daily activities and was most frequently mentioned as the reason for their perceptions of improved health, along with feeling healthier. One said

*with frequent and daily use of ARVs am stronger now than before. I used to be weak and sickly however this has changed because of ARVs.*

Increased participation in housework and being able to play with siblings and friends were mentioned frequently. Reducing the visible signs of their illness seemed to contribute to their feelings of physical well-being. One adolescent mentions his rash disappearing and another feels that “because of the ARVs I am now growing a little taller and putting on weight”.

Reasons given for the perceived improvement in health did not differ according to health rating. Those who judged their physical health as only slightly improved also named increased strength and less frequent illness. Although all adolescents rated their health as improved, some were disappointed with the effect of the ARVs. One adolescent, though rating his health as having improved somewhat, felt that “There’s not much difference even though am continuously taking my medicine”.

### ***Emotional Health***

Judging the changes in their emotional health proved more problematic than the comparison of their physical health. Ratings of the change in emotional health displayed much more variability than those of physical health (see table 5.1). Most participants felt their emotional health had improved to some extent, but some rated their emotional state as unchanged or worse.

Table 5.1

Rating of change in emotional health

	N
Much Better	12
A bit better	4
About the same	3
Bit Worse	2

Those who had rated their physical health as 'much better' were also more likely to rate their emotional health as better: 11 of 15 participants who judged their physical health as 'much better' also rated their emotional health as 'much better' and another two rated it as 'a bit better'. Participants who had rated their physical health as only slightly improved, however, displayed more variability in their emotional health rating: one rated their emotional health as much better, two as a bit better, two as same and one as worse.

The majority of adolescents felt their emotional health had improved to some extent. The effect of other worries on participants' emotional health, which may indirectly be linked to HIV, became apparent as one adolescent rated her emotional health as improved overall but mentioned that she had some difficulties and "worries". The other

adolescents reported decreased concern about their illness as the reason for their improvement, feeling "no longer worried and fearful about having HIV/AIDS".

Decreased concern about their physical health was also one of the main reasons for improvement in emotional health. One adolescent explained that they now worried less about dying and were free to focus on other things, like playing or school. Other reasons offered by these adolescents included their medications and feeling less helpless.

Three adolescents reported no change in their emotional health. One simply stated "there was no difference" while another agreed that treatment had "given me hope, but am still worried". The third adolescent's mother had passed away during the course of the research.

One of the two adolescents who rated their emotional health as worse than baseline, spoke of worries not directly related to his illness:

*There are many problems, there are days when you get up and have no money and I ask myself what (I) am going to do.*

The other adolescent was still "always worried about dying, I fear the end/judgement day".

### ***Coping Behaviour***

Interviews included three questions aimed at eliciting information on the coping strategies and behaviours employed. Questions focused on strategies for dealing with emotional as well as practical problems. Questions were based on items from existing scales and previous studies (table 5.2) but were open-ended, allowing adolescents to answer in their own words.

Table 5.2

## Questions regarding coping strategies

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When you feel upset/sad (or other emotion mentioned) what can someone do to make you feel better?

What do you do to make yourself feel better?

What do you do when you have a problem?

---

Questions did not specify illness-related problems, although conducting the interviews in the clinic setting may have predisposed adolescents to considering health related problems.

Most adolescents reported using more than one coping strategy depending on both the setting and the nature of the problem. One adolescent, for instance, reported actively trying to find a solution when faced with a practical problem while preferring avoidance behaviour such as sleeping when emotionally distressed.

While many adolescents mentioned their illness most focused more on general difficulties, perhaps an indication that some adolescents might have come to terms with their status and focused on other aspects of their lives. Three reported having "no problems", only one acknowledging her medical condition, stating that "apart from having illness, there is no other problem I get".

Almost half of the participants reported healthy, adaptive coping mechanisms, especially in terms of their illness. Four adolescents had accepted their HIV status and many mentioned seeking information about their illness and accessing care and treatment as the way they dealt with their illness. Three participants mentioned actively trying to find solutions to problems. As one adolescent put it, they would "think of something to get out of the problematic feeling". Another adolescent was trying to find

ways to support himself and his family, applying for loans and trying to start a small business to "earn a living".

The majority of adolescents discussed difficulties and the coping strategies they utilized in such situations, most relying on social support. The predominant sources of support mentioned were mothers, aunts, grandmothers and other caretakers with siblings, clinic staff and other adults also mentioned. Confiding in another person is therapeutic in itself, while also satisfying needs for emotional and/or instrumental support. Participating adolescents expressed a need for emotional support, to be comforted and encouraged to deal with their problems. Instrumental support either took the form of advice and guidance or monetary support for school and treatment.

Distancing themselves from their problems, whether physically or mentally, was mentioned frequently. Adolescents reported walking away from the situation or people to avoid conflict or isolating themselves to avoid the situation all together. Mentally distancing themselves was more common, with adolescents either trying not to think about it or actively engaging in other activities so as not to think about it.

Adolescents would also actively involve themselves in other activities, such as reading, playing or visiting friends, so as not to think about their problem. One adolescent stated that he would "leave home, visit friends so as to keep fears and thoughts away from my mind". Four others mentioned sleeping to avoid their problem or escape sadness. The impact and influence of their health is evident here, as another adolescent acknowledged sleeping a lot due to weakness and not necessarily in avoidance of external problems. Removal from the situation, ignoring the problem, doing nothing and keeping quiet about or thinking about it without actually doing something about it, could also be interpreted as avoidance strategies. Five adolescents reported doing nothing when they felt sad or had a problem. One said this was because she does not think about bad things but others were avoiding or ignoring the issue. Many tried not

to think about their problems. They either "learnt not to think about it" or tried to forget them as soon as possible. Three adolescents explicitly referred to their health here. One explained, "Whenever I feel like thinking about having HIV/AIDS, I just try not to think about it". The other two responses reflected a sense of acceptance more than avoidance: "I don't think about having HIV/AIDS". Five adolescents said they just kept quiet about their problems. A sense of hopelessness was evident in the response of one adolescent who stated: "I only think about it and keep quiet, I can not do anything about it."

Emotional responses such as feeling sad, crying or feeling afraid was reported by three adolescents while one adolescent tried to fight those he could.

## Stigma

Stigma is a social construct rooted in prevailing cultural norms and beliefs. An individual's stigma experience is therefore dependant on their environment and the situation in which they are living. An important goal of this research was to determine what stigma meant in the experience of an HIV positive adolescent attending an HIV clinic in Kampala, Uganda. A working definition was adopted to serve as guideline for the development of interview questions with the understanding that this definition was not final and would be adapted to suit the situation at the clinic in Kampala. The definition adopted was that of the 2001 Save the Children study in South Africa. According to this definition stigma is

*The imposition of a special, discrediting and unwanted mark on a person or a specific category of persons in such a way that in their interactions with others they are looked at as fundamentally and "shamefully different" by themselves and others.*

All stigma questions were open-ended, as can be seen in Tables 5.1 and 5.2 (full interview guide is in appendix F). There are few HIV/AIDS related stigma scales and those that exist (e.g. Berger et al, 2001) focus on adult populations in North America. As stigma is a social construct shaped by our social environment, these were not appropriate for HIV positive adolescents in Africa. The nature of stigma experienced by perinatally infected adolescents in Uganda was not documented either. It was decided to include open-ended stigma questions in the interviews and to explore not only the level of stigma experienced but also the nature of stigma in this environment. In Musisi and Kinyanda's (2003) study of HIV positive adolescents attending an HIV clinic in Uganda, open-ended questions were asked in focus groups and interviews to determine the level of stigmatization. The focus of their research was different, however, and the questions considered inappropriate for this study. Six questions were developed for this purpose. Questions were based on literature reviews, the Berger stigma scale, conversations with clinic staff and adolescents and the Horizons study of AIDS affected children (1991).

Conducting interviews every three months would have been time consuming and fatiguing for the adolescents. Research fatigue was a real concern. The decision was made to conduct only two interviews: one near baseline and a second at the conclusion of follow up. The aim of the first interview was to obtain a sense of adolescents' feelings and situation before, or at the start of ARV treatment. It would provide a 'baseline' idea of stigma, coping and social support to compare with responses from the second interview. Conducting an interview at the conclusion of the research allowed adolescents to review their feelings on stigma, but also to reflect on the research process.

At baseline, 46 adolescents were interviewed and at the conclusion of the research 33. No adolescent refused to participate in the interviews and the loss in sample size account for the smaller number. Adolescents interviewed did not responded to all questions, however and stigma-related information is available for 41 adolescents



at baseline and 28 from the second interview. The decline in sample size poses problems to the interpretation of the data. The decline was due to many factors. Adolescents younger than 12 would attend the paediatric clinic on days other than Mondays and the research team would not be able to follow up. The clinic setting imposed its own restrictions as well. Rapid growth in patient population had made space an issue, not only for the research but also for clinic functioning. There was no room to conduct interviews during the adolescent clinic and the family clinic on Thursdays meant we could not reschedule for this day. As a result, not all adolescents could be interviewed again before the conclusion of the research.

This section describes participants understanding of the term stigma, their experience of it as well as the perceived impact on their lives.

### ***First round of Interviews***

Stigma questions asked during the first interviews are shown in table 5.1. In the first question, participants were asked what meaning the word 'stigma' had for them. Five declined to respond and more than half of the remaining adolescents (29 of 41) indicated either no knowledge of the word or could not verbalize the meaning. Two others only knew 'stigma' as part of a flower, of which they had learned in biology. Eleven adolescents defined stigma. Asked if they felt people with HIV were treated differently, however, 22 adolescents agreed and could give examples of stigmatizing behaviour.

Table 5.3

Questions regarding stigma included in first interview

- 
- I know we have talked about stigma in peer support groups and we hear people say it, but what exactly does stigma mean to you?
  - Do you feel people with HIV are treated differently/stigmatized? How? Why do you say this (was it personal experience, hearsay, etc)?
  - Who have you told about your status? Why have you told these people? Why have you not told other people?
  - Do people's attitudes make you feel better or worse about yourself?
  - How do you feel yourself about having HIV?
  - Do you think you can talk to a friend who is not HIV positive about how you are feeling or your problems?
- 

Adolescents were asked to describe discriminating behaviour regarding others before they were asked about personal experience with HIV. Twenty-two adolescents felt HIV positive people in general were treated differently with nine reporting stigma or discrimination in their own lives. The remaining adolescents denied being treated differently themselves but recognised, or had witnessed first hand, that stigma and discrimination still existed. A third of the 41 adolescents interviewed denied differential treatment towards themselves or any HIV positive individuals. One adolescent felt HIV positive people were being treated better due to their status:

*People who have silimu<sup>3</sup> are always sick cannot walk and do not enjoy life. No, they are treated well because they are always ill, therefore cared for by friends and relatives.*

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<sup>3</sup> In Uganda HIV/AIDS is referred to as Silimu.

### **Defining stigma**

The definitions of stigma provided by the adolescents described it as a negative attitude or feeling that people have towards HIV/AIDS. One adolescent described stigma as “the way people feel about people who have HIV/AIDS”. The feelings in turn influence interactions with those who are HIV positive or suspected to be HIV positive adversely, leading to discrimination (or enacted stigma):

*It means people with HIV are being treated badly, friends don't want to be with them and they are discriminated against.*

The main categories of discrimination described were rejection, isolation, abandonment, abuse and being talked about. Neglect was described by many adolescents, but overlapped with rejection and abuse and are included in these categories.

### **Nature of stigma**

*It can be like other children do not want to sit near you, play with you, share or eat with you and make you feel dirty. To me it has never happened, but it's seen for other people.*

The above quotation describes the many faces of rejection experienced. School was not the only place adolescents experienced stigma, nor were children the only ones stigmatizing them. Other responses described similar experiences in different settings (at home and in their neighbourhoods). Their greatest concern, mentioned by the majority of participants, was that others would not share with them. They mentioned others not wanting to share food, toothbrushes and toothpaste, eating utensils, cups, clothes, bedding or a bathroom with them. At school, other pupils refused to share desks or socialize with them outside the classroom.

*At school the others do not want to sit with this person. You disgust them.*

*Other people do not want to get near you. At school other pupils never wanted to get near me because of my skin<sup>4</sup>.*

Fellow students shunned a young girl because they suspected she was HIV positive.

They went further, however, and actively discourage others from associating with her:

*At school fellow pupils scare others away from me; they do not want and prevent others from playing with me, labelling me an HIV/AIDS victim. At school it's difficult to share eats (snacks) with others. Like, when I want to share eats with others, other children sometimes prevent them from sharing with me and shout at them [that] I have AIDS and I will infect them with HIV. It happened and I responded to them that "have you seen me with AIDS", they said yes. I couldn't reply. I kept quiet and walked away.*

Participants also described rejection within their families. Three described occasions when caretakers would prevent HIV positive adolescents from sharing beds with, or wearing the same clothes as their own children. They were also not allowed to use the same plates, cups or cutlery as the rest of the household. In many cases, this seemed to stem from a fear of infection, as described here: "at home we do not share clothes, toothpaste, eat together, I'll infect them with HIV. " Two of the three adolescents describing these situations did so from personal experience and one had heard it from someone. The latter was an orphan living with his mother while the first two were double orphans, one living with extended family and one in a sibling household.

A few adolescents reported not being allowed to wash their cups in the same basin as others, or to store their plate in the cupboard with the other plates. This intensified their feelings of rejection and isolation from those around them. One

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<sup>4</sup> The 'skin' referred to is a facial rash caused by the Human papillomavirus.

participant was living with his grandmother at the time of his diagnosis and describes the situation following his disclosure to her:

*When I told jajja that my blood had been tested and found positive, they started separating my cup and plate. They would be washed separately and when anyone touched my cup or plate or put them together with the rest, they would say "that cup is for so<sup>5</sup> who is sick you do not deserve to touch it".*

Extended families were seldom seen contributing to the care of HIV positive adolescents and showed them no affection. One adolescent experienced a sense of dislike from family members she could not explain: "my other maternal aunties like the rest but they don't like me." They did not show the same disregard for the siblings and cousins she lived with, leading her to conclude that it resulted from her illness.

HIV is a costly disease and HIV positive people could be abandoned by friends and relatives who do not want to "stay or care for them when they are sick". Participants saw neighbours with AIDS struggling with little or no help or support. One participant did not experience any mistreatment or neglect in his own life, but could see that others were being treated badly "like abandoning them and leaving them to die in pain."

A female participant who had been hospitalized before enrolling in the study shared her experience:

*Some are treated otherwise. I saw from the way it was while in the hospital. Some people didn't have caretakers, no food and other requirements from relatives and friends*

In African hospitals, such as Mulago hospital in Kampala, families are sometimes expected to provide much of the patients care and needs. Family members often bring mats and sleep on the floor in the ward to be closer to the patient and be able to take

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<sup>5</sup> The word 'so' here, is used in place of 'so-and so', referring to an unspecified person. Can also indicate a reference to someone considered offensive.

care of them. Families supply bed linens and food, do the patients' laundry and, especially in the case of children, bathe them. The absence of a family member or other caretaker can therefore have far-reaching effects on an individual's hospital experience.

Abandonment by their families was not restricted to times of illness or increased need. Following the death of her mother, her father and his family abandoned one girl:

*My father's uncles do not care for me. Even when they are told that am sick they don't care at all, do not visit me, not even buying me clothes and other necessities, yet they do it for my step brothers and sisters.*

Adolescents also reported other forms of abuse experienced within their families. One adolescent living with his stepmother reported being "over worked with housework". Another felt her brother made her do too much of the housework. If she refused, forgot or felt she could not complete the tasks, she was threatened:

*Like chasing me away from home. They treat me badly. At times you can fail to remember what he tells you. When you tell him you have forgotten, he says "I will chase you from here so I remain alone".*

Discrimination can be a result of the stigma attached to being an orphan as well and the overlap of HIV stigma with the stigma of being an orphan is evident in the above statement. Here, the abusive behaviour is based on her dependence on this caregiver because of her orphanhood. Especially in the case of perinatally infected adolescents, there is a significant overlap between the stigma related to their HIV/AIDS and the stigma related to being an orphan. They contracted the disease from their mother and in the majority of cases it is also AIDS that ultimately claims the life of their parent. The root of the stigma experience may seem the same, but it is important to distinguish between the stigma resulting from HIV infection and that of being an orphan. The underlying assumptions and causes differ and would need to be approached differently. The stigma associated with being an orphan is much older relative to that attached to HIV/AIDS and

its underlying causes more entrenched. It also has implications for any intervention aimed at reducing the stigma experienced by these children, as any intervention focusing only on HIV/AIDS and not taking into account the stigma associated with the loss of a parent may not reduce the overall stigma experienced.

Participants were also concerned about their access to schooling and other services. One adolescent wanted to return to school and her stepfather was willing to pay her school fees, however, his wife felt "he should pay for the healthy ones". Her stepmother also felt that she should not be allowed to attend school as she would "infect other children, brothers and sister, with HIV". In this example, as in most of the statements relating to rejection, the stigma and discrimination were based on a fear of infection. Antiretroviral therapy has made AIDS manageable but it is not a cure and people are afraid of being infected with an incurable disease.

Medical treatment was not ensured either. One participant's grandmother would not bring her to hospital even though clinic doctors had prescribed the treatment and provided money for transport to the hospital:

*Now, my teeth are aching and they do not allow to bring me to hospital. The form was also given to her to have my eyes examined. She was given money, but when that day reaches, she says that she is not coming. When I tell her that I bring myself, she does not allow*

Another was afraid that her caretaker would stop providing funds for transportation to the clinic for routine care:

*Yes, they are stigmatized. For example us who have to come to the clinic most of the time. The person becomes tired of you and stops giving you transport and care.*

Many adolescents reported incidents of verbal abuse. Comments were not only based on HIV status (whether confirmed or suspected) and the fatality of the disease or

on looking ill but could be based on the adolescent being seen at the PIDC or The AIDS Support Organization (TASO). Becoming the topic of gossip and ridicule was what participants feared most. One adolescent's landlord had AIDS and he remembers not only the gossip, but how "Other people laugh at people living with HIV/AIDS". While living with his aunt, another adolescent had to endure many comments:

*When I used to stay at my auntie's place, people used to abuse me, scold me and jeer at me because I have HIV/AIDS, go to TASO and live on medicines for AIDS patients and that even though all this they told me I will die*

Adolescents who had not disclosed their status to anyone could still be taunted based on signs of their "prolonged illness which is incurable" or simply because they look ill. One participant related the following incident with a neighbour:

*There is a girl in the neighbourhood. One time she told me that I will die young because I am sick all the time, although the girl does not know that I have HIV/AIDS.*

The importance of visibility in stigma experience is evident in this excerpt. The girl was not taunted because she was HIV positive, but because she *looked* ill. Another girl described a similar situation, where a neighbour ridiculed her based on the possibility that she might be ill. Neither had disclosed their status to anyone outside their family but their visible symptoms were enough to make them targets. Siblings teased another not only because her 'silimu' kept her from attending school, but also because it made her look "bad and ugly". Visible signs of illness make it harder for adolescents to hide their HIV status, especially if the signs had become widely associated with HIV. As a result, visible signs of illness are important factors in their social relationships. They fear any symptoms or illness that could act as visual evidence of their illness and render them



targets for teasing and rejection. One adolescent described their situation as being “discriminated (against) for looking bad”.

Symptoms were not considered equal either, as some illnesses had become more synonymous with HIV/AIDS than others had. HPV skin rashes, mouth infections caused by Candida and wasting were considered signs of HIV infection by the general population, and caused adolescents more anxiety. Skin rashes were mentioned by many adolescents, and factored greatly into one participant’s school experiences:

*Maybe in boarding school, other children become disgusted about me because of the bad skin, they do not want me to touch anything of theirs. That is what I think about.*

He was not alone in this regard, as other participants also reported being shunned at school because of their appearance. Visible signs of illness were even seen as determining the level of care they received as “those who look well are cared for by relatives, while those who look bad are not so cared for”.

There is another element to the visibility of symptoms, however, that is especially important to adolescents: the symptoms made them ‘ugly’, undesirable and hampered their ability to interact with their peers. Peer relationships and acceptance by peers are very important aspects of adolescence. Being considered undesirable would negatively influence peer relationships and acceptance. Research also reports that especially girls are very concerned with their appearance and their bodies during adolescence (Bisegger et al., 2005) and having visible scars or signs of illness would be difficult to handle. Skin rash and red lips cannot be concealed. It is important in hiding their HIV status, but also because it has a negative effect on their appearance.

It was not only the demeaning nature of people gossiping and ridiculing them that concerned adolescents. They were also concerned with the disclosure factor: People

discussing their HIV status would divulge their status to an increasing number of people. All of whom could potentially abuse or talk about them. This was the major reason given for not disclosing their status to others or not discussing problems with HIV negative friends:

*No. You could tell them, then they go about and inform other people yet I don't want other people to know my HIV status.*

Though many adolescents did not think HIV positive individuals were treated differently, the fear of prejudice and discrimination remained. Most of the participants in this study were under the age of 18 and a parent or guardian had to sign their consent form. At least one person therefore always knew their status, but wider disclosure was rare. Only 11 participants had informed someone other than their caretaker of their status and of these, only four had told someone other than a relative. Over two thirds (30 adolescents or 73%) had not revealed their status to anyone. There were two differences between adolescents who disclosed and those who did not. Those who told others about their illness were older and more likely to be orphans. Of the 11 who had informed someone, only one was younger than 12. The other difference was in terms of parental loss as eight of the 11 adolescents who had revealed their status to someone were double orphans and only one had both parents. Focusing on the four participants who had told someone other than a relative, three were double orphans and one had both parents.

Most individuals simply stated they that they "did not want to" tell anyone about their status but for some the recognition that they need help (or would in the near future) was enough motivation to tell someone about their HIV status. It prompted one adolescent to tell her sisters so: "they could help me, like not letting me do hard

work/activity". Another informed her siblings "For them to know so they too could test and know their HIV status".

Some adolescents felt the need to explain their situation, especially to those caring for them, because they "wanted them to know why I was falling sick all the time and what was causing it". Another felt it only fair to tell his uncle, aunt and close friends as:

*These people have been caring for me while hospitalised, so I thought it would be wise to tell them. Family friends live in the neighbourhood and usually play and stay together, these I told because of how we are related.*

Non-disclosure was primarily motivated by fear of others' reaction to them. As mentioned above, most participants had not disclosed to anyone because they did not want to become the topic of discussion and ridicule. One participant would not disclose "because they might laugh at me and say that am already dead". There was also the possibility of being shunned by those around them or being subjected to other demeaning behaviour:

*Because I fear to tell them. They might hate me, refuse me from helping them, carry their things, and isolate me.*

A sense of futility was also present in some responses, a feeling that people would not be able to help them even if they did disclose to them. One participant did not disclose because he could not see any reason to:

*it's useless to tell other people, because they might not help me even though I tell them about my HIV status*

Not disclosing may shield adolescents from discrimination but keeping their secret caused conflicting emotions in some. This became apparent from responses such as this one:

*It's because I am not getting well. I have ever thought about it. I was going to tell ..... but I stopped myself, because my 'heart' stopped me from doing so*

The fear of disclosure could also be that of the caretaker and not only the adolescent. One participant's father advised him not to disclose and another's stepmother advised him "not to tell anybody, that it is not good telling other people that I have HIV/AIDS".

There were adolescents who felt comfortable talking to HIV negative individuals, because "we have the same equal rights; I am not different from them".

Other adolescents felt it would depend on the person, naming clinic counsellors as HIV negative people they could talk to.

### ***Factors contributing to stigma***

Participants defined stigma as a feeling or attitude people had towards HIV/AIDS. Though none of the adolescents specifically mentioned the feelings HIV/AIDS evoked, their responses revealed aspects of the disease they viewed as central to these feelings. Many adolescents reported fear of infection as the reason others were avoiding or shunning them. One mentioned others in her household not sharing with her for fear of contracting HIV. There was another dimension to this, however. One participant felt people thought they "serve it", 'it' being HIV. In this adolescent's experience, HIV positive people were seen as actively trying to infect others and distribute the virus. No further evidence of this belief was found.

The increased accessibility of antiretroviral therapy has changed HIV/AIDS into a manageable, although not curable disease. The fear of death remains associated with HIV infection, as people fear they will ultimately progress to AIDS and pass away. The fatality associated with the disease increases their fear of infection and influences their views of those who are HIV positive. This is illustrated in the comments participants made about being told they are 'finished' or going to die despite taking their medicine. The fear of death is another underlying contributor to HIV/AIDS stigma, separate from the fear of infection. The two are not mutually exclusive however as fear of death surely influences fear of infection. In the example above of the stepmother denying an adolescent schooling because she will not live long, the response is less fear of death than wasted resources. The behaviour does discriminate against the girl but would seem justified to the stepmother, who would rather send the healthy children to school - who could in turn find a good job and take care of them. In a resource-limited setting such as Uganda, this is an important consideration.

### ***Impact***

Perceived stigma and the fear of discrimination influenced participants' lives in many ways. It kept them from disclosing their status and caused emotional distress. Fear of death further contributed to adolescents' feelings of sadness and worry.

At baseline, 13 adolescents reported no negative feelings regarding society's attitudes towards those with HIV (or their own HIV status) and a further seven reported feeling "bad" after being diagnosed but being fine now. The remaining 21 adolescents reported feeling sad, worried, ashamed, guilty, embarrassed, angry and different from others. A sense of apathy was also described by one adolescent who felt "bad, not interested in life". Two adolescents experienced such profound sadness they considered

"taking poison" and committing suicide. Another adolescent wished he had never been born.

As we did not ask directly about the visible signs of illness, we do not know how many of the adolescents reporting negative feelings had visible signs of illness, compared to those who felt more positive. It did however, seem that double orphans reported more negative feelings than other participants did: 10 of the 21 adolescents reporting negative feelings were double orphans and another 10 were maternal or paternal orphans. This could be due to the overlap of HIV/AIDS stigma with the stigma of being an orphan, aggravating the situation for orphans.

Feeling ashamed or embarrassed usually resulted from a feeling of being different from other people. This difference is interpreted as negative and internalized as a reflection on their self worth: "I feel so bad and different. Ashamed, dirty and different".

Another adolescent described it as follows:

*Ok, sometimes other kids I live with don't want to share, play with me because of my skin rashes. This makes me feel embarrassed and dirty and makes me ashamed of what I am"*

Some try to avoid situations that could evoke these negative feelings altogether and isolate themselves, avoiding interaction with others:

*Maybe in the boarding school, other children become disgusted about me because of the bad skin, they do not want me to touch anything of theirs. That is what I think about. I find myself falling sick and I do not touch anything of theirs. And our rooms are down, even when I go there, I do not spend a lot of time because they look at me badly*

## ***Second Interviews***

At the conclusion of the study period, 33 participants were interviewed again. Questions are included in table 5.2.

Table 5.4

Questions regarding stigma included in second interview

- 
- In our first interview I asked you about stigma, do you remember? What does it mean? Do you remember its meaning from the interview or did you learn it somewhere else?
  - Do you now feel people with HIV are treated differently/stigmatized? How? Why (was it personal experience, hearsay etc)? Has this feeling changed since we last spoke?
  - Have you told anyone else about your status since we last talked? Who have you told? Why have you told these people?
  - Do people's attitudes make you feel differently about yourself now? How does it make you feel? Has this feeling changed since we last spoke?
  - Do you think you can talk to a friend who is not HIV positive about your feelings and problems?
- 

Determining if stigma experiences had changed during the course of the study was complicated by the loss to follow up. This section will provide a brief overview of the situation at the conclusion of the study period as well as describe any changes that may have occurred.

### ***Defining stigma***

Participants were asked if they could recall the meaning of 'stigma' and discussing it in the previous interview. Four adolescents explained the term, one of whom had also known the term at baseline. Three adolescents provided the biological definition but they were not the same adolescents providing this explanation at baseline.

### ***Nature of stigma***

Reports on the level of stigma experienced had not changed during the study period. Six adolescents now reported personal experience with stigmatization while nine felt others were discriminated against. Thirteen did not think any HIV positive people were discriminated against.

Four of the six adolescents reporting personal stigmatization were the same as baseline while four of the adolescents reporting no discrimination against HIV positive people also believed this at baseline. One adolescent describes the latter position:

*They are treated well especially when they are sick. Sometimes when I am sick, auntie/matron provides me with drinks, mealtimes and support because she knows my status.*

Only one of the adolescents who now felt all HIV positive people were treated well, had felt personally stigmatized at baseline. He provides no reason for the change in his perception. In the first interview, he describes rejection by his peers as a result of his skin rash and it is possible that his rash had cleared up and led to his more positive outlook. There is no evidence to support this however. Some of the examples he provided in the first interview were also based on his experience while living with his aunt, before he had moved to the orphanage he now lived at.

The types of stigmatization described in the second interview were all mentioned at baseline. The most prominent form of discrimination described was still being talked



about and people not sharing, including utensils, cups, clothes, beds and bathroom. Adolescents attending school experienced discrimination from other children who did not want to share desks with them or play with them.

Only one adolescent described verbal abuse based on her HIV status:

*Even my brother's girlfriend abuse me that very soon I will die because I have AIDS. This treatment has changed in the last two months. She said "look at her, she is suffering from silimu", "for us, we are ok. One day you will be dead and buried".*

Two adolescents mentioned the importance of visible symptoms in the treatment received from others. One adolescent was still experiencing problems with a skin rash and felt others at school were avoiding him because of this. The other adolescent was not experiencing any problems with his own appearance but described how skin rash and a "red mouth" can cause "people fear to touch them or share things with them".

### **Impact**

Seven adolescents declined to respond when asked how they felt about being HIV positive or about other's attitudes towards HIV/AIDS. Fourteen adolescents reported no negative feelings related to their HIV status, six of them having also reported no negative emotions at baseline. Four had not responded at baseline and four reported improved mood from baseline.

The majority of participants did not elaborate but some offered explanations. One adolescent explicitly mentioned the medication he was receiving, one was feeling fine as long as he could continue doing his school work and playing and others felt they were no different from healthy adolescents, that there was "nothing wrong" with them. The realization that many other Ugandans are HIV positive comforted one adolescent as he explains:

*I do not feel bad. Many people are sick. A percentage of Ugandans are sick. So I do not feel bad. Because I am not the only one with it*

Another girl did not feel bad for herself, but found people's attitudes towards others with HIV sad sometimes. When asked how she felt when people talked about HIV positive people, she replied:

*When they ignore them I feel bad. For instance there was a film on WBS where a girl in a boarding school was not involved in other activities. That is not good.*

Twelve adolescents reported negative feelings such as guilt, sadness, anger, anxiety, shame and feeling different from others. All these emotions were also reported at baseline. Half of the adolescents reporting negative feelings also did so at baseline. At baseline, three adolescents had reported feeling distressed immediately upon disclosure but having improved since then. At the second interview, this improvement had disappeared.

Only one adolescent offered an explanation for her negative mood, stating that she did not "feel good, because I have nothing to do". This links to one of the reasons offered for positive mood, as involvement in activities such as school and work can give adolescents a sense of purpose while other activities distract them.

None of the adolescents had told anyone about their status in the time between the interviews.

### ***Reported change in stigma***

Some respondents commented on changes in stigma perceptions. Responses reflected both changes attributed to treatment and perceived change in the general population.

Adolescents describing changes in stigma in the general population attributed the change to increased knowledge and understanding of the disease. Their responses did not reflect changes in their own perceptions of stigma as much as they were describing changes they had witnessed in other people's feelings about HIV:

*In some cases (they are treated differently)... for example in villages in the past they were discriminated. They wouldn't allow them to touch things. Now I think they are well versed with the knowledge and they no longer neglect them.*

*Ok, for me I think that HIV is like any other disease like malaria. OK, they take it simple<sup>6</sup>. They treat them well as compared to those days.*

On a personal level, adolescents reported being allowed to return to school and receiving better treatment. Change in appearance, such as skin rashes clearing up, was seen as the catalyst in some cases:

*From how I appear. There is a change as compared to the last time that I was here. Even my step mum treats me well.*

Even in baseline interviews, generally conducted during the first month of antiretroviral treatment, six adolescents mentioned feeling better as a result of receiving care and treatment at the clinic. Their comments do not only reflect the impact of treatment with ARVs, however but with the overall care received at the clinic:

*I rarely think bad about my illness because I know am being managed and cared for. I do not always think about it, because I know I am still alive.*

---

<sup>6</sup> 'Simple' in this context means to take it in stride, indicative of acceptance.

Other adolescents attributed the improvement directly to the antiretroviral therapy. As one adolescent explained: "I was so sad and afraid [even] 2 months ago, but after starting ARVs, I feel better"

## Discussion

This section of the research was qualitative and aimed to understand the lives of perinatally infected HIV positive adolescents and the context it provides to treatment experience. Overall, adolescents reported improved health and adaptive coping behaviour. The level of stigma and discrimination personally experienced also appeared low.

The subjective nature of emotional health as well as its susceptibility to external influences was clear in adolescents' comparison of their emotional health at the conclusion of the study to baseline. All adolescents judged their physical health as improved but showed much more variability regarding their emotional health. Life events, such as the loss of a parent, were mentioned as factors influencing emotional health. The majority of adolescents reported adaptive coping measures in some situations. This corroborates the high level of functioning reported on the SAS-M, indicating that adolescents in this sample may be functioning well in their social environments.

Nine adolescents reported personal stigma experiences with slightly more than half feeling HIV positive people in general were stigmatized. In a study of HIV infected and affected children in Kampala, Gillborn and colleagues (2001) had found the level of discrimination reported by the children to be low: 6.2% for children of HIV positive parents and 7.7% for orphans, which seem to support the findings from our study.

While only a small number reported personal stigmatization, the majority of participating adolescents could provide examples of differential treatment at the hand of relatives or peers. Almost half of the adolescents reported no personal experience with

stigma, but even they still feared possible stigmatization and did not disclose their HIV status to many people. This corresponds with findings from the UNAIDS report on HIV/AIDS stigma in Uganda (2001) which found that people were still experiencing stigma and discrimination at family and community level, even though overt stigma was declining.

The main forms of enacted stigma described in this study centred on social isolation (rejection, abandonment) and verbal taunts or gossip. Adolescents feared becoming the topic of discussion and ridicule most. This fear of stigmatization was also a powerful motivator for non-disclosure and the number of adolescents who had disclosed to someone other than their caretaker was low. These findings correspond with previous research from Uganda and South Africa that found social ostracization and verbal abuse to be the main forms of discrimination (Musisi and Kinyanda, 2003; Gilborn et al., 2001, Save the Children, 2001) and low levels among HIV positive adolescents, stemming largely from fear (Strydom and Raath, 2004).

Visibility proved to be an important factor in the adolescents' experiences. The reduction of visible symptoms contributed to adolescents' feelings of physical well-being. In Musisi and Kinyanda's study at Mildmay (2003) visible, obvious symptoms were also significantly associated with poorer psychological health. This suggests that visible symptoms are an important source of concern for adolescents. It also seemed to be an important factor in HIV positive adolescents experience with stigma and discrimination, as visible signs of illness could disclose their status to others and trigger abusive behaviour. As treatment with ARVs clear up skin rashes, diminish oral thrush and reduce other symptoms it may be an important tool in improving quality of life both through well-being and through reducing the discrimination experienced.

The specific role of ARVs in health improvements and stigma reduction was mentioned by some adolescents. The overall effect of the medication was less clear,

however. Some adolescents seemed disappointed with the effect of treatment on their physical health, having expected greater improvement. They were also still reminded of the fatality of HIV while taking ARVs. This could have important implications for adherence as adolescents may be less motivated to adhere to therapy if they do not see improvements in their health or in the way society responds to them.

Adolescents' responses also illustrated the range of problems and difficulties the adolescents experienced. Asked about their emotional health and coping strategies, adolescents mentioned problems and situations not all directly related to their HIV status. Similarly, the stigma experienced different although there was overlap between these. In this sample, HIV/AIDS stigma was based primarily on a fear of being infected but there is also a fear of dying expressed in verbal taunts about 'dying young'. These are not mutually exclusive and interact to create the adolescents' experiences. Another element of their experience comes from the overlap of HIV/AIDS stigma with the stigma associated with being an orphan. The stigma associated with HIV/AIDS exacerbates the disadvantaged position of orphans who are already experiencing stigma. In many of the adolescents' responses the stigma described was that associated with orphanhood and not HIV. The stigma associated with being an orphan exacerbates the HIV stigma experience. The influence of orphanhood and relationships with extended family on emotional well-being was also evident in the statements of the adolescents who reported deterioration in emotional health from baseline. Both double orphans, they experienced increased emotional distress due to the rejection from family members.

Stigma was a difficult concept for adolescents to define even if they were or had experienced stigma. The number of adolescents who did know the meaning also declined to the second interview suggesting retention was not good either. The discrepancy between defining stigma and describing enacted stigma (discriminatory actions) could be a result of the word used to translate stigma as it might have had a

different connotation for the children. It is possible that stigma as a term is too abstract for adolescents to articulate or remember but it may also be difficult for adolescents to treat stigma as an abstract concept when it is part of their experience of daily living and therefore they can describe the enacted stigma more accurately. This needs to be taken into consideration in future stigma research with this population.

## **Conclusion**

Although their health and the treatment of their illness is of central concern to HIV positive adolescents, this is not the only influence on their sense of physical and emotional well-being, functioning and stigma experience. These factors may be linked to HIV/AIDS (such as parental death and financial insecurity) but in the experience of the adolescents they have to be dealt with independently and with different strategies. Another issue adolescents felt was of central importance in their own experience of their illness, as well as others response to them and HIV, was the visibility of symptoms. Conditions causing the most visible symptoms may not always be life threatening and accorded lower priority by medical staff. The results reported here, however, suggests that treating these conditions would contribute greatly to quality of life while reducing adolescents' discrimination.

Despite the low level of personal stigmatization reported, results indicate that stigma is of major concern to adolescents, inhibiting disclosure and affecting relationships and therefore still warrants attention.

## Chapter 6: Conclusions

### Discussion

The objectives of this study were three fold. Firstly, to establish baseline levels of psychological distress and follow up on any changes during adolescents' first months on antiretroviral therapy. Secondly, to measure social functioning levels at baseline and document any changes, and lastly to explore the nature and level of experienced stigma and any changes that may have occurred. To this extent, the third chapter created a baseline profile of the sample, chapter four outlined changes occurring during the research period and chapter five presented an overview of stigma as experienced by the adolescents. This chapter will provide a brief overview of the findings and discuss them in terms of the stated objectives. Subsequent sections will discuss the limitations of the study and discuss the implications for future research and interventions.

The baseline profile revealed an almost equal number of males and females, more than half of whom were between the ages of 13 and 15. The majority of adolescents had experienced the loss of a parent and more than a third were double orphans. This is consistent with HIV/AIDS in a population believed to be perinatally infected. Adolescents also seem to think this, with only two not naming their mother as the source of infection. The sample was different from that in the Musisi and Kinyanda study (2003) – the only other study to explore similar objectives with HIV positive adolescents in Uganda. Their study was not receiving ARV treatment, however and the study was a crossection, not longitudinal.

The number of double orphans attending the PIDC (compared to Musisi and Kinyanda's sample) was lower and as a result, fewer adolescents were living with extended family members. School attendance was lower in the PIDC sample. This can partly be explained by the older mean age of our sample. Older adolescents are more



likely to be of high school age and not benefiting from Universal Primary Education. The Mildmay sample was younger, and 75% of the sample was in primary school.

The Strength and Difficulties Questionnaire (SDQ) and the Children's Depression Inventory (CDI) provided the psychological well-being data. Both instruments provide global scores: the SDQ a total difficulties scores and a total depression score from the CDI. The subscales constituting the questionnaires assess individual dimensions of psychological distress and can be analysed individually. On the SDQ, a separate subscale measures prosocial behaviour as an indicator of adolescents' resilience or 'strength'. The SDQ also has an optional Impact scale that was included for adolescents' to rate the effect of their difficulties on their lives.

The baseline level of psychological distress was lower than expected, based on Musisi and Kinyanda's research as well as the literature regarding chronically ill children. Reported depression rates (moderate depression) was however higher than that reported for a general school-based population (Nalugya, 2004). Peer problems were the only elevated difficulties. Mean scores for all the other subscales and total difficulties were in the normal range. Gender did not account for any significant difference, but female participants generally scored higher on scales related to emotions and mood. The variables accounting for the most differences were age and school attendance. In this sample, the overlap between these variables is significant. Older adolescents reported the worst psychological distress, but were also least likely to be attending school. School attendance also overlaps with parental loss as 58% of the adolescents not attending school were orphans.

Psychological quality of life improved during the first year on antiretroviral therapy. This is the only study of its kind with adolescents. A longitudinal study following improvement in quality of life in HIV positive adults in South Africa reported similar gains in quality of life (Jelsma et al., 2005). The most significant improvement occurred during

the first three months on therapy. Quality of life remained at this level during the first nine months before improving again to 12 months. Psychological distress overall improved but there were significant differences across groups that needs to be taken into consideration when planning interventions, especially regarding depression. The highest number of demographic variables (age, school attendance and parental loss) influenced depression scores yet depression scores were more resistant to overall change during the study than SDQ total difficulties. This suggests that many different aspects of the adolescent's life influences depression scores and changes in one area, such as physical health, will not necessarily lead to overall improvement. Any attempt to alleviate symptoms of depression should take this into account as an intervention focused on only one aspect of their lives may not have the intended effect. Age and school again accounted for the most significant differences in means and response. School attendance, age and parental loss, as well as the interaction between them need to be taken into account in planning interventions.

The level of social functioning reported at baseline was generally above average and adolescents reported problems only in the areas of housework and extended family relationships. The adaptive coping strategies reported is further evidence of the relatively high level of functioning. As with the psychological well-being scores, age and school attendance were responsible for most of the variability in functioning. Older adolescents reported the worst functioning, especially regarding relationships with family. School attendance was associated with improved family relationships. Although it also seems to illustrate the overlap between age and school is also evident here, it is also possible that better family relationships predict school attendance

Social functioning did not improve during the study period. Baseline rates were high however and a ceiling effect would make the maintenance of baseline functioning an acceptable treatment outcome. The reason for the higher level of social functioning

may lay in the criteria used to determine eligibility for antiretroviral treatment at the PIDC and by extension eligibility for this study. Adolescents have to prove that they have a stable source of social support to be considered for treatment. They also needed a parent or guardian to come to the clinic to sign consent papers. This meant that the majority of participants had at least one person in their life that cared enough to participate in their treatment. Participating adolescents reported seeking support from their parent/guardian as their main coping mechanism, further indicating that these adolescents had a high level of social support in their lives. This characteristic could contribute to the high levels of functioning and overall quality of life. Another possible reason for the high quality of life found even at baseline could be adolescents' attendance at the clinic. Receiving support and care may already have improved adolescents' quality of life.

The portion of the research focusing on stigma was qualitative and aimed at understanding the nature and level of stigma experienced by the adolescents in their own words. Personal stigmatization (feeling that you are stigmatized) was low, but slightly more than half of the participants felt HIV positive people in general were stigmatized. The low levels of personal stigmatization corresponds with a study of the stigma experience of HIV infected and affected children in Kampala (Gillborn and colleagues, 2001). The fear of stigma is still prevalent, even for adolescents who did not feel HIV positive people were stigmatized or who did not feel they personally had experienced stigma. Fear of possible stigmatization was the main reason for not disclosing their status and few adolescents had disclosed to someone other than their caretaker. None of the adolescents disclosed to anyone during the study period. The form of stigmatization adolescents reported occurring and fearing most, was becoming the topic of discussion and ridicule. They also feared being rejected by peers and family. This remained the same at the second interview.

Visibility of symptoms was mentioned often in relation to stigma in both the baseline and second interview. Adolescents made mention of being 'ugly' because of their symptoms. Visible symptoms also made it hard for them to hide their HIV status, especially if the symptoms have become associated with HIV/AIDS. Facial skin rashes, cause by the Human papillomavirus and 'red mouths' caused by Candida were the two symptoms most frequently mentioned. These can not be covered up, but their importance is also increased by the significance of appearance to adolescents, and what they value most in terms of appearance. Musisi and Kinyanda (2003) reported on the importance of visible symptoms in psychological well-being in their study. As treatment with ARVs improves physical health, visible signs of the illness will diminish and it is possible stigmatization will decrease. This study can not provide prove of this however, and it is an important question for future research.

In the second interviews, some changes in stigma perception were reported. These changes were ascribed either to treatment or to a decrease in stigmatizing beliefs and actions in the general population. For many of the participants, however, the stigma associated with HIV/AIDS interacts with the stigma experienced because they lost a parent. The stigma associated with HIV/AIDS further disadvantages the position of orphans. Attempts to alleviate stigma by focusing on HIV stigma alone would not improve the overall stigma experienced by the adolescents although changing social attitudes towards HIV was seen as helpful by some participants.

Peer support group attendance did not have an affect on overall quality of life but it was associated with decreased peer problems and increased prosocial behaviour. These interpersonal skills are important life skills and may in the end better equip adolescents for their interactions with others.

## Limitations

There are a number of limitations to this study and results should be interpreted with caution. The sample size was small: 52 adolescents were recruited at baseline and three passed away. The small size reduces the reliability of the findings and limits generalizability. This was an exploratory study of a relatively unknown field and the aim of this research was not to conclusively prove a hypothesis, but rather to understand these adolescents' situation and experience with treatment.

The structure and organisation of the clinic lead to logistic problems and there were missed data collection opportunities, as some adolescents would not attend their follow up appointments on specified days. These difficulties highlight the problems of doing research in situations where you are not in control of the context or the priorities of others. In this instance, research had to contend with the reality of the clinical staff, the needs of adolescents themselves and the need to procure funding from external sources. One of the consequences of this for the prospective adolescent study was high sample attrition. In this portion of the research, only 77% of adolescents followed to nine months and 70% to 12 months. In response to this, paired sample tests were used; ensuring only participants with data at both time points were included in analysis. Any adolescent missing more than two consecutive time points would also be excluded from research, but no one did. Analysis revealed no significant differences between adolescents not followed to nine or 12 months and those completing the study.

The population of HIV positive adolescents attending the PIDC are unique in many aspects and this affects the generalizability of findings to other populations. This is a hospital-based population at a teaching and referral hospital in an urban area. To be eligible for antiretroviral therapy adolescents had to live within 50 km of the clinic and most were urban adolescents. These adolescents had come to the PIDC to seek care

even though their attendance could lead to increased stigmatization. Attending an HIV clinic as a regular patient may make this population different from others who would rather receive more anonymous treatment.

The presence of social support is another clinic requirement for the initiation of antiretroviral therapy that biased the sample. The importance of social support in the lives of HIV positive adults and adolescents was discussed earlier and these adolescents already had social support systems which many other HIV positive individuals do not have.

The questionnaires contained only one self-report question regarding physical health. The focus of the study was primarily on the psychological and social quality of life, and physiological improvement was measured in the prospective adolescent study. This does make it impossible to determine whether changes in quality of life correspond to physical symptoms and improvements.

Another factor confounding the results of this study is the inability to separate the effects of treatment, HIV seropositive status and adolescence on the changes in psychological well-being in final analysis. The absence of a control group limits the extent to which such conclusion can be drawn. The actual level of quality of life compared to healthy peers could also not be established. The intention of the research was, however, exploratory and more focused on the overall experience of adolescents.

The instruments chosen for this study had all been used in Uganda in the recent past. None had accepted local scientific validity, however. The SDQ and the CDI are both well-known, internationally validated instruments but the data from these scales were primarily used as continuous variables to avoid using norms. The social adjustment scale is a lesser-known scale but had been used by Musisi and Kinyanda (2003) in research similar to this with an HIV positive adolescents population (2003) and in a comparison of orphans and non-orphans (2004).

All the data was gathered through the use of self-report questionnaires. This raises questions about the validity of the data.

### **Future directions**

Adolescents living with HIV are living longer and improving their quality of life is becoming more important. The findings from this research are very encouraging to this end. The results of this research also raise many questions that could facilitate future research and highlights a number of aspects that need to be taken into account in planning interventions.

The greatest improvement in quality of life occurs within the first three months. This could be an important period for adherence counselling. Determining the causes of this improvement could also inform interventions. The gains also seem to remain sustained for at least a year but future research needs to probe whether the gains are permanent or decline.

Antiretroviral therapy alone was not enough to alleviate the problems experienced with depression. Any future interventions aimed at improving the mental health of HIV positive adolescents should be aware of the multitude of factors influencing depression. Special attention should be paid to gender, and counselling may need to be adapted to consider the gender differences.

Age had a significant impact on quality of life and reported improvements. The difference between adolescents younger than 12 and those older than 12 were especially pronounced. This finding has implications for the definition of adolescents adopted in future interventions. It may mean that 10-12 years will not respond to the same interventions as older adolescents and will have to be addressed on their own.

This study provided only an overview of the stigma experienced in this population and further assessment is necessary. Quantitative measure that may be more suitable are now available, such as the AIDS-related stigma scale developed in South Africa (Kalichman et al., 2005) or the adolescent version of Berger's stigma Scale (Wright et al., 2007). The importance of the visibility of symptoms cannot be denied. Many times, the visible symptoms are not life threatening and not of primary concern to physicians. It does, however, seem to have a significant impact on adolescents experience with their environment and themselves. Stigma experience during treatment should be measured with a standardized measure that can determine whether any changes occur in experience as a result of treatment.

HIV does not occur in a social vacuum, as is evident by the stigma associated with it. There is overlap and interaction with other social factors. One of the most consistent findings of this study was the interaction between age, school attendance and to a lesser extent parental loss in this sample. Interventions aimed at improving the overall health of adolescents living with HIV cannot only focus on medical treatment. They have to take into account the effect of external variables such as parental loss in creating the adolescents' environment. The interaction between the variables is also important as it would likely not be possible to change one without affecting change in the other. To be successful, interventions have to be context-specific and take these factors into account.



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**Appendix A1: Baseline Demographic Questionnaire in English****Date:** \_\_\_\_\_**Study Number:** \_\_\_\_\_

1. Age at last Birthday \_\_\_\_\_

2. Sex

1 = male

2 = female

3. Current district of residence \_\_\_\_\_

4. Any of parents deceased?

1 = Yes

2 = No

If yes,

4.1. Which parent? \_\_\_\_\_

4.2. How old were you when your parent(s) died \_\_\_\_\_

5. Who do you live with? \_\_\_\_\_

6. What is the nature of your family?

1 = Single parent

2 = Polygamous

3 = Monogamous

7. Who heads your family?

1 = Father

2 = Mother

3 = Child

4 = Other, please specify \_\_\_\_\_

8. How many other children are there in the family you live with? \_\_\_\_\_

9. How many are siblings? \_\_\_\_\_

10. How many siblings do you have in total? \_\_\_\_\_

11. What is your birth order? \_\_\_\_\_

12. Do you attend school? \_\_\_\_\_

If yes,

12.1. What class are you in? \_\_\_\_\_

13. Who pays your school fees?

1 = Parent

2 = Relative. If yes, who \_\_\_\_\_

3 = Guardian

4 = NGO

5 = Government

6 = Self

7 = Other \_\_\_\_\_

14. In general, how would you describe your own physical health?

1 = Very Good

2 = Good, but not perfect

3 = Somewhat poor

4 = Very poor

5 = Other \_\_\_\_\_

**Appendix A2: Baseline Demographic Questionnaire in Luganda**

Date: \_\_\_\_\_

Study Number: \_\_\_\_\_

1. Emyaka ku lunaku lw'okuzaalibwa kwo olwasemba yo \_\_\_\_\_

2. Enkula

1 = mulenzi

2 = muwala

3. District kati gy'osulamu \_\_\_\_\_

4. Omu ku bazadde eyafa?

1 = Yye

2 = Nedda

Oba Yye,

4.1. Muzadde ki? \_\_\_\_\_

4.2 Walina emyaka emeka mukadde wo/bakadde bo we yafiira/baafiira \_\_\_\_\_

5. Obeera naani? \_\_\_\_\_

6. Amaka gammwe ga kika ki?

1 = Mulimu omuzadde omu

2 = Taata wa bakyala bangi

3 = Taata wa mukyala omu

7. Ani akulira amaka gammwe?

1 = Taata

2 = Maama

3 = Mwana

4 = Muntu mulala, Wattu mutubuulire \_\_\_\_\_

8. Abaana abalala bameka ababeera mu maka gy'osula? \_\_\_\_\_

9. Bameka baganda bo? \_\_\_\_\_

10. Okugatta awamu olina baganda bo bameka? \_\_\_\_\_

11. Oli wakumeka mu kuddinjanako? \_\_\_\_\_

12. Osoma?

Oba yye

12.1 Oli mu kibiina kya kumeka? \_\_\_\_\_

13. Ani akusasulira ebisale by'essomero?

1 = Muzadde

2 = Waluuganda. Oba yye, ani? \_\_\_\_\_

3 = Mukuza

4 = Ekibiina kya bannakyewa

5 = Gavumenti

6 = Nneeweerera nzekka

7 = Gwe soogedde ko

14. Mu kutwaliira awamu muli wewulira otya mu bulamu bwo?

1 = Bulungi nnyo

2 = Bulungi, naye si nnyo \_\_\_\_\_

3 = Bubiibibi

4 = Buubi nnyo

5 = Kye soogedde ko \_\_\_\_\_

**Appendix B1: Follow Up Demographic Questionnaire in English**

Date: \_\_\_\_\_

Study Number: \_\_\_\_\_

1. Have you moved in the past 3 months?

☐ Yes ☐ No

If yes:

Why? \_\_\_\_\_

Who do you live with now? \_\_\_\_\_

1.4 What is the nature of this family?

1 = Single parent

2 = Polygamous

3 = Monogamous

1.5 Who heads this family you live in now?

1 = Father

2 = Mother

3 = Child

4 = Other, please specify \_\_\_\_\_

1.6 How many other children are there in the family you live with now? \_\_\_\_\_

1.7 How many are siblings? \_\_\_\_\_

2. In general, how would you describe your own physical health?

1 = Very Good

2 = Good, but not perfect

3 = Somewhat poor

4 = Very poor

5 = Other \_\_\_\_\_

3. Have you attended a Peer Support Groups Meeting in the past 3 months?

☐ Yes ☐ No

4. Have you had sex in the past 3 months?

☐ Yes ☐ No



**Appendix B2: Follow Up Demographic Questionnaire in Luganda**

Date: \_\_\_\_\_

Study Number: \_\_\_\_\_

1. Emyeezi essatu egiwedde, wali osenguseeko okuva w'ewali osula?

☐ Yee      ☐ Nedda

Oba yee:

Lwaki? \_\_\_\_\_

Obeera naani kati? \_\_\_\_\_

1.4 Amaka gano g'akikaki?

1 = Mulimu omuzadde omu

2 = Taata wa bakyala bangi

3 = Taata wa mukyala omu

1.5 Ani akulira woobera kati?

1 = Taata

2 = Maama

3 = Mwana

4 = Muntu malala, wattu mutubuulire \_\_\_\_\_

1.6 Abaana abalala bameka abali mu maka woobera kati? \_\_\_\_\_

1.7 Kubano olinako baganda bo bameka? \_\_\_\_\_

2. Mu kwatiliira awamu muli wewulira otya mu bulamu bwo?

1 = Bulungi nnyo

2 = Bulungi, naye si nnyo

3 = Bubiibibi

4 = Buubi nnyo

5 = Other \_\_\_\_\_

3. Mu myezi essatu weetabye mu nkunnana z'abavubka wano?

☐ Yee      ☐ Nedda

4. Mu myezi essatu egiwedde weegasse n'omusajja oba omukazi yenna mu mukwano?

☐ Yee      ☐ Nedda

## Appendix C1: Strength and Difficulties Questionnaire in English

### Strength and Difficulties Questionnaire

For each item, please mark the box for Not True, Somewhat true or Certainly True. It would help us if you answer all items as best you can if you are not absolutely certain or the item seems daft. Please give your answers on the basis of how things have been for you over the last month.

	Not True	Somewhat True	Certainly True
I try to be nice to other people. I care about their feelings.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am restless, I cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get a lot of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually share with other (food, games, pens etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get very angry and often lose my temper	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am usually on my own. I generally play alone or keep to myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually do as I am told	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry a lot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have one good friend or more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I fight a lot. I can make people do what I want	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other people my age generally like me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am easily distracted, I find it difficult to concentrate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am nervous in new situations. I easily lose confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often accused of lying or cheating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other children or young people pick on me or bully me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I often volunteer to help others (parents, teachers, children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think before I do things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take things that are not mine from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get on better with adults than with people my own age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have many fears, I am easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I finish the work I'm doing. My attention is good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any other questions or comments?

Since coming to the clinic, are your problems:

Much Worse	A bit worse	About the same	A bit better	Much Better
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Has coming to the clinic been helpful in other ways, e.g. providing information or making the problems more bearable?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Over the last month, have you had difficulties in one or more of the following areas: emotions, concentration, behavior or being able to get on with other people?

No	Yes – minor difficulties	Yes – definite difficulties	Yes – severe difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you answered "Yes", please answer the following questions about these difficulties:

- Do the difficulties upset or distress you?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- Do the difficulties interfere with your daily life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
FRIENDSHIPS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CLASSROOM LEARNING	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LEISURE ACTIVITIES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- Do your difficulties make it harder for those around you (family, friends, teachers, etc.)?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Thank you very much for your help**

## Appendix C2: Strength and Difficulties Questionnaire in Luganda

### Ebibuuzo ebikwata ku maanyi n'obuzibu

Ku buli kibuzo, teeka akabonero mu kasanduuko akalaga **Si kituufu, Kumpi kituufu, Kituufu ddala**. Kya ndi tuyambye ssinga oddamu ebibuuzo byonna mu ngeri ekusingira okuba ennungi yadde nga kyozeemu tokikakasa kuba nti kye kkyo oba nti ekibuuzo kirabika nga eky'obusiru! Wattu bw'oba oddamu wesigamye by'oddamu ku bikubaddeko mu mwezi oguwedde.

	Si kituufu	Kumpi kituufu	Kituufu ddala
Ngezaako okuba omulungi eri abalala. Nfa ku ngeri gye bawulira	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ssitereera, ssiyinda kutuula wamu kumala bbanga ggwanvu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nnumwa emirundi mingi omutwe, olubuto oba okutanaka	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ennaku ezisinga nkolagana n'abalala (emmere, emizannyo, obufumu etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nnyiiga nnyo, ennaku ezisinga nva mumbeera	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ennaku ezisinga mbeera nzekka. Nzannya nzekka oba nneebeerera nzekka	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ntera okukola nga bwe ndagiddwa	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nneraliikirira nnyo	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nnyamba omuntu bwaba alumizibwa, anyiziddwa oba alwadde	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Buli kaseera mbeera nnetakulatakula oba nkata kino nkata kiri.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nnina owomukwano ow'essimbo omu oba okusingawo	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nnwana nnyo. Nsobola okukozesa abalala kye njagala	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ebiseera ebisinga siba musanyufu, siteredde mu birowoozo oba nkulukusa amaziga	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bannange bwe twenkanya emyaka okutwalira awamu banjagala	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ntwalirizibwa mangu, nkisanga nga kizibu okussaayo omwoyo	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ntya buli lwe mbeera mu kintu kye simanyidde. Nneenyooma mangu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mba wa kisa eri abaana abato	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Batera nnyo okunyangamba nti nnimba nti oba nziba	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Abaana abalala oba abansinga obuto bansuunasuuna oba bambonyaabonya	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ebiseera ebisinga nneetuma okuyamba abalala (abazadde, abasomesa, abaana)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nsooka kulowooza nga ssi nnakola kintu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ntwala ebitori byange okuva eka, ku ssomero oba awalala wonna	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nkolagana bulungi n'abantu abakulu okusinga ne betwenkanya emyaka	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nnina okutya kungi, ntiisibwatisibwa mangu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mmaliriza kye mba nkola. Nzisaayo nnyo omwoyo.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Olinayo ekirala ky'oyagala okutubuulira oba ky'otonnyonyose?

Kasookanga ojja mu kirinika ebizibu byo:

Byeyongedde nnyo	Byeyongedde mu katono	Tebikyuseeko	Birongoose mu katono	Birongoose nnyo
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Waliwo okujja kwo mu kirinika gye kuyambye mu ngeri endala yonna, okugeza, okukuwa amawulire oba okuweweeza ku bizibu byo?

Tekinnyambye n'akamu	Kinnyambye katono	Kinnyambye nnyo	Kinnyambye nnyo nnyo.
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Mu mwezi gwe tukubye amabega, ofunye mu obuzibu mu kimu oba mu bimu ku bino wammanga: embeera zo, okussaayo omwoyo, enneyisaayo, oba okukolagana obulungi n'abantu abalala?

Nedda	Yye – obuzibu obutonotono	Yye – ebizibu byennyini	Yye – ebizibu eby'amaanyi ddala
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Bw'oba ozzeemu "yye", wattu yanukula ebibuuzo bino ku bizibu bino:

- Ebizibu bikunyiiza oba bikubuzaako emirembe?

Nedda nakatono	Katonotono	Nnyo Ddala	Nnyo nnyo ddala
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- Ebizibu bino biyingirira obulamu obwa bulijjo mu bino?

	Nedda nakatono	Katonotono	Nnyo Ddala	Nnyo nnyo ddala
OBULAMU MU MAK	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
EMIKWANO	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
OKUSOMA MU KIIBINA	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
BISEERA	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
EBY'EDDEMBE				

- Ebizibu byo bizibuwalizisa abantu booba nabo (aboomu maka, ab'emikwano, abasomesa etc)?

Nedda nakatono	Katonotono	Nnyo Ddala	Nnyo nnyo ddala
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Webale nnyo olw'obuyambi bwo**

## Appendix D1: Children's Depression Inventory in English

Maria Kovacs, Ph.D

Kids sometimes have different feelings and ideas.

This form lists the feeling and ideas in groups. From each group of three sentences, pick one sentence that describes you best for the past two weeks. After you pick a sentence from the first group, go on to the next group.

There is no right answer or wrong answer. Just pick the sentence that best describes the way you have been recently. Put a mark like this ✕ next to your answer. Put the mark in the box next to it.

Here is an example of how this works. Try it. Put a mark next to the sentence that describes you best.

Example

- ☐ I read books al the time
- ☐ I read books once in a while
- ☐ I never read books

When you are told to do so, turn over this top page, pick the sentences that describe you best on the first page. After you finish the first page, turn ro the next page. Then, answer the questions on that page.

**Remember: pick out the sentences that describe you best in the PAST TWO WEEKS**

## Item 1

- ☐ I am sad once in a while
- ☐ I am sad many times
- ☐ I am sad all the time

## Item 8

- ☐ All bad things are my fault
- ☐ Many bad things are my fault
- ☐ Bad things are not usually my fault

## Item 2

- ☐ Nothing will ever work out for me
- ☐ I am not sure if things will work out for me
- ☐ Things will work out for me O.K.

## Item 9

- ☐ I do not think about killing myself
- ☐ I think about killing myself but I would not do it
- ☐ I want to kill myself

## Item 3

- ☐ I do most things OK
- ☐ I do many things wrong
- ☐ I do everything wrong

## Item 10

- ☐ I feel like crying every day
- ☐ I feel like crying many days
- ☐ I feel like crying once in a while

## Item 4

- ☐ I have fun in many things
- ☐ I have fun in some things
- ☐ Nothing is fun at all

## Item 11

- ☐ Things bother me all the time
- ☐ Things bother me many times
- ☐ Things bother me once in a while

## Item 5

- ☐ I am bad all the time
- ☐ I am bad many times
- ☐ I am bad once in a while

## Item 12

- ☐ I like being with people
- ☐ I do not like being with people many times
- ☐ I do not want to be with people at all.

## Item 6

- ☐ I think about bad things happening to me once in a while
- ☐ I worry that bad things will happen to me
- ☐ I am sure that terrible things will happen to me

## Item 13

- ☐ I can not make up my mind about things
- ☐ It is hard to make up my mind about things
- ☐ I make up my mind about things easily

## Item 7

- ☐ I hate myself
- ☐ I do not like myself
- ☐ I like myself

## Item 14

- ☐ I look O.K.
- ☐ There are some bad things about my looks
- ☐ I look ugly

**Remember, describe how you have been in the past two weeks.....**

**Item 15**

- ☐ I have to push myself all the time to do my school work
- ☐ I have to push myself many times to do my school work
- ☐ Doing school work is not a big problem

**Item 16**

- ☐ I have trouble sleeping every night
- ☐ I have trouble sleeping many nights
- ☐ I sleep pretty well

**Item 17**

- ☐ I am tired once a while
- ☐ I am tired many days
- ☐ I am tired all the time

**Item 18**

- ☐ Most days I do not feel like eating
- ☐ Many days I do not feel like eating
- ☐ I eat pretty well.

**Item 19**

- ☐ I do not worry about aches and pains
- ☐ I worry about aches and pains many times
- ☐ I worry about aches and pains all the time

**Item 20**

- ☐ I do not feel alone
- ☐ I feel alone many times
- ☐ I feel alone all the time

**Item 21**

- ☐ I never have fun at school
- ☐ I have fun at school only once in a while
- ☐ I have fun at school many times

**Item 22**

- ☐ I have plenty of friends
- ☐ I have some friends but I wish I had more
- ☐ I don't have any friends

**Item 23**

- ☐ My schoolwork is alright
- ☐ My schoolwork is not as good as before
- ☐ I do very badly in subjects I used to be good in

**Item 24**

- ☐ I can never be as good as other kids
- ☐ I can be as good as other kids if I want
- ☐ I am just as good as other kids

**Item 25**

- ☐ Nobody really loves me
- ☐ I am not sure if any body loves me
- ☐ I am sure that somebody loves me

**Item 26**

- ☐ I usually do what I am told
- ☐ I do not do what I am told most times
- ☐ I never do what I am told

**Item 27**

- ☐ I get along with people
- ☐ I get into fights many times
- ☐ I get into fights all the time



## Appendix D2: Children's Depression Inventory in Luganda

Maria Kovacs Ph.D

Abaana oluusi bawulira mu ngeri ya njawulo era baba n'ebirowoozo bya njawulo.

Olupapula luno luwa empulira n'ebirowoozo mu kikuukuulu. Okuva mu buli kikuukuulu ekirimu emboozi essatu, londa emboozi emu ekunnyonnyola ko obulungi mu ssabbiiti ebbiri eziyise. Bw'omala okulonda emboozi okuva mu kikuukuulu ekisooka, genda ku kikuukuulu ekiddako.

Tewali kuddamu kutuufu oba kuddamu kukyamu. Londa bulonzi emboozi emboozi esinga okunnyonnyola gy'obaddemu mu biseera eby'akayita. Teeka akabonero nga kano ✕ okuliraana okuddamu kwo. Akabonero kasse mu kasanduuko akaliraanye

Kino kya kulabirako nga kino bwe kikola. Kigezeeko. Teeka akabonero okumpi n'emboozi ekunnyonnyolako obulungi mu ngeri esingayo obulungi.

Eky'okulabirako

- ☐ Nnetaaga ebitabo buli kaseera
- ☐ Nsoma ebitabo oluusinooluusi
- ☐ Ssisomerako ddala bitabo

Bw'onolagirwa, yuzaako olupapula luno olusooka, londa emboozi esinga okukunnyonnyola ku muko ogusooka. Bw'omala omuko ogusooka, bikkula. Olwo oyanukule ebiri ku muko gw'obikudde.

**Jjukira, londa emboozi esinga okukunnyonnyolako obulungi MU SABBIITI  
EBBIRI EZIYISE**

## Ekisooka

- ☐ Mbeera mwennyamivu oluusinooluusi
- ☐ Mbeera mwennyamivu emirundi mingi
- ☐ Mbeera mwennyamivu ekiseera kyonna

## Eky'omunaana

- ☐ Buli bibi biva ku nsobi yange
- ☐ Ebibi bingi biva ku nsobi yange
- ☐ Ebibi tebitera kuva ku nsobi yange

## Eky'oburi

- ☐ Buli kyenkola tekijja
- ☐ Sikakasa nti ebintu birinnamira
- ☐ Ebintu bijja ku nnamira

## Eky'omwenda

- ☐ Ssirowooza ku bya kwetta
- ☐ Ndownooza ku by'okwetta kyokka ssiyinza kukikola
- ☐ Njagala kwetta

## Eky'okusatu

- ☐ Ebintu ebisinga obungi mbikola bulungi
- ☐ Nkola ebintu bingi mu bukyamu
- ☐ Nkola ebintu ebisinga mubukyoomu

## Eky'ekkumi

- ☐ Mpulira nga ayagala okukaaba buli lunaku
- ☐ Mpulira nga ayagala okukaaba ennaku nnyingi.
- ☐ Mpulira nga ayagala okukaaba oluusinooluusi

## Eky'okuna

- ☐ Nsanyusibwa ebintu bingi
- ☐ Nsanyusibwa ebintu ebimu
- ☐ Tewali kinsanyusa yadde n'akamu

## Eky'ekkumi n'ekimu

- ☐ Ebintu bintawaanya buli kaseera.
- ☐ Ebintu bintawaanya emirundi mingi
- ☐ Ebintu bintawaanya oluusinooluusi.

## Eky'okutaano

- ☐ Ndi mubi ekiseera kyonna
- ☐ Ndi mubi emirundi egisinga obungi
- ☐ Mba mubi oluusinooluusi

## Eky'ekkumi n'ebibiri

- ☐ Njagala okubeera n'abantu
- ☐ Saagala kubeera na bantu emirundi mingi.
- ☐ Saagala kubeera na bantu n'akatono

## Eky'omukaaga

- ☐ Ndownooza ku bibi ebiyinza okuntuuka ko oluusinooluusi
- ☐ Nneraaliikirira nti ebintu ebibi bijja kumba
- ☐ Nkakasa nti ebintu ebibi bijja kuntuuka ko

## Eky'ekkumi n'ebisatu

- ☐ Sisobola kusalawo ku kintu.
- ☐ Kizibu okusalawo ku kintu.
- ☐ Nsalawo mangu ku buli kintu.

## Eky'omusanvu

- ☐ Nnekyawa
- ☐ Ssagala mubiri gwange
- ☐ Njagala omubiri gwange

## Eky'ekkumi n'ebina

- ☐ Ndabika bulungi.
- ☐ Waliwo ebintuntu ebirabika obubi ku mubiri gwange
- ☐ Ndabika bubi.

## Eky'ekkumi n'ebitaano

- ☐ Nnina kwewaliriza buli kaseera okukola ebintu byange ebyo ku ssomero.
- ☐ Nnina kwewaliriza emirundi mingi kukola ebintu byange ebyo ku ssomero.
- ☐ Okukola eby'essomero si kizibu kya maanyi

## Eky'ekkumi n'omukagga

- ☐ Buli kiro nzibuwaliirwa okwebaka
- ☐ Nzibuwaliirwa okwebaka ebiri bingi
- ☐ Nnebakira ddala bulungi

## Eky'ekkumi n'omusanvu

- ☐ Mba mukoowu oluusinooluusi.
- ☐ Mba mukoowu ennaku nnyingi
- ☐ Mba mukoowu ebbanga lyonna.

## Eky'ekkumi n'omunaana

- ☐ Ennaku ezisinga ssiwulira nga ayagala okulya.
- ☐ Ennaku nnyingi ssiwulira nga ayagala okulya.
- ☐ Ndyala bulungi ddala.

## Eky'ekkumi n'omwenda

- ☐ Sseraliikirira biruma na bulumi.
- ☐ Nneraliikirira ebiruma n'obulumi emirundi mingi.
- ☐ Nneraliikirira ebiruma n'obulumi essaawa zonna.

## Eky'amakumi abiri

- ☐ Sseewunika.
- ☐ Emirundi mingi mba nneewunise.
- ☐ Mba nneewunise buli banga.

## Eky'amukumi abiri mw'ekimu

- ☐ Ku ssomero ssifuna ssanyu
- ☐ Ku ssomero nfuna essanyu luusinaluusi
- ☐ Ku ssomero nfuna essanyu emirundi mingi.

## Eky'amakumi abiri mw'ebibiri

- ☐ Nnina emikwano mingi
- ☐ Nnina emikwano naye nandyagadde bangi okusingawo
- ☐ Ssirina mikwano mingi

## Eky'amakumi abiri mw'ebisatu

- ☐ Emisomo gyange mirungi.
- ☐ Emisomo gyange tegikyali mirungi nga bwe gyali nga edda.
- ☐ Amasomo ge nnakola nga obulungi kati ngakola bubi nnyo

## Eky'amakumi abiri mw'ebina

- ☐ Ssiyinda kutuuka bana balala mu kusoma
- ☐ Nnyinda okutuuka abaana abalala singa mba njagadde
- ☐ Ndi mugezi nga abaana abalala

## Eky'amakumi abiri mw'ebitaano

- ☐ Teri anjagala noomu
- ☐ Ssi kakasa nti waliwo anjagala.
- ☐ Nkakasa nga waliwo anjagala..

## Eky'amakumi abiri mwomukaaga

- ☐ Emirundi egisinga nkola ekiba kindagiddwa.
- ☐ Emirundi egisinga sikola kiba kindagiddwa
- ☐ Ssikola kiba kindagiddwa naakamu

## Eky'amakumi abiri mwomusanvu

- ☐ Nkolaagana n'abantu
- ☐ Nnwana emirundi mingi.
- ☐ Nnwana buli kaseera.

## Appendix E1: Modified self-report measure of Social Adjustment Scale in English

### The Modified self-report Measure of Social Adjustment Scale

We are interested in how you have been in the past two weeks. We would like you to answer some questions about your work, spare time activities and your family life.

All questions are scored on 5-point scale: all the time; most of the time; about half the time; occasionally; not at all.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All the time	Most of the time	About half the time	Occasionally	Not at all

#### **A. Work outside the home (including schoolwork)**

The following questions are about things that have been in your job (school) full time or half time. If you do not have a job or go to school, go straight to the next section.

Over the past two weeks, have you:	All the time	Most of the time	About half the time	Occasionally	Not at all
1. Missed any time from school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Been doing your school work well?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Felt ashamed of how you have been doing your school work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Got angry with or argued with other kids at school?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Felt upset, worried or uncomfortable at school?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Been finding your school interesting?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

#### **B. Housework/chores**

The following questions are about how the work at home has been

Over the past two weeks, have you:	All the time	Most of the time	About half the time	Occasionally	Not at all
7. Done the necessary housework/home chores every day?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Been doing the housework/home chores well?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Felt ashamed of how you have been doing the housework/home chores?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Got angry with or argued with other children or neighbours?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Felt upset, worried or uncomfortable while doing the housework/home chores?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Found the housework/home chores boring, unpleasant or a drudge?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**C. Social and Leisure activities**

The following questions are about your friends and what you have been doing in your spare time

Over the past two weeks, have you:	All the time	Most of the time	About half the time	Occasionally	Not at all
13. Been in touch with any of your friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Been able to talk about your feelings openly with your friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Done things socially with your friends (e.g. visiting, entertaining, playing together)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Spent your available time on hobbies or play time interests?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Got angry with or argued with your friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Been offended or had your feelings hurt by your friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Felt ill at ease, tense or shy when with other children?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Felt lonely and wished for companionship?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Felt bored in your free time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**D. Extended Family**

The following questions are about your extended family, i.e. your parents, brothers, sisters, uncles, aunts, cousins and children not living at home. Please do not include children living at home.

Over the past two weeks, have you:	All the time	Most of the time	About half the time	Occasionally	Not at all
22. Got angry with or argued with any of your relatives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Made an effort to keep in touch with your relatives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Been able to talk about your feelings openly with your relatives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Depended on your relatives for help, advice or friendship?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Worried more than necessary about things happening to your relatives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Been feeling that you have let your relatives down at any time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Been feeling that your relatives have let you down at any time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**E. Parents/Guardians**

The following questions are about how things have been between you and your parents/guardian. If you are NOT living with your parents or guardian go straight on to the next section.

Over the past two weeks, have you:	All the time	Most of the time	About half the time	Occasionally	Not at all
29. Got angry with each other or argued with your parents or guardian?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Been able to talk about your feelings and problems with your parents/guardian?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Been making most of the decisions at home yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Tended to give in to your parent/guardian and let him/her have his/her own way when there was a disagreement?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. And your parents/guardian shared the responsibility for practical matters that have arisen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Had to depend on your parents/guardian to help you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Been feeling affectionate towards your parents/guardian?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Have you had unpleasant/forced sexual relationships?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Had any problems during play (e.g. pains, injury)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Enjoyed your relations with your parents/guardians?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**F. Siblings**

The following questions are about how things have been between with your brothers and sisters. If you do not have an immediate family, please ignore this section.

Over the past two weeks, have you:	All the time	Most of the time	About half the time	Occasionally	Not at all
39. Been interested in your brothers and sisters activities, e.g. school, friends, etc?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Been able to talk to and listen to your brothers and sisters?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Been shouting at or arguing with your brothers and sisters?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Been feeling affectionate towards your brothers and sisters?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**G. Family Unit**

The following questions are about how things have been with your immediate family, that is your parents, brothers and sisters at home. If you do not have an immediate family, please ignore this section.

Over the past two weeks, have you:	All the time	Most of the time	About half the time	Occasionally	Not at all
43. Been worrying more than necessary about things happening to your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. Been feeling that you have let your immediate family down at any time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. Been feeling that your immediate family has let you down at any time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Please make any comments, remarks or concerns**

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**REFERENCE**

Musisi, S., Kinyanda, E. (2003). The psychological and social problems of HIV-seropositive adolescents and their parents/guardians as seen at Mildmay Center, Kampala, Uganda. Proceeds of the WPA Eastern Africa Regional Annual Psychiatric Conference, Dar Es Salaam, Tanzania. April 2003.

## Appendix E2: Modified self-report measure of Social Adjustment Scale in Luganda

Twagala kumanya nga bw'obadde mu ssabbiiti ebiri eziyise. Twandyetaaze oddemu ebimu ku bibuuzo ebikwata ku mulimu gwo, by'okola mu biseera byo eby'eddembe n'ebifa ku bulamu awaka.

Buli kibuzo kya kubalirwa ku lupimo lwa bubonero butaano: Buli kiseera; ebiseera ebisinga; kumpi mu makkati; oluusinooluusi; tekibeerera wo ddala

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Buli kiseera	Ebiseera ebisinga	Kumpi mu makkati	Oluusinooluusi	Tekibeerera wo ddala

### A. Emirimu egikolerwa ebweru wa waka (kino kizingiramu eby'oku ssomero)

Ebibuuzo bino wammanga bikwata ku bintu ebiri mu mulimu gwo (essomero) ogw'enkalakkalira oba ogw'alejjalejja. Bw'oba tolina mulimu oba tosoma, buuka ogende ku kitundu ekiddirira kino

Mu ssabbiiti bbiri eziyise:	Buli kiseera	Ebiseera ebisinga	Kumpi mu makkati	Oluusinooluusi	Tekibeerera wo ddala
1. oyosezza ku ssomero	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. osomye bulungi emisomo gyo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. oswadde olw'engeri gy'obadde okolamu emisomo gyo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. onyiigide oba owalazza empaka n'abaana abalala ku ssomero?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. owulidde okwenyamira, okweraliikirira oba obutawulira mirembe ku ssomero?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. osanze nga by'osoma bisanyusa?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### B. Emirimu gy'o munju/emirimu awaka

Ebibuuzo bino wammanga bikwata ku ngeri emirimu gya waka gye gibaddemu.

Mu ssabbiiti bbiri eziyise:	Buli kiseera	Ebiseera ebisinga	Kumpi mu makkati	Oluusinooluusi	Tekibeerera wo ddala
7. okoze emirimu gy'omunju egyetaagibwa/emirimu egikolebwa awaka buli lunaku?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. okoze emirimu gya waka/emirimu egikolebwa awaka bulungi?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. oswadde olw'engeri gy'obadde okolamu emirimu gya awaka/ emirimu egikolebwa awaka buli lunaku?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. onyiigide oba owalazza empaka n'abaana abalala oba ab'oku muliraano?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. owulidde okwenyamira, okweraliikirira oba obutawulira mirembe nga okola emirimu gya waka/emirimu egikolebwa awaka?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. osanze nga emirimu gya waka/emirimu egikolebwa awaka giwuubaaza tegikusanyusa oba gikooya?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



**C. Okwesanyusa ne bikolebwa mu biseera eby'eddembe.**

Ebibuuzo bino wammanga bikwata ku mikwano gyo ne ky'obadde okola mu biseera byo ebitali bya kukola.

Mu ssabbiiti bbiri eziyise:	Buli kiseera	Ebiseera ebisinga	Kumpi mu makkati	Oluusinooluusi	Tekibeerera wo ddala
13. owulizza ku mukwano gwo yenna?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. osobodde okwogera kaati ku ngeri gy'owuliramu ne mikwano gyo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. okukolera awamu ebintu ebisanyusa ne mikwano gyo (okugeza, okukyala, okusanyusa abalala, okuzannya ne banno)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. okozesezza ebiseera byo by'olinawo ku bintu by'okola mu biseera byo eby'eddembe oba emizannyo egikusanyusa?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. onyigide oba owalazza empaka ne mikwano gyo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. oyisibwa bubi oba okosebbwa mu birowoozo mikwano gyo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. owulidde olina ekikubulako, okutya oba ensonyi nga oli n'abaana abalala?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. owulidde okwewunika nga wandyagadde okubeera awamu n'omuntu?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. owulidde okuwuubaala mu biseera byo eby'eddembe?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**D. Aboolulyo lwo.**

Ebibuuzo bino wammanga bikwata ku beeyjaanda zo bakadde bo bagandabo bannyoko bataata abato bakojja, ba ssenga ba maama abato abaana ba bataata ne ba maama abato n'abaana abatabeera waka. Wattu toteekamu baana ba waka.

Mu ssabbiiti bbiri eziyise:	Buli kiseera	Ebiseera ebisinga	Kumpi mu makkati	Oluusinooluusi	Tekibeerera wo ddala
22. onyigide oba owalazza empaka n'abooluganda lwo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. ogezezza ko okuwuliza abeyjaanda zo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. osobodde okwogera kaati ku ngeri gy'owuliramu n'abooluganda lwo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. abooluganda lwo beebadde bakuyamba, bakuwa amagezi era n'okukulaga okwagala?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. weeraliikiridde kinene nyo okutwala ewalaolw'ebintu ebisobolaokugwa ku booluganda lwo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. obadde owulira nti abooluganda lwo olina ekiseera woobayiriddeyo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. obadde owulira nti abooluganda lwo balina ekiseera webayiriddeyo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**E. Abazadde/abakuza**

Ebibuuzo bino wammanga bikwata ku bintu ebibadde wo wakati wo n'abazadde bo/abakuza bo. Bw'oba nga TOSULA na bakadde bo oba abakuza bo buuka ogende buterevu ku kitundu ekiddako.

Mu ssabbiiti bbiri eziyise:	Buli kiseera	Ebiseera ebisinga	Kumpi mu makkati	Oluusinooluusi	Tekibeerera wo ddala
29. buli omu anyiigidde munne oba owalazza empaka ne bakadde bo oba abakuza bo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. osobodde okwogera engeri gy'owuliramu n'ebizibu byo ne bakadde bo/abakuza bo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. obadde ggwe kennyini asalawo ku by'omumaka?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. osinze kulekera bakaddebo/bakuza bo n'obalekera bbo beeba bayisaamu ebyabwe nga wabaddewo obutakkaanya?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. ne bazadde bo/abakuza bo mukolaganidde wamu okugonjoola ensonga zonna ezibaddewo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. obadde wesigama ku bakadde bo/abakuza bo okukuyamba?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. obadde owulira okwagala eri bakaddebo/abakuza bo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. wegasse n'omusajja/omukazi ne kitakuwa ssanyu/nga okakiddwabukakibwa?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. ofunye emitawaana gyonna nga ozannya (okugeza, obulumi, okulumizibwa)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. weyagadde bulungi ne bakaddebo/abakuza bo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**F. Baganda bo/bannyoko**

Ebibuuzo bino wammanga bikwata ku bintu nga bwebibadde wakati wo nebaganda bo ne bannyoko. Bw'oba nga tolina ba luganda bakuli ku lusegere, wattu ekitundu kino tokifaako.

Mu ssabbiiti bbiri eziyise:	Buli kiseera	Ebiseera ebisinga	Kumpi mu makkati	Oluusinooluusi	Tekibeerera wo ddala
39. obadde osanyukira ebintu ebikolebwa baganda bo ne bannyoko, okugeza essomero, emikwano etc?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. osobodde okwogera era n'okuwuliriza baganda bo oba bannyoko?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. obadde okayukira oba okuwalaza empaka baganda bo oba bannyoko?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. obadde owulira okwagala eri baganda bo oba bannyoko?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**G. Ab'enju**

Ebibuuzo bino wammanga bikwata ku bintu nga bwebibadde wakati wo n'abenju yammwe. Bw'oba nga toline ba mu nju, wattu ekitundu kino tokifaako.

Mu ssabbiiti bbiri eziyise:	Buli kiseera	Ebiseera ebisinga	Kumpi mu makkati	Oluusinooluusi	Tekibeerera wo ddala
43. obadde weraliikirira nnyo okusinga bwe kyetaagisa ku bintu ebiba ku booluganda lwo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. obadde owulira nti abooluganda lwo obayiiyeyo olumu n'olumu?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. obadde owulira okwagala eri abooluganda lwo olumu n'olumu?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Wattu baako ne kyoyogera kyonna, ku bino oba ku bikuluma**

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## Appendix F1: Interview guide for first interview

### Interview 1

We are going to talk about your experiences. Some things we will talk about may be painful for you or make you angry and I want you to feel free to express this. What I learn here, from you today will help us to better understand what life is like for you. We can use this information to find ways to help you, but it will also help us understand what we can do for other children who are in the same position you are. There are no right answers or wrong answers today, not everybody feels the same way about everything.

I would like to record this discussion. It will be difficult to take note of everything said during this interview and I might miss something important. Only the research team members will hear the tapes, no one else will know what has been said. Is that OK?

**First, I would like to clarify some of the answers you have gave in the questionnaires:**

**How long have you been living here in Kampala?**

**How did you come to this clinic?**

**When did you find out about your status?**

- Who told you?

**How do you think you got HIV?**

**Who have you told about your HIV status?**

**Why have you told these people?**

**Why have you not told other people?**

**I know we have talked about stigma in peer support groups and we hear people say it, but what exactly does stigma mean to you?**

**Do you feel that people with HIV are treated differently/stigmatized?**

- How?

- Why?

*(Probe: Is it from personal experience? Note/record experiences.)*

**Do people's attitudes or what people say about HIV make you feel better or worse about yourself and having HIV?**

**Who makes you feel bad?**

- How?
- Why? How exactly do you feel?

**Who makes you feel better?**

- How?
- Why does this make you feel better?

**How do you feel about being HIV positive?**

*(Do not read the list: use only as guide. Record their own words. Probe for as many feelings as possible.)*

Guilty      Ashamed      Embarrassed      Angry      Dirty

**When you feel this way (what was said above, if bad. If not use upset /sad) what can someone do to make you feel better?**

**Possibilities:** make you laugh (comical), give you a hug (affectionate), discuss the situation with you (intellectual)

**What do you do to make yourself feel better?**

*Coping strategies can fall in following categories – do not read. Use only as a guide to probe.*

Self-distraction	Use of instrumental support	Humour
Active coping	Behavioural disengagement	Acceptance
Denial	Venting	Religion
Substance use	Positive reframing	Self-blame
Use of emotional Support	Planning	

**Other possible responses from the coping with AIDS scale**

Try to learn more about AIDS	Avoid being with people
Tell yourself to accept it	Go on as if nothing happened
Think about people who are less fortunate than you	Keep your feelings to yourself
Look on the bright side	Feel sorry for yourself
Make plans for the future	Keep others from knowing how bad things are
Try to push it out of your mind	Feel so angry that you want to hit or smash something
Think about better times in the past	Seek sympathy and understanding from friends
Make yourself feel better by drinking or taking drugs	

**What do you do when you have a problem?**

*Coping strategies can fall in following categories – do not read. Use only as a guide to probe.*

Self-distraction	Use of instrumental support	Humour
Active coping	Behavioural disengagement	Acceptance
Denial	Venting	Religion
Substance use	Positive reframing	Self-blame
Use of emotional Support	Planning	

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**Other possible responses from the coping with AIDS scale**

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Try to learn more about AIDS	Avoid being with people
Tell yourself to accept it	Go on as if nothing happened
Think about people who are less fortunate than you	Keep your feelings to yourself
Look on the bright side	Feel sorry for yourself
Make plans for the future	Keep others from knowing how bad things are
Try to push it out of your mind	Feel so angry that you want to hit or smash something
Think about better times in the past	Seek sympathy and understanding from friends
Make yourself feel better by drinking or taking drugs	

**Who do you spend most of your time with?****Can you confide in this person?**

*If no, follow with: Do you have someone you can confide in?*

**How helpful is this person:**

- **When you have a personal problem?**
  - o Is there anybody else you can talk to about it? Anybody at all? Who?
- **When you need money and/or other things?**
  - o Is there anybody else you can ask? Anybody at all? Who?
- **How much fun do you have with this person?**
  - o Who else do you have fun with? And?

**Do you think you can talk to a friend who is not HIV positive about your feelings and problems?****What is your favourite activity, what do you do for fun?**

- Like, what is something you can do tonight for fun?

**Do you have a boyfriend or girlfriend?**

**Do you take any alcoholic drinks?**

- How often?
- What kind?

**Have you ever had sex?**

**What makes you happy?**

- Tell me something about your life that makes you happy?

**Who do you admire most?**

## Appendix F2: Interview Guide for Interview 2

### Interview 2

Hallo again. Thank you for coming back to talk to us. Like last time we would like to talk about some of your experiences. Some things we talk about may be painful for you or make you angry and I want you to feel free to express this. All information you give, and have given us will help us to serve you better at the clinic as I explained last time. Remember, there are no right or wrong answers today, not everyone feels the same.

I would like to record this discussion. It will be difficult to take note of everything said during this interview and I might miss something important. Only the research team members will hear the tapes, no one else will know what has been said. Is that OK?

**OK, let's start by clarifying some of the answers you have gave in the questionnaires:**

**In the questionnaires we ask you to rate your own health. When you have to think about that who do you compare yourself to?**

**Have you stopped going to school or starting going to school since we last spoke?**

- Why/how did that happen?  
(ie, are they feeling better, did they get funding from somewhere etc. What is the MAIN reason)

**In our first interview I asked you about stigma, do you remember?**

**Do you remember what it means?**

**Do you now feel that people with HIV are treated differently/stigmatized?**

- How?
- Why?  
(Probe: Is it from personal experience? Note/record experiences.)

**Have you told anyone else about your status since we last talked?**

- Who have you told?
- Why have you told these people?



**Do people's attitudes or what people say about HIV make you feel differently about yourself?**

- How does it make you feel?

**Who makes you feel bad?**

- How?
- Why?

**Who makes you feel better?**

- How?
- Why does this make you feel better?

**How do you feel about being HIV positive?**

*(Do not read the list: use only as guide. Record their own words. Probe for as many feelings as possible.)*

Guilty      Ashamed      Embarrassed      Angry      Dirty

**When you feel** (what was said above, if bad. If not use upset /sad) **what can someone do to make you feel better?**

**Possibilities:** make you laugh (comical), give you a hug (affectionate), discuss the situation with you (intellectual)

**What do you do to make yourself feel better?**

**What do you do when you have a problem?**

**Who do you spend most of your time with?**

- Can you confide in this person?
- 

*If no, follow with: Do you have someone you can confide in?*

**How helpful is this person:**

- **When you have a personal problem?**
  - o Is there anybody else you can talk to about it? Anybody at all? Who?
- **When you need money and/or other things?**
  - o Is there anybody else you can ask? Anybody at all? Who?
- **How much fun do you have with this person?**
  - o Who else do you have fun with? And?

**Do you think you can talk to a friend who is not HIV positive about your feelings and problems?**

**What is your favourite activity, what do you do for fun?**

- Like, what is something you can do tonight for fun?

**Have you had sex since we last spoke?****Do you have a boyfriend or girlfriend?****Do you take any alcoholic drinks?**

- How often?
- What kind?

**What makes you happy?**

- Tell me something about your life that makes you happy?

**Who do you admire most?**

## Appendix G: School Achievement and Attendance Questionnaire

ADL # \_\_\_\_\_

### School achievement and attendance

(To be filled out during interview)

Not currently attending school: ☐

Reason for not attending school: \_\_\_\_\_

Last year completed in school: \_\_\_\_\_

***If not currently in school DO NOT fill out rest of the form***

### 1. ACADEMIC PERFORMANCE

#### 1.1 REPORT CARD

Report Card received ☐

*Check box if report card received, attach copy*

#### 1.2 SELF EVALUATION

This term I performed \_\_\_\_\_

### 2. SCHOOL ATTENDANCE

#### 2.1 SELF REPORT

I attend school:

- ☐ Every Day
- ☐ Most of the time (miss one day a week or less)
- ☐ Some of the time (miss more than one day a week)
- ☐ Very irregularly, mostly at home

The number of school days absent in previous month: \_\_\_\_\_

**3. Extra-Curricular activities**

Are you a member of any sports teams at your school?

Yes

☐

No

☐

If yes, what teams are these? \_\_\_\_\_

Do you participate in any other school activities?

Yes

☐

No

☐

If yes, what activities are these? \_\_\_\_\_

Do you hold any leadership positions at school, i.e. are you a captain of a sports team, a prefect etc?

Yes

☐

No

☐

If yes, what position(s) are these? \_\_\_\_\_

**4. OTHER**

Who pays your school fees? \_\_\_\_\_

Anything else you would like to add?

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## Appendix H1: Informed Consent for adolescents younger than 18.

### RESEARCH PARTICIPANT INFORMATION CONSENT TO PARTICIPATE IN A RESEARCH STUDY

**Title of study:** Quality of life and stigma in HIV-seropositive adolescents attending Mulago Hospital, Kampala, Uganda.

**Principal Investigator:** Elsabé du Plessis  
Plot 91 Kira Road  
Kampala, Uganda  
078 464 406

You are being asked to allow your child to participate in a research study. Please take your time to review this consent form and discuss any questions you or your child may have with the study staff. You/your child may take your time to make your decision about participation in this study and you may talk it over with your friends, family, doctor or counselor before you make your decision. This consent form may have words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

This study is independent of treatment. Participation or deciding not to allow participation in this study **will in no way affect the treatment decisions** made by the clinic or the treatment received at the clinic.

## **PURPOSE AND BACKGROUND**

We are interested in learning more about the course of HIV among adolescents (between 10-19 years) and how best to take care of this group. The study your child is being asked to participate in will look at aspects of adolescents' quality of life. It will also track changes in the psychological status of HIV-seropositive adolescents who are receiving antiretroviral therapy.

A total of 100 participants will participate in this study.

## **PROCEDURES**

If you permit your child to participate in this study, she/he will be asked to respond to questionnaires on four separate occasions. Once before, or just as they start medication, then (second) when adolescent has been taking drugs for three months, when adolescent has been on treatment for six months and finally at nine months.

Adolescents will also be asked to participate in two interviews: one at the beginning of the study and another at the end of the nine months. Interviews will be between 45 minutes and an hour in length and we will be discussing issues around stigma, social support and coping.

Focus groups for participating adolescents will also be conducted at three months and around six months discussing similar topics as the interviews.

Participation in the study will be for a total of nine months.

## **RISKS / DISCOMFORTS**

This study will require your child to fill out questionnaires on four occasions, attend two interviews and two focus groups, and may take some of you or your child's time. There is also the risk of psychological distress as a result of recalling painful memories.

Discussions within focus group settings may also ask adolescents to reveal confidential information in the presence of their peers.

## **BENEFITS OF THE STUDY**

Participation in the study may or may not directly benefit your child. We hope the information learned from this study will help us understand HIV disease better and help other people with HIV disease here in Uganda and in other countries.

## **COSTS**

There is no cost to you/your child for participation in the study.

## **COMPENSATION**

Your child could be asked to travel to the clinic on a day that they would not normally come. They will be given the same transportation refund of 2,000 shillings that they get to attend the monthly support group meetings. As during clinic appointments, participating adolescents will receive refreshments if their appointments last for an extended period of time. There will be no other form of compensation.

Parent's/Guardian's Initials: \_\_\_\_\_

Adolescent's Initials: \_\_\_\_\_

### **RIGHTS TO PARTICIPATE AND WITHDRAW FROM THE STUDY**

Your and your child's decision to take part in this study is voluntary. You may refuse to have your child participate or you may withdraw him/her from the study at any time. All adolescents also have the right to decide if they want to be part of the study or not. All adolescents have to assent.

If you or your child chooses not to participate or to withdraw later, your child will continue to receive health care and any drugs that would normally be offered to any HIV infected patients in the IDC. There is no penalty for not joining or completing the study.

Both you and your child are free to discuss the research with a counselor before making a decision.

### **CONFIDENTIALITY**

The research team will protect information about your child and her/his participation in the study as much as possible.

All personal information about you or your child will be kept confidential. A study code number will be used on all of your child's study related documents, for example interview transcripts. There will be only one list that connects this code to your child's name, but this list will be kept locked in a private place. Information gathered in this research study may be published or presented in public discussions but your child's name and/or any other identifying information will not be used or revealed.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include the Academic Alliance for HIV/AIDS Care and Prevention, Makerere University Medical School and the University of Manitoba Health Research Ethics Board.

### **QUESTIONS**

You are free to ask any questions that you may have about your treatment and your rights as a research participant.

If your child has any problems or questions during the study, you can contact Dr. Sabrina Bakeera-Kitaka (077401790) a pediatrician at the Pediatric Infectious Disease Clinic, Mulago Hospital.

If you believe that your child has been harmed by being in the study or that your child's private information has been given out, contact the chairman of the Makerere University Medical School Internal Review Board, Dr. Elly Katabira (telephone 533800).

Do not sign this consent form unless you have had a chance to ask any questions you or your child may have and you have received satisfactory answers to all of your questions.

### **STATEMENT OF CONSENT**

This consent form has been read and explained to me in a language I understand. I have had the opportunity to discuss this research study with one of the researchers, and she/he has answered my questions. I understand that I may keep a copy of this consent form after I signed it.

Parent's/Guardian's Initials: \_\_\_\_\_

Adolescent's Initials: \_\_\_\_\_

I have been told the purpose of the study. I have been told what happens during the research and the risks and benefits have been explained to me. I understand that my child's participation in this study is voluntary and that I may choose to withdraw her/him at any time without giving a reason and without affecting her/his normal care and management. I have been told that I can talk with a study counselor before I agree to let my child participate. My child can also discuss this with the counselor to make her/his own decision.

I have not been influenced by any study team member to let my child participate in the research study. Any relationship I may have with the study team has not affected my decision to let my child participate. I voluntarily agree to let my child participate in this study.

I understand that information regarding my child's personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my child's records that relate to this study by the Academic Alliance, the Internal Review board of the Makerere University Medical School and the University of Manitoba Research Ethics Board, should they want to make sure that the information is of good quality.

By signing this consent form, I have not waived any of the legal rights that my child or I have as a participant in a research study.

Parent's/Guardian's Initials: \_\_\_\_\_

Adolescent's Initials: \_\_\_\_\_



**SIGNATURES:****Parent / Guardian:**

Adolescent's name: \_\_\_\_\_

Parent / Guardian's printed name: \_\_\_\_\_

Parent/legal guardian's signature /  
Thumbprint: \_\_\_\_\_Date signed: \_\_\_\_\_  
(day / month / year)**Adolescent:**

If the adolescent has participated in and understood the informed consent process and agrees to participate in the study he/she should sign below.

Adolescent's Name: \_\_\_\_\_

Adolescent's Signature /  
Thumbprint: \_\_\_\_\_Date signed: \_\_\_\_\_  
(day / month / year)**Person administering consent:**

I have explained the purpose of this study to above-mentioned adolescent's parent/guardian and have answered all her/ his as well as the adolescent's questions. To the best of my knowledge, they understand the purpose, the procedures, risks and benefits of the study.

Printed Name: \_\_\_\_\_

Role in study / Position: \_\_\_\_\_

Signature: \_\_\_\_\_

Date signed: \_\_\_\_\_  
(day / month / year)

## **Appendix H2: Informed Consent for adolescents older than 18.**

### **RESEARCH PARTICIPANT INFORMATION CONSENT TO PARTICIPATE IN A RESEARCH STUDY**

**Title of study:** Quality of life and stigma in HIV-seropositive adolescents attending Mulago Hospital, Kampala, Uganda.

**Principal Investigator:** Elsabé du Plessis

You are being to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participation in this study and you may talk it over with your friends, family, doctor or counselor before you make your decision. This consent form may have words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

This study is independent of treatment. Participation or deciding not to allow participation in this study **will in no way affect the treatment decisions** made by the clinic or the treatment received at the clinic.

## **PURPOSE AND BACKGROUND**

We are interested in learning more about the course of HIV among adolescents (between 10-19 years) and how best to take care of this group. The study you are being asked to participate in will look at aspects of adolescents' quality of life. It will also track changes in the psychological status of HIV-seropositive adolescents who are receiving antiretroviral therapy.

A total of 100 participants will participate in this study

## **PROCEDURES**

If you agree to participate in this study, you will be asked to respond to questionnaires on four separate occasions. Once before, or just as you start medication, then (second) when you have been taking drugs for three months, when you have been on treatment for six months and finally at nine months.

You will also be asked to participate in two interviews: one at the beginning of the study and another at the end of the nine months. Interviews will be between 45 minutes and an hour in length and we will be discussing issues around stigma, social support and coping.

Focus groups will also be conducted at three months and around six months discussing similar topics as the interviews.

Participation in the study will be for a total of nine months.

## **RISKS / DISCOMFORTS**

This study will require you to fill out questionnaires on four occasions, attend two interviews and two focus groups, and may take some of your time. There is also the risk of psychological distress as a result of recalling painful memories.

Discussions within focus group settings may also ask you to reveal confidential information in the presence of your peers.

## **BENEFITS OF THE STUDY**

Participation in the study may or may not directly benefit your child. We hope the information learned from this study will help us understand HIV disease better and help other people with HIV disease here in Uganda and in other countries.

## **COSTS**

There is no cost to you/your child for participation in the study.

## **COMPENSATION**

You could be asked to travel to the clinic on a day that you would not normally come. You will be given the same transportation refund of 2,000 shillings that you would get to attend the monthly support group meetings. As during clinic appointments, you will receive refreshments if your appointment last for an extended period of time. There will be no other form of compensation.

## **RIGHTS TO PARTICIPATE AND WITHDRAW FROM THE STUDY**

Adolescent's Initials: \_\_\_\_\_

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. All adolescents also have the right to decide if they want to be part of the study or not.

If you choose not to participate or to withdraw later, you will continue to receive health care and any drugs that would normally be offered to any HIV infected patients in the IDC. There is **no penalty** for not joining or completing the study.

Both you and your child are free to discuss the research with a counselor before making a decision.

### **CONFIDENTIALITY**

The research team will protect information about you and your participation in the study as much as possible.

All personal information about you will be kept confidential. A study code number will be used on all of your study-related documents, for example interview transcripts. There will be only one list that connects this code to your name, but this list will be kept locked in a private place. Information gathered in this research study may be published or presented in public discussions but your name and/or any other identifying information will not be used or revealed.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include the Academic Alliance for HIV/AIDS Care and Prevention, Makerere University Medical School and the University of Manitoba Health Research Ethics Board.

### **QUESTIONS**

You are free to ask any questions that you may have about your treatment and your rights as a research participant.

If you have any problems or questions during the study, you can contact Dr. Sabrina Bakeera-Kitaka (077401790) a pediatrician at the Pediatric Infectious Disease Clinic, Mulago Hospital.

If you believe that you have been harmed by being in the study or that your private information has been given out, contact the chairman of the Makerere University Medical School Internal Review Board, Dr. Elly Katabira (telephone 533800).

Do not sign this consent form unless you have had a chance to ask any questions you may have and you have received satisfactory answers to all of your questions.

### **STATEMENT OF CONSENT**

This consent form has been read and explained to me in a language I understand. I have had the opportunity to discuss this research study with one of the researchers, and she/he has answered my questions. I understand that I may keep a copy of this consent form after I signed it.

I have been told the purpose of the study. I have been told what happens during the research and the risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time without giving a reason and without affecting my normal care and management. I have been told that I can talk with a study counselor before I agree to participate.

Adolescent's Initials: \_\_\_\_\_

I have not been influenced by any study team member to participate in the research study. Any relationship I may have with the study team has not affected my decision to participate. I voluntarily agree to participate in this study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by the Academic Alliance, the Internal Review board of the Makerere University Medical School and the University of Manitoba Research Ethics Board, should they want to make sure that the information is of good quality.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

**SIGNATURES:**

**Adolescent:**

If the adolescent has participated in and understood the informed consent process and agrees to participate in the study he/she should sign below.

**Adolescent's Name:** \_\_\_\_\_

**Adolescent's Signature /  
Thumbprint:** \_\_\_\_\_

**Date signed:** \_\_\_\_\_  
(day / month / year)

**Person administering consent:**

I have explained the purpose of this study to above-mentioned adolescent's parent/guardian and have answered all her/ his as well as the adolescent's questions. To the best of my knowledge, they understand the purpose, the procedures, risks and benefits of the study.

**Printed Name:** \_\_\_\_\_

**Role in study / Position:** \_\_\_\_\_

**Signature:** \_\_\_\_\_

Adolescent's Initials: \_\_\_\_\_

**Date signed:**

\_\_\_\_\_  
(day / month / year)

**Adolescent's Initials:** \_\_\_\_\_