

# **Adolescents living with HIV in Botswana: What contributes to an HIV positive adolescent thriving?**

**A qualitative study**

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## **Abstract**

**Background:** HIV positive adolescents' well-being is becoming an increasingly important issue, as antiretroviral medications are contributing to more HIV positive children surviving into adolescence and adulthood. Sub-Saharan Africa has the world's highest HIV incidence, with about two thirds of the 34 million people infected worldwide, living in this region. Botswana has the second highest infection rate in the world, and the epidemic has left a large proportion of children and adolescents orphaned. Many of the adolescents living with HIV in Botswana today have been HIV positive since they were born, or contracted HIV as infants via breastfeeding. A large number of these have for a great part of their lives been unaware of their diagnosis, as their caregivers have kept it a secret. Previous studies have looked at different aspects of disclosure of HIV status to children and adolescents, HIV-stigma and the mental health of HIV positive children and adolescents. However, few studies have explored these issues from the adolescents' point of view, and the majority of the studies are conducted in developed countries. Furthermore, a lot of the existing literature has explored the negative aspects of living with HIV; few have evaluated HIV positive adolescents who are thriving.

**Objectives:** Two objectives were addressed: Objective 1) what makes HIV positive adolescents thrive, in spite of a complex difficult life situation? The following research questions were identified and addressed: 1) what contributes to well-being in an HIV positive adolescent? –Are there any positive factors in his/her environment? 2) What is important for the adolescents in the disclosure process? 3) Are there any differences in coping before and after being disclosed to? 4) How do the adolescents deal with the stigma related to HIV? Objective 2) is there evidence in the participants' narratives that Sense of Coherence plays a role in positive coping?

**Theoretical framework:** For this study a salutogenic approach was implemented, which views health in relation to what creates health rather than what causes disease. Salutogenesis encompasses two main components: Generalised Resistance Resources (GRR) and Sense of Coherence (SOC). By exploring what was positive and strengthening in an HIV positive adolescent's life, it was possible to identify pathways to what creates health and well-being among this group of adolescents.

**Methods:** A phenomenological approach was implemented, facilitating the understanding of the lived experiences to seek a deeper explanation of a phenomenon. Data were collected in an urban and a rural area of Botswana, through focus group discussions, individual interviews and observations during a three month period from June to September 2011. 16 adolescents and three key personnel were enrolled in the study. Translators were used in all the interviews except one, to translate between English and the local language, Setswana. All the interviews were recorded and transcribed, and the Setswana recordings were translated into English. The data were analysed using directed content analysis, categorising ideas from the data into themes, based on the research questions. Permission to do the study was obtained from the required instances in Botswana and Norway, and informed consent was obtained from all the participants, and from caregivers of participants under the age of 18 years.

**Results and discussion:** Several positive resources and coping strategies were identified. To be disclosed to was identified as one of the major positive resources, contributing to several other positive factors, such as knowledge and understanding about their condition and life situation, and improved access to social support. Family, friends and leisure activities were also important positive factors that contributed to well-being. All of the participants saw disclosure as very important to them, and they emphasized that disclosure should not be delayed, and the importance of openness and presence of their caregivers in the disclosure process. Most of the participants had a better understanding of their life situation after disclosure, and it enabled them to see the importance of adhering to their treatment regimen. Most of them kept their status a secret to avoid stigma, however, some reported to have disclosed their status to some friends. Furthermore, some developed a form of individual sense making as a coping strategy, pointing out that at least they knew their status and how to live healthily with their disease, compared to others who did not know their status and thereby did not have the opportunity to live healthily with their disease.

**Conclusions:** The participants in this study had several resources at hand, including being disclosed to, the treatment system and social support, which contributed to thriving in spite of a complex difficult life situation. Furthermore, several of the participants can be said to have a strong sense of coherence, which can be related to their ability to use the resources they had available in managing stressors in life, enabling them to cope positively in their situation.



## **Acronyms and abbreviations**

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Treatment
BIPAI	Baylor International Pediatric AIDS Initiative
DRC	Democratic Republic of Congo
GRR	General Resistance Resources
HIV	Human Immunodeficiency Virus
IDC	Infectious Disease Clinic
PLHIV	People Living with HIV
SOC	Sense of Coherence
SSA	Sub-Saharan Africa
UNAIDS	the Joint United Nations Programme on HIV and AIDS
USA	United States of America
WHO	World Health Organisation

## **Terminology from Botswana**

Botswana	The country
Motswana	One citizen
Batswana	Two or more citizens
Setswana	The language

# **1 Introduction**

## **1.1 Background**

In the context of antiretroviral treatment (ART), an increasing number of children infected with Human Immunodeficiency Virus (HIV) are now surviving into adolescence and adulthood. In the early days of the epidemic, before the roll out of ART, children who were born with HIV were not expected to survive into adolescence. The roll out of ART has given this group of children a chance to live, and to live a close to normal life. This also means that a new generation of patients has emerged, together with issues that were not considered in the early days of the epidemic. Some of these new issues include disclosing children's and adolescents' HIV status to them, and providing treatment and support to this new group of patients, enabling them to live a good quality life. The HIV epidemic is now approaching the end of its 3<sup>rd</sup> decade, and at the end of 2010, an estimated 34 million people were living with HIV worldwide (1). Sub-Saharan Africa (SSA) has the world's highest prevalence of HIV incidence, with about two thirds, or 68%, of the global total of those infected by the virus living in this region (2). Botswana has the second highest infection rate in the world, with an estimated 300 000, or 24.8%, of the population between 15 and 49 years old, and 16 000 children between the age of 0-14, being infected (2). Many of the adolescents living with HIV in Botswana today have been HIV positive since they were born or contracted HIV as infants via breastfeeding. The disease has devastating effects for everyone involved and at all levels of society. In Botswana the epidemic has left a large proportion of children and adolescents orphaned, and life expectancy at birth fell from 65 years in the early 1990s to less than 40 years in the 21<sup>st</sup> century. However, as ART has become more widely available, there has been a reduction in mother to child transmission of the HIV virus, and Acquired Immune Deficiency Syndrome (AIDS) related deaths in Botswana have declined by half from the initiation of treatment in 2002 up to 2009 (2).

## **1.2 Problem statement**

With its high infection rate, HIV concerns a large number of Botswana's citizens, either directly or indirectly, making it an important health issue. A large number of HIV positive adolescents have for a great part of their life been unaware of their diagnosis, as their parents or caregivers have kept it a secret. This trend seems to remain in spite of HIV positive

children entering adolescence and evidence pointing to positive effects of disclosing adolescents' HIV status to them (3-7). In Botswana it is not common to speak openly about HIV and AIDS, and many keep their diagnosis a secret in fear of being stigmatised, discriminated against and isolated from the rest of the community (8). Furthermore, the AIDS epidemic has left many children and adolescents orphaned, having to adapt to new family arrangements. Little is known about what enables these adolescents to thrive. Knowledge about what promotes health and well-being in this group is important in order to enable them to improve and sustain their quality of life.

### **1.3 Context**

According to UNAIDS it was estimated that 49% of those eligible for ART in SSA received treatment in 2010 (9). ART is not a cure, but it can slow down the development of HIV and AIDS for many years. Botswana introduced its ART program in 2002, aiming to offer treatment for all HIV positive citizens (10), and by 2009, ART coverage exceeded 90% of those eligible<sup>1</sup>(11, 12) for treatment (2). These numbers indicate that Botswana is in a unique situation within SSA concerning ART coverage. In Botswana, ART are mostly supplied by the Botswana National Government, however, international organisations, such as the Baylor International Pediatric AIDS Initiative (BIPAI), are involved in organising the services around the treatment. The Botswana-Baylor International Center of Excellence is a partnership between BIPAI at Baylor College of Medicine in Houston, the Princess Marina Hospital in Gaborone (the capital of Botswana) and the government of Botswana (13). In addition to facilitating treatment to HIV positive children and families, the centre also provides psychosocial services, and additional services for adolescents, like Teen Club. Teen Club is a peer support group for HIV positive adolescents between 13 and 19 years old, it can be found at several different sites in Botswana, and aims to improve the adolescents' clinical and mental health outcomes (14). In order to become a member of Teen Club, the adolescents have to be disclosed to, furthermore, it is more accessible to those who live in urban, or close to, urban areas, with the majority of the groups located in the south-eastern part of the country (14).

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<sup>1</sup> A CD4 test is usually used to determine when a person should start ART. A CD4 test measures the number of T-helper cells, which are an essential part of the immune system. HIV damages and destroys T-helper cells, resulting in a weakened immune system (11). WHO recommends to start with ART when a person with HIV have a CD4 count lower than 350 (12).

## **1.4 Literature on adolescents living with HIV**

Previous studies have looked at disclosure of children's and adolescents' HIV status in relation to barriers to disclosure (3, 15-20), positive effects of disclosure (3-7) and the disclosure process in itself (4, 21-23). Most of the studies are conducted from the caregiver's (15, 18, 24) or health care professional's points of view (22, 25-27), very few have focused on the adolescents' points of view, especially within SSA (3, 28). An extensive body of literature exists on stigma, however, a lot of the literature focuses on reasons for HIV-stigma (29-37), how HIV-stigma and discrimination further complicate living with a serious disease (15, 38), and how it makes prevention and treatment efforts challenging (37, 39, 40). A limited number of studies has focused on what resources HIV positive adolescents in SSA use to cope with stigma (8, 41). Literature on HIV positive children's and adolescents' mental health is most common from developed countries, especially from the United States of America (USA) (42-45), literature from SSA is much more uncommon (46-48). The literature mostly focuses on what mental health problems and challenges children and adolescents with HIV experiences, and to what degree they experience these problems compared to the general population. All of the above are important studies; however, few studies have evaluated HIV positive adolescents who are thriving, in spite of living with a chronic and much stigmatised disease, and what resources contributes to this phenomenon. Reviewing previous literature it is evident that a lot of it tends to explore the negative aspects of living with HIV. There is a gap in the literature concerning studies conducted from the adolescents' perspectives within SSA, and studies focusing on HIV positive adolescents thriving, and the mechanisms behind this. As more HIV positive children now enter adolescence, as mentioned previously, these are important gaps to fill in order to gain knowledge about what promotes well-being in this group of adolescents, and to enable them to reach their health potentials. Furthermore, studies applying the theory of Salutogenesis, which are looking at pathways to health rather than causes of disease, (the theory of Salutogenesis will be defined in chapter 2.2) in the context of adolescents living with HIV in SSA have not been conducted previously, as I am aware of.

## **1.5 Terminology**

Expressions such as 'thriving' and 'resilience' are well known within the psychology literature. Carver explains the concept of thriving as benefitting from adversity (serious physical or psychological stress or trauma) (49). Carver suggested that after a physical or

psychological downturn, there are four possible outcomes: succumbing, survival with impairment, resilience (recovery) or thriving which Carver refers to as “*the person may not merely return to the previous level of functioning but may surpass it in some manner*” (49, p. 246). These concepts imply that the person must have experienced adversity in order to show resilience or thrive.

Throughout this thesis I will use both the expressions children and adolescents. Even though adolescents are the main focus of the thesis, I still use the term children in addition, as some of the literature I refer to includes both children and adolescents. Furthermore, when referring to caregivers and their children, it is more natural to refer to someone’s child rather than someone’s adolescent.

## **1.6 Aims and objectives**

### **1.6.1 Aim of the study**

The aim of the study was to gain understanding of the experiences of HIV positive adolescents in Botswana, and to gain knowledge about what resources they have that makes some of them thrive in spite of challenging life situations.

### **1.6.2 Objectives**

- What makes HIV positive adolescents thrive, in spite of a complex difficult life situation?
- Is there evidence in the participants’ narratives that Sense of Coherence (SOC) plays a role in positive coping?

### **1.6.3 Research questions**

- What contributes to well-being in an HIV positive adolescent? –Are there any positive factors in his/her environment?
- What is important for the adolescents in the disclosure process?
- Are there any differences in coping before and after being disclosed to?
- How do the adolescents deal with the stigma related to HIV?

## **1.7 Structure of thesis**

Following the introduction above, I continue with reviewing relevant literature on adolescents living with HIV in chapter 2, and identify gaps in the literature. I also introduce the concept of Salutogenesis, and how it can be applied to thriving adolescents living with HIV in Botswana. In chapter 3 I go through the methodologies before I continue with writing up the results that emerged from the data collection in the field in chapter 4. In chapter 5 I discuss and analyse the results in light of previous literature and my own reflections. I furthermore apply the findings to the theory of Salutogenesis, draw conclusions and reflect on limitations of the study. In chapter 6 I provide recommendations on basis of the study results.

## **2 Literature review and Theoretical framework**

In this chapter I will review the literature and identify common, general and contradicting findings from previous literature written on the subjects concerning my research questions. The focus of my study is well-being and thriving among HIV positive adolescents, particularly looking at their experiences of disclosure and dealing with stigma. I will therefore start with an overview of the literature on disclosure of children's and adolescents' HIV status and children and adolescents disclosing their own status. I will then give an overview of literature on stigma before I continue with what is written concerning mental health and social support in HIV positive children and adolescents. In the last section of this chapter I will explain the concept of Salutogenesis, which provides the theoretical framework of this study, and show how this framework can be relevant in the context of adolescents thriving with HIV.

### **2.1.1 Literature on disclosure of children's and adolescents' HIV status**

Several studies suggest that disclosure of HIV status to children and adolescents has a positive impact on their lives, compared to keeping their status a secret (3-7). Positive outcomes from disclosure of HIV status to children and adolescents include improved adherence to treatment regimen (4, 6), better access to social support (50), furthermore, adolescents report to perceive more support from their social network after being disclosed to (4). In addition, children and adolescents have reported that they feel it is important to know their status (3, 4, 28). Although few, negative impacts of disclosure reported include initial emotional reactions such as getting upset, feeling sad and angry, and symptoms of anxiety during the first week after disclosure (3, 4), however, these feelings have been reported to decrease to being uncommon within a 6 month period (4). However, it is important to mention that much of the literature on disclosure focus on what is positive about disclosure, which may hide some of the negative aspects about it.

Abadia-Barrero et al suggest that keeping children's and adolescents' HIV status a secret from them can contribute to confusion, mistrust, compromised disease knowledge and an increased vulnerability to risk behaviour (23). One of the barriers to disclosure has been found to be fear of negative psychological outcomes for the child, however, findings from the USA and Zambia (7, 50, 51) suggest that disclosure does not have a negative impact on children's and adolescents' mental health. In fact, a review on HIV status disclosure to perinatally infected children and mental health outcomes find that children who are disclosed

to experience less depression than those who are not disclosed to (7). One study found that when the caregivers had kept the child's HIV diagnosis a secret from the child, the child expressed feelings of being isolated within the family (16). The same study also suggests that children sometimes are aware of the disease but pretend not to know because they have not been told by their caregiver (16). Even though the issue of disclosing children's and adolescents' HIV status has been discussed in the literature for several years now, with studies dating back to the mid 1990's (20), and a growing body of evidence is pointing to positive impacts of telling children the truth about their HIV diagnosis, the level of disclosure remains low. The low level of disclosure is evident in SSA (24, 52, 53), as well as worldwide (7, 19). Studies also show that it is common to provide children with partial disclosure, which means that they are given some, but not all the information about their health (6, 28, 54, 55). Partial disclosure includes telling the child that he or she is suffering from a disease and has to take the medications to stay healthy (54, 55), or that the child is partly aware or suspicious, asking questions about the disease (6). In addition, several studies find that there exists a considerably high level of caregivers who provide children and adolescents with deflecting information about their health status, with evidence from SSA, Asia and Europe (19, 24, 28, 52, 54). Deflecting information includes lying to the child by saying that he or she has a disease but it is not HIV (24), calling it allergy, tuberculosis, or a spleen condition (19, 28, 52), and saying the medications will help the hair grow (16).

The barriers to disclosure of children's and adolescents' HIV status are many, and they have been found to be similar across different countries and cultures. Some of the most common barriers include: negative social impacts for both the children and the families such as discrimination, social rejection and isolation if the children tell anyone (3, 15-20), guilt over perinatal transmission (3, 16), that the child is too young to understand (3, 15, 17-20), the caregiver's feeling of lack of knowledge about HIV (17), fear of negative psychological impacts for the children (18-20, 24, 54) and that disclosure is emotionally and psychologically challenging for the caregiver (3). The literature says a lot about the barriers to disclosure, more knowledge should be gained regarding whether or not these barriers are realistic, and how to address them. Factors that move a caregiver towards disclosure have been found to include worsening of the child's illness and the child asking questions about the illness more frequently (16), older age (24), onset of sexual activity by adolescents and to protect others from becoming infected (3, 24, 54).



Disclosure of children's HIV status has been compared with disclosure of other chronic diseases that children live with, including cancer. Studies have found that children with cancer generally have better coping skills and fewer psychosocial problems when properly informed about their health situation and the nature of their disease (56, 57).

As early as in 1999 the American Academy of Pediatrics strongly recommended disclosure of HIV status to school-age children, and that all adolescents should be fully informed about their HIV status (5). This is supported by the World Health Organisation's (WHO) guideline on HIV disclosure counselling for children up to 12 years of age from 2011 (58). Other authors with a health care perspective have also contributed in giving recommendations and advice regarding the disclosure process (22, 25-27). Comparing the view of a health care professional in the USA and in South Africa suggests that health care professionals generally support disclosure across cultures. However, disclosure in developed countries and in SSA still requires different considerations due to the different cultures and social constructions (26). Furthermore, in both developed and developing countries it is generally recommended that the disclosure process should be viewed as a process rather than a single event (4, 21-23).

Literature on children and adolescents disclosing own HIV status to others is rare in the Sub-Saharan setting. Studies from SSA, Europe and the USA reveal that because of fear of stigma many HIV positive adolescents restrict the number of people they would disclose their status to (8, 59-61). Disclosing ones status to a boy-friend or girl-friend has been found to be particularly challenging (60, 61). However, findings from the USA suggest that those adolescents who chose to disclose report greater self-competence with their friends (43, 60), increased social support and decreased problem behaviour (43). On the contrary, it has been found that self-disclosure is not related to self-concept or problem behaviour, however, the same study found a significant increase in CD4% of those who had disclosed their status to friends compared to those who had not disclosed their status (62). This finding might imply that self-disclosure is positively related to adherence to treatment regimens, considering the increase in CD4%. Overall, the children and adolescents who choose to disclose their status to friends seem to be outnumbered by those who choose not to disclose, predominantly due to fear of stigma, or their caregivers fear of stigma.

Although the majority of what has been written on the subject of disclosure is from developed countries, such as the USA and countries within Europe, there is now a growing body of literature also from Sub-Saharan Africa (3, 6, 17, 18, 21, 24, 26, 28, 50, 52). However, a greater deal of the literature is based on the caregiver's and health professional's point of view, little is written from children's and adolescents' point of view.

To sum up, it seems the level of disclosure of children's and adolescents' HIV status remains low, in spite of documented positive effects of disclosure. The barriers to disclosure are many, and I previously questioned whether these are all realistic or not, and how these can be addressed. Very little literature exists on children and adolescents in SSA who disclose their status to peers. Several studies indicate that children and adolescents disclosing to peers is a rare event, but still, some do disclose their status and this would be interesting and important to gain more information on. Furthermore, as mentioned above, little is written on this issue from the point of view of HIV positive adolescents living in SSA. The above findings represent gaps in the literature which I have tried to investigate further in this study.

### **2.1.2 Literature on stigma**

Goffman related the process of stigma back to the Greeks who originated the term stigma as "*bodily signs designed to expose something unusual and bad about the moral status of the signifier*" (63, p.1). Goffman further explains how the stigmatised person is viewed as different and discounted by other people, easily becoming a victim of discrimination (63). However, Goffman stresses that stigma can not only be seen as a language of attributes, but also as a language of relationships, meaning that it is not only the attribute in itself that causes stigma, but rather the relationship between that attribute and what other people may ascribe to it (63). The Joint United Nations Programme on HIV and AIDS (UNAIDS) has defined HIV related stigma and discrimination as "...a '*process of devaluation*' of people either living with or associated with HIV and AIDS...*Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status*" (64). Stigma and discrimination intensify the suffering of the disease and are major contributing factors to the secrecy related to HIV, resulting in many people living with HIV (PLHIV) keeping their status a secret (8, 15, 37, 39). Furthermore, stigma is said to be one of the contributing factors to sustaining the epidemic due to secrecy and denial (37, 39, 40). A literature review by Mbonu et al shows that HIV and AIDS stigma is still highly present in SSA (65). Studies from Zimbabwe and South Africa show how extreme the denial of the disease can become,

when people that are clearly dying from AIDS are said to have some other sort of illness and are hidden away from the rest of the community (31, 39). Several studies have found that fear, ignorance, lack of basic knowledge and misconceptions about the disease are some of the factors contributing to stigmatisation (29-37). Misconceptions about HIV include believing one can get infected by sharing a meal, through witchcraft or a mosquito (29, 37). HIV is furthermore strongly associated with being promiscuous, resulting in attitudes that HIV positive people can only blame themselves, getting little support from others (29, 37, 39). HIV and AIDS stigma is in addition accompanied by other types of stigma, such as stigma related to poverty, gender and family status (29, 66, 67). This is important to note when dealing with HIV and AIDS stigma, since it is suggested that the majority of AIDS affected children live in poverty and many of them are also left orphaned (68).

Different types of HIV and AIDS stigma are described in the literature, including stigma against those living with HIV and AIDS, internalized stigma, and stigma towards those affected by HIV and AIDS (secondary stigma) (29, 68). Effects of HIV and AIDS stigma include physical and social exclusion, gossiping, loss of identity, role or respect (29). Internalized stigma refers to a situation where the person living with HIV or AIDS starts to believe in the attitudes of the people stigmatizing, devaluating him or herself on the basis of perceived stigma (68). Some of the coping mechanisms used to handle stigma include disclosing one's status to seek support, at the same time as non-disclosure is also seen as a coping mechanism in order to protect oneself, spending time with other HIV positive people, engaging in HIV and AIDS education, or turning to religion for comfort (29).

Factors associated with decreased levels of social stigma include increased knowledge about HIV (69, 70), and peer influence (frequency of discussing HIV and AIDS with friends) (69). It has furthermore been found that in an African setting, family members, teachers and elders have more influence on young people regarding dispelling myths about HIV and AIDS and in being sources of useful information, compared to the mass media (69). Another important factor in reducing stigma is the availability of ART. Studies from Botswana and Brazil suggest that access to ART is associated with lower levels of perceived stigma towards oneself and holding stigmatising attitudes toward others (66, 70). This finding is related to ART transforming AIDS from a fatal to a chronic and manageable condition, which results in a change in the way people perceive the disease (66). The availability of ART has helped individuals with advanced HIV and AIDS symptoms in diminishing their visible symptoms of

disease, enabling them to return to socially and financially productive lives. This contributes to a higher rate of testing for HIV and willingness to initiate HIV treatment (71, 72). As a positive consequence, ART can ultimately reduce HIV and AIDS stigma.

Children are affected by HIV-related stigma in a number of different ways, including directly, when the child is the subject to stigma, and indirectly, which is when caregivers are the subject of stigma (68). Most studies to date look at the indirect impact. For example, stigma has been found to influence the decision of parents or guardians to tell their child that he or she is HIV positive – undermining the child’s ART adherence (6). Parents or guardians with a HIV-infected child on ART, and who struggle to facilitate the child’s ART adherence, refrain from seeking support from neighbours or other community members because of non-disclosure and fear of stigma (15, 38).

Several studies have focused on effects of- and factors influencing HIV stigmatisation and discrimination (36, 37, 39, 69), not so many have looked at what mechanisms young people use to cope with the stigma (8, 41). Studies from Botswana and Tanzania have found that adolescents adhere to ART to avoid getting sick, and keep their status a secret in order to protect themselves from stigmatisation and discrimination (8, 41). However, it has also been found that adolescents cope with stigma through knowledge and understanding about their situation, which give them a sense of strength and control (41).

Summing up the literature on stigma, it is evident that stigmatisation of PLHIV and AIDS further complicates living with a serious disease, and makes prevention and treatment efforts challenging. A limited number of studies have focused on what resources HIV positive adolescents in SSA use to cope with stigma, during this study I have investigated further what some of these resources could be.

### **2.1.3 Literature on mental health and social support**

It is suggested that HIV positive children and adolescents experience high rates of psychosocial challenges compared to the average population, with evidence from the USA (42-45) and SSA (46-48). Challenges include disclosure, anxiety about medical prognosis, physical appearance and body image (wasting and dermatologic conditions), and disturbances in neurocognitive development (45). HIV positive adolescents from both the USA and South Africa have reported emotional problems such as feeling angry and fearful about the virus,

emotional pain due to loss of biological parents, minimally supported foster arrangements, worrying about who will take care of them, poverty, crime, drug use, violence and stigma (42, 47, 48). It is furthermore suggested that children with HIV are at risk for psychosocial problems such as anxiety and depression and disruptive behaviours (44, 73). However, in spite of these stressors, some of the adolescents still have a positive view of the present and the future, and they are grateful for what they have (48).

On the contrary, a review providing an overview of research on psychosocial functioning of children with AIDS and HIV infection in the USA offers mixed findings, some studies finding there are greater level of problems among HIV positive children, while others find there are no significant differences between those who are HIV positive and those who are not (73). A reason for these mixed findings could be that in some studies the data are based on reports from the caregiver, which might not give an accurate picture of the children's and adolescents' real experiences. Furthermore findings from the USA suggest that HIV positive children and adolescents experience fewer problems than those who are affected by HIV and AIDS but are not positive themselves (44). This finding was related to how those who were HIV positive were part of a multidisciplinary treatment system, while those who were not directly infected did not have the same access to support within the treatment system (44). This might be an issue that needs further considerations and action.

Some of the protective influences that have been found to buffer some of the psychosocial challenges that HIV positive adolescents may be facing are strong family support and extensive supportive networks, which have also been found to contribute to how a child thrives (74, 75). Studies from both SSA and the USA have found social support and greater disclosure to be positive factors (43, 50). Being with other HIV positive children, the availability of life prolonging medications, performing daily activities like helping out at home and being able to study and keep up leisure activities has also been found to contribute to make life positive (47, 48). Furthermore, it has been suggested that daily functioning is the most significant factor of life satisfaction in both SSA and in developed countries (76).

Recent studies have found contrasting evidence to the average described situation of HIV positive children and adolescents as being subject to psychosocial problems and major challenges. Studies from Canada, Botswana and Tanzania show a new picture where

perinatally infected adolescents on ART live healthy and normal lives and view themselves as positive identities, in spite of living with a chronic disease (41, 77).

Few studies have evaluated the impact of social support groups for HIV positive children and adolescents in SSA (50). However, several studies point to the positive effects of social support as a buffer in mediating stressful events and improving emotional well-being (78, 79). It has been suggested that peer support group therapy for HIV positive adolescents positively affects their acceptance and perception of their disease, they are able to talk about their health with other HIV positive adolescents and it is also suggested that peer support groups enable the adolescents to develop good self-esteem (79). Group membership has also been related to sense of belonging and social connectedness, contributing to a sense of worth and personal integrity (80). Studies furthermore find that HIV positive youth are positive towards social support groups (4, 50). Some studies have found positive impact of perceived social support in relation to HIV positive children's psychological stress (43), whereas a study from the USA did not find that social support moderates psychological distress in a group of HIV positive adolescents (42). A suggested explanation for this finding was that adolescents' primary draw on support from friends, in this study the source of support was not assessed. Participating in social support groups have furthermore been found to be helpful to HIV positive children and adolescents adhering to medication regimens (27, 73). A literature review by De Matteo finds that this is also the case considering adherence to medication regimens in general (81).

Reviewing the literature on HIV positive children's and adolescents' mental health and well-being, most of the literature originates from developed countries, especially the USA. Less is written on the situation of children and adolescents in resource limited settings, such as SSA (46-48, 75, 76). Furthermore, the literature is mixed, with evidence pointing to HIV positive children and adolescents experiencing more mental health problems than those who are negative, and also some suggesting that this is not the case. However, little is written on adolescents thriving in spite of living with HIV, and the mechanisms behind this phenomenon. Literature on the effect of social support groups for children and adolescents living with HIV in SSA is also slim. During this study I have tried to identify some of the factors that enable HIV positive adolescents in SSA to thrive in their situation.

## 2.2 Theoretical Framework

In this study a salutogenic approach was implemented, exploring what was positive and strengthening in an HIV positive adolescent's life.

The salutogenic model builds upon the question of what causes health, rather than the more traditional question of what causes disease (pathogenesis), it considers how to “*create, enhance, and improve physical, mental, and social well-being*” (82, p. 1). Salutogenesis was introduced by Aaron Antonovsky in the late 1970s, as a theory to explain why some people become ill when experiencing stress, while others remain healthy and even thrive.

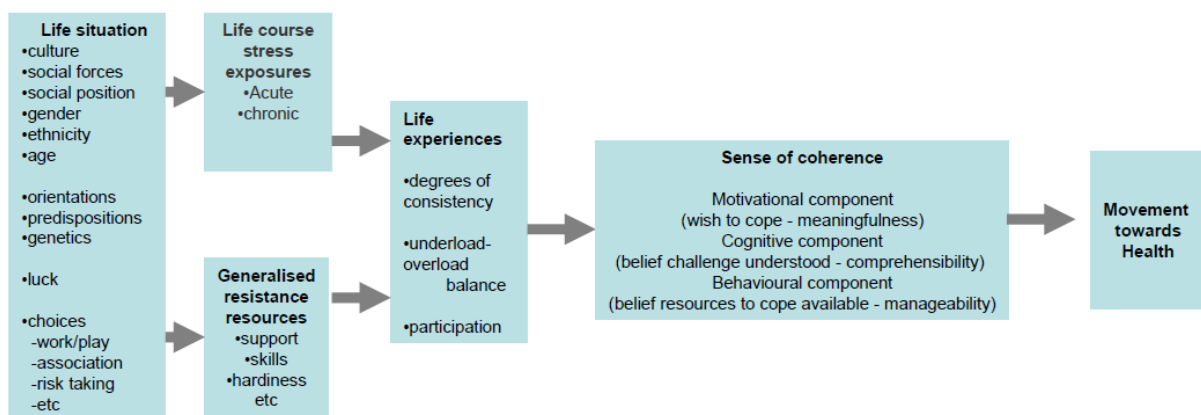
Antonovsky considered disease and stress as natural part of our environment, or omnipresent, searching to find out why many people still survive and do well (83). The core concepts of Salutogenesis are Generalised Resistance Resources (GRR) and Sense of Coherence (SOC). The GRRs are “*biological, material and psychosocial factors that make it easier for people to perceive their life as consistent, structured and understandable*” (84, p. 241), or, according to Antonovsky: “*any phenomenon that is effective in combating a wide variety of stressors*” (83, p. xii). Examples of GRRs include knowledge, coping mechanisms, self-esteem, experience, social support, money, and cultural capital, to mention some (84).

The ability to make use of the GRRs is influenced by the person's SOC, which refers to how an individual views the world, and it encompasses three components: comprehensibility, manageability and meaningfulness. Comprehensibility, the cognitive component, refers to seeing the world as understandable, that the stimuli one is confronted with make cognitive sense, and to having confidence that a sense of order can be sustained also when facing unknown territory (83). Manageability, the behavioural component, refers to the extent people feel they are equipped with resources to face events and challenges in their life. According to Antonovsky those with a high sense of manageability will not feel victimized or that life treats them unfairly when they meet unhappy challenges, they will willingly take up the challenge and do their best to overcome it (83). Meaningfulness, the motivational component, and also the one Antonovsky regarded the most crucial component, refers to how things make sense, having areas in life that are important and which one really cares about, not only in the cognitive meaning but also emotionally. People view these areas as challenges worth the energy they invest in it (83, 85). Experiencing a high degree of these

three components is associated with a strong SOC, which Antonovsky claimed to be crucial in order to cope with stressors (86). Figure 1 shows the relationship between these concepts. Antonovsky provided the following definition of SOC:

*The sense of coherence is a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement" (83, p.19).*

Figure 1: The salutogenic model (87)



As shown in figure 1, the life situation refers to the general situation a person will find him or herself in, such as gender, age, and ethnicity, but also choices in life that people are in control of. The life course stressors are acute or chronic stressors in people's lives, such as disease or being discriminated against. The balance between life course stressors and GRRs affects the way people perceive their life experiences. The life experiences which shape the SOC are shown in figure 1. Consistency implies that specific actions produce specific consequences, making life predictable, which is related to degree of comprehensibility, the cognitive component. Underload/overload, balance is related to degree of manageability, the behavioural component. Underload/overload occurs when not being able to deal with the stressors, or on the other hand, when not experiencing enough stimuli to use one's resources.



Balance is experienced when the GRRs are appropriate to what the life course stressors demand. Participation is related to degree of meaningfulness, the motivational component, and can be characterized by for instance participation in shaping outcome or participation in important decision making processes that affect a person's life (83, 85). When exposed to stressors and successfully able to deal with these, this further develops and strengthens a person's SOC (88). Furthermore, SOC is related to perceived health, mental well-being and quality of life (84), generating health promoting behaviour and a movement towards health. Antonovsky suggested that Salutogenesis can be used as a theoretical basis for developing and implementing strategies that promote health and well-being (82).

Adolescents in Botswana living with HIV experience multiple life course stressors. To have a chronic disease is a stressor in itself, but additional stressors related to HIV and AIDS include the disclosure process, adhering to medication regimens, stigma and discrimination, and in some cases adaption to new family arrangements. These life course stressors are the basis of some of my research questions, which explore what is important in the disclosure process, and how these adolescents deal with stigmatisation. The answers to these questions can contribute to knowledge about important GRRs for this group of adolescents. The purpose of this study is to identify GRRs that contribute to an HIV positive adolescent thriving. For the adolescents participating in this study, the treatment system is likely to provide some of the GRRs, such as medications, social support and knowledge regarding their disease. When adolescents perceive that GRRs are available, for instance social support, skills and knowledge, and know how to use them, it will help them deal with the stressors, which in turn can enhance the perception of mastering life and its challenges, i.e. manageability. Many of the HIV positive adolescents in Botswana have not been told about their disease, in spite of receiving treatment, and because of stigma and discrimination, HIV and AIDS is not talked about openly. The situation of being on a treatment regimen without knowing why, and also finding themselves within a web of secrecy regarding their health status, can contribute to a low feeling of comprehensibility, making life unpredictable and difficult to understand. The motivation to deal with challenges such as adhering to medication regimens might be compromised when the reason for the regimen is not understood; meaning the challenge is not seen as meaningful.

HIV positive adolescents, who thrive in spite of difficult challenges, can be said to have a strong SOC and resources at hand that enable them to cope with the challenges or stressors present in their lives. The knowledge of what these resources are can be used to promote SOC, leading to increased quality of life and well-being for this group of adolescents.

## **3 Methodology**

### **3.1 Research design**

For this qualitative study a phenomenological design was implemented. A phenomenological approach facilitates the understanding of the subjective/lived experiences to seek a deeper explanation of a phenomenon. This requires in-depth study of the subjects over an extended period of time, and the researchers own experiences and assumptions of the phenomena have to be put aside in order to fully capture the lived experiences of the subjects and how they perceive their reality (89-91). The purpose of this study is to gain understanding of the experiences of HIV positive adolescents in Botswana, and to gain knowledge and understanding about resources in these adolescents' lives that enable some of them to thrive in spite of their challenging life situations.

### **3.2 Study area**

The participants were recruited via two different sites; a hospice in one of the cities of Botswana (hereafter referred to as the urban study site), and a hospital in one of the city's neighbouring villages (hereafter referred to as the rural study site). In order to protect the participants' identities, I do not use the names of the study sites. These were not the initial planned sites of study, but as the organisation I had planned to do the data collection through had some issues approving the study in time, I had to change the site of study after I arrived in Botswana. At the time of the study, the hospice had just lost its funding, so the employees there were working on voluntary basis. The hospice is located in one of the poorest suburbs of the city; and the difference in the standard of living from here to other more wealthy parts of the city was quite distinct.

The village hospital was laid out in a quite big, spread-out village. I got the impression that the hospital was a good place to work, and it also seemed as a good place to be for the patients and their visiting relatives. This was evident through random conversations with people that I met in the hospital area. On one occasion a lady that was there with her daughter, who was in labour, invited me to come in and meet her daughter. I did not find it appropriate to come as a stranger to see this woman in labour, but I think it tells something about the good atmosphere in the hospital, people generally seemed happy there. The staff that I observed there were also very friendly, and the communication between them struck me as very positive, smiling and laughing. The staff who helped me with my study had worked

there for several years, one of them had been there as a nurse for the past eleven years. When I asked one of the nurses and the social worker who helped me with my project, whether I was right in this assumption that it was a positive place to be, they confirmed that it was a good place to work. One of the staff also told me how she appreciated that the workdays always started with a 15 minutes morning mass in the gathering area, for all the employees. The hospital had an Infectious Disease Clinic (IDC), through which the study was conducted.

### **3.3 Participants**

In a phenomenological study the aim is to get in-depth information of a given phenomenon, this can be achieved through purposeful selection of participants (89). This approach was used for this study, as far as possible, selecting participants that were likely to provide useful data about the topic.

**Participant selection:** Inclusion criteria were HIV positive adolescents between the age of 13 and 15 years old, who had been disclosed to. However, it proved challenging to recruit enough participants within the age-limit, and because of this the limit was expanded to 13-19 years. Furthermore, two of the participants were not within this age-limit, being 12 and 20 years old. They were still enrolled into the study as their age only differed by one year, and I did not want to disappoint them, since they had been asked by the gatekeepers if they would like to participate. Since the purpose of the study was to identify resources that make an HIV positive adolescent thrive, the selection of participants should include, but not exclusively, adolescents that seemed to be able to cope in their life situation. A total of 16 adolescents were enrolled in the study (see table 1 below), in addition to three key personnel, to get further information about the adolescents' environment, and how people who work closely with the adolescents understand the adolescents' situation. Furthermore, for ethical reasons, adolescents in a state of acute illness were not enrolled in the study.

The participants were identified by key personnel, or gatekeepers, at the study sites, after I had informed them about the study, its purposes and the inclusion criteria of the participants. At the urban study site, my gatekeeper was a volunteer employee, who also had the role as translator between Setswana and English during the interviews. Even though most people speak some English in this area, a translator was still needed in order for the adolescents to be able to express themselves freely. The gatekeeper knew the area very well,

as she was born and raised there herself; she also knew a great number of the people who lived there. To find adolescents and caregivers who agreed to be part of the study, she visited the adolescents in their homes, to ask them if they would like to participate in the study, and to ask the caregivers for permission. I did not take part in these first visits, in order to respect the family's privacy, as they might not be comfortable with a stranger coming to their homes without being asked beforehand. A total of five adolescents between the age of 12 and 16 were interviewed in the urban study site, of these were three boys and two girls (see table 1 below). I also interviewed the translator as a key informant at this site.

In the rural study site I first spoke to the hospital Director, who gave permission for the study to be conducted there, and who presented me to one of the doctors working in the IDC. This doctor introduced me and my study to the staff there, and teamed me up with one of the nurses working in the clinic. This nurse/gatekeeper was the one who initially identified possible participants and made the first contact with them. After this, one of the social workers at the hospital helped me when contacting participants for later interviews and a second nurse was the one who assisted me as a translator for the actual interviews. This hospital had a Teen Club, which is a peer support group for HIV positive adolescents between 13 and 19 years (92) (section 1.3), and the participants on this site were all identified via the Teen Club's member list. The first contact with some of the participants' caregivers was made at a caregiver meeting that I attended at the hospital, arranged by the same organisation that runs the Teen Club. In this meeting the nurse presented me to the caregivers of four of the adolescents that she had identified as possible participants. The nurse explained the study to them and they got the informed consent forms to take home. They all agreed for their children to participate, and that they would ask them if they would like to take part. This first gatekeeper at this site was the one who normally worked with the Teen Club there, but she was also working as a counsellor, seeing the adolescents when they came to the clinic for their regular check-ups. She presented the study to them when they came for check-ups together with their caregivers. We then contacted the caregivers and the adolescents again, by phone, to schedule the first focus group. We only managed to get confirmation from three of the adolescents, but when the day of the focus group came, they had let their friends from the Teen Club know, so altogether, eight showed up for the focus group interview. The four individual interviews that I conducted at the rural site were with participants from this focus group. As it proved challenging to find convenient times for the interviews, and it happened a

couple of times that the interviewee did not turn up at the scheduled time, the translator suggested to invite a group of participants at once, because then we would be sure that at least some would turn up. For this session I interviewed three of the adolescents from the first focus group, in addition to conducting a second focus group, but with only three participants. The last individual interview on this site was conducted after a Teen Club meeting, also with a participant from the first focus group. At this study site I interviewed both the nurses that assisted me, as key informants.

Table 1: Overview study participants

	<b>Girls</b>	<b>Boys</b>	<b>Age</b>
Individual interviews Urban	2	3	12-16
Individual interviews Rural	3	1	14-19
Focus group 1 Rural	6	2	14-20
Focus group 2 Rural	2	1	14-19
Staff urban	1		
Staff rural	1	1	

### **3.4 Setting**

Initially the interviews were supposed to take place at the premises of the hospice and the hospital, but at the hospice, this was not how it turned out. The translator thought this would be very challenging to go through with, as there were problems with transport, and that the participants then might not turn up for the interviews at all. Because of this the interviews were conducted in the participants' homes, using a room where the interviewee, the interviewer and the translator could be alone. If a room was not available (some families only had one room where they all lived), the interviews were conducted outside, behind the house, or an attempt was made to find a place that was as quiet and undisturbed as possible. Still there was always a certain amount of noise surrounding these interviews, like music from the street, chickens running around, and in one of the interviews a little brother interrupted to fetch something. At the urban study site three interviews were conducted inside, and two interviews were conducted outside.

At the rural study site all the interviews were conducted within the hospital's premises, in one of the offices at the IDC, except for one individual interview that was conducted outside. For the first interview the translator chose one of the offices, but after getting in there, the adolescents decided that they liked the room across the hall better, and we then switched, since they seemed to be most comfortable in that room. This office was used for all the focus groups and the individual interviews, except one, and the interviews were conducted without being disturbed by anyone. Because all the interviews were made over three Saturdays, the IDC-area, and also the rest of the hospital, was quite quiet and undisturbed compared to a week-day, when the clinic would have a lot of people coming in for check-ups. In the first focus group a fellow student, Ingvild Marie Kvissellien, assisted me to do additional observations during the interview, in addition to the translator. For the rest of the interviews, except one, I and the translator were the only people present in the room with the interviewees. The last individual interview was conducted outside, still on the hospital's premises, without a translator, as the interviewee was confident speaking English.

### **3.5 Data procedures**

#### **3.5.1 Data collection**

I intended to conduct focus groups at both study sites; however, because of challenges regarding transport and finding convenient interview times for the participants, focus groups were not held at the urban study site. For this study, the focus groups served as a tool in getting to know the participants, to get an idea of what the participants felt about certain themes, and as a tool in the process of selecting participants for the individual interviews. For this reason, focus groups were not run until saturation was achieved. Two focus groups were held at the rural study site, the first consisting of eight participants, the second of three participants. In both groups there were both girls and boys present. The original plan was to keep boys and girls separate in the focus groups, because I thought being in a mixed group could make them shy or uncomfortable. On the day of the first focus group, the girls that were invited had also brought two of the boys from the Teen Club. They all seemed to be really good friends and very comfortable in each-others' company, and it became natural to have them all in the same group. I also discussed it with the translator, who worked in the clinic on a daily basis, and asked the adolescents what they felt about this, and for them it didn't seem

to be an issue. The fact that there were both girls and boys in the group did not seem to affect the adolescents in a negative way.

Focus groups can capture a broad range of ideas concerning a given topic (89), and it allows the adolescents to discuss together, they can respond to each-others ideas and it can be easier for them to talk when being with other adolescents in the same situation. Observing this interaction can potentially provide even more understanding of a phenomenon. The setting of being in a group might feel more natural compared to the in-depth interviews, inviting an honest discussion. In addition it can reduce power imbalance between the researcher and the subjects. However, peer pressure and the fear of being perceived as different by expressing different ideas and thoughts than the others, can be an issue within the age group chosen for this study. Also, in a group setting there will often be someone more dominant and talkative than others, who can end up talking on behalf of the rest of the group. Trying to overcome this, ground rules were made at the beginning of each focus group, trying to facilitate emotional ‘safety’, an environment where it feels ‘safe’ to speak, this can encourage the participants to express their honest thoughts. Mosley and Tew (93) suggest that this type of safety is the most important factor in order to achieve meaningful progress in a group.

We began the focus groups with casual talk, where everybody introduced themselves with name and age, and me and my fellow student told the participants a little bit about Norway where we are from. The participants then got the chance to ask questions about Norway, before I introduced the study and its aims. Group rules were made, the participants were invited to contribute with their own rules, when they didn’t come up with any I suggested that what was said in the group should not be told to others outside the group, we should not make fun of each-other’s contributions to the conversation, and we should try not to interrupt when someone else was talking. This was followed by playing cards as a “warming up” activity, and the participants taught me a card game that they used to play. This worked well in creating a relaxed atmosphere, where the participants talked and laughed, and seemed to be comfortable in the setting. Before starting the group interview, the consent procedure was completed. The themes for these focus groups evolved around what makes a day a good day and the issues of disclosure of HIV status and stigmatisation. After the first focus group, I identified four participants that were likely to provide rich information in an individual interview. These adolescents were the ones who were the most articulate and talked



the most in the group setting, and I got the impression that these adolescents were strong and handled their situation well.

Individual interviews were completed with 12 participants, three of these were key personnel from the study sites, five were adolescents in the urban study site, and four were adolescents from the rural study site. The interviews were conducted using a semi structured interview guide (see appendix p. 89). The semi structured interview has a prepared set of questions, covering the topics of interest for the researcher. However, the semi structured interview is flexible in how the questions are asked, they can be asked in any order, it allows for following up questions, leaving out questions if they have already been answered, and for the interviewee to touch upon other themes as well as the asked topic (89). By using this method topics of importance that the researcher may not have been aware of can be identified. The interview questions evolved around what were positive resources in the adolescents' lives, relationship with family and friends, their experiences of- and thoughts about- disclosure, and how they handled stigmatisation and challenges.

Observations were used throughout the whole research process, and for different purposes. In the urban study site, I was able to observe the participants' surrounding environment during interviews, since the interviews were conducted in their homes. It gave insight into contextual issues like poverty, socialisation customs and the interaction between family members of the interviewee. At the rural study site observations were used during the focus groups as part of the procedure of selecting participants for individual interviews. Furthermore, observations can be seen as a tool to supplement the information gained from focus groups and individual interviews. It was also very useful to see how the adolescents interacted with each-other during the focus groups. Additional observations were also made by attending Teen Club. I attended Teen Club on two occasions, the first time in the city at the original study site, and the second time at the rural study site. Since the study participants from the rural study site were all members of the Teen Club, attending Teen Club at the rural site generated particularly useful additional information.

All the participants agreed that a tape recorder could be used during the focus groups and the individual interviews. This contributed to ensure that valuable information and quotes were not missed. Also, it was easier to interact with the interviewees and to listen actively

when not being dependent on writing everything; furthermore it is sometimes not possible to write everything that is being said.

A fellow Norwegian student was assisting me for the first focus group discussion, as mentioned in section 3.4, to help by taking notes during the session, and to get a second person observing the interaction among the participants. For the second focus group my fellow student did not assist me, because several adolescents, some of them who were part of the first focus group, were waiting outside in the clinic to be interviewed. I saw it as more important that my fellow student was together with these adolescents outside, while I was doing the focus group. Furthermore, there were only three participants in the second group, which makes it easier to observe interactions and body language compared to if there were eight participants, like in the first focus group.

### **3.5.2 Data management**

After the interviews, the recordings were transcribed and saved on my laptop, which has a personal password that only I know. A back-up was saved to a memory stick, which was always stored in a safe place. The recordings were erased after they were transcribed. The transcribed documents do not contain any names that make it possible to trace the identity of the participants; the original names have been replaced with pseudonyms. The transcribed documents are marked with numbers that match a participant list that is stored separately. This will be deleted in May 2012, as promised in the research permits. The interview transcripts will be stored for two years after submission of this thesis, in case of a follow up report; this means they will be deleted in May 2014. Furthermore, what was said in the interviews in Setswana was transcribed by a local student. The transcriptions in Setswana were translated back to English by a second local student.

### **3.5.3 Data analysis**

There are different methods of content analysis, based on the goal of the study and earlier research conducted on the issue (94). For the purpose of this study, I analysed the data using directed content analysis. Using this approach means that ideas are categorised into themes, based on the research questions that the researcher set out to answer. The condensed data were organised under the different research questions, making keyword/sentences for each idea, including quotations related to the key words. Additional themes were made for data that did not fit into one of the predetermined research questions.

Step 1: Familiarising with the data, I read through the interviews several times, and also listened through the recordings one last time to make sure the transcription was really accurate.

Step 2: I coded all the interviews, using excel, one excel sheet per individual interview, one per focus group, and one for interviews with rural staff and one for the interview with the urban staff, and ended up with 75 codes/basic themes. Quotes were attached from the text explaining the codes where this was possible.

Step 3: I divided the informants into four groups: Rural adolescents (see appendix table 2, p. 91), rural staff (see appendix table 3, p.92), urban adolescents (see appendix table 4, p. 93) and urban staff (see appendix table 5, p. 93). The frequency of each keyword, under the different research questions, within a group was counted, to be able to get an impression of what ideas that seemed to be major or repetitive. This allows for identifying key elements and common patterns of the respondents answers (89). On basis of the meanings of the basic themes, 26 organising themes were identified, which the different key words were sorted under.

Step 4: I drew thematic networks using the research questions as global themes, meaning one network per research questions, and the organizing and basic themes that I had identified in the process explained above. I drew these networks in order to get a better overview of the information. It also allowed me to draw lines between themes and codes that are connected to each-other, that I might not have been able to spot without creating a thematic network (95). For instance sometimes the same basic theme appears under different organizing themes, because one theme can be involved in several processes. For instance, Teen Club appears as a basic theme under both the organising themes disclosure and supportive relations (see appendix table 2, p. 91). This is because Teen Club was seen as something positive that contributed to social support and enabled the adolescents to share their problems. But Teen Club is also a positive consequence of disclosure, without being disclosed to, one cannot be part of the Teen Club and its advantages.

## **3.6 Validity, reliability and generalisability**

### **3.6.1 Validity**

There are different perspectives regarding validation of qualitative work. According to Somekh & Lewin (96) the validity of a study refers to whether the results of the study have precisely addressed the research question. Green and Thorogood (89) define validity in a qualitative study as “*the ‘truth’ of the findings...and involves attention to the quality of analysis and techniques to aid the credibility of interpretation*” (p. 287). This can be done using several steps:

Transparency refers to providing a clear explanation of the study’s procedures, the steps on how the content analysis is conducted are explained carefully throughout the thesis, showing examples of how specific themes, or codes, were chosen (89). A triangulation of data in the form of focus groups, semi structured interviews with the adolescents and key personnel at the study sites, in addition to observations can also add to the validity of the study. Furthermore, an extended period of time at the study site allowed me to get to know the area, the people and their traditions through repeated observations. The data were collected over three months, from mid-June to mid-September 2011. Reflexivity, or the role of the researcher, is also discussed in section 3.7, showing that I have reflected on my role as the researcher and the interaction with the participants, and how the data are results of this interaction (89). Providing an understanding of the context which the data are collected in can also add credibility to the study.

### **3.6.2 Reliability**

According to Somekh & Lewin (96) the reliability of a study refers to that the truth of the findings are “*supported by sufficient and compelling evidence*” (p. 348). Green and Thorogood (89) describe reliability in qualitative studies as “*issues such as accuracy of reporting, consistency of reporting, consistency of coding, and thoroughness of analysis*” (p. 287).

There are several challenges when it comes to the reliability of this study. As qualitative study strongly relies on results from in-depth interviews, the reliability of the interviews is extremely important. Kvale and Brinkmann (97) raise the issue of whether the interviewee is

changing his or her answers during an interview and whether the interviewee will give the same answer to different interviewers. The interviews in this study are conducted in both English and Setswana, the first one which is not the native language spoken of either the interviewee or the researcher. When using Setswana, the quality of the translation greatly influences the matter of reliability of the interviews, and also when transcribing and translating the Setswana parts from the audio tape. When using English it meant that the interviewee sometimes might not be able to find the words that describe exactly what he or she was thinking, in addition, I had to make sure that the interviewee understood the questions I was asking. The translators used for this study were not chosen by me, at the first study site I had to use the translator they could provide me with there. After the Setswana parts of the interviews were transcribed and translated back to English, I realised that the translations during some of the interviews were not always accurate. It seems that part of the problem sometimes was for the translator to translate the question from English into Setswana. Perhaps it was sometimes difficult to find a Setswana word that described accurately the English question. For this reason the answers were sometimes to something else than what I had asked about. Doing the study over again, I would have had the interview guides translated into Setswana by someone who knew both English and Setswana fluently, to make sure the questions really reflected what I was asking about. Regarding the power relationship between the interviewee and the researcher which can also lead to a reliability issue regarding the interviews, this is further described and addressed in section 3.7, role of the researcher.

Steps to provide reliability in this study includes:

A tape recorder was used when conducting the interviews and the focus groups. A local Setswana speaking person transcribed the Setswana parts on the audio tape, and a third Setswana person translated these parts back to English. In addition, a fellow Norwegian student assisted me, taking notes during the first focus groups and at the Teen Club Meetings. Using quotes from the interview transcripts when doing the analysis and writing the thesis shows what data the interpretations are built on, the reader can then assess the reliability of the researchers interpretations of the data (89).

### **3.6.3 Generalisability**

According to Green and Thorogood (89) generalisability refers to “*The extent to which the findings of a study can be extended to other settings, populations or topics*” (p. 285). In

qualitative research conceptual generalisability might be the most appropriate way of addressing generalisability (89). This means that it is the concepts, or the way of making sense of the world that are generalisable from the study. Another way of thinking refers to what is context specific and what can be more generally applied (89).

This study aims to gain in-depth understanding of adolescents' experiences of living with HIV in Botswana, and what is positive and strengthening in their lives. The results gained from this study could help understand HIV positive adolescents' situation elsewhere as well. The findings from this study, to some extent, can be extended to other Sub-Saharan countries, as the contextual factors such as poverty, lack of resources, multiple family losses and issues of stigmatization and discrimination of PLHIV and AIDS, are similar to those in Botswana. On the other hand, Botswana as a society is undergoing changes through rapid modernization, as a result of diamond production and economic growth (98). This, along with urbanization and new global lifestyles contributes to changes that might be different from the rest of the Sub-Saharan area, and might put the adolescents in Botswana in a different position. However, insight into phenomena itself, in this case adolescents living with HIV and AIDS, could be extended to adolescents experiencing the same phenomena elsewhere.

### **3.7 Role of researcher**

I am previously trained as a nurse and have experience of working with people in different age groups and different life situations. I can handle meeting, and working with adolescents who are visibly ill and in a situation of crisis. Saying this, I did not take the role of nurse during the data collection for this study and it was important for me that the participants also didn't view me as a nurse because this could interfere negatively with the research process. If the participants viewed me as a nurse, different types of data could have emerged from the interviews, being focused on treatment and medications; this was not the main type of information needed for this study. I therefore tried to focus on my role as a student, aiming to learn from these adolescents' experiences of living with HIV.

Considering the power relationship that easily can become an issue, it was important that the participants understood that I was there to learn from them, and that the information they could provide was very valuable for me and for the study. The participants are the experts in their situation, not the researcher. As a white, western, educated woman I also had

to be aware that this in itself might interfere with what information the participants provided, they may provide information that they think the researcher wants to hear instead of what is the actual reality.

As far as I could, I tried to spend time with the adolescents before the interviews, which could help the adolescents become familiar with me and contribute to honest answers in the interviews. I think that to some extent this power difference between me and the participants was difficult to even out, especially at the urban study site, where I didn't have the opportunity to interact with the adolescents before the interviews. In these cases where we just came into the adolescent's homes and did the interviews without any "warming up" activities, I think it must have been difficult for the adolescents to be completely open and honest. Especially since I came from "outside", as a white woman, and there were not a lot of other white people in that area, it would have been preferable to have spent some time with the interviewees before the actual interview. On the other hand, the participants might also have viewed me as an outsider, coming into an environment where they felt safe and familiar, contributing to make them feel safe in the situation. In the urban study site the focus groups might have contributed to reduce power difference between me and the participants, as the participants then were in a group.

My thoughts about what a person needs for support and what creates well-being have developed from a nursing perspective, which sometimes focuses on biomedical rather than social issues. It was important that I was aware of this throughout the whole study. The purpose of the study was to identify possible factors that can contribute to an HIV positive adolescent thriving. These factors could be anything, and it could certainly be factors that I had not thought of before and during previous work experience with people in difficult situations. For this reason it was important that I kept my mind open and free of assumptions, to the degree this was possible, throughout the process.

I was aware that the culture I am from is very different from the culture in Botswana, ways of communicating and what is considered polite and not is different and I tried to adjust to this as far as possible.

### **3.8 Ethical considerations**

Permission to do the study was obtained from the Ministry of Health in Botswana, from the Regional Committees for Medical and Health Research in Norway, and from the Norwegian Social Science Data Services (see appendix on study permissions p. 94). In order to be allowed to do research at the original study site, I also had to complete a web based training course: “Protecting Human Research Participants”, which is a tutorial developed by the National Institutes of Health through the National Cancer Institute in the USA (99). As it turned out that I had to change the site of study (section 3.2), I had to hand in an amendment to the Ministry of Health to seek permission to change the site of study, which was approved.

Informed consent and assent was obtained from everyone that participated in the study. For participants under the age of eighteen years, consent had to be sought from their caregiver, the participating adolescents had to give assent to participate. These two different concepts of consent and assent are used by the Ministry of Health in Botswana, and I had to follow their guidelines in creating the consent and assent forms (see appendix, consent forms p. 100). In these guidelines assent is used instead of consent for participants under the age of 18 years, because persons under the age of 18 are considered too young to give an informed consent. In the urban study site written consent was obtained from four of five caregivers, for the fifth participant, a fifteen year old boy, the interview was conducted with only oral permission from the caregiver. This happened because the caregiver was not present in the homestead at the time of the interview, but the translator had visited the home the previous week, and got the permission from the caregiver.

At the rural study site, only one of the caregivers of the participants under 18 years handed back the signed consent form. These caregivers had received the consent form previously when they came to check-ups in the IDC with their children, and when the study had been explained to them by the nurse there. When scheduling the interviews, it was the caregivers that were contacted, since they sent their children to the clinic for the interviews, this was seen as giving consent for their children to participate, even though most of them did not remember to return the signed consent form with their child, as we had asked them to do in the phone conversation. The adolescents were asked to sign an assent form to show that they agreed to be part of the study. Before signing the forms it was carefully explained to the participants what the study was about and its purpose. This was repeated for every interview and focus group. The participants were also given time to read through the consent and assent



forms, where details about the study and their rights as participants were written down. However I got the impression that most participants didn't really take their time to read through this, they tended to just sign without questioning it. Because of this I tried to make sure that all the most important details were read out loud, such as the right to withdraw from the study at any time, that it was voluntary, that they didn't have to answer any questions if they didn't want to, that choosing not to participate would have no negative implications, and that their identity would be protected. The identity of the participants will be kept confidential and there will be no way of identifying the participants from this thesis.

The student who transcribed the Setswana parts did this at our house, to ensure that commitments to confidentiality were upheld. The same applied for the one who translated the Setswana transcriptions into English.

It is important to be aware that many of the children and adolescents in Botswana are taught to respect adults strictly. They might believe that they have to attend a study even though they don't feel comfortable with it, because they might believe that it is disrespectful not to (100). Some parents in Botswana believe that children/adolescents have no rights (100) which may influence the adolescent's belief of having no rights. For this reason it was of great importance that the participants understood that the study was voluntary and that it was not disrespectful, nor would it result in negative implications for them, should they choose not to attend. This is very relevant for this study since it was the participant's caregivers that were contacted when scheduling the interviews, except for one 19 year old girl that we contacted directly. It was extremely important that the adolescents really understood that the study was voluntary. Their caregiver could have told them to attend without letting them know that it was their own choice to participate or not.

The topics being dealt with in the study are sensitive themes that can be difficult to talk about and certainly sometimes could bring up bad memories and sad feelings. It was very important to let the participants know that they never had to talk about things they thought were too difficult to talk about or didn't want to talk about and that they could stop at any time or withdraw from the study if they wish to, also during interviews. Also, if a topic should become too difficult for the participant, I could give the participant the option of another theme to focus on. This became an issue during one of the individual interviews, when the interviewee, a fifteen year old boy in the urban site, became emotional and tearful when

talking about his mother, who did not treat him well. This happened towards the end of the interview, I did not continue asking the rest of the questions that I had planned to, but instead tried to focus on what he was good at doing. The translator, who knew the boy quite well, also tried to arrange a meeting for the boy and his sister with a social worker, to try to sort out the problems that they had.

No payment or gifts were given for participating in the study, but transport expenses to and from the study site for the participants were covered. This applied to all the participants in the rural study site. It can feel wrong not to give anything to the participants that contribute to the study, and especially when some of them also come from poor families. However, it would be wrong to give gifts and payment in the sense that people then might participate because of the money or the gifts. This means that people who don't feel comfortable with participating in a study might do it anyway because they get paid for it, which doesn't make participation completely voluntary. The participants were informed about this before the interviews, and it was also written in the consent and assent forms. However, refreshments were served after the interviews in the rural study site, as a compensation for spending time there. In the urban study site this was not done, because it did not feel right to bring refreshments to the interviewees when their families, neighbours and a lot of other children were so close. This would have felt unfair, and could also potentially attract unnecessary attention to the interviewee and why I was there in the first place.

Considering the benefits of the study to the participants, this study may not have any directly benefit to the participants, I also informed about this in the consent procedure. Hopefully the results of the study will contribute to new knowledge about the phenomena, and may then benefit adolescents in the future, who are in the same situation as the participants in this study.

Copies of this thesis will be sent to the two study sites through which the study was conducted and to the Ark n' Mark Trust, furthermore the results from the study may potentially contribute to an article published in a peer reviewed journal.

## **4 Results**

These results reflect the information gained from the focus groups, individual interviews with adolescents and staff, and also observations I made during the time I spent with the participants. I report on the results related to each of the original research questions, as mentioned previously. Each of the interviewed group's experiences will be reported on, meaning from the view of the rural adolescents, the urban adolescents, and the rural and the urban staff.

### **4.1 Positive resources**

A range of different positive resources were identified during the interviews with the participants. These resources evolve around self-fulfilment, the treatment system and social relationships.

#### **4.1.1 To be disclosed to**

To be disclosed to was very important to the adolescents, both from the urban and the rural study site. For the purpose of this study I define disclosure as being told about own HIV status, or to disclose own HIV status to others. All the adolescents in this study had been told about their own HIV status. However, they had been told at different ages, and some reported to have known their status for such a long time that they did not remember the disclosure process clearly anymore. The age when disclosure had taken place ranged from around 7 years old to 13 years old, with the majority being told after 12 years of age. Most of the adolescents had been told by their caregivers. The exceptions were one boy who had been told by the staff at the hospital, one girl who had been told by her aunt, and one girl who had discovered her status herself. The adolescents found it important to be aware of their own status for several reasons, including knowing why they had to keep on taking medications and go to hospitals check-ups. Serama, 13 years old from the urban site explained the importance like this: "*Because I was not going to understand why I am taking treatment*". Other reasons included that the adolescents saw it as important in order to be able to take care of themselves, Kasigo, 19 years old from the rural site expressed that "*...we have to grow up knowing our status and how to live, to share our problems with others*". Tebogo, 19 years old from the rural site also pointed to how they had to learn to accept their status: "*So that I can accept my status...be comfortable and to accept everything that happens in my life*". Furthermore, some of them also expressed a feeling of confidence because they after all knew their status,

compared to others who didn't know. Tebogo, 19, from the rural study site, explained that *"We have self-esteem because we know our status"*. The importance of disclosure was also evident in the participants' engagement when this theme was discussed. Most of them had strong opinions on it, and wanted to express why it was important to them. This was the case in both the rural and the urban study site. A boy in the urban site who did not speak much during the interview, at one point interrupted the translator to tell more about why disclosure was important to him:

*"Just only to be aware of HIV, because I used to find myself at the hospital without knowing what was going on"* (Henry, 12, urban)

To Henry disclosure meant that he no longer had to go to check-ups at the hospital without knowing the reason for it. Another boy, Thobo, felt that the person who told him about his HIV status saved his life. If he hadn't been told, he wouldn't know how to live with the disease and how to take care of himself:

*"It is important to know because I feel like that person who told me...saved my life...Without that person, maybe I would have been dead by now..."* (Thobo, 19, rural)

Both the urban and the rural staff saw disclosure as important, and they also thought the adolescents themselves saw it as important to be disclosed to. The staff related this to enabling the adolescents to know what was going on in their lives:

*"...they find it important for them to be disclosed to. So they really know what is happening in their life...they are starting to realise who they are, to take care of themselves..."* (Boitumelo, rural staff)

The staff emphasized that even though receiving an HIV diagnosis can be tough for the children and adolescents, making them feel sad, it gives them a chance to take care of themselves, the opportunity to live healthy.

*"...they can feel sad, but after all they know...they know how to look after themselves and handle themselves"* (Letsego, urban staff)

#### **4.1.2 Supportive relations**

##### **Teen club and other treatment services**

Teen club and other treatment services like counselling and medical treatment were found to be important resources for the adolescents in different ways. Teen club is a social support group for HIV positive adolescents aged 13-19 years old, which can be found in several sites throughout Botswana (section 1.3). During my stay in the field I attended a Teen Club meeting in the urban area, and one in the rural area. The Teen Club in the urban area was a quite large department, with over a hundred participating adolescents at the meeting that I attended. They were split up in two different age groups, with one group of 12-15 year olds, and one group of 16-19 year olds. I spent the day with the group of 12-15 year olds. This group was further divided into smaller groups of about 15-20 adolescents in each group, by randomisation. The Teen Club in the rural area was quite small with about 20 participating adolescents at the meeting that I attended. This group was not split by age or further divided into sub groups. The program combines both giving the adolescents knowledge and information on various themes, with health personnel available to answer questions, and sports and games activities. Themes discussed in the meetings included HIV, treatment, reproductive health, how to prevent transmission of the virus, and how to deal with different challenges related to HIV such as stigma and discrimination. Many of the adolescents attending Teen Club showed a great level of confidence, being active in games and discussions, and taking part in organising the games that were being played. During the discussion sessions with staff and health personnel, the adolescents also showed a great level of knowledge regarding the themes discussed.

All the participants at the rural study site were members of the Teen Club, and it seemed to be a very important part of their lives. It was a place where they could be open to each other, to share problems and to find support.

*"...in Teen club we are just open to talk to everyone..."*, *"...share the problems..."*,  
*"...to share something same..."* (Kasigo, 19, rural)

Kasigo illustrates how Teen Club was important to her in relation to social support. Thobo, 19, from the rural site stated that: *"Our team united us"*. I got the impression that they had a strong relationship to each-other, and seemed very comfortable in each-other's company. When recruiting participants to the first focus group, we only managed to get confirmation from three of the participants, but on the day of the focus group, eight showed up, they had all been in contact with each-other, letting the others know about the interview. They also

seemed to have a lot of fun in each-others company, talking and laughing a lot, dancing together to the music from their mobile phones. Thobo, 19, explained that "...*I have a lot of friends here...we are having a good time*". Teen Club is also related to disclosure in the sense that the members have to be disclosed to in order to participate.

Teen club seemed to make the adolescents confident and to believe in themselves. The first day I met the adolescents at the rural study site, I was waiting for them outside the hospital where we would conduct the focus group. There were a few people outside and since I had not met the participants before, I was not sure who to look for. After a while I was approached by a group of teens telling me they were from Teen Club, they assumed that I was the one they were going to meet, since I was the only white person around.

Also the rural staff saw Teen Club as a positive resource for the adolescents, expressing that "...*the Teen Club is making a big difference in these kid's life*" (Kefentse, rural staff).

None of the adolescents from the urban study site mentioned Teen Club in any of the interviews. However, the urban staff was very clear, without mentioning Teen Club specifically, that grouping HIV positive adolescents together could make them feel safe. She pointed out that because everyone was hiding their status, children and adolescents that were HIV positive felt alone and different from the others, even though other children and adolescents in their community were HIV positive, they just didn't know about each-other. She further explained that being together in a group meant that the adolescents could talk about their life and their disease. They could be open to each-other and become friends, knowing that they were not alone in their situation.

*"...sometimes they think I'm not the same as that child, maybe they are the same, they didn't know...they don't know whether they are positive just because they can't get open to each-other. They don't know, each and everybody is hiding their status"*  
(Letsego, urban staff).

Medication was reported by the adolescents in the urban study site to be one of the most important things for them. When asking about what made them feel safe or secure, all the urban participants replied one of the following statements: "*the tablets*", "*only the tablets*" or "*taking on my treatment*". Statements like these, regarding the medications, did not come up in the interviews in the rural study site.

Hospital staff were also mentioned as a positive resource by one of the rural participants. Kasigo, 19, explained how she felt supported by the nurse at the hospital: "...*just keep on supporting, just guiding, what to do and what not to do*".

However, hospital staff could also be a source of frustration among the rural participants. Sometimes they felt that they were not treated well, especially when receiving their medications, Kasigo explained it like this:

*"At the pharmacy there are some other people who make us sick, more than we are sick"* (Kasigo, 19, rural)

They felt that the staff in the pharmacy did not have enough time for them, and that they were not patient enough. Furthermore, the adolescents also thought it was a problem that they had to share the clinic with adults and patients coming for other reasons than HIV. They thought this created long waiting periods, and that there were too many people there. Some of them suggested that the clinic should allow a day a week especially for children's and adolescents' reviews. They thought this would make the venue less crowded and shorten the waiting periods. Sometimes poor continuity when it came to the doctor seeing them at their check-ups was also reported as a problem. The adolescents thought it was difficult to develop a trusting relationship to the doctors when they often had to see different doctors at each check-up.

## **Friends**

Friends were important to the adolescents both in the urban and in the rural group. Hanging out with friends was reported as one of the activities that made a day good, some also reported that being with friends was the most enjoyable part of the day. In the rural group, some adolescents also reported that they had disclosed their HIV status to some of their friends, and they said it felt good that some of their friends knew (section 4.1.4). The adolescents in the rural group seemed to find particularly good friendships with their friends from Teen club (section 4.1.2).

## **Family**

Family was reported as the most important source of support by adolescents from both the urban and the rural study site. In most cases the caregiver was the most important person, but also uncles or aunts and grandmothers were mentioned as important sources of support. Kasigo, 19, also mentioned how she felt loved by her family: "*I just think it's the love they*

*give me*". In addition to giving love and support, family was also important in relation to giving guidance in life, on what to do and not to do. Marea, 14, felt safe when someone was there to guide her in life, helping her to make the right decisions:

*"...That someone corrects my mistakes and tells me not to do, if it is dangerous, and do this, this is good"* (Marea, 14, rural)

I also got the chance to meet Marea's mother on several occasions, and she seemed to be a very resourceful person, who actively took part in her daughter's life and following up of her treatment regimen. Marea's mother was very helpful when I was scheduling the interviews, both with Marea, and also with the other adolescents, she spoke English very well, and she also ran her own little shop. On one occasion the organisation that ran Teen Club held a seminar for caregivers of HIV positive adolescents in the rural research area, which I attended. Not many of the caregivers turned up, but Marea's mother was one of the few who were there. It was quite obvious that she found it important to be there for her daughter and to access information that could help her child.

In the urban group, the family was not mentioned in relation to giving guidance. However, the church was mentioned as a place that gives guidance.

For some of the adolescents, their extended family was extra important, as they had lost their biological parents. Two of the rural participants were living with their grandmothers, because their parents had died, and one of the urban participants was living with her aunt. Kasigo told how her aunt was including her; *"My aunt, just taking me like her own child"* (Kasigo, 19, rural). Also Thobo told about how he experienced a lot of support from his extended family, after his mother died from AIDS: *"...they give me all the support they can give me...it is like I am their child, you know"* (Thobo, 19, rural). Both Kasigo and Thobo came across as extremely strong and confident adolescents, in spite of the difficulties they had been through previously.

However, extended family was also important for those who were still living with their immediate family. For example, 12 year old Mmaserame, from the urban study site told how she would go to her auntie to ask for food if her mother did not have enough to give her, and her auntie was also the one who disclosed Mmaserame's HIV status to her.



The importance of the family's role was also mentioned by the staff in both the urban and the rural study site. They were raising the importance of a supportive and encouraging family that were there for the adolescents, communicating, making them feel supported. They also saw the importance of telling their children the truth, not to hide anything for them, such as their HIV status.

*"...communication with their parents...and that the parents are not trying to hide anything from them, they feel the support..."* (Kefentse, rural staff)

The rural staff also pointed out the importance of the caregiver giving support in their children's treatment situation.

*"...go with them also for reviews...until the time when the kid says no, I think I am old enough to go there myself"* (Boitumelo, rural staff)

The staff thought that the waiting area in the hospital was often very crowded, and that this could be a stressful situation for a child who is left alone to go for his or her check-up.

However, even though most of the adolescents in this study found their caregivers and family supportive, one of the urban boys, Rrapula, 15, reported that he did not have a good relationship to his mother. When asking if he could talk to his mother about HIV, he replied that: *"I never use to talk to my mom because she hates me»*. He thought his mother hated him, and he wanted to live with his aunt rather than with his mother, his mother did not allow him to do this. This boy genuinely seemed unhappy with his living arrangement, and the difficulties with his mother was also confirmed by two of his older sisters who did not live at home anymore, but lived close by.

#### **4.1.3 Leisure activities**

Leisure activities seemed to be important in both the urban and the rural group, with sports being the most important activity. The adolescents were doing a range of different sports activities, but football was the activity most frequently mentioned. Others included table tennis, basketball, badminton and karate. A 19 year old, rural girl, Kasigo had been a member of a karate club in the city for some years, and she explained that her sport was very important to her. She used to compete in competitions, including Botswana's National competition. She participated in the first focus group interview, and when she was asked by the translator if she would like to show us some moves, she actually did. Her presentation was

followed by applause by the other participants in the focus group. Other leisure activities included playing with friends, watching TV, singing, going to the city, and one was also very passionate about drama or acting.

#### **4.1.4 Acceptance**

Acceptance and the importance of being accepted and understood were evident in different statements, especially from the rural group. Some reported that not being bullied, or being invited to a party could make a day a good day. Furthermore, some adolescents from the rural group reported to have disclosed their HIV status to some of their friends outside the teen club.

*"I told because I felt better after I told them...so that they can understand..."* (Marea, 14, rural)

Marea wanted some of her friends to understand her situation and therefore she disclosed her HIV status to them. Another of the rural girls who had disclosed to a friend expressed that it felt good to tell someone, and had not experienced that the friend had told others about her status. None of the adolescents from the urban group reported to have disclosed their status to people outside the family. One of the rural participants talked about how it could be painful to feel different or be perceived as different because of his HIV diagnosis. He especially elaborated on this when it came to romantic relationships. He was wondering what he could do when he fell in love with someone who was not HIV positive, and thought this was difficult.

In the urban group statements related to accepting were more focused on accepting their own situation, Henry, 12, mentioned to "*...focus on life*", and Katie, 16, gave this advice to an adolescent that had recently found out about his/her HIV status "*...to not give up... accept his status.*"

#### **4.1.5 Skills and meaningful activities**

Skills and meaningful activities such as school, reading, doing housework and cooking were reported by some as things they enjoyed doing. Furthermore, many of the participants, both from the rural and the urban study site, had plans or dreams for the future which included further education. Because of this school was viewed as important, but also as something they enjoyed. All of the participants also had specific things they would like to do or to be in the

future, such as a teacher, doctor, policeman, carpenter, singer and football player. One urban girl also had a dream of one day building a big house for her mother.

In summary, the adolescents in this study had access to a lot of positive resources, and many of the participants managed to effectively make use of these resources. Disclosure seemed to be an important factor for many of the participants, enabling them to take control over their own health. However, disclosure also seemed to be a key factor when it came to being able to access many of the resources that were available to the adolescents, including Teen Club, counselling services, information about HIV, treatment and how to live healthily and safely with HIV. Family was a very important source of support, as well as friends both inside and outside of the treatment system. Many had meaningful activities in their lives, both when it came to school and dreams for the future, and also leisure activities. Even though a lot of positive resources were identified, challenges were also a part of the adolescents' lives. For instance, as mentioned above, some of the adolescents experienced that the hospital staff was not always patient and that they often had to see different doctors when coming for their check-ups. Furthermore, to feel different than others because of the HIV diagnosis was also mentioned. However, the resources many of the adolescents had access to, enabled them to deal with these challenges, and to talk about their problems, for the rural group, this especially occurred through Teen Club.

## **4.2 Important in the disclosure process**

There are on-going discussions in the literature on how caregivers should disclose their children's positive HIV status to them. The participants in this study had quite strong opinions that they wanted to know the truth, and that their family was the most important actors in the disclosure process.

### **4.2.1 Openness**

To be open about what was happening and to get answers to their questions were important to the participants. In the rural group many of the adolescents were of the opinion that it was important not to delay the disclosure. When asked what age they thought children should be disclosed to, they had different answers, ranging from five years old to at least ten years old. While discussing this in the first focus group, Thobo, 19, raised the issue of also understanding the caregiver's situation when it came to disclosing a child's status. Thobo said

that this was also a very difficult situation for the caregiver, and that it wasn't their caregiver's intentions to hurt them by not disclosing, but that they maybe had a fear to tell them. When the participants were confronted that maybe some caregivers didn't disclose their child's positive HIV status because they feared the child would be very sad or upset, Lerato, 14, pointed out that: *"That is why they have to start early"*. Lerato realised that she was HIV positive after seeing some papers that she was not meant to see. She asked her caregiver questions regarding her status.

*"He refused to answer me saying I am tiring him"* (Lerato, 14, rural)

To get answers Lerato turned to her grandmother, whom she could talk to and who gave her the answers she was searching for. During the focus group Lerato also felt free to ask the translator, who was also one of the counsellors at the hospital, questions about HIV.

In the interviews with the urban adolescents the age at which they thought disclosure should occur, was not discussed.

Staff from both the rural and the urban study site agreed that it was better to disclose at an early stage. One of the rural staff explained it like this:

*"...if they are younger, obviously it doesn't affect them that much, but if they are older you know, they would probably get a bit depressed..."* (Kefentse, rural staff)

#### **4.2.2 Family**

Family was regarded as important in the disclosure process, and in the rural group most participants agreed that the caregiver should be the one who disclose the child's status to the child. In addition to Lerato above, two of the participants from the urban group had not been disclosed to by their caregivers either, one girl had been told by her aunt, and one boy had been told by staff at the hospital. However, the two adolescents from the urban group did not mention it as negative being disclosed to by others than their caregiver. Staff thought the disclosure should start at home because the caregivers were those who were there with the children most of the time and who knew their children well. The staff at the rural site also emphasized that they would always be available if the caregivers needed assistance and support in the disclosure process.

*"...we are here to support and we emphasize and give them information...but it should start from home" (Boitumelo, rural staff)*

It seemed important that caregivers were open about the children's HIV status, not delaying the disclosure, and were willing to answer questions. For many it was also important that the caregiver was the one who disclosed, rather than the staff at the hospital.

### **4.3 Differences in living with HIV before and after disclosure**

Disclosure seemed to change the life situation of the participants positively; this was most evident when it came to knowledge about and understanding of their life situation.

#### **4.3.1 Knowledge**

Most of the participants in the rural study site, and some of the participants in the urban study site reported that disclosure enabled them to know how to take care of themselves. Some said that if they didn't know they wouldn't have been caring about themselves in the right way. This was one of the reasons why the adolescents saw it as important that they were disclosed to. Many of the participants stated how they were more able to take care of themselves after disclosure, such as Marea below:

*"Because now I know my status and when I grow up I can take care of myself. If I didn't know...I wouldn't be caring about myself" (Marea, 14, rural)*

After being disclosed to, the adolescents were also able to access more knowledge and information regarding their status, and how to live safely with HIV. This particularly occurred through Teen Club (discussed in more detail in section 4.1.2), where the adolescents gained knowledge on HIV, treatment, how their body works and advice on disclosure and how to handle discrimination, just to mention some. This is evident in Kasigo's advice, where she recommends others, both those that are HIV positive and HIV negative, not to get involved in multi concurrent partnerships, as this can be a route of infection for the uninfected, and also reinfection for the already infected.

*"...if you are positive or negative, just don't practice the MCP, multi concurrent partner, don't do it..." (Kasigo, 19, rural)*

Some also said that before disclosure they didn't really know the meaning of HIV.

*"I only heard that there was something like HIV...not really knowing the meaning of it"* (Henry, 12, urban)

The rural staff also confirmed that information was one of the most important things they could provide the adolescents with at the clinic.

Incidences of wrong use of medications before disclosure were also reported. Lerato told that even though she was only supposed to take the medications in the morning and in the evening, she used to take it also during the day if she had a headache, because she had been told that the medications would make her feel better. Kefilwe, 19, from the rural study site also confirmed this issue:

*"If we are not addressed there is a possibility that we can overdose on them"* (Kefilwe, 19, rural)

For some participants, when not knowing what the medications were for, and they had been told that it would make them feel better, it made sense to take the tablets whenever they felt ill.

Problems with adherence also emerged as a result of not knowing their status; Kasigo reported that she sometimes refused to take her medications, because she was angry about not knowing the reason for why she had to keep on taking the same medications.

*"...it is important to know. Sometimes I just refused to take the pills"* (Kasigo, 19, rural)

#### **4.3.2 Understanding life situation**

Understanding one's life situation can be difficult when information about why things are happening is lacking. Many of the participants, both in the rural and in the urban study site talked about having to continue taking medications without knowing why. Kasigo explained that she could not understand this: *"Why should I keep on taking the same medicine?"*. When asking for reasons for the never ending medication regimes, the most common answer the adolescents got was *"to make you feel better"*.

*"They said for me to get better. They just told me that if I don't take the pills I will continue getting ill"* (Kasigo, 19, rural)

For Kasigo, feeling angry and refusing to take her medications showed how the feeling of not knowing what was going on could contribute to make the life situation difficult and uncertain before she was told.

*"Because I was angry for them...why can I keep on taking these pills, then they just told me"* (Kasigo, 19, rural)

Kasigo experienced to finally be disclosed to, when she started to question her medication regimen, and to refuse to take her tablets.

Furthermore, having to go to check-ups at the hospital could also be confusing before being disclosed to. Henry experienced having to go to hospital check-ups without knowing the reason behind it, as shown in section 4.1.1.

Thobo expressed the importance of feeling strong and normal:

*"I will say the important things in my life right now, I'm strong, and I lead a normal life like each and every one other..."* (Thobo, 19, rural)

Thobo felt in control of his life, he knew how to lead his life, how to stay healthy and had access to social support, this might have enabled him to find peace in his situation.

Thobo also pointed out the importance of not giving up or losing hope when he was disclosed to. After disclosure he found it difficult to view himself as the same person he was before he got to know his status.

*"...I have to do whatever it takes to feel better, to be the Thobo who I saw myself as. I don't have to feel like now is the end of the world for me...my mother died of HIV...so I knew that was the reason why it happened...So I am glad I am alive..."* (Thobo, 19, rural)

Thobo knew the reason for why his mother died, but now he also know that even though he has the same disease as his mother did, he can keep on living because he knows how to take care of himself, and he is glad he has this opportunity.

Both the rural and the urban staff confirmed many of the issues that the adolescents reported above, talking about how it became difficult when the children were taking medications without knowing why, making adherence a problem, as well as confusing them, and potentially contributing to wrong use of the medications. Kefentse from the rural staff explained how children and adolescents who were not disclosed to started wondering about their medication as they grew older. Because HIV is talked about on TV and radio, and they also see the medications on for instance TV, the children are able to draw the connection between their own medication and what they see on TV. Still, no one has really disclosed to them, so they are left with their suspicions about what their medications are for.

*"...most of them will just be taking their medication not knowing this why...But as they grow up they wonder, because they hear about the HIV on TV and radio and stuff like that..."* (Kefentse, rural staff)

Kefentse also gave an example of how difficult this situation could be, when the child was curious about his or her diagnosis, asking questions, but the caregiver refused to disclose to the child.

*"...right now she is 13 and her mother is still telling her that she takes asthma medications, she is refusing for the child to be disclosed to. She is doing everything to make sure that the child doesn't...all this child knows is that she is taking asthma medications...She is getting curious because she can tell other kids are here, every time they talk about this and this, kids when they are together they will talk, so she asks her mother, the mother is like, defensive. But it can go on for a long time"*  
(Kefentse, rural staff)

Kefentse's story shows how difficult this situation can be, for the child, the caregiver and the health care staff. The mother is insisting on keeping her child's HIV status secret to her child, which must be a stressful situation, and the child is starting to get suspicious, but does not get the opportunity to discuss her worries. The health care staff can only advice the mother on what to do, but cannot force her to disclose, or disclose to the child without permission from the mother.



The staff were also pointing to how non-disclosure affected the adolescents in the way that they did not have a chance to understand the consequences of not following up, or adhering to their treatment.

*"...they should understand how it will affect them if they don't take their medications..."* (Kefentse, rural staff)

Furthermore, staff also confirmed the concern of wrong use of the medications by taking too much of it, when not being properly informed about its purpose.

*"...someone would just go and take a tablet because they were told from the beginning...this treatment is going to make them well...they thought...head ache or stomach ache...just go and take this treatment..."* (Boitumelo, rural staff)

As mentioned previously, when feeling unwell, some adolescents had reported that they took the medication because they were told that it would make them feel better.

For these adolescents it seemed that the life situation was changed in a positive direction after disclosure. This was related to being able to draw connections between events in their lives, like for instance knowing why they were taking medications, and also in the sense of being able to take care of them-selves and live healthily. It also seems that with disclosure, access to social support and knowledge becomes easier.

#### **4.4 How to deal with stigma**

Stigmatisation of PLHIV and AIDS remains a challenge in Botswana, and was very much part of the reality for the adolescents that participated in this study. Stigmatisation is the main reason for people choosing to keep their status secret. However, many of the participants showed that they were able to somehow cope with it, and some even managed to turn the knowledge of their status into something positive when dealing with stigma.

##### **4.4.1 Protect themselves**

To keep their HIV status a secret seemed to be one of the major coping strategies used by the participants to protect themselves from stigma. Most of the participants, both in the rural and in the urban study site reported that they kept their status secret from their friends and other people in the community. Katie, 16, from the urban site expressed that *"I don't tell*

*them because they will broadcast to other people".* The only one who knew about their status was their family; in most cases family included the immediate family and extended family such as uncles and aunts. Kasigo explained why she kept her status a secret like this:

*"...it is because of they will just discriminate me, I think there will just come a time when they will discriminate me, and they will just shout at me like, in school"* (Kasigo, 19, rural)

Many thought that some of the reasons for stigmatising were lack of knowledge about HIV and how it transmits.

*"...I feel like they will abandon me...I feel like they really don't know anything about HIV..."* (Thobo, 19, rural)

Kasigo also expressed similar thoughts:

*"...they think childish; they think that if you touch somebody you will get infected...they don't have to shout at you without knowing what is going on"* (Kasigo, 19, rural)

However, three of the participants in the rural site had disclosed their status to some close friends (section 4.1.4). These participants still reported that they would keep their status secret for others than these.

The rural staff explained that stigmatisation often was the reason for the caregiver not disclosing to the child in the first place, to protect their family from stigmatisation. They feared the child would tell others about his or her status. Kefentse, one of the staff at the rural study site, explained that some viewed families with HIV as promiscuous, not taking care of themselves.

*"sometimes when people are told that this family has HIV, it's like this family is careless, it's not protecting itself, it is not using condoms...they are trying to...protect their families"* (Kefentse, rural staff)

Furthermore, the rural staff recommended children and adolescents to keep their status within their family until they grew older and were able to defend themselves from stigma.

*"I think they still have to keep it within the family...at that age they are still fragile minds...until the adolescent grows up, coming to a state where they can also defend themselves verbally"* (Boitumelo, rural staff)

The urban staff confirmed in her statements that these issues applied in the city as well.

*"...if you start telling them that you are positive, most of people will run away..."*  
(Letsego, urban staff)

Most participants, both in the rural and the urban study site also reported that they would tell someone if they experienced being stigmatised. They would tell caregivers, teachers, the principal and one also mentioned to report to the social worker. To support the one being stigmatised was also mentioned. One rural girl also suggested that the one being stigmatised should talk to the person stigmatising and explain how it makes someone feel to be stigmatised.

#### **4.4.2 Confidence**

Interestingly some of the participants from the rural study site showed a high level of confidence when discussing issues of stigmatisation of PLHIV and AIDS. Some of them reported that knowing their status was a strength to them, one boy stating that *"we have self-esteem because we know our status"* (Tebogo, 19). They pointed to those out there, who were stigmatising without even knowing their own status, one girl saying that *"...at least I know my status"* (Kefilwe, 19). Thinking that maybe some of those who were stigmatising might be HIV positive themselves, without knowing, helped them to ignore the person doing the stigmatising.

Furthermore, some of the participants said they knew it was not their fault they were HIV positive, they knew they had been born with it and that they were not to blame: *"I have been born with the HIV-virus"* (Tabia, 14, rural). This knowledge and also knowing that the people stigmatising 'did not know what they were talking about', contributed to help them deal with it and to say it was better for them because they knew their status, than as for those who didn't know. They explained this by being able to take care of themselves and knowing what they were heading for, compared to those who didn't know.

The adolescents in this study seemed to have found different ways of coping with the stigma they experienced, or the stigma they perceived would occur if they disclosed their

status to the other people in the community. Many chose not to disclose their status to people outside the family because of fear of stigmatisation. However, many also found confidence in knowing their status, and managed to have a sense of pride in that they at least knew how to live their lives with HIV, compared to those who did not know their status.

#### **4.5 Summary results**

In this chapter I have reported on the lived experiences of the adolescents and staff interviewed for the purpose of this study. I have reported on how adolescents experience living with HIV, and distinguished between the experiences of those living in the rural area, and those living in the urban area. There seemed to be some situations that are experienced differently according to where the participants lived. For instance, in the urban study site, medicines were reported to be the most important source of safety, whilst in the rural study area, the family was reported to be the most important source of safety. Furthermore, the rural group seemed to gain more from support groups than the participants in the urban group did, as the urban participants did not mention this at all. However, the rural participants were all interviewed in a setting where many of their peers from their support group were also present, which probably led them to put more focus on the support group. Participants from the rural group also seemed to have confidence that they could live positively with their disease, and they felt strong because they knew their status and how to take care of themselves. However, there were also similarities between the groups, all of the participants saw it as important to be disclosed to, and most saw disclosure as important in order to be able to take care of them-selves and to understand their life situation. Furthermore, many would not disclose their status to someone outside the family because they feared that they would be stigmatised. Family and friends was important to most of them, and all of them had hopes and dreams for the future.

## **5. Discussion**

In this chapter I will discuss the results presented in the previous chapter in light of previous literature and my own reflections. The themes that will be discussed are divided into different sections, however, many of the themes are closely related to each other, and it is sometimes difficult to solely focus on one theme without mentioning one of the others in the same relation. For this reason I cross-reference as much as possible to show links between the themes. For instance disclosure is difficult to discuss without mentioning stigma and mental health, but stigma and mental health are also discussed in separate sections.

### **5.1 Disclosure as a positive resource**

In this study I found that being informed about own HIV status influenced the adolescents' life positively in different arenas of their life. This included being able to take care of themselves, to understand their life situation, to access social support, to deal with stigma, and in relation to mental health and well-being. Before I discuss these five domains more thoroughly, I will discuss the issue of disclosure of HIV diagnosis to children and adolescents more generally.

All the participants in this study had been disclosed to, which makes them an unusual group, as recent studies report on low levels of disclosure to children and adolescents in SSA as well as world-wide (19, 21, 24, 52, 53). The low levels of disclosure seem to have remained in spite of evidence of positive effects of disclosing HIV status to children and adolescents. Positive outcomes from disclosure of HIV status to children and adolescents include good adherence to treatment regimen, better access to social support, and very importantly, adolescents feel that it is important to know their status (3, 4, 6, 28, 50). Some of the barriers for disclosing children's HIV status have been found to be the caregiver's fear of psychologically damaging the child, fear of discrimination, social rejection and isolation for the child and the rest of the family if the child discloses to other people, that the child is too young to understand, and that the caregivers feel they lack information about HIV to answer potential questions (3, 17, 18, 54, 101, 102). These are barriers found worldwide, and can be seen as the caregiver's wish to protect the child. However, could it be that caregivers also delay disclosure because they are protecting themselves? Telling a child or adolescent that he or she has HIV obviously is a hard and emotional thing to do. Furthermore, by disclosing the status of a perinatally infected child, the caregiver (if it is the biological parent), often also

discloses his or her own status. A feeling of guilt for having passed on the disease to the child has also been found to be a barrier to disclosure (5), and fear of being perceived as promiscuous by people in the community if the child discloses his or her status to someone, could also be a factor in why caregivers delay disclosure.

Interestingly, one of the participants in my study, Thobo, from the rural study site, was aware of the caregivers' dilemma of disclosing, saying that they also had to forgive their caregivers for not disclosing. He expressed that it wasn't their caregivers' intention to hurt them by not disclosing, and that it was a difficult situation for the caregiver. He thought that their caregivers maybe had a fear to tell them (section 4.2.1). Thobo seemed to have a deep understanding of the dilemma their caregivers had when it came to disclosure of children's HIV status. Thobo was 19 years old at the time of the interview. His mother died from AIDS when he was about 11 years old, and now he stayed with his grandmother. Thobo had been told about his HIV status when he was 13 years old, and he saw the disclosure as a very important and even lifesaving event in his life (section 4.1.1). I will come back to Thobo's situation several times throughout this chapter.

Similar issues to those discussed when it comes to children and HIV, have been discussed in relation to children and cancer (55, 57, 103). Studies show similar patterns regarding disclosure of children's cancer diagnosis and disclosure of children's HIV status, where the caregiver may choose to tell the child part of, but not the whole truth, about the condition (103). It has been suggested that children who are informed about their cancer diagnosis shortly after being diagnosed, showed fewer signs of anxiety and depression compared to those who were not informed (57). Also in these cases, it was pointed to the importance of being informed about the benefits of and the way the treatment worked. It is argued that withholding information about the children's health status takes away their opportunity to gain knowledge about own health status and isolates them from meaningful communication regarding their disease, as will be discussed in the section below about disclosure in relation to be able to take care of themselves. Furthermore it is argued that by knowing the facts, the children are able to express worries and negative feelings, preventing feelings of loneliness and isolation (57). This could be transferred to the issue of disclosing children's and adolescents' HIV status, which is a serious and potentially life threatening condition, like cancer can also be. However, cancer can be cured, compared to HIV which cannot be cured. Furthermore, HIV is accompanied with the additional burden of

stigmatisation. The serious nature of the disease and the stigma involved are arguments for not disclosing HIV status to children and adolescents.

However, it is still important to enable HIV positive children and adolescents to create a way of living with the disease in a positive way, both when it comes to handling stigma, and the disease in itself, already from childhood age. This is difficult to achieve when the child is not informed about his or her status. When growing up with the knowledge, the child somehow gets used to the facts, compared to receiving shocking news at a higher age, when the child or adolescent might have defined the person he or she sees him or herself as. This was exemplified by Thobo, who said that after disclosure he had to do whatever it took to see himself as the boy he used to be before he was disclosed to (section 4.3.2). Mellins et al also pose an interesting view on this, arguing that the 'unknown secret' can actually be worse than knowing the reality (7). The American Academy of Paediatrics suggests that when caregivers try to protect their children by not disclosing, adverse effects might be a consequence, for instance the child starting to fantasize and making up facts about the disease that might be hurtful (5). By not telling the child there will always be a risk that the child will find out from somewhere else, maybe without a supportive context (5, 26). Furthermore, there is also evidence that children sometimes know they have HIV, even though their caregivers have not disclosed to them, and are not aware that the children know (17). The participating staff in my study confirmed this dilemma, and explained how children who were not disclosed to often started wondering as they grew older, drawing connections between their own medications and the medications they saw on for instance TV (section 4.3.2). No one had disclosed to these children, but they were left with their own thoughts and suspicions about what their medications were really for.

Negative outcomes documented from disclosure are not as many as the positive, but in studies from the DRC and Puerto Rico, youth report initial emotional reactions such as getting upset or feeling sad immediately after disclosure (3, 4). Furthermore there are reports of cases of crying, anger and symptoms of anxiety during the first week after disclosure; however, 6 months after disclosure negative emotions were uncommon in this group of youth (4). This suggests that the negative reactions might be of short duration and that the adolescents manage to overcome the initial shock or negative feelings related to receiving the truth about their disease. In spite of these feelings, the majority of the participants still thought it was better to know what they were suffering from and felt that it was a benefit to them (3, 4). The

results of my study did not suggest any negative effects of disclosure on the participating adolescents. However, the main focus of the study was to identify the positive factors, hence the question of whether something was negative with disclosure was not asked directly. On the other hand, the adolescents were invited to talk about what was good and what was bad during the disclosure process itself (section 4.2).

Even though disclosure of children's and adolescents' HIV status continue to be a much debated issue, the majority of the people involved, including caregivers, health care providers and HIV positive children and adolescents themselves, seem to agree that disclosure is important, positive and necessary in relation to many different aspects of children's and adolescents' lives. During the next part of this discussion I will look at the most important issues that emerged from the results of this study concerning disclosure of adolescents HIV status.

### **5.1.1 Disclosure in relation to enabling the adolescents to take care of themselves**

The participants in this study found disclosure important in relation to several aspects, but the one most frequently mentioned was that disclosure enabled them to take care of themselves. They related this to the opportunity to learn how to live with their condition by gaining information and knowledge about HIV and the treatment regimen, enabling them to adhere to treatment, to use the medical and support services more actively, and to protect themselves and others from re-infection and infection of the virus.

All the participants in my study were clear that it was important for them to be disclosed to, and they wanted to know their status. When we were discussing the issue of disclosure the adolescents had strong opinions on it, and it was one of the themes that was discussed most actively by the participants. Studies from both Tanzania and the DRC (3, 28, 41) report on similar findings, where children prefer to know their status. In Vaz's studies from the DRC children express gratefulness that they were told about their status as children and not when they were adults (3, 28). In spite of negative feelings at the moment of disclosure they thought it was better to know what they were suffering from. Many of the adolescents in my study, from both the rural and the urban study site expressed similar feelings, advising that caregivers should not delay the disclosure, and that it would have been worse to be told when they were adults. This view was also backed up by staff from both the rural and the urban study site, where all of them saw it as important to be open with children



and adolescents about their status. The staff, or the health care personnel's view in this study was consistent with reports from previous studies, where health care personnel are found to support disclosure to children and adolescents more often than the children's caregivers are (21, 26).

Several participants expressed that if they did not know their status they would not be able to take care of themselves and learn to live with their condition and everything that comes with it. They related being able to take care of themselves to knowledge about the HIV virus itself and their treatment regimen. Studies from Uganda and the DRC have found disclosure of HIV status to children and adolescents to be one of the factors that facilitate good adherence to drug regimens (3, 6). Studies from Kenya and Thailand also suggest that caregivers, in spite of not disclosing their children's HIV status, still perceive positive outcomes of disclosure such as improved adherence to ART (18, 19). Strong statements like the way Thobo expressed gratefulness to the one who told him about his positive HIV status (section 4.1.1) clearly illustrate how important he found disclosure to be. Thobo felt that if he was not told he might have been dead by now. All the adolescents in my study saw the importance of adhering to their treatment, and many said medication was among the most important things in their lives. This coincides with statements from children in Bikaako-Kajura et al's study from Uganda, where children who were disclosed to reported that they depended on the drugs, and made sure they did not miss a dose (6). Not missing a dose sometimes involved hiding somewhere while taking their medicine, because they did not want others to see them take it (6). Even though they were hiding away to take their medications, at least they made sure that they took them and managed to adhere. With evidence like this pointing to important, potentially lifesaving, effects of disclosure to children and adolescents, and also when considering how important disclosure was to the participants in my study, the continuing low level of disclosure implies that many HIV positive children and adolescents have their chances of survival undermined.

The participants in my study had very logical and realistic thoughts and reflections regarding the importance of disclosure. Considering that all adolescents at some point normally will have to start taking care of themselves, independently from their caregiver, it is important that they learn how to take care of their health and handling their HIV infection as well, the way they are also taught to help their family working in the compound, cooking and cleaning etc. Adhering to the treatment, strictly keeping the right medication times is crucial

for a person with HIV in order to keep the virus at bay. In an American study, Battles et al also point out the importance of preparing children and adolescents for independently living with a serious medical condition (43). Disclosure has proven to be a very complex and difficult issue for caregivers, however, it needs to be promoted and to be seen as an important factor in ensuring HIV positive children and adolescents' health and well-being in the future.

Disclosure also enabled the participants to use the medical and support services more actively, because they now knew what they were there for, they were no longer going to check-ups without knowing why. Disclosure meant they could ask questions and seek advice from the health care personnel when attending their check-ups. The quality of the communication with the health care personnel naturally becomes poor when the patient does not know the real reason for the consultation. It makes it impossible for the patient to ask relevant questions about his or her health condition, at the same time as it is difficult for the health care personnel to give the patient advice about how to best handle his or her condition. One of Vaz et al's studies from the DRC confirms this dilemma, reporting that the children rarely communicated directly with health care providers about their illness before disclosure (28). Furthermore, a study from Romania suggests that children and adolescents, in the context of ART, who are informed about their HIV status, might receive closer clinically monitoring, and that the opportunity to discuss their HIV status in light of ART might have an empowering effect on the adolescents (104). Kouyoumdjian et al also argue that children with HIV will not be able to reach their full health potential if they are not able to discuss HIV, including with their families (17).

In addition to the importance of being able to use the treatment system by knowing one's HIV diagnosis, it is also important that the treatment system is laid out in a way that facilitates good communication and a trusting relationship between the adolescent and the health care facilitator. When discussing how the adolescents in the rural group experienced going to check-ups at the hospital, the participants explained that they sometimes had negative experiences. This was due to often having to talk to different doctors, not getting the continuity of having the same doctor to relate to each time they came for their check-ups. They also experienced that the staff giving them their medications were not very patient, and that they sometimes made them feel more ill than they were. Furthermore, the adolescents' experience of their check-ups also seemed to be overwhelmed by a crowded waiting area and having to wait for a long time for their appointments. These reports could mean that the

check-up situation for some felt unsafe or even frightening, contributing to an uncomfortable experience. For the adolescents to get the most out of the treatment services, it is important that they feel safe and that the check-up is something that they see as beneficial and as a resource to them. For this reason, the recommendation that some of the rural adolescents gave regarding special days when only children and adolescents came for reviews (section 4.1.2) could be useful in making sure that their treatment environment feels safe and easily accessible. In a study from Tanzania, HIV positive children had their own ‘children’s day’, as suggested by the participants in my study (105). Furthermore, the doctors were also known to the children, which was very much appreciated by the children in the study.

Many of the participants showed a very mature and constructive way of dealing with their situation, and at the same time they were clear that they would not have been so well off if they were not informed about their HIV status. In some cases I found that the level of knowledge among many of them, for instance detailed knowledge about HIV, the medications, the way the body works and issues concerning reproductive health and how to keep themselves and others safe from transmission, was above the level of what I would have expected from adolescents at this age, especially from the group as young as 12-14 years old. These findings are very similar to findings from Tanzanian, where children and adolescents who were disclosed to and enrolled into a treatment regimen also showed a significant level of knowledge; even referring to their improving CD4 counts (41). For the participants in my study, a lot of this knowledge was gained through Teen Club (explained in detail in section 4.1.2) and conversations with health care staff. Similarly the participants from the Tanzanian study accessed knowledge and skills through group activities and seminars arranged as part of their treatment regimen (41). Important knowledge as mentioned above would have been difficult to access if the adolescents were not disclosed to. When not disclosed to these issues would not have been natural to discuss with them, and it would not have been logical for them to access support groups and HIV knowledge.

The participants clearly saw disclosure as very important in order to be able to take care of themselves. When disclosed to they appreciated the importance of adhering to their treatment regimens, and they were able to have meaningful communication with health care staff, gaining important knowledge regarding their health situation. These factors contribute to enable the adolescents improving their health status, and to learn to live with a serious chronic disease in a healthy way.

### **5.1.2 Disclosure in relation to understanding life situation**

For the participants disclosure was also important in order to be able to understand and accept their life situation. There are different patterns of disclosure, from not disclosing anything at all, to partial disclosure, to full disclosure. According to Wiener et al partial disclosure is the most common form of disclosure, which means that the child is told something, but not everything about his/her condition (55). In addition, several studies suggest that a number of caregivers provide their children with deflecting information about their disease, with evidence from SSA, Europe, the USA and Asia (16, 19, 24, 54). Giving the child deflecting information includes telling the child that he or she has a lung disease, allergy, or explicitly lying to the child by saying that he or she is sick, but does not have HIV (19, 24). In my study many of the participants, both in the rural and the urban area, seemed to have been partly disclosed to before being fully disclosed to. Many reported that before disclosure they were told that they had to take the medications to stay healthy and to prevent them from getting ill, or to make them feel better. Many of the participants expressed that they did not understand what was going on in their life in relation to having to take medications every day and go to hospital check-ups. When they were told that the medications were going to make them feel better, it was difficult to understand why they had to keep taking them when they did not feel ill.

The situation of not understanding what was going on clearly created a feeling of confusion. Kasigo from the rural study site reported that she sometimes refused to take her medications because she was angry for not knowing why she had to take them. Similar reports are found from a study in Uganda, where children who were partly disclosed to had poor adherence and were questioning their medication regimen (6). In my study there were also examples of taking the medications at the wrong times and taking too much of it, due to lack of information about the medication regimen and the reason for it.

Studies from South Africa and the United Kingdom reveal that children frequently ask questions about their disease, and that caregivers still avoid to disclose to the child, giving other explanations than the truth or avoiding the question (17, 54). Similar situations were also reported by the participating health care staff in my study. Kefentse, one of the rural staff told about a situation with one of her patients, a 13 year old girl with HIV who had still not been disclosed to (section 4.3.2). The girl was starting to get curious, asking her mother questions about her disease. The mother kept telling her the medications were to treat asthma,

refusing to disclose to her child and doing everything she could to make sure the girl did not find out she was HIV positive. This is an example of how caregivers still fear to disclose their children's HIV status to their children, and how this situation can become very stressful, and does not enhance a good, trusting relationship between the child and the caregiver. Rather the opposite happens, when the caregiver feels that she needs to lie to her daughter, protecting her from what she sees as 'the harmful' truth, and the child is left to draw her own conclusions on what is wrong with her. This situation was also very difficult for the health care staff, who saw how disclosure would be beneficial for the girl, and how the girl was confused and curious about her situation. However, Kefentse could not disclose to the girl without permission from the girl's mother.

In a case study from South Africa, Pfaff discusses a similar situation on the dilemma of keeping the HIV status secret from a child (26). He discusses the concept of beneficence of knowing versus non maleficence, and how a child's knowledge of the disease can affect disease knowledge and thereby prognosis. However, Pfaff also admits that one has to consider the situation and the child's environment and cultural factors. He highlights how western cultural values focus on the individual rights; while in an African context one has to consider a more family centred approach, evaluating what is in the best interest for the family. Pfaff recommends that the disclosure should be carefully planned and that one should avoid the child discovering his or her diagnosis accidentally, which might add to the conspiracy of silence (26). I will elaborate more on the disclosure process in itself in section 5.2.

One of the rural participants, Thobo, showed clearly that he managed to relate previous life experiences to his diagnosis when he eventually was disclosed to (section 4.2.2). His mother had died from AIDS when he was around 11 years old, and when he was disclosed to at the age of 13 he knew the reason for why he had got the disease was because his mother also had it. In spite of the experience of losing his mother, and being told the truth about his HIV diagnosis Thobo expressed that he was glad he was alive, and felt that the person who told him he had HIV had saved his life. He adhered to his medications and stated that he was strong and able to lead a normal life like everyone else (section 4.1.1 and 4.3.2). Knowing what he was up against and how to handle it might contribute to a feeling of consistency and that life made sense.

For many of the participants in this study some aspects of their life were difficult to understand prior to disclosure, such as the medication regimens and hospital check-ups. Disclosure enabled the adolescents to make sense out of these life events, and also helped them to see them as meaningful and important. When it comes to the theory of sense of coherence with consistency and meaningfulness, it is quite clear that the situation changed to a more meaningful life situation after disclosure.

### **5.1.3 Disclosure in relation to access social support**

The findings from the study did not imply that any of the participants had suffered from being disclosed to; rather I found the opposite was the case. One of the most important reasons I found for supporting disclosure of HIV status to children and adolescents was that with disclosure comes an improved access to social support and treatment services, compared to if one is not disclosed to.

**Teen Club:** In the rural study site the relationship between disclosure and improved access to social support became evident through Teen Club (more on Teen Club in section 4.1.2), which can only be accessed by those who are disclosed to. Teen Club was part of the treatment system, which will be elaborated more on in section 5.3. All the participants from the rural study site were members of the local Teen Club, which was without doubt a huge resource for these adolescents, both when it came to social support and gaining knowledge about their condition. From the meetings I had with the group from the rural study area I got the impression that they had a lot of fun together, they trusted each other and the members were supportive and cared about each other. Kasigo mentioned how disclosure was important to her in relation to being able to share problems with others, and how it was good to be able to “*share something same*” see (section 4.1.2). Kasigo’s statement shows how it can be strengthening to engage with others who have similar life experiences as oneself, which can prevent feelings of loneliness in ones’ situation and enhance the feeling of belonging (80). Teen Club provided the opportunity to meet other adolescents in the same situation, and in a safe environment where they did not worry about being looked down at or discriminated because of their HIV status. The participants expressed that it was good to have a place where they could be completely open. Expressions like “*our team united us*” (section 4.1.2) clearly explain how the adolescents felt about their support group. Peterson et al in a study from South Africa (47) report that being with others in the same situation is particular helpful, something that is also supported by the findings in this study.

The adolescents from the rural study site saw others living healthily with HIV, which helped them to not feel alone in their situation. Also the staff at the rural study site thought Teen Club made a considerable difference in these adolescents' lives, and had a very positive attitude towards the support group. When the club-meetings were held (always by a trained Teen Club facilitator that held Teen Club meetings several places in Botswana), one of the staff from the adolescents' treatment venue was always present. The presence of one of the permanent staff may have also contributed to the adolescents feeling comfortable and safe within their support group, in addition to add consistency in their lives. For these adolescents, having access to support like this represents a valuable tool in dealing with stress related to being HIV positive. There is evidence that quality social support minimizes the effects of childhood stress (88), in this case these childhood stressors could represent living with a chronic disease and limited access to economic resources. The rural adolescents seemed to be strong as a group, which was very well illustrated the first time I met them, when they approached me, saying they were from Teen Club (section 4.1.2). Approaching a stranger like this implies that these adolescents had confidence and self-esteem.

Teen Club furthermore may have contributed to the participants adhering to their treatment regimens. Being in a group together, sharing the same challenges makes it easier to approach and deal with them, especially because of the feeling of not being alone in their situation. Previous studies have found that being member of a social support group has a positive effect on adhering to medication regimens (27, 73). Furthermore, a review on the correlates between social support and adherence to medical treatment of a variety of diseases and conditions, found consistent evidence on the positive effects of social support on adherence (81). Even though this review does not focus solely on HIV treatment, it still suggests that there is a correlation between adherence and social support.

Teen Club was not mentioned in the urban study site, which was surprising, since the city they lived in had a quite big hospital department that included a large Teen Club group and other counselling services for HIV positive teenagers. This could mean that in spite of Teen Club's efforts to reach out to all adolescents within their community, adolescents are still missing out on this opportunity. Considering the positive impact Teen Club seemed to have for the adolescents who attended it, I think it is worth mentioning the importance of making sure that Teen Club is easily available to the adolescents who live within each Teen Club's geographical area. For instance, the Teen Club in the urban study area had a much

larger number of adolescents within its geographical area, compared to the Teen Club in the rural study area. This is natural since the number of people living in a city is so much higher than in a village in the country side. However, the environment in the rural Teen Club with around 20 members might be more appealing to access for an adolescent, especially if he or she has only just been disclosed to.

The Teen Club in the urban area had over a hundred adolescents participating on the occasion when I attended, which might appear as a more frightening or difficult situation for some adolescents to access. The adolescents were split into smaller groups by randomisation, which means the adolescents would often be part of new groups. For some adolescents being in a new group every time might not enhance good trusting peer-relationships the way Teen Club seemed to do in the rural area, where there was a more consistent group. Furthermore, if the Teen Club is laid out in a rich area of the city, it might not be natural for those living in the poorer area to access it, even though everyone is welcome to join. For the urban adolescents in my study it might have been better if the Teen Club was divided into smaller groups, located in different parts of the city. However, many of the adolescents in the urban Teen Club group did seem very confident and comfortable in the group setting, actively participating, while some kept themselves more anonymous, not participating so much. Even though the urban adolescents participating in my study did not mention Teen Club, the urban staff, Letsego, was very clear that it was important for the adolescents to be united in groups, because there were so many of them feeling alone in their situation, believing they were the only one with HIV in their community. Letsego underpinned the importance of openness around HIV; she wanted people to stop hiding their status. She clearly saw hiding one's status as a barrier to social support.

The relationship between social support and disclosure has been discussed by Menon et al, who argue that "*interventions to promote disclosure could facilitate access to emotional and peer support*" (50, p. 349). This coincides with the findings from my study, where the participants were in a better position to access social support after they had been disclosed to, like for instance Teen Club. Furthermore, a recent study from Canada suggests that supportive contexts, including supportive family and treatment systems enhance positive identities among HIV positive adolescents (77). Peterson et al's study from South Africa also found that adolescents with an extensive supportive network in addition to strong family support appear to cope better with HIV (47). This suggests that social support and extensive supportive



networks can have a positive influence on HIV positive adolescents' lives across different cultures and environments. In relation to supportive networks, it was quite evident how Teen Club was a positive resource for the rural adolescents in my study. For those who are not disclosed to, it is likely that they miss out on important social support by not being able to access Teen Club, or meaningfully make use of other types of social support.

**Self-disclosure:** Three of the participants from the rural study site had disclosed their status to some, or one, good friends that they trusted outside their family and the treatment system. In a setting where fear of discrimination and stigmatisation due to HIV is deeply rooted in the society, adolescents who disclose their positive HIV status to someone outside the family or the treatment system are extraordinary. The participants' motivation for disclosing their status to others was that it felt good that their friends knew, and they wanted them to understand. It was also easier to explain why they had to miss school on the days when they had to go to the hospital for check-ups. These findings are similar to findings from studies in the USA and Switzerland (59, 60), where participants experienced that disclosure made the situation easier, and they felt more self-competent with peers. Another study from the USA also suggests that greater disclosure is associated with increased social support, social self-competence and decreased problem behaviour (43). By disclosing their status to peers, the adolescents in my study showed that they were empowered and in a position to take their own decisions regarding who to disclose to and where to seek support. This indicates self-esteem and confidence.

To disclose their status to friends could also be related to seeking acceptance for who they were, which in turn also can be helpful in creating a feeling of normalcy, to not having to lie and hide aspects of one's life. This finding contradicts Thupayagale-Tshweneage's findings in a recent study from Botswana, assessing adolescents behaviours to prevent stigmatization (8). None of the participants in Thupayagale-Tshweneage's study reported to have disclosed their status to friends; they kept silent to avoid people finding out they had HIV. However, Thupayagale-Tshweneage's findings are similar to what most of the participants in my study reported; they kept silent to avoid being stigmatised and discriminated against. Keeping ones status secret is common, not only in Botswana, but also elsewhere in SSA as well as countries outside of Africa (59, 60). One of the challenges in combating the spread of HIV is the remaining stigma that surrounds HIV, which in turn contributes to people's fear to talk about the disease (8, 39). Considering resources like

disclosure and social support groups, such as Teen Club, in a greater perspective, adolescents who are confident to disclose their status to friends, could potentially contribute to break down some of the stigma associated with HIV.

When asking the rural staff what they thought about adolescents disclosing their status to others, they did not recommend this, due to the possibility of being stigmatised. However, the adolescents showed that they were able to be careful and strategic in the process of whom to disclose to. Even though they chose to share their status with some friends, they were still selective and would not tell everyone, due to fear of stigmatisation. This echoes the findings from the Swiss study, where the adolescents were quite selective with whom they would disclose to, choosing a few close friends (59). I will discuss more on the issue of disclosure and stigma in section 5.1.4. Literature on adolescents in SSA disclosing their status to friends, or someone outside the family, treatment system or school system is rare. However, there is a study on the theme from Uganda, reporting that many of the adolescents saw disclosure as a form of relationship, meaning that disclosure or non-disclosure reflected the relationship they had to the different people they were communicating with. Disclosure occurred in an environment where they felt comfortable with others (61). The adolescents in my study did not mention disclosure as a relationship, but they did report to disclose only to certain people they trusted, indicating that with these entrusted friends they were in an environment where they felt safe. Studies from the USA furthermore suggest that adolescents who disclose their status to peers, have a significantly larger increase in their CD4% compared to those who have not disclosed their status, and that they are able to have a more open and satisfactory relationship with their friends, not having to worry about what will happen if their friends find out about their status (60, 62). Furthermore, a study on HIV positive adults' experiences on going public with their diagnosis as AIDS educators reveal that the study participants found it very rewarding to finally be able to be open about their status (106). On the contrary, public disclosure has also been found to be associated with lower self-competence (43). Going public with one's status is on the extreme continuum of disclosing, and to tell some close trusted friends probably is the best place to start. However, studies suggest that most adolescents keep their status secret from people outside of the family and the treatment system, like the participating rural staff in my study also advised (7, 47). WHO has recommended the issue of social disclosure, or the benefits of identifying a 'safe' person

outside the family, as one that needs further research, as there is not much empirical literature written on the subject (58).

None of the participants in the urban study site reported to have disclosed their status to someone outside their family or the treatment system. This could be a coincidence, or it could be related to the fact that none of the urban participants mentioned any social support groups such as Teen Club, which all of the rural participants were members of. This could underpin the important role support groups potentially can have in an HIV positive adolescent's life. However, the urban adolescents still reported to experience support from their family, both immediate and extended family, this will be more elaborated on in section 5.4.

Disclosure enabled some of the participants in this study to seek social support both within and outside the family and the treatment system. The fact that the adolescents had to be disclosed to in order to attend Teen Club makes disclosure as important as Teen Club. However, it is important to mention that disclosure on its own, without access to knowledge and social support through for instance Teen Club, might not facilitate the same level of thriving as I found in this group of adolescents. It seems the combination of disclosure and social support gave the adolescents a unique group feeling, a feeling of belonging, which seemed to be some of the key factors in their development of self-esteem and coping with HIV (also important in relation to adherence to treatment). It furthermore seems that this type of support also can enhance the process of disclosing own HIV status to others, outside the family, like disclosure to friends.

#### **5.1.4 Disclosure in relation to handling stigma**

Interestingly, some of the adolescents from the rural study site found strength in knowing their own status, and reported that it gave them self-esteem. Previous research from the USA has also found that children who know their HIV status have higher self-esteem than those who do not know (5). A recent study from Rwanda furthermore identifies self-esteem as a contributing factor in resilience in children affected by HIV (107). Knowing their status made the participants in my study able to take care of themselves (as discussed in section 5.1.1), but they also pointed out that there were people 'out there' who did not know their status, and because of this did not know how to take care of themselves. They also saw that those stigmatising might be HIV positive themselves without knowing. As a strategy to resist

stigma, the adolescents felt sorry for those untested and in the dark of their HIV status. These findings echo a study in Zimbabwe (72), which observed that adults on ART, in an attempt to cope with stigma, made a distinction between ‘us’ (the HIV positive) and ‘them’ (those who do not know their status). Disclosure in relation to being able to handle stigma is also closely connected to being able to use the treatment system more effectively and meaningfully when disclosed to (as discussed in section 5.1.1). The knowledge they obtained through the treatment system not only enabled them to take care of themselves physically, but it also helped them create a form of individual sense making, to know the reality, such as how the virus is transmitted, and get confirmation that being HIV positive was not their fault, but something they had been born with. However, because of the still existing stigma, many children and adolescents are not disclosed to (3, 15-20), which means many miss out on the opportunity to effectively make use of the treatment system.

HIV-stigma remains high in Botswana, and many of the adolescents, both in the rural and in the urban study site, chose to keep their status a secret from people outside the family, as discussed in section 5.1.3. The adolescents acknowledged some of the reasons for stigmatising as lack of knowledge about HIV and how it transmits, and that people were stigmatising without knowing what they were doing. These reflections again show how the adolescents were able to make sense out of what was happening, because they had the appropriate knowledge to attempt to understand and explain the underlying causes of why people were behaving the way they did. The participants’ conceptions about the reasons for stigma are confirmed in Buseh et al’s study from Swaziland, finding that the level of knowledge about HIV and routes of transmission is closely related to the degree of social stigma (69). In spite of this knowledge, many of the adolescents protected themselves by keeping their status a secret and thereby avoiding stigma. This can be an action of both protecting themselves, but also to protect their family. These findings are consistent with findings from Switzerland, where adolescents also referred to the lack of knowledge about HIV within the general population, causing discrimination and a fear to disclose their status to others (59). However, as I mentioned previously (section 5.1.3), three of the rural participants in my study had disclosed their status to friends outside the family, enabling them to gain additional social support. As mentioned in the same section, this finding of adolescents disclosing their status to friends might have a positive impact on the situation with HIV stigma in Botswana in the future. When posing the question whether any of them had

experienced discrimination, many of the participants, in both the rural and everyone in the urban area denied ever having experienced this. This might be related to the fact that many of them refrained from disclosing their status to people outside their family and most of them did not have physical signs that could be related to HIV or AIDS. Furthermore, this might also mean that stigmatisation within the family was not a problem in these adolescents' environments, as all the adolescents reported that their family, both immediate and many in their extended family knew about their HIV diagnosis. This contradicts findings from Bukino Faso and Tanzania, which suggest that stigma, or fear of stigma also is evident within families (15, 105).

### **5.1.5 Disclosure in relation to mental health and well-being**

As mentioned in the introduction to this chapter, many caregivers fear that disclosure of children's HIV status will affect their mental health negatively (3, 17). This study did not involve any mental health assessments of the participants; neither did I include a group of participants who had not been disclosed to, in order to compare the mental health of adolescents who had been disclosed to and those who had not been disclosed to. However, I will still suggest that the adolescents in this study had not suffered negative mental health outcomes because they were disclosed to. Two studies looking at mental health outcomes and disclosure for perinatally HIV infected children and adolescents in the USA suggest that disclosure is not associated with increased levels of mental health problems or decreased quality of life (7, 51). Similar findings have also been reported in a study from Zambia, where disclosure was not found to have a negative effect on adolescents' mental health (50). Rather the opposite has been reported, Mellins et al found that children who were disclosed to experienced less depression than those who were not disclosed to (7). These findings imply that disclosure should not be delayed due to fear of a reduction in the quality of life for the child or the adolescent. Considering the participants in my study, most of them were thriving and managed to remain positive, even though they knew they had HIV and had to be on ART for the rest of their lives. Most of them had hopes and dreams for the future and had specific thoughts about what they wanted to do when they grew older. Most of them also had leisure activities which they enjoyed, and some were very passionate about these activities, finding it a very important part of their lives (section 4.1.5). The section above (section 5.1.4) shows how the adolescents were more effectively able to deal with stigma because they were disclosed to, and how they managed to create a form of individual sense making. In addition

to this, the increased ability to access social support (section 5.1.3), improved understanding of life situation (section 5.1.2), as well as being more in control of their lives by knowing how to take care of themselves (section 5.1.1), contributed to an overall good well-being among these adolescents.

The participants in this study clearly showed how disclosure was a positive resource in their lives. They managed to take control over their lives by adhering to and actively participate in their own treatment regimens, they understood their life situation, were able to access social support and adapt coping mechanisms related to both the disease, and social issues such as dealing with stigmatisation. Many of them were able to create a positive self-image, which in turn enhance their health and well-being in general.

## **5.2. The disclosure process**

The average age for when disclosure had occurred among the participants in this study was around 12 years old. The adolescents in the rural research area discussed their views on when and how a child should be disclosed to (section 4.2). They found it important that the disclosure process was not delayed. When discussing what age was appropriate for disclosure to occur, their answers ranged widely from 5 to at least 10 years old. Previous studies suggest that disclosure often occurs later than what these adolescents suggested. A study from Ethiopia reveals that caregivers delay disclosure to the age above 14 (52). Furthermore, Vaz et al's study from the DRC indicates that children between the age of 8 and 13 are more likely to receive deflecting information (untruthful information) than partial information about their health situation (24). The same study also revealed that caregivers, in spite of not disclosing to their children, still felt that the children should know. Studies furthermore suggest that children and adolescents generally find it important to be informed about their HIV status (3, 4, 28), similar to the participants in my study. The delay of disclosure until children are older is therefore conflicting with what HIV positive children and adolescents find important for themselves. It also seems that the caregivers' choice of not disclosing sometimes also conflicts with their own belief of what is right and wrong, considering the finding that some caregivers don't disclose in spite of feeling that the children should know. This could imply that more caregivers possibly would disclose to their children, if they felt adequately supported and equipped to deal with the child's reactions and how to deal with their fear of stigma.

Furthermore, most of the participants thought that the caregiver was the one who should tell the child, rather than a health care worker. They also saw it as very important that their caregivers were open with them, answering their questions. This was also how disclosure had occurred for most of them, being told by their caregivers. The health care staff in both the rural and the urban area also pointed out that disclosure should start from home, because the family, or the caregivers, were those who really knew the child and who would also spend a lot of time with the child in the future. However, the health care staff underpinned that they would always be there to support the caregivers in the disclosure process if they needed it. Vas et al's study from the DRC also shows that caregivers, even those who have not yet disclosed to their children, feel like they should be the ones who tell the child (24). The same study furthermore finds that some of the caregivers wish to have support from health care staff or another family member in the disclosure situation.

Two of the urban participants in my study had not been told by their caregiver, one of them had been told by health care staff, and one had been told by her aunt. Furthermore, one of the rural girls, Lerato had discovered her status accidentally, from reading a letter that was not meant for her. When she tried to ask her father about her status, he refused to answer her (section 4.2.1). This situation reflects what has been described also in previous studies, where caregivers avoid disclosure because they feel they lack knowledge to answer potential questions that the child may ask in the disclosure situation (17). Even though a lot of information about HIV and AIDS exists today, both in the developed and the developing world, findings from both previous studies and this study implies that information is not adequately available for everyone. It may also be that because of the situation with stigma people fear to access information, because it can relate them to the virus. Lerato felt that it was important that caregivers told their children the truth, and she wished that she had been told about her status earlier (she was around 13 when she found out). In a study from Puerto Rico the participants who discovered their status accidentally viewed the disclosure as a negative event, and wished that they had been told by their family or by health care providers rather than finding out on their own (4). The same study also reports that the adolescents wish they were told earlier to avoid getting surprised when they were finally told. A previous study from South Africa also highlights that there is a greater chance of disclosure being emotionally difficult if there is a lack of information in the disclosure situation (47). The adolescents reported feelings of not being able to lead a normal life and perceived shortening

of life, because of lack of information about HIV in itself and treatment (47). Another study from the USA furthermore suggests that silence and unwillingness to discuss the subject of HIV with children may reinforce the message that it is a subject too difficult to discuss, resulting in loss of reassurance and supportive information for the children (16).

In spite of Lerato's disclosure experience, she came across as a very strong and resourceful person. When her father did not answer her questions, she knew what to do, and turned to her grandmother, who gave her answers. Lerato still had questions about HIV and she had the confidence to ask the translator about things she was wondering about also during the focus group she attended. Lerato was an example of a girl who was thriving, even though she was living with HIV, and had found out about it in a less desirable way. She saw the importance of knowing her status, and she actively sought information about her condition. There are several factors that might have contributed to Lerato thriving, including support from her grandmother and friends at school, in addition to the support she received from her peers in Teen Club. I have elaborated more on Teen Club in section 5.1.3.

Consistent with what previous literature shows, the adolescents in my study also found that the disclosure process should be on-going, giving the child more information as they grow older (22). Several authors recommend that disclosure should be seen as a process, rather than an event, meaning that disclosure should be a process that goes on over time, taking into consideration the age, cognitive level and coping capacity of the child (5, 21), and trying to avoid that the child or adolescent finds out accidentally on his/her own (as happened to Lerato) or inadvertently (26). In 1999 the American Academy of Pediatrics strongly recommended disclosure of HIV status to school-age children, and that all adolescents should be fully informed about their HIV status in order to be able to make appropriate decisions about their future (5). They furthermore recommend that the child's cognitive ability and social circumstances should be considered, including close following up and on-going counselling with the caregiver. It is also recommended that the disclosure process is well planned, the caregiver prepared, with pre- and post-disclosure following up assessment of the child/adolescent (4). Blasini et al's disclosure model, tested in Puerto Rico (4), proved to be a useful tool, making disclosure a positive event for the participants. However, as good as this sounds, these carefully planned and organised steps towards a disclosure can be difficult to apply in real life, outside a study setting, especially in resource limited settings and rural areas.



An interesting observation was that the adolescents were aware of the issue their caregivers had, concerning their difficulties of disclosing their status to them. As mentioned in the beginning of this chapter, one of the rural participants, Thobo, acknowledged that it was hard for the caregivers to tell their children they had HIV and that they might be worried that the children would get upset when they got to know (section 4.2.1). This is consistent with what is found in several studies identifying barriers to disclosure of children's HIV status (19, 20, 24, 54). This was also used as an argument for Lerato on why the caregiver had to start disclosing earlier, to avoid the child getting a shock. Lerato's view was also supported by the health care staff from both the rural and the urban study site, saying that disclosure would affect the adolescents less if they were disclosed to at younger age. This discussion between the participants shows that they were able to reflect on their own and their caregivers' situation in a quite mature and realistic way. Furthermore it could be an advantage for these adolescents to bring this ability to reflect on and discuss their situation into their homes as well, as it can be valuable to have these discussions and conversations with their caregivers and families.

The dilemma of disclosure of children's HIV status is one that needs careful handling, and it needs to be done at the right time and in the right setting. However, for a child to know that he or she has a serious condition, without the caregiver discussing it with him or her could be worse than knowing the truth and being able to talk about it.

### **5.3 The treatment system as a positive resource**

#### **5.3.1 Teen Club and counselling**

In addition to Teen Club, which is discussed in section 5.1.3, counselling and regular check-ups were also part of what the treatment system offered HIV positive adolescents. The health care staff working at the treatment facilities was also a source of support to the adolescents, in addition to Teen Club, family and friends. One of the rural participants, Kasigo, expressed how the nurse at the hospital supported her, and guided her in what was right and wrong (section 4.1.2). However, the regular check-ups could also be a challenging and sometimes a negative experience for the adolescents, due to for instance often having to see different doctors. These challenges are more elaborated on in section 5.1.1.

### 5.3.2 Antiretroviral treatment

Antiretroviral treatment has changed the course of the HIV and AIDS epidemic from being a fatal disease into being a chronic and manageable condition. Not surprisingly, ART proved to be very important to many of the participants in my study. The importance of ART to this group of adolescents is closely related to disclosure, as the participants would not have had the knowledge about the importance of their medications if they were not disclosed to. The urban adolescents had a very strong confidence or trust in their medications, and the fact that they had access to ART seemed to be one of their most important sources of safety. When asked the question what made them feel safe or secure, all of the urban participants replied “*the tablets*” or “*only the tablets*” (section 4.1.2). I found it a bit peculiar that all of them answered the same to this question, and have been wondering if the translator asked the question in a way that implied that this was the answer I wanted (I will elaborate more on this in section 5.6- limitations, in the end of this chapter). On the other hand, ART is after all one of the main contributing factors to these adolescents managing to stay healthy and live long, close to normal lives, which naturally makes ART an important part of these adolescents’ lives. These findings are consistent with what Bikaako-Kajura found in a study from Uganda, where the children express similar attitudes to their medications, trusting the treatment will keep them healthy (6). Also a study from South Africa shows how life prolonging medications can contribute to coping with HIV (47). Furthermore, the urban adolescents participating in my study all lived in one of the poorest areas of the city, and sometimes had limited access to food and money. The availability of ART might have been one of the few consistent things in their life.

ART was also important to the rural participants, and as I mentioned previously, they saw disclosure as very important in order to be able to adhere to their medications. All of the participants in this study reported to understand the importance of adhering to their medications, suggesting they had good knowledge regarding their status and the treatment regimen. Previous studies also point to the improved adherence facilitated by disclosure (4, 6). Recently some studies have pointed to the effect ART potentially can have on coping with HIV-stigma. This is related to the way ART transforms the body back into a healthy state with few or no visible symptoms of having HIV or AIDS, and the fact that HIV is no longer synonymous with death (72). A study from Romania finds that knowledge of HIV status in the context of ART is related to delayed disease progression in children and teens. As

mentioned in section 5.1.1, the same study also suggests that being able to discuss their diagnosis in the light of ART could have an empowering effect for the teens (104).

What these examples show is that HIV services such as ART, counselling and support groups were important resources for the adolescents, enabling them to improve their health through knowledge and participation.

#### **5.4 Family as a positive resource**

Family was seen as the most important source of support by the participants in both the rural and the urban study site (section 4.1.2). Several of the participants felt love and support from their caregiver and extended family. Kasigo and Thobo from the rural study site are good examples of how important a supportive family can be, and in their cases, the extended family was particularly important. Both Kasigo and Thobo were orphans and lived with their grandmothers. They reported to experience a high level of support from both their caregivers (grandmothers) and the rest of their extended families. Kasigo explicitly expressed how she felt loved by her family, which made her feel supported. And Thobo expressed how his family helped him to become the person he was today. Kasigo and Thobo both came across as extremely strong and confident. They were among those who spoke the most during focus group discussions, and both of them would take responsibilities and leading positions during activities at Teen Club meetings.

Most of the urban adolescents reported to experience support from their family, both immediate and extended family. This was exemplified by 12 year old Mmaserame (section 4.1.2). Mmaserame lived with her mother, but she saw her auntie as one of the most important persons who supported her in addition to her mother, and the aunt was also the one who disclosed Mmaserame's HIV status to her. Mmaserame would go to her aunt to seek assistance, for instance if her mother did not have enough food for her. Mmaserame was empowered in the way that she knew where she could go for help. Even though Mmaserame lived in a poor area and did not always have access to all the basic needs such as enough food, she had a support network where she could seek help. Several studies have pointed to the importance of a supportive family in enabling HIV positive children and adolescents coping (47, 77, 107).

## 5.5 Theory

In this section I will discuss the results of my study in light of the theoretical framework, Salutogenesis, as described in section 2.2. The purpose of this study was to gain knowledge and understanding about the resources HIV positive adolescents living in Botswana have that contribute to some of them thriving, in spite of challenging life situations. These resources can be seen as generalised resistance resources (GRR), which are explained in detail in section 2.2. Adolescents living with HIV in Botswana experience a variety of stressors, which include being disclosed to, stigma and discrimination and adhering to life saving medications. As shown in the discussion above, the adolescents in this study had several positive resources that enabled them to deal with potential stressors in their lives. However, merely having adequate GRRs available is not enough; one still needs to have the ability to make use of these resources. The life experiences which include consistency, underload/overload/balance and participation shape the adolescents' degree of Sense of Coherence (SOC), and their ability to use their available GRRs.

The adolescents in this study had several factors which added consistency in their lives. These included access to ART, and regular hospital check-ups in relation to their treatment, even though some of the adolescents found it challenging that they often had to see different doctors for their check-ups (section 5.1.1). Furthermore, Teen Club and the presence of consistent staff in this setting, and the fact that most of the participants had a consistent family situation, living with their immediate or extended family, also added consistency in their lives. However, many of them seemed to have experienced less consistency in their life situation before they were disclosed to, as reasons for life events connected to treatment and hospital check-ups did not make sense. Through the participants' stories it is evident that this situation changed positively to a more predictable and consistent one after disclosure had occurred. Information about their health status, even though it is a chronic and serious disease, can still add positively to consistency, because they know what is going on and have the opportunity to gain knowledge about what they have to do to control it. Consistency furthermore is connected to comprehensibility, as mentioned in section 2.2, referring to seeing the world as understandable, and that the stimuli one is confronted with make cognitive sense. Considering what I have mentioned above under consistency, many of the adolescents in this study found their situation comprehensible.

As mentioned above, the adolescents had several resources, or GRRs, that enabled them to deal with stressors, contributing to a balance between stressors and GRRs. These GRRs included to be disclosed to, which is also identified as a potential stressor. However, disclosure has in previous studies been found to be stressful only in the short term (section 5.1), and in this study disclosure proved to be much more a positive resource than a stressor. This was evident through the participants' statements on how important they saw it to be disclosed to, especially in relation to be able to take care of themselves, and how it contributed to a feeling of confidence and self-esteem (section 5.1). Other GRRs identified in this study were the treatment system including social support groups, ART and available knowledge, self-disclosure, leisure activities, and friends and family. In most of the participants' cases they seemed to have adequate GRRs to deal with the stressors in their lives, meaning they experienced a balance between stressors and GRRs. This furthermore is connected to manageability, as mentioned in section 2.2, the behavioural component, which refers to the extent people feel they are equipped with resources to face events and challenges in their life.

Considering participation, the adolescents participated actively in their own treatment regimen which they, after being disclosed to, saw as meaningful considering their own future and staying healthy. Furthermore, for the rural participants, being part of Teen Club gave them the opportunity to also support other adolescents in the same situation, contributing to meaningful participation that affected other persons' lives positively. Many of them also had chores to do at home, such as helping out with the work in the compound, cooking and cleaning etc., which can be regarded as meaningful participation. Leisure activities such as sports and drama was also activities that some of the participants were very passionate about. As mentioned in section 2.2, participation is connected to meaningfulness, which is the motivational component. Meaningfulness refers to having areas in life that are important and which one really cares about. One of the challenges mentioned frequently among the participants was adhering to their treatment regimen. As mentioned previously, most of the adolescents in this study saw adhering to their treatment regimen as very important, and in other words this can be said to be a challenge they found worthy of the energy they invested in it.

Through the life experiences discussed above, it is evident that many of the adolescents in this study experienced to have SOC. Seeing the world as comprehensible was

largely related to the fact that the adolescents were disclosed to. Disclosure enabled them to understand their challenges, and disease related experiences and what they had to do to manage it, made sense. Disclosure furthermore enabled them to access and make use of GRRs that they would otherwise not been able to if they were not disclosed to, such as social support through Teen Club, gaining important knowledge about their disease, treatment and how to take care of themselves through the treatment system. This contributed to the adolescents being able to manage their lives and the stressors they were exposed to. Like for instance handling stigma was by some related to the fact that they knew their status and then how to take care of themselves, while those who did not know their status did not have this opportunity, this furthermore contributed to self-esteem for some of the participants. Disclosure was also found to be important in relation to meaningfulness, as it enabled the adolescents to see it as meaningful to invest time in handling their challenges in order to be able to live a positive and healthy life. In other words it can be said that disclosure was a main contributing GRR in enabling many of these adolescents develop and strengthen their SOC, which furthermore contributes to a movement towards health.

## **5.6 Study limitations**

This study has some limitations, especially when it comes to language barriers. The issues with the language and use of translators are discussed in more detail in section 3.6.2. The consequences of these issues included that in at least one situation I suspect the participants' answers might have been coloured by the way the translator asked the question in Setswana. This applies to the theme discussed in section 5.3.2 about what made the adolescents feel safe or secure. The fact that all of the urban adolescents answered their medications to this question, made me wonder whether the adolescents got the impression that this was the answer I wanted. Studying the parts of the interviews that are translated from Setswana into English it looks like this question was asked slightly different each time by the urban translator. In the translations this question appears as 'what protects you to feel better?', 'what makes you live better and to be secure?', 'what makes you to be secure?', '...makes you secure to live a better life?', and 'what makes you feel happy about your status?'. To some of these questions it is very natural to answer the medication; however, these different ways of asking the same question can also be a result of how the Setswana parts of the interviews were translated back to English later in the process. Another limitation can be that the gatekeeper in

the urban study site had several different roles, including being the ‘gate’ to reach the participants, the translator and also organizing the location of the interviews. In a way she had power over me, because I was totally dependent on her in order to get my interviews, which made me accept to do the interviews in the participants’ homes instead of conducting them in the hospice as I initially planned (section 3.4). Doing the interviews in the urban study site in the participants’ homes may have restricted them in how open they were during the interviews, considering they were so close to family members and neighbours during the interview situation. In addition, I had not met the urban participants on any occasion before the interviews, which means that they might not have been as open as they might have been if I had the chance to interact with them before the interviews. Furthermore, the rural participants were all members of a social support group (Teen Club), which makes it difficult to generalise the findings from this group to other HIV positive adolescents in Botswana who are not members of a support group. However, these adolescents were chosen because they were regarded as thriving, or doing well, which was one of the inclusion criteria when recruiting participants for the study. Other limitations may be that this study has not included HIV positive adolescents who are not disclosed to and who are not receiving ART, or whether the age of disclosure and the length of knowing HIV-status, affect coping mechanisms. Lastly, this is a small study, but it has provided in-depth insights into the lives of HIV positive adolescents in Botswana.

## **5.7 Conclusions**

The aim of this study was to identify positive resources that enabled HIV positive adolescents in Botswana to thrive, in spite of their complex and sometimes difficult life situation. For this qualitative study a phenomenological approach was implemented, drawing on the theory of Salutogenesis, which looks at health in relation to what creates health rather than what causes disease. Two objectives were addressed: Objective 1) what makes HIV positive adolescents thrive, in spite of a complex difficult life situation? The following research questions were identified and addressed: 1) what contributes to well-being in an HIV positive adolescent? –Are there any positive factors in his/her environment? 2) What is important for the adolescents in the disclosure process? 3) Are there any differences in coping before and after being disclosed to? 4) How do the adolescents deal with the stigma related to HIV? Objective 2) is there evidence in the participants’ narratives that Sense of Coherence

plays a role in positive coping? Through focus group discussions, individual interviews and observations several positive resources and coping strategies were identified in two groups of HIV positive adolescents in a rural and an urban area of Botswana. All the participants in the study had been disclosed to, which makes them a unique group of adolescents in a setting where many children and adolescents are not informed about their HIV status due to fear of stigmatisation and negative psychological impacts.

To be disclosed to represented an important positive resource for the adolescents that participated in this study, and they especially related this to how disclosure enabled them to take care of themselves in relation to living with HIV. Disclosure enabled them to actively take part in their treatment regimens and many of them showed a high level of knowledge concerning the nature of their disease and how to handle it. If not disclosed to, the adolescents would not have been able to adapt this important knowledge into their lives, leaving them with a decreased opportunity to reach their full health potential. Disclosure also contributed to the adolescents understanding their life situation in the sense that their treatment regimen made sense and they were able to make sense out of previous disease related experiences and loss of family members. Another very important resource facilitated by disclosure was the opportunity to access social support through support groups such as Teen Club, and seeking support from family and friends. Seeking support from friends by disclosing their status to friends outside of their family or treatment system is rare, and was a surprising finding among some of the rural participants. Disclosure furthermore contributed to coping with HIV stigma, in the way that some of the adolescents classified themselves as lucky who after all knew their status and how to take care of themselves, compared to others who didn't know their status. Knowledge about the disease enabled them to see some of the mechanisms behind the reasons for why HIV stigma remains, such as lack of knowledge, and helped them to see that they were born with the disease and was not to blame for being HIV positive. Furthermore, the treatment system in itself, including Teen Club, counselling and ART were identified as important resources in the participants' lives, providing social support, as mentioned above, and as a source of safety in order to stay healthy. Family was also an important resource, and many reported that their family was their most important source of safety and support.

Most of the participants thought that the caregivers should be the one who disclosed the status to the child/adolescent, and the age of when they thought disclosure should occur



varied from 5-10 years old. Openness and getting answers to their questions were listed as important for the adolescents in the disclosure situation.

Differences in coping before and after disclosure were evident in many of the participants' statements. Many of them explained how they were confused by their treatment regimen before they were disclosed to. They did not understand the meaning of the never ending medication regimen and the check-ups at the hospital. Furthermore, after disclosure they had improved access to support compared to what they had prior to disclosure. It seemed that these factors contributed to the adolescents becoming more confident and accepting towards their situation.

The adolescents in this study had several strategies to cope with stigma. Many kept their status a secret in order to avoid stigma. Many also seemed to be empowered to deal with stigmatisation through being disclosed to, as mentioned above. In addition, the fact that other people were unaware of their positive HIV status contributed to a feeling of self-esteem among some of the participants in this study, because they at least knew their status. As a strategy to resist stigma, the adolescents felt sorry for those untested and in the dark on their HIV status, and made a distinction between 'us' (the HIV positive) and 'them' (those who do not know their status).

These results indicate that the adolescents participating in this study had several resources, or General Resistance Resources that enabled them to cope with stigma and other challenges and stressors they were confronted with. Furthermore, it seems that the feeling of having control over one's life, having the knowledge about why the things in life are the way they are, and having the ability and confidence to handle the challenges that might come, leads to self-esteem and well-being in these adolescents' cases. Being disclosed to and having adequate social support from their families, the treatment system and friends were identified as main contributors/facilitators to these adolescents thriving.

Sense of Coherence was evident in many of the participants' stories. This was evident through all the three components that encompass the theory of Salutogenesis; comprehensibility, manageability and meaningfulness. Comprehensibility implies that the adolescents understood their challenges and life events. Manageability implies that the adolescents had the resources at hand to deal with challenges or stressors, and lastly, meaningfulness implies that the adolescents saw the challenges they were up against as

worthy the investment they put in to deal with them. However, there was a clear difference in the participants' narratives considering life before and after disclosure, suggesting that sense of coherence was considerably stronger after disclosure compared to before disclosure. Furthermore, it is possible that the most important coping resource that these adolescents had was that they were aware of their HIV diagnosis. This was the resource/factor that all of the participants in both the rural and the urban research area identified as very important. Disclosure made their life situation comprehensible, as well as it was important for the motivational factor, enabling them to see their treatment regimen as meaningful and important. There might have been a small difference in the level of confidence between the rural and the urban participants, which can be explained by the high level of social support the rural participants gained from their support group (Teen Club). The urban adolescents did not mention being part of a support group, however, most of them still came across as thriving in their situation.

This study has contributed empirical evidence on the lives of HIV positive adolescents from the perspective of the adolescents themselves. It has also put focus on adolescents living with HIV in SSA, and it has focused on HIV positive adolescents who are thriving. This contributes to fill gaps in the literature on HIV positive adolescents. The findings from this study might help adolescents in similar situations elsewhere in SSA.

To conclude, the participants in this study had several resources at hand, including being disclosed to, the treatment system and social support, which contributed to thriving in spite of a complex difficult life situation. Furthermore, several of the participants can be said to have a high sense of coherence, which can be related to their ability to use the resources they had available in managing stressors in life, enabling them to cope positively in their situation.

## **6 Recommendations**

The findings from this study clearly underpin the importance of disclosure of adolescents' HIV status. This emerges strongly from the adolescents themselves and from evaluating the effects disclosure had in their lives. Based on this evidence I would suggest that disclosure should be encouraged for all adolescents living with HIV. Furthermore, from this study it is evident that disclosure in the context of available treatment and social support facilitates advantages that disclosure alone might not be able to facilitate. This implies the importance of a well laid out treatment system which enables the adolescents to develop strength and knowledge, in addition to the availability of social support.

Considering further research, it would be interesting to do a similar study on a larger scale. Furthermore, I would also suggest comparing the Teen Clubs in regard to the adolescents' experiences of participating in a large versus a smaller Teen Club group. It would also be interesting to explore further the finding of adolescents disclosing their own status to peers. Is this a phenomenon that is becoming more common in SSA, and what are the adolescents' experiences of disclosing their status to peers?

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# Appendices

## Interview guides:

### Focus group interview guide

- What makes a day a good day?
- Do you think it is important to let children/adolescents know about their HIV-diagnosis? Why?
- What are your thoughts about stigmatisation/discrimination of people with HIV?
- What do you do if people treat you badly, ie call you bad things or exclude you from activities?
- How does, or how can, family/friends/the community support you?
- In what way can you help and support each-other?

### Interview guide for the adolescents

Gender:

Age:

Where do you live? (lived in Gaborone all life, or moved from somewhere else?):

- Can you tell me about what you do during a day? –How a ‘normal’ day would look like? (morning duties, going to school, leisure activities, etc).
- Which parts of the day do you enjoy the most?
- What things do you think you are good at? (for inst. School, helping out at home, playing football...)
- Who do you live with?
- How many children does your mother have? (do you all live together or are some of the siblings living elsewhere?)
- How is the relationship with your family/caregivers?
- Can you tell me about how you got to know that you have HIV? (who told you, when, where)
- How did you feel? (sad, scared...)
- What makes you feel safe/do you feel that someone is supporting you?
- Did you know anything about HIV/AIDS before you were told about your status?
- What do you think was good or right about how you were told about your disease?
- Do you feel that you can talk freely with your parents/caregiver about HIV, and that you get answers to your questions?
- Do you think it is important that you were told about your status? Why?
- Who knows about you disease apart from your caregiver? (do you talk to people outside of where you get treatment about HIV/AIDS?)
- What do you think are the challenges/what things are the most difficult in your situation?
- How do you handle them?
- How do people that know you have HIV treat you?
- Have you experienced to be discriminated against or in other ways been treated badly by other people? If yes, how do you react/what do you do?
- What things are important to you? (family, friends, school, support, availability of treatment, etc.)
- What do you think is your most important source of support?
- What, in the end of the day, contributes to make you feel safe?
- What advice would you give another adolescent who has just discovered that he or she is HIV positive?
- What are your goals and wishes for the future?

## Interview guide for employees

- Can you tell me about what you do in your job?
- What part of your job do you think is the best part?
- In what way do you feel that the clinic/hospital is a positive resource for the HIV positive adolescents visiting the clinic?
- Do you think that the adolescents talk openly with the nurses, social workers, doctors and others if they need assistance or help with something, if they do, what kind of questions or problems are most common among the HIV positive adolescents?
- How will you describe the relationships between the adolescents and their caregivers?
- What do you think about the issue of disclosing children's and adolescent's positive HIV status to them?
- Are there many caregivers who delay a disclosure? (How long would some wait from diagnosed until telling the child?) What are the most common reasons for not telling their children? Why DO they tell their children?
- How does the disclosure process normally proceed? (How, when, average age...)
- Do you think that one way of disclosing is better than another?
- How do you think the caregiver can be supported in the disclosure process?
- How do children and adolescents normally react when they are disclosed to?
- How much do they normally know about HIV/AIDS before they are disclosed to?
- Do you think that adolescents think it is important that they are told about their status? Why?
- What do you think makes children and adolescents living with HIV feel safe and that someone is supporting them?
- Do the adolescents disclose their status to others? (Family, friends, teachers etc.) If not, why?
- What do you think is most challenging for HIV positive adolescents?
- How do they handle this?
- Do you know how adolescents that are open about their status are treated?
- In your experience, how do you think the issue of stigmatization of adolescents living with HIV is in Botswana today?
- Have you had any experience with adolescents that have been stigmatised and what they did to handle it?
- What things do you think is the most important to adolescents living with HIV in Botswana?
- What do you think is their most important source of support?
- What do you think is the caregiver's most important source of support?
- What do you think, in the end of the day, contributes to make the adolescents feel safe?
- What advice do you think an HIV positive adolescent would give another adolescent in the same situation?
- What advice do you think a caregiver of an HIV positive adolescent would give another caregiver in the same situation?
- What do you think is the most important contribution you can do in your job to support HIV positive adolescents?

## Table 2-5: Structure of codes / themes:

(The numbers in brackets after each code/basic theme represents the frequency of how many units/interviews in which the code was mentioned)

### Table 2

#### Rural adolescents

Codes/Basic themes	Organizing themes	Global themes
Teen club (6) Able to take care of themselves (5) Share problems (2) Hospital staff (1) Learn to accept status (1?)	Disclosure (Disclosure gives access to positive resources such as...)	Positive factors
Teen club (6) Share problems (2) Social support (1) Hospital staff (1) Friends (2) Disclose to a friend (3) Caregivers (4) Grandmother (1)(3) Uncle/aunt (2) Guidance (2) Communication (1)	Supportive relations (Treatment system, friends, family)	
Sports (4) Drama/acting (1) Singing (1) Watching TV (1) Going to the city (1)	Leisure activities	
Disclose to a friend (3) To not be insulted/bullied (2) Invited to a party (1)	Acceptance	
School (2) Cooking (2) House work (1) Reading (1)	Skills/Meaningful activities	
To get answers (2) Early disclosure (2) Understand caregivers' situation (1) Caregiver should be the one who disclose (1) Grandmother (1)	Openness and family	Important in the disclosure process
Know how to take care of themselves (5) Know what HIV is (1) Adherence (1) Safety (wrong/right use of medicines) (1)	Knowledge	Differences in living with the disease before and after disclosure
Knowing why medications (3) Feeling angry (before disclosure) (1)	Understanding life situation	
Report if experience (5) Keep status a secret (4)	Protect themselves	How to deal with stigma
To know your status is a strength (1) The people stigmatizing don't know what they are talking about Born with the virus (know it is not their fault) (1)	Confidence	
Hospital staff (2) Stigma (2)	Understanding from society	Challenges
Romantic relationships (1)	Feeling different	

**Table 3**

## Rural staff

Codes/Basic themes	Organizing themes	Global themes
Disclosure Disclose to family Teen club Information/education Talk about HIV Accepting HIV	Disclosure	Positive factors
The clinic Open to each-other Supportive caregivers Communication with caregivers Disclose to family Friends in same situation Teen club	Social support	
Communication with caregivers Disclose to family Supportive caregivers	Family	
Friends in same situation Information/education Talk about HIV Accept HIV Open to each other	Teen club	
Early disclosure On-going process Answer questions	Openness	
Disclosure should start at home	Family	Important in the disclosure process
Why medications To know what is happening in their lives	Understanding life situation	
Wrong use of medication Access to information	Knowledge	Differences in living with the disease before and after disclosure
Wrong use of medications before disclosure	Safety	
Caregiver's don't disclose Keep status a secret	Protect their family	How to deal with stigma
Peer pressure Stigmatization	Acceptance	Challenges

**Table 4**

## Urban adolescents

Codes/Basic themes	Organising themes	Global themes	
To know importance of medicines (5)	Disclosure	Positive factors	
Family (5) Caregiver (4) Auntie (2) Church (gives guidance) (1)	Supportive relations		
Sports (3) Play (2) Being with friends (1)	Leisure activities		
School (3) Read (1)	Hobbies/meaningful activities		
Focus on life (1) Stay positive, don't give up (1) Accept status (1)	Accept situation		
Important to be told by family (1)	Family		Important in the disclosure process
Knowing why medications (1) Knowing why check-ups (1)	Understanding life-situation		Differences in living with the disease before and after disclosure
Knowing what HIV is (3) Know how to take care of themselves (1)	Knowledge		
Keep status a secret (5) Report if experience (3)	Protect themselves	How to deal with stigma	
Poor family relationships (1) Diseased family members (1)	Family	Challenges	
To talk about HIV (1)	Communication		

**Table 5**

## Urban staff

Codes/Basic themes	Organizing themes	Global themes
Disclosure Group activities Open about status Family aware of status	Disclosure	Positive factors
Family Caring Open about status Baylor Group activities Medications	Supportive relations	
Early disclosure When start to read Tell straight away	Openness	Important in the disclosure process
Able to take care of themselves Adherence	Knowledge	Differences in living with the disease before and after disclosure
Know why medicines	Understanding life situation	
Keep status a secret Report if experiencing	Protect themselves	How to deal with stigma
Stigma Relationship to caregivers	Feeling alone	Challenges

## Study permissions:

Telephone: (267) 363200  
FAX (267) 353100  
TELEGRAMS: RABONGAKA  
TELEX: 2818 CARE BD



MINISTRY OF HEALTH  
PRIVATE BAG 0038  
GABORONE

### REPUBLIC OF BOTSWANA

REFERENCE NO: PPME 13/18/1 PS V (178)

12 May 2011

Health Research and Development Division

Notification of IRB Review: New application

Vivian Midtbo  
Baneveien 37,  
5010 Bergen  
Norway

Protocol Title: ADOLESCENTS LIVING WITH HIV IN  
BOTSWANA: WHAT CONTRIBUTES TO AN  
HIV POSITIVE ADOLESCENT THRIVING?

HRU Approval Date: 11 May 2011  
HRU Expiration Date: 10 May 2012  
HRU Review Type: HRU reviewed  
HRU Review Determination: Approved  
Risk Determination: Minimal risk

Dear Ms Midtbo

Thank you for submitting new application for the above referenced protocol.  
This approval includes the following:-

1. Application form
2. Protocol

This permit does not however give you authority to collect data from the selected site without prior approval from the management. Consent from the identified individuals should be obtained at all times.

The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal must be submitted to the Health Research and Development Division in the Ministry of Health for consideration and approval.

Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research, Ministry of Health within 3 months of completion of the study.

Approval is for academic fulfillment only. Copies should also be submitted to all other relevant authorities.

If you have any questions please do not hesitate to contact Mr. P. Khulumani at [pkhulumani@gov.bw](mailto:pkhulumani@gov.bw), Tel +267-3914467 or Mary Kasule at [mkasule@gov.bw](mailto:mkasule@gov.bw) or [marykasule@gmail.com](mailto:marykasule@gmail.com) Tel: +267-3632466

#### **Continuing Review**

In order to continue work on this study (including data analysis) beyond the expiry date, submit a Continuing Review Form for Approval at least three (3) months prior to the protocol's expiration date. The Continuing Review Form can be obtained from the Health Research Division Office (HRDD), Office No. 9A 11 or Ministry of Health website: [www.moh.gov.bw](http://www.moh.gov.bw) or can be requested via e-mail from Mr. Kgomotso Motlhanka, e-mail address: [kgmmotlhanka@gov.bw](mailto:kgmmotlhanka@gov.bw) As a courtesy, the HRDD will send you a reminder email about eight (8) weeks before the lapse date, but failure to receive it does not affect your responsibility to submit a timely Continuing Report form

#### **Amendments**

During the approval period, if you propose any change to the protocol such as its funding source, recruiting materials, or consent documents, you must seek HRDC approval before implementing it. Please summarize the proposed change and the rationale for it in the amendment form available from the Health Research Division Office (HRDD), Office No. 9A 11 or Ministry of Health website: [www.moh.gov.bw](http://www.moh.gov.bw) or can be requested via e-mail from Mr. Kgomotso Motlhanka, e-mail address: [kmotlhanka@gov.bw](mailto:kmotlhanka@gov.bw) . In addition submit three copies of an updated version of your original protocol application showing all proposed changes in bold or "track changes".

#### **Reporting**

Other events which must be reported promptly in writing to the HRDC include:

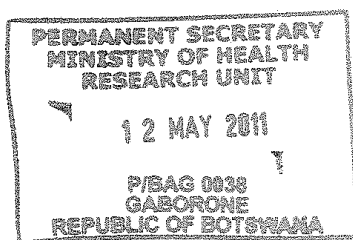
- Suspension or termination of the protocol by you or the grantor
- Unexpected problems involving risk to subjects or others
- Adverse events, including unanticipated or anticipated but severe physical harm to subjects.

Do not hesitate to contact us if you have any questions. Thank you for your cooperation and your commitment to the protection of human subjects in research.

Yours sincerely



P. Khulumani  
**For Permanent Secretary**







Marguerite Daniel  
HEMIL-senteret  
Universitetet i Bergen  
Christiesgt. 13  
5015 BERGEN

Vår dato: 04.05.2011

Vår ref: 26761 / 3 / AMS

Deres dato:

Deres ref:

### TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 18.03.2011. All nødvendig informasjon om prosjektet forelå i sin helhet 03.05.2011. Meldingen gjelder prosjektet:

26761	<i>Adolescents living with HIV in Botswana. What contributes to an HIV positive Adolescent Thriving?</i>
Behandlingsansvarlig	Universitetet i Bergen, ved institusjonens øverste leder
Daglig ansvarlig	Marguerite Daniel
Student	Vivian Midtbø

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, [http://www.nsd.uib.no/personvern/forsk\\_stud/skjema.html](http://www.nsd.uib.no/personvern/forsk_stud/skjema.html). Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://www.nsd.uib.no/personvern/prosjektoversikt.jsp>.

Personvernombudet vil ved prosjektets avslutning, 31.05.2014, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen  
  
Vigdis Namtvedt Kvalheim

  
Anne-Mette Somby

Kontaktperson: Anne-Mette Somby tlf: 55 58 25 83  
Vedlegg: Prosjektvurdering  
Kopi: Vivian Midtbø, Baneveien 37, 5010 BERGEN



I henhold til prosjektmeldingen vil utvalget være HIV-positive barn/ungdommer i alderen 13-15 år, som mottar behandling for sin sykdom ved Botswana-Baylor Children's Clinical Center of Excellence. Dette er et behandlingssenter for familier som lever med HIV, og er ett samarbeid mellom Baylor International Pediatric AIDS Initiative ved Baylor College of medicine, Princess Marina sykehus i Gaborone og myndighetene i Botswana. Noen av de unge sine omsorgspersoner og ansatte ved senteret vil også delta i studien. Deltagerne vil i henhold til prosjektmeldingen bli rekruttert fra Baylorsenteret i samarbeid med personalet ved senteret. Studenten vil delta i gruppeaktiviteter ved senteret på forhånd av rekrutteringen for å bli kjent med ungdommene, og for å kunne identifisere mulige deltagere for studien. Da formålet med studien er å få kunnskap om hva som bidrar til at noen er i stand til å takle den vanskelige livssituasjonen bedre enn andre, vil det bli lagt vekt på å rekruttere deltagere som viser tegn til å takle sin livssituasjon bra, eller etter forholdene bra. I henhold til prosjektmeldingen skal det innhentes tillatelse til å gjennomføre studien fra Ministry of Health i Botswana og fra Baylor International pediatric AIDS initiative.

Personvernombudet finner at opplegget for inklusjon av deltakere tilfredsstillende vilkårene i personopplysningsloven. Det skal gis skriftlig informasjon og innhentes skriftlig samtykke fra alle deltakere og foreldre. Informasjonsskrivet mottatt 3. mai tilfredsstillende vilkåret til informert samtykke.

Opplysningene skal innhentes gjennom gruppeintervjuer og individuelle intervjuer. Det vil bli benyttet lydopptak som skal behandles på pc. Intervjuene skal transkriberes fortløpende og opptakene slettes etter transkribering. Datamaterialet skal oppbevares aidentifisert i prosjektperioden, og det er kun studenten som skal ha tilgang til navnelisten.

Det vil inngå sensitive opplysninger om helseforhold, jf. personopplysningsloven § 2 nr. 8 c i datamaterialet.

Prosjektet skal etter planen avsluttes i mai 2012, men studenten ønsker å lagre datamaterialet aidentifisert til 31. mai 2014 for eventuelt å skrive tilleggsrapporter på materialet. Det er innhentet samtykke til dette. Innen 31. mai 2014 skal datamaterialet anonymiseres. Dette vil innebære å slette eller omskrive direkte og indirekte personidentifiserende opplysninger. Navneliste/kopplingsnøkkel skal slettes og transkripsjoner skal slettes eller omskrives.

Studenten opplyser i e-post mottatt 26. april at studien ikke vil omfattes av bestemmelsene i Helseforskningsloven, og at det derfor ikke er aktuelt å søke om godkjenning fra REK.

---

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Anne Berit Kolmannskog	55978496	06.05.2011	2011/767/REK vest
			Deres dato:	Deres referanse:
			22.03.2011	

Vår referanse må oppgis ved alle henvendelser

Marguerite Daniel  
[marguerite.daniel@uib.no](mailto:marguerite.daniel@uib.no)  
HEMIL Senteret

### Hva bidrar til at Hiv positiv ungdom i Botswana mestrer sin livssituasjon 2011/767

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional forskningsetisk komité for medisinsk og helsefaglig forskningsetikk, Vest-Norge (REK Vest) i møtet 14.04.2011.

#### Prosjektomtale (revidert av REK):

*REK Vest anser Universitetet i Bergen som forskningsansvarlig for prosjektet. Formålet med denne studien er å få mer kunnskap om unge HIV-positive i Botswana og se nærmere på hva som kjennetegner de ungdommene som synes å klare seg bra tross sin vanskelige livssituasjon. Deltakerne vil være ungdommer med HIV i alderen 13-15 år, deres omsorgspersoner og helsepersonell ved The Botswana-Baylor Children's Clinical Center of Excellence.*

#### Forskningsetisk vurdering

Komiteen mener prosjekt har en interessant problemstilling. Prosjektet skal utgjøre en masteroppgave i Health Promotion ved Universitetet i Bergen.

Det er lagt opp til å gjennomføre fire fokusgruppeintervju og rundt 15 dybdeintervju av HIV-positive ungdommer samt intervju med omsorgspersoner og helsepersonell. Komiteen er noe usikker på omfanget og gjennomførbarheten av en så omfattende protokoll når den utgjøre en mastergrad. Komiteen anbefaler at en ser til at prosjektet som helhet er gjennomførbart innenfor de tidsrammer som er gitt.

Omsorgspersonen/foreldrene skal samtykke til deltakelse og signere samtykkeerklæringen for barn frem til de er 16 år. Det er i dag ikke et krav om at barna selv skal signere samtykkeformularet. Barna skal informeres om studien og respekteres om de ikke ønsker å delta.

I samtykkeerklæringene må ” The purpose of the study has been explained to me, and I understand what it is about” utgå.

#### Dataoppbevaring

I henhold til søknad skal forskningsprosjektets data oppbevares, etter forholdene, forsvarlig. Prosjektsslutt er satt til 31.05.2012. Personidentifiserbare forskningsdata skal anonymiseres eller slettes straks det ikke lenger er behov for dem og senest fem år etter prosjektsslutt.

Prosjektet skal sende sluttmelding til REK vest på fastsatt skjema senest 30.11.2012.

#### Vedtak

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Besøksadresse:  
Universitetet i Bergen Det medisinske  
fakultet Postboks 7804 5020 Bergen

Telefon: 55975000  
E-post: rek-vest@uib.no  
Web: <http://helseforskning.etikkom.no/>

All post og e-post som inngår i  
saksbehandlingen, bes adressert til  
REK vest og ikke til enkelte personer

Kindly address all mail and e-mails to  
the Regional Ethics Committee, REK  
vest, not to individual staff

*Prosjektet godkjennes på betingelse av at ovennevnte vilkår tas til følge.*

Med vennlig hilsen,

Jon Lekven (sign.)  
leder

Anne Berit Kolmannskog  
sekretariatsleder

**Kopi til:** Vivian.Midtbo@student.uib.no,  
[postmottak@uib.no](mailto:postmottak@uib.no)

*Saksbehandlingen følger forvaltningsloven. Komiteenes vedtak etter forskningsetikklovens § 4 kan påklages (jfr. forvaltningsloven § 28) til Den nasjonale forskningsetiske komité for medisin og helsefag. Klagen skal sendes REK Vest (jfr. forvaltningsloven § 32). Klagefristen er tre uker fra den dagen du mottar dette brevet (jfr. forvaltningsloven § 29).*

*De regionale komiteene for medisinsk og helsefaglig forskningsetikk foretar sin forskningsetiske vurdering med hjemmel i helseforskningsloven § 10, jfr. forskningsetikkloven § 4. REK Vest forutsetter at dette vedtaket blir forelagt den forskningsansvarlige til orientering. Se helseforskningsloven § 6, jfr. § 4 bokstav e.*

*Vi ber om at alle henvendelser sendes inn via vår saksportal: <http://helseforskning.etikkom.no> eller på e-post til: [post@helseforskning.etikkom.no](mailto:post@helseforskning.etikkom.no). Vennligst oppgi vårt referansenummer i korrespondansen.*

## Consent forms:

### Assent form for participating adolescents

#### ASSENT TO TAKE PART IN A RESEARCH STUDY

**TITLE OF STUDY:** *Adolescents living with HIV in Botswana: What contributes to an HIV positive adolescent thriving?*

#### **Who are we and why are we meeting with you?**

*My name is Vivian Midtbø. I am a student at the University of Bergen in Norway, and a researcher on a research study team. Sometimes other people will work with me. We would like to tell you about a study that involves children like yourself. We would like to see if you would like to participate in this study.*

#### **What is this research study about?**

*This study is about how HIV positive adolescents can be supported. It is also about how the caregivers can be supported. The study will try to find out what is positive in your lives.*

#### **Why have I been asked to take part in this study?**

*The researcher would like to learn from you how you experience living with HIV. This can help HIV positive adolescents in the future to live a better life.*

#### **Who can be in this study? And who may not? How long will the study take?**

*This is a study for adolescents living with HIV. Adolescents that are very ill will not be asked to participate. If you choose to be in the study, you will be asked to participate in 1 or 2 activities during July or August 2011.*

#### **What will happen to me if I choose to be in this study?**

*If you participate in the study you will take part in one group discussion. There will be 6 other adolescents in the group. This group discussion will last for about 1,5-2 hours. You might also be invited to do an individual interview. The interview could last for about 1 hour. Things that you say during interviews will not be told to others, for example they will not be told to your caregiver. You can refuse to answer any questions without any specific reason. A tape recorder will be used during the interview if this is ok by you. The recordings will be destroyed after they are written down.*

#### **Will I get better if I am in the study?**

*This study is not medical so it will not affect your disease in any way.*

#### **Can something bad happen to me or will I feel uncomfortable if I take part in this study?**

*Sometimes things happen to people in research studies that may hurt them or make them feel bad. These are called risks. The risks of this study are that sometimes we might talk about things that can make you feel sad. If this happens, you don't have to talk about these things if you don't want to.*

#### **Have you requested for permission from my parents/guardians?**

*The researcher has explained your parents/caregiver about this study. The researcher has asked your parents/caregiver for permission to let you participate in this study.*

#### **What if I don't want to take part in this study?**

*You don't have to be in this study if you don't want to. No one will get angry or upset if you don't want to be in the study. Just tell us. And remember, you can change your mind later if you decide you don't want to be in the study anymore.*

#### **Will I be given anything to take part in this study?**

*You will not be given payment for being in this research study.*

#### **What if I have questions?**

*You can ask questions at any time. You can ask now. You can ask later. You can talk to me or you can talk to someone else at any time during the study. Here is the telephone number to reach the researcher:*

*If I have questions about the study I can call the study doctor at:*

*Study researcher: Vivian Midtbø  
Address: Box 46412, Gaborone*

Tel: 71974780

If I have any questions about my rights as a research subject, I can call:

Chair of Health Research and Development Committee  
Address: private Bag 0038  
Tel: 3914467

**What are my rights if I decide to take part in this research study?**

I understand that I have the right to ask questions about any part of the study at any time. I understand that I should not sign this form unless I have had a chance to ask questions and have been given answers to all of my questions. I understand that the study is voluntary. I can withdraw from the study at any point. I can also withdraw from the study during interviews.

**Child**

I have read this entire form, or it has been read to me, and I believe that I understand what has been talked about. All of my questions about this form and this study have been answered.

I.....confirm that the purpose of this study has been explained to my parent/guardian. He/she agrees for me to be in the study if I want to. I do want to be in the study, but I know that I can stop being in the study any time I want to. I know that my study researcher can talk about the study with my parent/guardian, but will not talk about it with anyone else who is not working on the study unless I and my parent/guardian say it is OK. I can call the study doctor any time I have any questions.

Signature of Child  
Date.....

I ..... (Researcher) have sought permission from the child and the child has agreed to participate in the study.

Signature of Person Obtaining Assent/Consent  
Date.....

**Consent of Parent or Guardian:**

I agree with the manner in which assent was solicited and given by my child and I agree to have my child participate in the study. Although my child did or could not give his/her assent, I agree to have my child participate in the study. I will be given a signed copy of this Consent Form.

I give permission for my child to take part in this research study.

Print Name of Parent(s)  
Date.....

Signature of Parent(s)  
Date.....

Print Name of Legal  
Date.....

Signature of Legal Representative  
Date.....

Parent's Initials: \_\_\_\_\_ Date: \_\_\_\_\_

**Signature of Investigator or Responsible Individual:**

To the best of my ability, I have explained and discussed the full contents of the study, including all of the information contained in this consent form. All questions of the research subjects and those of his/her parent(s) or legal guardian have been accurately answered.

Investigator/Person Obtaining Consent: \_\_\_\_\_

Signature: \_\_\_\_\_

---

**HRDC Official Use Only**

This Consent Document is approved for use by the Botswana Ministry of Health, national Ethics Committee.

**Approved From:** \_\_\_\_\_ **To:** \_\_\_\_\_

The study expiration date applies for this form

## Assent form for participating adolescents, Setswana

### TUMALANO LE TESELETSO YA GO TSAYA KAROLO MO THUTO-PATLISISONG

**SETLHOGO SA THUTO-PATLISISO:** *Banana ba ba tshelang ka mogare wa HIV mo Botswana: ke eng se se fang monana yo o tshelang ka mogare wa HIV bokgoni jwa go tswelera sentle ka botshelo?*

*Re bo-mang, ebile ke eng re kopana le wena?*

*Leina lame ke Vivian Midtbø. Ke moithuti kwa Yunibesithing ya Bergen kwa Norway. Ke mmatlisi mo lekokong la thuto-patlisiso. Dinako tse dingwe batho ba bangwe ba tlaa bereka le nna. Re eletsa go go bolelela ka thuto e itebagantseng le bana jaaka wena. Re eletsa go botsisisa le go tlhomamisa botsaya-karolo jwa gago mo thuto-patlisisong e.*

**Thuto-patlisiso e, e bua ka ga eng ebile e itebagantse le eng?**

*Thuto-patlisiso e, e itebagantse le go batlisisa gore banana ba ba nang le mogare wa HIV ba ka thusiwa jang. Thuto-patlisiso e, gape e itebagantse le go batlisisa gore bathokomedu ba banana ba, ba ka thusiwa jang. Thuto-patlisiso e, e tla leka go batlisisa gore ke eng se se itumedisang gape se nametsa mo matshelong a lona.*

**Ke eng ke tlhophilwe ebile ke kopilwe go tsaya karolong mo thuto-patlisisong e?**

*Mmatlisi o eletsa go itse go tswa mo go wena gore go tshela ka mogare wa HIV go nse jang. Se, mo dinakong tse di tlang se ka tswela mosola le go thusa banana ba ba nang le mogare wa HIV go tshela botshelo jo bo botoka.*

**Ke mang yo ka tsayang karolo mo thuto-patlisisong e? Gape ke mang yo o sa tshwanelang go tsaya karolo? Ka go reng? Thuto-patlisiso e, e tsaya lobako lo lo kae?**

*Se ke thuto-patlisiso e e itebagantseng le banana ba ba tshelang ka mogare wa HIV. Banana ba ba gateletsweng ga ba kitla ka kopiwa go tsaya karolo. Fa o ka dumalana le go tsaya karolo mo thuto-patlisisong e, o tla kopiwa go tsaya karolo mo ditiragalong tse di itebagantseng le patlisiso tse pedi kana e le nngwe ka kgwedi ya Phukwi kana Phatwe, 2011.*

**Ke tla bo ke lopiwa go dira eng fa ke ka tsaya tshwetso ya go tsaya karolo mo thuto-patlisisong e?**

*Fa o le motsaya karolo mo thuto-patlisisong e, o tla tsaya karolo mo thutong-seka -dipuisanyo e le nngwe e e tla bong e na le wena le banana ba bangwe ba le barataro. Thuto-seka-puisanyo e, e tla tsaya sebaka sa oura le sephatlo go ya kwa go tse pedi. Go ka nna ga diragala gore o lalediwe ka bonosi go tsaya karolo mo puisanong ya patlo maikutlo ya sebaka sa oura. Tsoitlhe tse o di buang mo puisanong ya patlo- maikutlo ga di kitla di bolelelwa ba bangwe. Sekai, ga di kitla di bolelelwa mothokomedu wa gago. O na le tetla ya go gana go araba potso epe kapa epe o sa tlamiwe ke sepe go fa lobaka. Sekapa-mantswe se tla a dirisiwa mo dipuisanong tsa patlo maikutlo fa le gore o a dumalana ebile o na bothata ka se. Dikgatiso tsoitlhe tsa sekapa-mantswe di tla sennngwa fa di sena go kwalwa.*

**A ke tla tokafala fa ke tsaya karolo mo thuto-patlisisong e?**

*Thuto-patlisiso e, ga e amane ka gope le bongaka, melemo le tsa kalafi, ka jalo ga e amane le bolwetse kwa gago gope.*

**A ke kgona go diragalelwa ke sengwe se se maswe kana a ke kgona go tlelwa ke maikutlo a a iketlang fa ke ka tsaya karolo mo thuto-patlisisong e?**

*Dinako tse dingwe mo dithutong-patlisisong batho ba kgona diragalelwa ke dilo tse di kgonang go ba utlwiwa bothoko kana tse di sa ba tseeng sentle. Tse tsoitlhe ke bodiphatsa le masaitseweng a dilo tse di sa tlhomamisegeng. Masaitseweng kana bodiphatsa jwa thuto-patlisiso e ke gore dinako tse dingwe re ka bua ka dilo tse di re utlwisang bothoko. Fa se, se ka diragala, ga o patelesege go bua ka dilo tse fa o sa batle.*

**A o kopile tetla go tswa mo batsading/bathokomeding bame?**

Mmatlisisi o tlhaloseditse batsadi/bathokomedi ba gago ka ga thuto-patlisiso e, gape o kopile batsadi/bathokomedi ba gago tetla ya gore o tseye karolo mo thuto-patlisisong e.

**Ke dira jang fa ke sa batle go tsaya karolo mo thuto-patlisisong e?**

Ga o patelesege go tsaya karolo mo thuto-patlisisong e fa o sa batle. Ga go ope yo o ka go galefelang kana a tshwenyega mabapi le tshwetso ya gago ya go sa batleng go tsaya karolo mo thuto-patlisisong e. Gape, gakologelwa gore o kgona go fetola maikutlo a gago ka go tsaya karolo mo thuto-patlisisong e, morago ga nako e thuto-patlisiso e ntse e tswelsetse.

**A ke tla fiwa sengwe go nteboga go tsaya karolo mo thuto-patlisisong e?**

Ga o na go duelelwa go tsaya karolo mo thuto-patlisisong e.

**Ke dira jang fa ke na le dipotso?**

O ka botsa dipotso nako nngwe le nngwe. O ka botsa gone jaanong. Gape o ka botsa morago. O ka bua le nna kana mongwe nako nngwe le nngwe thuto-patlisiso e, e ntse e tswelsetse. O ka leletsa mmatlisisi mo mogaleng o latelang: 71974780

Fa ke na le dipotso ka ga thuto-patlisiso e, ke ka leletsa ngaka ya thuto-patlisiso e kwa:

Mmatlisisi wa thuto-patlisiso: Vivian Midtbø  
Aterese: Box 46412, Gaborone  
Mogala: 71974780

**Fa ke na le dipotso mabapi le ditshwanelo tsame ke le motsaya-karolo mo thuto-patlisisong e, ke ka leletsa:**

Modulasetilo wa Health Research and Development Committee  
Aterese: Private Bag 0038  
Mogala: 3914467

**Ke na le ditshwanelo dife fa ke ka tsaya tshwetso ya go tsaya karolo mo thuto-patlisisong e?**

Ke tlhaloganya gore ke na le tshwanelo ya go botsa dipotso nako nngwe le nngwe mabapi le thuto-patlisiso e. Gape ke tlhaloganya gore ga ke a tshwanela go baya foromo e monwana ka go e saena pele ga ke nna le tshono ya go botsa dipotso ebile gape ke filwe dikarabo tse di nametsang tsa dipotso tsoitlhe tse ke eng ke na le tsone. Ke tlhaloganya gore ke tsaya-karolo mo thuto-patlisisong ka bo game, ke sa patelege ka gope. Ke kgona go tswa mo botsaya-karolong jwa thuto-patlisiso e, ka nako nngwe le nngwe. Ke kgona gape go tswa mo botsaya-karolong jwa thuto-patlisiso e, ka nako ya fa dipuisano tsa patlo maikutlo di ntse di tswelsetse.

**Ngwana**

Ke badile/ ke baletswe foromo e yotlhe ka kelothoko. Ke dumela gore ke tlhaloganya se go buiwang ka ga sone. Dipotso tsoitlhe tsame mabapi le foromo e, le thuto-patlisiso e, di arabilwe.

Nna \_\_\_\_\_ ke tlhomamisa gore motsadi/mothokomedi wame kana motsaya-bokarabelo wame o tlhaloseditswe kgang-kgolo kana moonwa wa thuto-patlisiso e. O dumalana mo boemong jwame gore ke tseye karolo mo thuto-patlisisong e, fa ke batla. Ke batla go tsaya karolo mo thuto-patlisisong e mme gape ke itse gore ke ka emisa go tsaya karolo mo thuto-patlisisong e ka nako nngwe le nngwe fa ke batla. Ke itse gore mmatlisisi wame wa thuto-patlisiso o ka bua le motsadi/mothokomedi/motsaya-bokarabelo wame ka ga thuto-patlisiso e mme fela ga a kitla a bua ka ga yone le ope yo o sa berekeng mo thuto-patlisisong fa e se fa nna le motsadi/mothokomedi wame re dumalana le gore o ka dira jalo. Ke gololesegile go leletsa ngaka ya thuto-patlisiso e ka nako nngwe le nngwe fa ke na le dipotso.

---

Monwana wa ngwana  
Letsatsi: .....

Nna ..... (Mmatlisisi) ke kopile tetelelo mo ngwaneng, ebile ngwana o dumalane le go tsaya karolo mo thuto-patlisisong e.

---

Monwana wa motho yo o kopang tetelelo:  
Letsatsi: .....

**Tetelelo go tswa mo motsading/motsaya-boikarabelo wa ngwana:**

Ke dumalana le mokgwa o tetelelo e kopilweng ebile e dumalanweng ka teng, e e filweng ke ngwanake. Ke dumalana le gore ngwanake e tseye karolo mo thuto-patlisisong e.

Le ntswa ngwanake a file kana a sa fa tetelelo le tumalano ya gagwe, ke dumalana gore ngwanake a tsee karolo mo thuto-patlisisong e. Ke tlile go fiwa moruti o beilweng monwana wa foromo e.

Ke fa ngwanake tletla go tsaya karolo mo thuto-patlisisong e.



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Maina a motsadi/ batsadi

Letsatsi: .....

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Monwana wa (mo)batsadi

Letsatsi: .....

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Leina la moemedi/mmueledi ka fa molaong

Letsatsi.....

---

Monwana wa moemedi/mmueledi ka fa molaong

Letsatsi.....

Diinshiale tsa batsadi: \_\_\_\_\_ Letsatsi: \_\_\_\_\_

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**Monwana wa mmatlisisi kana motho yo o nang le maleba:**

Go ya ka kitso yame e e tseletseng, ke tshalositse le go buisanya ka ga tsotlhe tse di mo foromong e ya tetelelo. Dipotso tsotlhe tse di boditsweng batsaya-karolo le batsadi/bathokomedi ba bone ka fa molaong di arabilwe ka botlalo le ka manontlhotlho.

Mmatlisisi /motho yo kopang tetelelo: \_\_\_\_\_

Monwana: \_\_\_\_\_ Letsatsi: \_\_\_\_\_

---

**Fa go kwala ba ofisi ya HRDC fela:**

Foromo e ya tetelelo le tumalano e dumalanwe go dirisiwa fela ke ba Botswana Ministry of Health, national Ethics Committee.

**Approved From:** \_\_\_\_\_ **To:** \_\_\_\_\_

The study expiration date applies for this form

# Consent form for caregivers of participating adolescents

## CONSENT TO TAKE PART IN A RESEARCH STUDY

**STUDY TITLE: Adolescents living with HIV in Botswana: What contributes to an HIV positive adolescent thriving?**

### INVESTIGATORS

*Vivian Midtbø, student from the University of Bergen, Norway*

### SPONSOR

*N.a.*

### WHY ARE YOU BEING ASKED TO TAKE PART?

*This study aims to find out what can help HIV positive adolescents to live a better life. The study will also try to find out how the caregivers of HIV positive children and adolescents can be supported in the care of their children in a difficult situation. The researcher would like to talk with HIV positive adolescents and some of their caregivers about their experiences of living with HIV. The researcher is very interested in what is positive in your lives.*

This is a research study that includes only people who choose to take part. Please take your time to make your decision and feel free to ask any questions you might have.

For participants less than 18 years old, the use of “you” in this consent form is the same as saying “your child” or a “minor for whom you are a legally appointed representative.”

### WHAT ARE SOME IMPORTANT DETAILS ABOUT THIS STUDY?

*About 20 people will take part in this study, which will only be conducted in Gaborone and Ramotswa. If you choose to take part in the study it will involve one group interview of about 1.5-2 hours, and possibly one individual interview of about 1 hour, in July or August 2011. The results of the study will be written in a report which is part of the researcher’s Master’s degree. The results will be shared with the Holy Cross Hospice in Gaborone, The Bamalete Lutheran Hospital in Ramotswa, and the Ark n’ Mark trust, they may also potentially contribute to an article published in a peer reviewed journal.*

### WHEN SHOULD YOU NOT TAKE PART?

*This is not a medical study. You should not take part if you don’t feel comfortable with being interviewed.*

### WHAT IS INVOLVED IN THE STUDY?

*The study involves one group-interview of about 1.5-2 hours; there will be 6 other adolescents in the group. The other adolescents in the group are also recruited through the Holy Cross Hospice. In addition there may be one individual interview of about 1 hour. This will happen either in July or August 2011. The interviews will be recorded if you are comfortable with it.*

### WHAT IS THE RISKS OF THE STUDY?

*Because this is not a medical study there are no medical risks involved. However, some topics discussed in the interviews might be difficult or sad to talk about. If this happens, you can always choose not to talk about it if you don’t want to. You never have to talk about something you don’t want to talk about.*

### ARE THERE BENEFITS TO TAKING PART IN THE STUDY?

*If you agree to take part in this study, there may or may not be direct benefit to you. There is no guarantee that you will personally benefit from taking part in this study. We hope the information learned from this study will benefit other adolescents and their caregivers living with HIV in the future.*

### WHAT ABOUT CONFIDENTIALITY?

*All information from the interview will be maintained in strict confidence. Your name will not be used in the report, and it will not be possible to identify you in the results of the study. Things that you say during interviews will not be told to others, for instance personnel at the hospital or other people in the community. Recordings made during the interview will be destroyed after they have been written down. The researcher will store the interview transcripts in a safe place for two years after the end of the study, in case a follow up report will be written. This means that all the data will be anonymised by the 31<sup>st</sup> of May 2014.*

### WHAT WILL PARTICIPATION IN THE STUDY COST OR PAY?

*This study will not cost anything, and you will not get paid to take part in the study.*

### WHAT IF YOU GET INJURED?

*This is not a medical study; there are no injuries involved in this study.*

**WHAT ARE YOUR RIGHTS AS A PARTICIPANT?**

*Taking part in this study is your choice. If you decide not to take part, your choice will not have negative effects for you. You may choose to leave the study at any time, or refuse to answer any questions that are being asked, without any specific reason. If you leave the study it will not result in any negative consequences for you.*

**WHOM DO YOU CALL IF YOU HAVE QUESTIONS OR PROBLEMS?**

*For questions about the study, contact the investigator, Vivian Midtbø, at 71974780. For questions about your rights as a research participant, contact a member of the Health Research Division office at (267- 3914467). You may also contact Mr. P. Khulumani, the Chief Research Officer, Health Research Division at (267- 3914467).*

**SIGNATURE**

You will get a copy of this signed form. You may also request information from the investigator. By signing your name on the line below, you agree to take part in this study.

..... Signature of Participant/LAR  
..... Typed or Printed Name  
..... Signature of Participant/LAR  
..... Typed or Printed Name  
..... Relationship to Subject

\_\_\_/\_\_\_/\_\_\_  
MM/ DD/ YY

This signature must be present if the consent was presented orally to a subject in any manner. The witness may not be an individual named as an investigator or a person authorized to negotiate informed consent.

\_\_\_\_\_  
Signature of Witness  
Witnessed Consent Process

\_\_\_\_\_  
Typed or Printed Name  
\_\_\_/\_\_\_/\_\_\_  
MM/ DD/ YY

I certify that I have explained to the above individual the nature and purpose of the study, potential benefits, and possible risks associated with participation in this study. I have answered any questions that have been raised and have witnessed the above signature. I have explained the above to the volunteer on the date stated on this consent form.

\_\_\_\_\_  
Signature of Investigator or Approved Designee  
\_\_\_/\_\_\_/\_\_\_  
MM/ DD/ YY

**Consent form for caregivers of participating adolescents, Setswana**

**TUMALANO YA GO TSAYA KAROLO MO THUTO-PATLISISONG**

**SETLHOGO SA THUTO-PATLISISO: Banana ba ba tshelang ka mogare wa HIV mo Botswana: ke eng se se fang monana yo o tshelang ka mogare HIV bokgoni jwa go tselela sentle ka botshelo?**

**BABATLISISI**  
*Vivian Midtbø, moithuti go tswa kwa Yunibesithing ya Bergen, Norway*

**MOTHUSI**  
*N.a.*

**KE ENG O KPIWA GO TSAYA KAROLO?**

*Thuto-patlisiso e e itebagantse le go batlisisa gore banana ba ba nang le mogare wa HIV ba ka thusiwa jang go tshela botshelo jo bo botoka. Thuto-patlisiso e gape e itebagantse le go batlisisa gore batho ba ba tlhokomelang bana le banana ba, ba ka thusiwa jang mo gareng ga mathata le dikgwetho tse ba leng mo go tsone. Mmatlisisi o eletsa go bua le banana ba ba nang le mogare wa HIV ga mmogo le bathokomedi ba bone ka ga botshelo jwa go tshela ka bolwetse jwa HIV. Mmatlisisi o na le keletso ya go itse gore ke eng se se le inumedisang gape se le nametsa mo matshelong a lona.*

Thuto patlisiso e, e akaretsa batho fela ba ba ithlophelang go ya go tsaya karolo. Tsweetswee, tsaya sebaka o iphe nako o ikakanye pele ga o ka tsaya tshwetso, ebile gape o phuthologe go botsa dipotso tsotlhe tse o ka tswang o na le tsone. Tiriso ya lefoko “wena” mo batsaya-karolong ba ba nang le dingwaga tse di kwa tlase ga lesome le bobedi mo foromong ya tetelelo le tumalano, go tshwana le fa o re ngwana wa gago kana ngwana yo o mo tlhokometseng ka fa molaong.

#### KE DIFE DILO TSA DI BOTLHOKWA KA GA THUTO-PATLISISO E?

*Palo ya batho ba ba ka tshwarang masome a mabedi ba tlaa tsaya karolo mo thuto-patlisisong e, e e tlaa tshwarelwang mo Gaborone ka thuso ya ba Holy Cross Hospice mo Gaborone le kwa kokehlaneng ya motse kwa Letlhakane West. Fa o dumalana le go tsaya karolo mo thuto-patlisisong e, o tla tselela kgang ya patlo-maikutlo ya sebaka sa oura ka kgwedi ya Phukwi kana Phatwe, 2011. Maduo le ditshwetso tsa thuto-patlisiso e, a tla kwalwa mme gape a nne bontlhabongwe jwa maduo a dithuto tsa Master's a mmatlisisi. Maduo le ditshwetso a tla lotlegethwa le go nankolelwa ba Holy Cross Hospice mo Gaborone; ba kokehwana ya motse kwa Letlhakane West ga mmogo le ba Ark n' Mark trust, gape le bone ba na le tshono ya go tlaletsa ka go kwala pampiri e e tlaththobilweng ke ba bangwe e e tla tswang mo jenaleng.*

#### O KA SE TSEE KAROLO LENG?

*Thuto e, ga se ya tsa bongaka, melemo le kalafi. O seka wa tsaya karolo fa mowa wa gago o ikutlwa o sa phuthologa go ka batliwa maikutlo ka go bodiwa dipotso tse di tlhokang dikarabo*

#### KE SOLOFELE ENG MO THUTO-PATLISISONG E?

*Thuto- patlisiso e, e akaretsa puisano ya tlhoko-maikutlo e le nngwe e e tsayang sebaka sa oura ka kgwedi ya Phukwi kana Phatwe, 2011. Puisano ya tlhoko-maikutlo e, e tla gatisiwa fa se, se sa go tshwenye.*

#### BODIPHATSA LE MASAITSEWENG A THUTO-PATLISISO E KE ENG?

*Ka lebaka la gore thuto e ga e amane ka gope le tsa bongaka, melemo le kalafi, ga gona bodiphatsa bope jo bo amanang le tsa bongaka, melemo le kalafi. Mme fela, go na le dikgagolo dingwe tse di tlhagelelang mo dipuisanong tsa tlhoko-maikutlo tse di ka kgonang go nna boima gape di hutsafatsa go buwa ka tsone. Fa se se dirafala, o gololesegile go emisa go bua ka tsone fa o sa batle. Ga o kake wa patelediwa go bua ka selo sengwe fa ele gore ga o batle.*

#### A KE SOLEGELWA MOLEMO KE SENGWWE FA KE TSAYA KAROLO MO THUTO-PATLISISONG E?

*Tumalano ya botsaya karolo mo thuto-patlisisong e, e ka nna ya go solegela molemo gape e ka nna ya seke ya go solegela molemo. Ga gona tlhomamisego ya gore botsaya-karolo mo thuto-patlisisong e, e tla go solegela ke molemo o itebagantseng le wena. Re solofela gore thuto e angwilweng mo thuto-patlisisong e, e tla solegela banana ba bangwe ba ba tshelang ka mogare wa HIV ga mmogo le bathokomedi mo nakong e tlang.*

#### GA TWENG KA BO-SEPHIRI?

*Tshotlhe tse di builweng mo dipuisanong tsa tlhoko-maikutlo ke sephiri se se tseletseng. Leina la gago ga le kitla le diriwa mo mokwalong ka ga maduo, ka jalo go thata go ka itse ka botlalo gore maduo a a teng le mo mokwalong ka ga maduo ke a ga mang. Tshotlhe tse o di buang mo dipuisanong tsa tlhoko-maikutlo ga di kitla di bolelwa ope, jaaka, sekai, babereki ba Holy Cross Hospice, kana batho fela mo sechabeng. Dikgatiso tse di dirilweng ka nako ya dipuisano tsa tlhoko-maikutlo di tile go sennwa fa di sena go kwalelwa gongwe. Mmatlisisi o tla baya mokwalo o nankolang dipuisano-patlo maikutlo mo lifelong le le babalesegileng lobaka la dingwaga tse pedi morago ga thuto-patlisiso fa go ka diragala gore mokwalo mabapi le thuto-patlisiso o dirwe. Se se raya gore dintlha kgolo tsotlhe ka ga thuto-patlisiso di tla bewa ka sephiri go fitlha ka Motsheganong 31<sup>st</sup> 2014.*

#### KE DUELA BOKAE GO TSAYA KAROLO MO THUTO-PATLISISONG E KANA KE DUELWA BOKAE?

*Thuto-patlisiso e, ga e duediwe ebile ga o duelelwe go tsaya karolo mo go yone.*

#### GO KA DIRAFLA ENG FA KE KA GOBALA?

*Thuto-patlisiso e, ga e amane ka gope le tsa bongaka, melemo le kalafi ka jalo ga gona dikgobalo dipe tse di tla mang mo thuto-patlisisong e.*

#### DITSWANELO TSA GAGO KE ENG JAKA MOTSAJA-KAROLO?

*Go tswa mo go wena go tsaya-karolo mo thuto-patlisisong e. Ga o kake wa diragalelwa ke sepe se se maswe fa o sat see karolo mo thuto-patlisisong e. O na le kgololesego ya go tlogela botsaya-karolo mo thuto-patlisisong nako nngwe le nngwe, kana wa gana go araba dipotso*

dife kana dife go sa tlhokege gore o fe lobaka le le utlwalang. Go tlogela botsaya-karolo ga go ka ke ga go tsenya mo diphatseng kana go go utlwisa bothoko ka gope.

#### O LELE TSA MANG FA O NA LE DIPOTSO KANA MATHATA?

Leletsa mmatlisisi Vivian Midtbø, kwa 71974780, fa o na le dipotso mabapi le thuto-patlisiso e. Leletsa mmereki mongwe le mongwe wa ofisi ya Health Research Division kwa 267- 3914467 fa o na le dipotso tse di amanang le ditshwanelo tsa gago jaaka motsaya-karolo wa dipatlisiso. O ka leletsa Rre P. Khulumani, yo o leng mookamedi mogolo wa ofisi ya tsa dipatlisiso (Chief Research Officer) ya Health Research Division kwa (267- 3914467).

#### MONWANA

O tla fiwa moruti o beilweng monwana wa foromo e. O kgona go kopa ditlhaloso mo mmatlising. Go baya monwana kana go saena fa tlase mo mothalong o fa tlase ke sesupo sa gore o dumalana le go tsaya karolo mo thuto-patlisisong e.

..... Monwana wa motsaya-karolo/LAR  
..... Maina  
..... Sesupo sa gore o itsane jang le motsaya-karolo  
\_\_\_/\_\_\_/\_\_\_  
MM/ DD/ YY

Monwana kana sakinachara e tshwanetse go nna teng fa ele gore mokgwa wa tlelelo le tumalano o dirilwe ka molomo eseng ka mokwalo. Mmatlisisi kana motho yo o kopileng tetla go dira thuto-patlisiso e ga a tshwanela go nna mosupi.

\_\_\_\_\_  
Monwana wa mosupi  
Thulaganyo ya tlelelo le tumalano e e bogetswe ke:

\_\_\_\_\_  
Kwala leina la gago  
\_\_\_/\_\_\_/\_\_\_  
MM/ DD/ YY

Ke tlhomamisa gore ke tlhaloseditse motho yo o kwadilweng fa godimo maikaelelo le sebopego sa thuto-patlisiso e, ditshono, bo-diphatsa jo mabapi le go tsaya-karolo mo thuto-patlisisong e. Ke arabile dipotso tsothe tse di boditsweng ebile le bone bogetse peo ya monwana e fa godimo. Ke tlhaloseditse motsaya-karolo sengwe le sengwe se se mofomong e, se se kwadilweng fa godimo.

\_\_\_\_\_  
Monwana wa mmatlisisi kana yo o dumeletsweng  
\_\_\_/\_\_\_/\_\_\_  
MM/ DD/ YY

# Consent form for participating staff

## CONSENT TO TAKE PART IN A RESEARCH STUDY

**STUDY TITLE: Adolescents living with HIV in Botswana: What contributes to an HIV positive adolescent thriving?**

### INVESTIGATORS

*Vivian Midtbø, student from the University of Bergen, Norway*

### SPONSOR

*N.a.*

### WHY ARE YOU BEING ASKED TO TAKE PART?

*This study aims to find out what can help HIV positive adolescents to live a better life, and how the caregivers of HIV positive children and adolescents can be supported in the care of their children in a difficult situation. The researcher would like to talk with HIV positive adolescents and some of their caregivers about their experiences of living with HIV, and what is positive and strengthening in their lives. In addition the researcher would like to talk to some of the staff at the Baylor centre, to get additional information regarding the surroundings and environment of the adolescents life, from the perspective of someone who knows this group of adolescents well.*

This is a research study that includes only people who choose to take part. Please take your time to make your decision and feel free to ask any questions you might have.

### WHAT ARE SOME IMPORTANT DETAILS ABOUT THIS STUDY?

*About 20 people will take part in this study, which will only be conducted in Gaborone through the Holy Cross Hospice, and in Ramotswa through the Bamalete Lutheran Hospital. If you choose to take part in the study it will involve one interview of about one hour in July or August 2011. The results of the study will be written in a report which is part of the researcher's Master's degree. The results will also be shared with the Holy Cross Hospice, the Bamalete Lutheran Hospital and the Ark n' Mark trust, and they may also potentially contribute to an article published in a peer reviewed journal.*

### WHEN SHOULD YOU NOT TAKE PART?

*This is not a medical study. You should not take part if you don't feel comfortable with being interviewed.*

### WHAT IS INVOLVED IN THE STUDY?

*The study involves one interview of about one hour in July or August 2011. The interview will be recorded if you are comfortable with it.*

### WHAT ARE THE RISKS OF THE STUDY?

*Because this is not a medical study there are no medical risks involved. However, some topics discussed in the interviews might be difficult to talk about. If this happens, you can always choose not to talk about it if you don't want to.*

### ARE THERE BENEFITS TO TAKING PART IN THE STUDY?

*If you agree to take part in this study, there may or may not be direct benefits to you. There is no guarantee that you will personally benefit from taking part in this study. We hope the information learned from this study will benefit adolescents and their caregivers living with HIV in the future, and that knowledge will be produced about how this group can be supported.*

### WHAT ABOUT CONFIDENTIALITY?

*All information from the interview will be maintained in strict confidence. Your name will not be used in the report. Recordings made during the interview will be destroyed after they have been written down. The researcher will store the interview transcripts in a safe place for two years after the end of the study, in case a follow up report will be written. This means that all the data will be anonymised by the 31<sup>st</sup> of May 2014.*

### WHAT WILL PARTICIPATION IN THE STUDY COST OR PAY?

*This study will not cost anything, and you will not get paid to take part in the study.*

### WHAT IF YOU GET INJURED?

*This is not a medical study; there are no injuries involved in this study.*

### WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Taking part in this study is your choice. If you decide not to take part, your choice will not have negative effects for you. You may choose to leave the study at any time, or refuse to answer any questions that are being asked, without any specific reason. If you leave the study it will not result in any negative consequences for you.

WHOM DO YOU CALL IF YOU HAVE QUESTIONS OR PROBLEMS?

For questions about the study, contact the investigator, Vivian Midtbø, at 71974780. For questions about your rights as a research participant, contact a member of the Health Research Division office at (267- 3914467). You may also contact Mr. P. Khulumani, the Chief Research Officer, Health Research Division at (267- 3914467).

SIGNATURE

You will get a copy of this signed form. You may also request information from the investigator. By signing your name on the line below, you agree to take part in this study.

.....Signature of Participant/LAR

..... Typed or Printed Name

..... Relationship to Subject

\_\_\_/\_\_\_/\_\_\_

MM/ DD/ YY

This signature must be present if the consent was presented orally to a subject in any manner. The witness may not be an individual named as an investigator or a person authorized to negotiate informed consent.

\_\_\_\_\_  
Signature of Witness

Witnessed Consent Process

\_\_\_\_\_  
Typed or Printed Name

\_\_\_/\_\_\_/\_\_\_

MM/ DD/ YY

I certify that I have explained to the above individual the nature and purpose of the study, potential benefits, and possible risks associated with participation in this study. I have answered any questions that have been raised and have witnessed the above signature. I have explained the above to the volunteer on the date stated on this consent form.

\_\_\_\_\_  
Signature of Investigator or Approved Designee

\_\_\_/\_\_\_/\_\_\_

MM/ DD/ YY