AN INVESTIGATION INTO THE SCHOOL EXPERIENCES OF HIV-POSITIVE SECONDARY SCHOOL LEARNERS ON ARV TREATMENT IN KATUTURA, WINDHOEK

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DECLARATION

I, **EMILIE HAIPINGE**, hereby declare that the work submitted in this thesis is original and a result of my own study except where otherwise acknowledged. This thesis has not been submitted for another degree award in this or any other university or institution.

Signature:..... Date:.....

DEDICATION

I dedicate this work to my family, especially to my lovely husband, for all the financial and emotional support and for keeping my dreams alive and realistic.

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ARVs	Antiretroviral drugs
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
MoE	Ministry of Education
MOHSS	Ministry of Health and Social Services
NGO	Non-Governmental Organization
PLWHA	People Living With HIV and AIDS
PMTCT	Prevention of Mother to Child Transmission
TB	Tuberculosis
UNAIDS	United Nations Agency for International Development
UNAM	University of Namibia
USA	United States of America
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

ABSTRACT

What are the school experiences of HIV-positive secondary school learners on ARV treatment?

Although the provision of life-saving antiretroviral (ARV) treatment is central in the medical and policy response to the HIV pandemic, relatively little research (in the SADC region and in Namibia particularly) attends to people's experiences and the social effects of taking ARV treatment. This study probed the experiences of high school learners on ARV treatment in Khomas Region, Namibia.

As researcher I used a qualitative case study design based mainly on interviews with a purposive, select sample of eight learners at the school where I am a teacher-counsellor. Methods used also included: observations; focus group interviews with eight teachers at the site school; a questionnaire survey with Life Skills teachers from 25 schools in the Khomas Region; and document analysis.

Using a theory of health-related stigma and discrimination as well as perspectives on resilience and agency as conceptual and analytical lenses, this study found that only a handful of these learners were living openly with HIV and AIDS. Being both HIV-positive and on ARV medication was a double bind for learners facing pervasive stigma and discrimination in and out of school. Discourses associated with HIV and AIDS, sex, and sexuality shaped people's response to them and they feared being 'caught out'. Here the study explores the complex reciprocal relationship between cause and effect in stigma, showing some consequences for these learners: isolation (both voluntary and imposed), mental anguish, depression and suicidal leanings; also (at school) absenteeism, grade repetition and dropout.

Distinguishing stigma from discrimination in this study enabled insight into actual practices that constrain learner participation and inclusion in and out of school. Trust between learners on ARVs and teachers proved to be low. Teacher respondents not only felt unequipped to deal with the psychosocial needs of learners on ARVs but also indicated that confronting these needs animated their personal vulnerability (around HIV-related experiences in their own families).

However, hopeful patterns also emerged. Some mediatory factors out of school shaped these learners' experiences and identities positively, with implications for in-school experiences and participation. Some learner journeys reflected shifts from deep despair towards the emergence of voice, positive self-concepts and resilient dispositions. Here, also, this study enters a neglected area of research, showing how the complex interplay of learners' own agency with social support brought these positive outcomes. Most learners had experienced rejection from immediate family, receiving support rather from community members who became 'family'.

The study thus also raises pressing questions on the nature of support structures (both in and out of school) in contexts shaped by HIV and AIDS, where stigma and discrimination are pervasive and where stable family structures, parental oversight and 'normal' progression through school cannot be assumed. It recommends that schools gain better insight into how learners' circumstances shape their experiences, and develop internal policies, procedures and networks to reduce stigma and discrimination against HIV-positive learners on ARV treatment, as well as. ensuring material, medical, emotional, and psychological support for them.

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1.1 Introduction and Background

As the world marks 30 years of AIDS, (UNAIDS, 2011), estimates are that about 34 million people are living with the HI-Virus and nearly 30-million have died of AIDS-related causes since the first case was reported in June 1981. HIV and AIDS are part of the daily life of vast numbers of people around the globe. According to UNAIDS (2012) there are 34 million people living with HIV and AIDS today compared with 26.2 million in 1999. The increase has come as a result of the significant scale-up of antiretroviral treatment (ARVs) which has allowed many HIV-positive people not only to survive but also to live normal and productive lives. This UNAIDS report further indicates that the worldwide incidence of HIV infection has stabilized and begun to decline in many countries which have had widespread epidemics, and also that the number of people accessing treatment increased by 63 per cent from 2009 to 2011. On the other hand, 7 million people eligible for treatment are not getting it. Of even more concern is the fact that 72 per cent of children worldwide who qualify for treatment are not accessing it, according to the report (UNAIDS 2012).

According to the UNAIDS Report on the global AIDS epidemic (2012, p8)

> Sub-Saharan Africa remains most severely affected, with nearly 1 in every 20 adults (4.9%) living with HIV and accounting for 69% of the people living with HIV worldwide. Although the regional prevalence of HIV infection is nearly 25 times higher in sub-Saharan Africa than in Asia, almost 5 million people are living with HIV in South, South-East and East Asia combined. After sub-Saharan Africa, the regions most heavily affected are the Caribbean and Eastern Europe and Central Asia, where 1.0% of adults were living with HIV in 2011.

The above information supported trends reported by UNICEF in 2009. According to the latter report, in 22 countries in sub-Saharan Africa, new infections dropped by more than 25 per cent between 2001 and 2009, including in some of the countries with the largest epidemics, such as Ethiopia, Zambia and Zimbabwe. The report further highlighted that Zimbabwe was the first country in Southern Africa to record a significant, sustained decline in HIV infection (from 29 per cent in 1997 to 16 per cent in 2007). The annual HIV incidence in South Africa, though, was still high at 1.5 per cent in 2009, having dropped from 2.4 per cent in 2001. The epidemics in Botswana, Namibia and Zambia also appear to be declining, while those in Lesotho,

Mozambique and Swaziland seem to be leveling off. Angola's relatively younger epidemic, on the other hand, still appears to be growing (UNICEF, WHO, UNAIDS and Global Fund (2009).

According to UNAIDS data, prevalence among 15 to 24 year olds has decreased by more than a third between 2001 and 2010. Nonetheless, in Swaziland, Botswana and Lesotho, between 8.5 and 11 per cent of young people are living with HIV (UNAIDS 2012).

Although sub-Saharan Africa is estimated to be the most heavily affected in the world, the latest UNAIDS Report (2011) indicates that the HIV epidemic in this region is stable or declining. The report further shows that the number of people newly infected with HIV dropped from about 2.2 million people in 2001 to about 1.8 million in 2009. There seems to be a positive change in sub-Saharan Africa's HIV incidence, with about 22 countries showing a decline in HIV-related deaths by more than 25% between 2001 and 2009. This suggests that either people have taken the information on HIV and AIDS seriously and as a result have changed their sexual behaviour or they have access to anti-retroviral (ARV) medication. This has been supported by the UNAIDS 2012 report which suggested that much of the reduction comes as a result of changes towards safer behaviour patterns among young people, including delay of first sex, reduction in the number of partners, and increased condom use.

Huge quantities of resources have gone into a search for a cure and vaccine for HIV AND AIDS, with little success so far. ARV drugs have been developed and are currently used to prolong the lives of HIV-positive patients. About 6.6 million people were receiving antiretroviral therapy in low- and middle-income countries at the end of 2010, a 22-fold increase since 2001 (UNAIDS, 2011). This UNAIDS report also shows that the world is still vulnerable to the emergence and spread of HIV and AIDS.

In 2010 alone, about 1.4 million people in the world started life-saving ARV treatment; an indication that the number of people taking ARVs to prolong their lives is on the increase globally (UNAIDS, 2011). The majority of these people are from sub-Saharan African countries of which Namibia is a part. Goldstein, Zivin & Thirumurthy (2008) support this claim by proposing that in sub-Saharan Africa, the region most heavily affected by HIV and AIDS, the

number of HIV-positive people receiving ARV treatment has risen from 100,000 in 2002 to nearly 2million in 2007.

The increase in access to treatment has not only had a positive impact on HIV-related mortality but also in enabling people to lead healthy lives. The availability and accessibility of the ARV's though is not always guaranteed especially in developing countries, like Namibia, where availability and distribution is usually dependent on donor-driven external funding from developed countries (UNAIDS, 2011).

Children are not immune to this epidemic, with some receiving ARVs. According to the UNAIDS Report (2011), at least 420 000 children were receiving ARV's globally at the end of 2010, a significant increase since 2008 when only 275 000 children were on treatment.

1.2 Context of the Study

The Ministry of Health and Social Services (MoHSS, 2007) in Namibia estimates that in 2006 alone, 200,000 Namibian adults and children were living with HIV; an estimation that is high given that the country has a population of only 2-million. In an attempt to combat the impact of the epidemic, the Namibian government and other stakeholders set aside financial support for ARV treatment (UNAIDS, 2007).

The WHO (World Health Organization) Report (2005) not only provides an indication of the number of people initiating ARV treatment for the first time but also the rapid increase in access to ARV treatment in Namibia in the last five years. In June 2004, it was said that 2500 people in Namibia were estimated to be receiving ARV therapy, mostly through the public health services (WHO, 2005). This number grew rapidly; increasing to 4000 by September 2004, 9600 by March 2005 and 17 000 by June of the same year (WHO, 2005). Data compiled by the Ministry of Health and Social Services (MoHSS, 2010) shows that by the end of 2007, about 52,000 people in Namibia were receiving ARV therapy. This number increased to more than 100, 000 at the end of 2009.

Namibia is the second most sparsely populated country in the world. Providing comprehensive HIV and AIDS services to the population requires a fully decentralized system in order to ensure follow-up once ARV treatment has been initialized. However, insufficient numbers of skilled technical personnel and limited managerial capacity at all levels of the healthcare system has exacerbated the challenges of ARV treatment follow-up.

The above notwithstanding, the government's commitment to provide ARV treatment has seen a decline in deaths caused by HIV and AIDS amongst children in the country. Reported outcomes on child patients on ARVs show that 84% of those who initiated ARV treatment are still alive, 5% have died, 2% defaulted, and the status of 9% is unknown (MoHSS Report, 2007). This report also shows that the percentage of adults and children with HIV known to be on treatment 12 months after initiation of antiretroviral therapy stands at 69% and 82% respectively (MoHSS Report, 2007).

Stigma, discrimination, high rates of unemployment, and poverty pose major challenges to adults and children taking ARV drugs particularly in a country like Namibia, which has one of the highest levels of income disparity and illiteracy in the world.

1.3 Statement of the Problem

The Namibian government and her partners (e.g. Global Fund, USAID and Catholic AIDS Action), in their fight against HIV and AIDS, set aside funds from the fiscal budget for antiretroviral drug treatment to prolong the lives of people living with HIV in Namibia, including children.

Much of the current research on medication experience focuses on the adult health-related issues of taking drugs for diseases such as tuberculosis (TB), malaria, and HIV and AIDS. Medication experience is a practice concept that attempts to understand patients' medication experiences and medication-taking behaviours in order to meet their medication-related needs. Emphasis here usually is on the health consequences related to the medication experience (Shoemaker & de Oliveira, 2007).

However, not all diseases have the same response from members in particular societies. Many societies view diseases such as HIV and AIDS as taboo, associating them with 'deviant' behaviour (e.g. homosexuality, prostitution, and drug addiction), thus making the medication experience one that goes beyond a health-related issue.

Little research in the SADC region and Namibia in particular, attends to peoples' experiences and the social effects of taking ARV treatment. Thirumurthy, Zivin & Goldstein's (2007) research in Kenya emphasize that while the provision of life-saving antiretroviral (ARV) treatment has emerged as a central part of the medical and policy response to HIV and AIDS, little empirical research investigates the impact of this important intervention and, in particular, concerning children's experiences.

Like the rest of the HIV-positive adult population, children[1] on ARV treatment might face stigma, isolation, blame, fear, silence, and non-adherence (to treatment) in their daily lives, yet little is known about how such experiences shape their daily lives in general, and access to and experience of school in particular. Even though the treatment may have improved their lives and decreased mortality, being HIV-positive while young may still present a challenge to many learners on ARV medication.

My experience as a counsellor at a secondary school triggered the questions I address in this study. I noticed that some of the HIV-positive learners on ARV treatment seemed to experience marginalization despite common perceptions (especially amongst youth) that HIV and AIDS is similar to any other chronic disease such as diabetes, high blood pressure, or tuberculosis. I also became aware that some people in the community where I teach believe that learners on ARV treatment are a curse, or bring bad luck to their families. Others think that these 'marked' learners are a waste of resources as in the future they may not contribute to the wealth of the family or give birth to their own children. My discussions with teachers and with parents whose children are on ARV treatment revealed that both groups question the merit of teaching learners

[1] I use this term to distinguish adults and children in the introduction of the thesis only. In the rest of the thesis, I refer to children as learners, given the context of the study.

on treatment and query the educational investment, given that (as they see it) one cannot guarantee the future of these learners.

Such discussions sparked my interest to understand the school experiences of HIV-positive children on ARV treatment. I wondered how they made meaning of their school experience and the aspects in school that shaped this experience. I was also intrigued with how learners on ARV treatment positioned themselves and how were positioned in the school community. The role of schools in shaping this experience became important; all of which led to the focus and aim of this study.

1.4 Research Goals

The main aim of the study was to gain insight into the school experiences of HIV-positive learners on ARV treatment. It posed questions on the extent to which taking ARV's shape their experience of and in school. While not central, a secondary goal related to school responses (by implication, teachers and school management) to HIV-positive learners on ARV treatment.

While the central goal focused on learners' school experiences, I realized during the fieldwork that I could not separate their daily life outside of school from school experiences. For this reason and while not the main feature, the study incorporates elements of learners' daily life experiences that impacts their positioning and experience of, and in school.

1.5 Main Research Question

What are the school experiences of a select sample of HIV-positive secondary school learners on ARV treatment?

Sub Questions

- What are the daily life experiences of a select sample of learners on ARV treatment?
- What are the school experiences of a select sample of learners on ARV's?
- What are school responses to learners on ARV treatment?

1.6 Significance of the Study

The results of the study may be vital to educational practitioners since understanding the schooling experience of HIV-positive learners taking ARV medication may raise awareness of the form and nature of support this group of learners need. This information may also be important to school internal policy makers and management to monitor HIV stigma reduction or progression in schools alongside other indicators. Finally, the result of this study may be useful to the Ministry of Education in their efforts to strengthen support at the national, regional and local levels for vulnerable learners, particularly those who are HIV-positive and on ARV treatment.

1.7 Chapter by Chapter Breakdown

This study is presented in seven chapters. Chapter 1 deals with the general overview of the study by outlining the introduction and background of the study, research context, statement of problem, research goals, main and sub research questions, and significance of the study. This chapter also provided an overview and structure of the thesis.

Chapter 2 presents the conceptual and theoretical framework of the study. I begin with contextualising the phenomenon under study by situating ARV taking within the medication - taking discourse. Second section of this chapter covers the theory of stigma. After collecting the data, I discovered that my data animated individual *agency* and *resilience* as significant elements, while the literature I had so far chosen to examine had only stigma and discrimination and ignored agency and resilience of the individual. As a result, I then revised my literature review to include a theory of resilience, which emphasized learner agency. The final section in this chapter is a brief critique of resilience theory that underplays agency.

Chapter 3 presents the research design that was used in conducting this study. I provide a description of the methodology and specific research approach, the site and sampling technique, methods of data gathering (procedures and instruments used to collect data), the data analysis process as well as the ethical considerations. I end this chapter by highlighting the limitations of my study.

I present the results in Chapters 4 and 5. I begin Chapter 4 with an overview of the eight respondents who participated in the study by presenting individual profiles derived from life history interviews. The second section highlights participant learners' life experiences out of school that shaped and continues to shape their daily experiences. The third section presents the school experiences of the learners in the study.

Continuing with presenting results, Chapter 5 outlines the results derived from questionnaires distributed to 25 secondary schools in the Khomas Region to Life Skills teachers and teacher counsellors. I include these data because the original research design included interviews with learners from more than one school. The ethical implications proved a challenge. I decided to include the views of teachers on their experiences of working with learners such as those in the study to situate the case under scrutiny. This chapter begins with a brief demographic profile followed by results on the nature, form, duration and institutions of training. This chapter ends with awareness of HIV-positive learners, disclosure of their status, and school policies that govern their responses to this group of learners.

Chapter 6 presents the discussion and analysis of the findings in relation to the research goals and questions. The discussion draws on the theoretical and conceptual work in Chapter 2 to make claims. The discussion is organized in sections according to participant learners' responses and school responses: it includes findings on the following: medication-taking; stigma; HIV status disclosure; coping mechanisms; agency resilience; systems and structures; policies and guidelines; and training.

Chapter 7 is the conclusion, which summarizes the findings of this study. It provides a concluding overview of my research findings as well as a brief discussion on the implications of this work for school management and policy development and implementation in relation to HIV-positive learners on ARV treatment. I also make recommendations for further research.

CHAPTER 2 CONCEPTUALIZING MEDICATION-TAKING AND IMPLICATIONS FOR UNDERSTANDING SCHOOL EXPERIENCES OF HIV-POSITIVE LEARNERS ON ARV TREATMENT

2.1 Introduction

This chapter comprises two broad sections. The first contextualizes the study by providing a conceptual framework while the second offers two theoretical frameworks applied later on in the analysis. In 2.2, I begin a discussion on medication-taking as a phenomenon and thereafter proceed to discuss ARV medication-taking. I do this to show that there are distinct differences between taking ARV drug treatment and taking other drugs for general medication. I highlight how the experience of taking ARVs is shaped by discourses on sex and sexuality (and the attendant discourses of shame, silence, taboos, fear, and blame), which makes taking this medication different to taking other medication. Section 2.3 examines specific research that indicates some of the difficulties and challenges people experience in taking ARV medication. One of the major challenges reflected in this literature is stigmatization, which emanates not only from taking the medication but also from the reason why the medication must be taken in the first place, namely a person's HIV status. I therefore present theories and models of stigma in 2.4.

After collecting the data, I discovered that my data reflected individual agency and resilience as significant elements, while the literature I had so far chosen to examine had featured only stigma and discrimination, and ignored agency and resilience of the individual. Consequently, I revised this chapter to incorporate perspectives, debates, and theorization on resilience and agency in 2.5. I trace perspectives on resilience, a brief analysis and critique of resilience theory and related research that underplays agency. I do this to highlight the role of agency and its link to resilience in this study, while I also briefly describe (although not as the primary focus) ways schools can support children to create conditions that might establish and facilitate resilience.

2.2 Medication-taking: Issues and Challenges

In this section, I describe medication-taking as a phenomenon related to health care and wellbeing. I also include a discussion on ARV medication-taking to show the distinction between this treatment and treatment for other chronic illnesses. Both section 2.2.1 and 2.2.2 situate this study conceptually.

2.2.1 Medication-taking as a Phenomenon

Taking medication is one of the main options in the cure, treatment, and prevention of numerous diseases and medical conditions. However, medication experiences differ and depend on the type of medication, its purpose, and the type of disease that is being treated. Many societies rely on medication-taking to treat different diseases and conditions, prevent hospitalization, and improve people's quality of life (Shoemaker & de Oliveira, 2007). Thus, taking medication is a normalized practice in many societies around the world, including Namibia. Commonly, health practitioners and family members, friends or community members respond positively to someone who commits to taking medication for the purpose of getting better or staying healthy. They might even encourage them to take their medication (Shoemaker, & de Oliveira, 2007).

A National Action Plan (NAP) by the National Council on Patient Information and Education (2007) in the United States of America suggests that there is much to celebrate about the improved health status of many people in the world because they are taking medication. Deaths and infant mortality declined because of people taking medication, with major advancements in the treatment of serious diseases that once devastated the lives of millions. This includes more than 300 new drugs, biologics, and vaccines approved by the U.S. Food and Drug Administration (FDA) since 1993 to prevent and treat over 150 medical conditions (NAP, 2007).

Medical science has made possible new therapies for treating AIDS, cancer, and other once fatal diseases. The advancement in treatments for serious diseases notwithstanding, Osterberg & Blaschke (2005) argue for the need to pay more attention and be even more mindful of the public health problems that come along with medication-taking that include, amongst other factors, poor adherence which they state has reached crisis proportions globally. The National Council on Patient Information and Education confirms the challenges of non-adherence to medication in the

USA and around the world, and locates these in society rather than the individual. Medication non-adherence, as suggested by Osterberg & Blaschke (2005), is a problem that applies to all chronic disease states and it affects all members of society, often irrespective of demographic and socio-economic status. The consequences might lead to unnecessary disease progression, complications, and reduced useful abilities, which can lead to a lower quality of life, and may even cause death (Osterberg & Blaschke, 2005).

Not all illnesses or diseases have the same status or recognition, in many societies. As a result, the experience of taking medication depends on the type of illness, type of medication, person taking it and importantly, on the context in which the medication is taken. That is, the type of illness and the type of medication determines the context (where, how, and in what way) medication may be taken, and vice versa. For example, it is not uncommon for someone to take painkillers or medication for flu or cold in a public space without fear of ridicule. This is not the case with every type of medication. Medication such as ARV medication invokes aspects of one's personal identity, which creates a challenge for taking it in public. This raises further questions about the nature of ARV medication-taking and the consequences this has for the individual, as I detail below.

2.2.2 Discourses on ARV Medication-taking

Antiretroviral medication is a combination of two or more antiretroviral drugs that treats the HI-Virus and potentially prolongs the lives of infected people (Wilhelm-Solomon, 2010). ARV therapy might improve the quality of life of HIV-positive patients; reduce HIV related morbidity and mortality; restore and/or preserve immunologic function; and suppress viral replication (Abadia-Barrero & Castro, 2006).

The development of ARV medication altered the face of HIV and AIDS, transforming it from a deadly disease into a chronic illness. The expectation was that as more people gained access to ARV treatment and as the disease itself was thus transformed, stigma would decline. Brazil is an example where a study of young people living with HIV showed that taking ARV treatment did reduce stigma (Abadia-Barrero & Castro, 2006), making the association between access to ARV and stigma reduction.

However, some studies do not support findings such as those of Abadia-Barrero & Castro (2006). Phaladze, Human, Dlamini, Hulela, Hadebe & Sukati (2005) conducted a cross-national study in five countries in sub-Saharan Africa and found that HIV and AIDS-related stigma and discrimination shaped the life experiences of people living with HIV and on ARV treatment. Others like Weiss & Ramakrishna (2001) also revealed that stigma was found to be a major barrier to HIV prevention, treatment and care of people. Newman, Grusky, Roberts & Rivkin (2002) reported similar results, adding that stigma might be a deterrent to HIV and AIDS testing, treatment, and medication-taking.

A study on antiretroviral treatment in Uganda by Wilhelm-Solomon (2010) revealed that while treatment brought substantial improvement in the lives of those with HIV, there was also intense stigmatization. He found that while there was a decline in stigmatization linked to fear of transmission, new forms manifested, particularly stigma linked to the perceived invisibility of illness and the threats of further transmission. He also found that the language of stigmatization was socially and culturally embedded (Wilhelm-Solomon, 2010).

The literature regarding HIV and AIDS-related stigma is not easily synthesized. Different researchers define stigma, explore its many constituent parts, and try to measure it, but often have not clearly distinguished between the causes of stigma and its consequences. Makoae et al, (2002) argue for the importance of addressing the issue of HIV stigma given that ARV treatment is currently the only medical hope for people infected with the HI-Virus. To help people with the disease to have a better quality of life in the long term, they urge recognition that taking ARVs might increase HIV stigma and that this increased stigma might create a barrier to continuing the treatment if it is not addressed by health care providers. Although community-level HIV stigma may be on the decrease, this might not always hold true at the individual level for people taking ARVs. This group of researchers suggests further investigation of the relationships between stigma, HIV-positive people seeking health care, treatment and subsequent adherence to treatment. It is here that my study (among others) seeks to make a contribution.

In order to fill this gap, Holzemer et al, (2007) developed a conceptual model of perceived HIV and AIDS-related stigma, based on data from focus groups conducted with 251 people in countries in sub-Saharan Africa. In this model HIV and AIDS stigma is described as a process, with four dimensions, namely: triggers, stigmatizing behaviours, types of stigma, and outcomes of stigma. These four dimensions of stigma are conceptualized as cyclical in nature. In other words, the outcomes of stigma (for example, poor health) may also serve as a trigger, starting a new form of stigma that might not have manifested during HIV disclosure; and thus starting the process again. The stigma process occurs within a complex political, social, and economic context that shapes medication-taking experiences, despite the health care systems being available.

Holzemer et al, (2009) conducted a follow-up study that indicated that HIV stigma significantly decreased over time, but those taking ARVs reported higher levels of total HIV stigma. This they found to be related to the double bind of HIV disclosure and taking ARVs. Participants reported that frequent clinic visits, blood drawn in public, and taking pills are aspects of antiretroviral therapy that are difficult to hide.

A study conducted by Makoae et al, (2009) revealed that another factor that might increase stigma reported by people taking ARV medication is the belief prevalent in communities that one only takes ARVs when one is already very sick. Taking ARV medication is seen to signal the acuteness of the illness, a perception that these authors suggest might in itself increase stigma, since it increases fear (ibid).

In agreement, Musheke, Bond & Merten (2012) also suggest that despite the availability of antiretrovirals and the good health of many people living with HIV and AIDS, the moral dimension of HIV has not diminished. They found that coupled with low economic status that leads to insecurity, disclosure of HIV status and taking ARVs creates conditions that not only increase stigma, but also lead to HIV-positive people on ARVs experiencing social insecurity. Often such people may experience loss of material and emotional support from spouses, families, and friends. These authors found that the coping strategies exercised in the attempt to re-

establish normalcy, often included halting antiretroviral medication; an issue that has health consequences.

Musheke et al (2012) also reveal that social exclusion and discrimination is anticipated in cases of disclosure of HIV status. Because HIV and AIDS is associated with unacceptable and immoral behaviour, HIV-positive people might not access or adhere to ARV treatment because of the individual shame and disgrace as well as the shame that it might bring to families (Musheke et al, 2012). This might fuel stigma and in particular lead to families wanting the HIV-positive family member to leave the household, community or, in the case of learners, even leave school so as not to disgrace them. In some cases, families might even attempt to hide the person living with HIV.

As indicated above, discourses on stigma and discrimination have particular consequences for those on ARV treatment. Challenges in taking such treatment might be experienced to varying degrees, with very little yet known about the school experiences of learners who are not only HIV-positive but also on ARV treatment - the issue under focus in this study. Deacon, Stephney & Prosalendis (2005) and Sontag (2002) agree that those living with the HI-Virus are widely associated with immorality, death and worthlessness. People taking ARVs might be faced with stigma and viewed as useless or worthless in various contexts; at home, school, church, or other social contexts, and also at work. ARV adherence is therefore likely to be influenced by the social relationships that exist between people taking ARVs and those they live or interact with on a daily basis, such as family and community members and also (as in the case of this study) teachers, peers, and other service providers.

While death caused by HIV and AIDS has been reduced in the past few years as a result of ARV treatment, there are distinct differences between taking medication for general illnesses and taking ARVs. As ARVs become more widely available, there is hope that ARV medication-taking will reduce HIV stigma because HIV-positive people will be able to live longer and healthier lives regardless of living with the virus. Even though the literature indicates that taking medication is one of the main options in the cure, treatment, and prevention of numerous

diseases and medical conditions, medication-taking experiences differ and depend on the type of medication the person is taking, the purpose of the medication and the type of disease.

Because HIV discourses are rooted in sex and sexuality, and can thus trigger stigma, shame and rejection, people taking ARVs often take medication in private so as to avoid stigma. HIV stigma can also be a barrier to accessing ARV treatment in the first place. Stigma can be shaped by fears around disclosure of HIV status, exposure and judgments that might come along with the status that itself can take many forms as I indicate later on in this chapter. In the next section, I analyse research that examining experiences of ARV-taking in general and the experiences of learners in particular.

2.3 Research on ARV Taking

Research carried out in Zimbabwe by Skovdal, Campbell, Madanhire, Mupambireyi, Nyamukapa & Gregson (2011) used a case study to identify social obstacles that influence adherence to ARV treatment and how to deal with them. They drew on interviews and group discussions with 25 nurses and 53 adult ARV users. Their findings suggest that ARV adherence is influenced by the material, symbolic, relational, and institutional contexts in which ARVs users live as well as the patient's motivation, participation and psychosocial responses to ARVs. They found that a key component of the counselling and support that people provide to ARV users involves advice on the importance of patients eating nutritional foods as part of their treatment regimen. The study also revealed that ARVs work best if complemented with a nutrition-rich diet. It found that some discontinue their treatment when they struggle to find food and take medication on an empty stomach, which causes severe discomfort. Thus, the results reveal the important link between non-adherence of ARV treatment and nutrition.

The same study found that although some HIV patients reported a reduction in the stigmatization of PLWHA since ARV treatment began, many patients still feared stigmatization and spoke of experiencing embarrassment associated with being recognized as an AIDS patient (Skovdal et al, 2011). They stated that this fear led to them not accessing treatment timeously and sometimes not adhering to the treatment. The study revealed that fear of stigmatization led to people seeking health care only after they become seriously ill, when treatment might be too late.

Concerns over stigma directed at people taking ARVs were found to be common among respondents in a study conducted in Zambia in 2010 by Fox, Mazimba, Seidenberg, Crooks, Sikateyo & Rosen. They report that about 30% of the total population of 50 children indicated that they had experienced stigma.

Another study conducted in Nigeria by Monjok, Smesny & Essien (2009) reveals that stigma and discrimination among adolescents on ARV treatment led to identity crises, isolation, loneliness, low self-esteem, and lack of interest in mitigating HIV and AIDS. It also led to lack of motivation to practice safer sex. In addition, this study showed that fear of stigma and discrimination limited the efficacy of ARV taking programmes because it not only prevented individuals from taking ARV openly, but also reduced care-seeking behaviour and adherence.

Rosen, Fox & Gill (2007) present results from a systematic review of patient retention in ARV programmes in sub-Saharan Africa. They reviewed reports on whether patients stayed in treatment in ARV programmes in sub-Saharan Africa and also examined the reasons why they dropped out. This review reveals that only 60% of people using ARVs in sub-Saharan Africa were still taking their ARVs after two years. They singled out poverty and stigma as social barriers to a number of patients not adhering to ARV treatment.

A study in Nigeria in 2009 by Uzochukwu, Onwujekwe, Onoka, Okoli, Uguru & Chukwuogo examined factors that influence people on ARV treatment. They found that reasons for non-adherence amongst those sampled included the following: physical discomfort (including side effects); non-availability of drugs at treatment centres; people forgetting to carry drugs during the day; fear of social rejection; treatment being a reminder of one's HIV status; and some patients even selling off their own drugs to those unable to enrol in projects. This study thus highlighted the complexity encountered in addressing issues that undermine adherence to ARV treatment.

A study done by Kelly (2004) at the University of Botswana found negative attitudes towards students who were HIV-positive but particularly towards those on ARV treatment. He suggests

that there is a personal and institutional silence about HIV and AIDS in general as well as about ARV-taking amongst students. He proposes that it is difficult to determine the prevalence of ARV-taking among students due to stigma associated with HIV and AIDS; silence inhibits discussions about treatment among both students who are on treatment and those who are not. He notes that parents, too, were unwilling to disclose that their children were on ARV treatment because of fear of stigmatization at the institution as well as in their communities (Kelly, 2004).

An essential feature of most, if not all, the studies referenced above, is that they focus primarily on the health care consequences of ARV medication-taking. In other words, the focus is primarily on how HIV status and ARV treatment cause stigma which in turn causes fear amongst those on ARV treatment, often resulting in non-adherence to treatment. While many of the studies acknowledge social exclusion as an inhibiting factor, few, if any, examine institution-related social experiences of HIV-positive people on ARV treatment. In particular, none of the studies focus on schools as institutions and the experiences of learners who are HIV-positive on ARV treatment; an aspect that my study contributes to.

Although the above studies reveal many challenges associated with ARV-taking, most identify stigma as a major barrier to health care, ARV adherence, and the quality of life in HIV illness management. It is for this reason that I briefly theorize stigma in the next section.

2.4 Theory of Stigma

Stigma has been identified as a major barrier to health care and quality of life in illness management globally, and Namibia is no exception.

Goffman (1963) provides a framework to understand this concept. He defines stigma as a significantly discrediting attribute possessed by a person with an undesired difference. Stigma may be experienced at two levels - what is felt, and the actions stemming from those feelings. Felt stigma is the feelings that individuals harbour about their condition and the likely reactions of others. Felt stigma happens inside the heads and imaginations of the individual. The second, enacted stigma refers to actual experiences of stigmatization - the withholding of emotional

support, the withdrawal of material support, isolation and all the other ways in which to devalue people.

Since Goffman, other theorists have offered various definitions. For instance, Stafford & Scott (1986:80) suggest that stigma is "a characteristic of persons that is contrary to a norm of a social unit where a norm is defined as a shared belief that a person ought to behave in a certain way at a certain time." Crocker, Major & Steele (1998:504) indicate that stigmatized individuals are believed to possess some characteristics, which convey a social identity that is devalued in a particular social context. Another definition is that of Jones, Farina, Hastorf, Markus, Miller & Scott (1984) who use Goffman's (1963) observation that stigma can be seen as a relationship between an attribute and a stereotype to produce a definition of stigma as an attribute that links a person to unwanted characteristics.

Over the years, various theories and models have been developed to help society understand health-seeking behaviour (UNAIDS 1999; Mackian, Bedri & Lovel 2004). While the general definitions and conceptions above are important, for the purposes of this study I needed to focus on theories that begin to demonstrate links between stigmatized health problems and their consequences. In this regard, Deacon's (2006) health-related theory on stigmatization was deemed most appropriate because she calls for a deeper theoretical understanding of stigma, which she proposes would help researchers to understand and analyze how the domains of stigma relate to HIV stigma and ARV taking. I expand on this theory below as it served to guide the methodology, the interview questions, as well as the analysis in this study.

Health-related stigma is not a new phenomenon. Weiss & Ramakrishna (2004) suggest that stigma occurs when others devalue a person or a group of people because they are associated with a certain disease, behaviour or practice. Like Weiss & Ramakrishna (2004), Parker & Aggleton (2003) propose that health-related stigma can also be associated with other features of a person's identity such as ethnicity, sexual preference, or socio-economic status, which can result in limited access to health services. The consequence for marginalized or vulnerable groups is discrimination and prejudice, which in turn has consequences for their health and well-being.

Deacon (2006) argues that if research and interventions against health-related stigma are to develop and improve, there is need for a coherent and sustainable theory on health-related stigma, prejudice, and discrimination. She argues that in order to develop such a theory, researchers need a better understanding of stigma and its relation to discrimination and disadvantage. A sustainable theory of stigma, Deacon argues, would begin to highlight the process of stigmatization, its origins, and effects. She proposes a distinction between stigma and discrimination for analytic purposes so that their interrelationship may be examined. To her, discrimination caused by stigma is "only one element of stigma-related disadvantage" (Deacon, 2006:418).

Deacon thus argues that there is a difference between stigma and discrimination. She advocates for a definition of stigma that allows examination of both psychological and social dimensions of the stigmatizing process, without conflating stigma with discrimination. She explains how stigma and discrimination relate to other forms of disadvantage and distinguishes between different sources of disadvantage related to stigma (Deacon 2006:419). Separating stigma from discrimination is important in that while stigma may result in blame, shame and status loss for the stigmatized person or group, the effects do not necessarily always lead to discrimination having a negative effect.

Drawing on Herek (2002), Deacon defines discrimination as "behaviour or actions that are differentiated according to membership of a specific group, which only becomes a manifestation effect of stigma when society defends or encourages it" (2006, p420). Therefore, discrimination is related to, but not synonymous with stigma. Their relationship creates disadvantage, but Deacon suggests that this needs to be seen in relation to other forms of disadvantage.

Deacon draws on Joffe's (1999) work, which defines stigmatization as a form of social representation. As such, she states that stigma should be understood as a social process or practice that includes "othering, blaming and shaming (often called symbolic stigma)" (2006:418). Health-related stigma is produced by blaming certain groups of people for having an

illness. This can make people who stigmatize others separate themselves and their self-defined in-groups from risk of being infected with diseases (Deacon 2006:419).

Deacon (2006) suggests that stigma is rooted in power relations in which diseases (such as HIV and AIDS) are constructed as if they are preventable and controllable. She also suggests that people living with diseases are usually blamed for their own infection and labelled as practising immoral behaviour, which caused their ill health. She indicates that the negative effects of stigma may include status loss, discrimination, internalization of the stigma and failure to take advantage of social, economic, educational and health care opportunities. To her, stigma may be expressed at the instrumental, symbolic and/or resource levels and includes both individual (internal) and social dimensions. I briefly explain these various forms or levels of stigma below, using examples that show how each form relates to HIV and AIDS. In addition, I discuss the consequences and explain yet another level of stigma by briefly outlining how it is embodied by the recipient and those who are associated with the individual who is living with the disease. These two forms are described in the literature as internal and secondary stigma.

Health-related Instrumental Stigma

Instrumental stigma is expressed through an individual's concern about his or her risk of contracting a disease. For example, Herek & Capitanio (1998) and Deacon (2006) both make the point that people may hold the perception and be concerned that they might contract HIV through casual contact with someone who is HIV-positive. Both theorists propose that instrumental stigma can also arise when people experience a psychological need to protect themselves. This response is based on the real physical risk posed by an infectious disease, which is potentially life threatening in nature. While this may well be an incorrect perception, it might still lead to people avoiding contact with the person bearing the illness. Such a conception of stigma links to Goffman's (1963) notion of 'felt' stigma.

Health-related Symbolic Stigma

Symbolic attitudes are informed by deeply held values. Symbolic stigma thus is based on "judgmental attitudes towards those perceived to have put themselves at risk of infection through immoral and/or irresponsible behaviours" (Stein 2003:8) and is driven by religious, political, or

other attitudes expressed by society. This type of stigma, for example, occurs when others hold perceptions that people have contracted the disease due to their irresponsible behaviour, and thus judge people living with HIV and AIDS. The society judges such people and believes that they did not stick to their values. Symbolic stigma is an emotional problem based on fear that draws on broader prejudices, identities and power relations in society (Deacon 2006). This form of stigma also links with Goffman's (1963) concept of 'felt' stigma.

Health-related Resource Stigma

Resource stigma is when there is intended discrimination based on resource concerns due to judgements about the likely social contribution of a person being discriminated against. This type of stigma refers to both attitudes and behaviours that discriminate against people with certain characteristics. It is expressed when individuals are denied access to services (e.g. public, educational and health), jobs and leisure activities, which violates their rights. Stigmatized people may experience discriminatory attitudes or separation from people who do not have the disease (Stein, 2003; Deacon, 2006). In addition, there may be economic consequences of stigma and discrimination directed at individuals because they have an illness or they are poor or have a low social status. This type of stigma may affect personal income and wellbeing. Individuals might typically experience discrimination in the form of poor treatment and disrespect, an example of enacted stigma (Goffman, 1963).

In relation to HIV and AIDS, unemployed HIV-positive individuals attempting to access medication in public hospitals might experience resource stigma. Using their economic status as a reason not to provide them with medication is an example of resource stigma.

Internal Stigma

According to Banteyerga, Miz-Hasab, Nyblade, MacQuarrie & Pande (2004), internal stigma is the acceptance and internalization of society's stigmatizing attitudes by people living with the disease. For example, HIV-positive people taking ARVs may believe that they deserve the stigmatizing and/or discriminatory treatment they get.

Secondary Stigma

Secondary stigma is stigma directed at those associated with the person who has the disease. For example, relatives or friends of someone who is HIV-positive may experience stigma from the community as a result. Banteyerga et al. (2004) report on data that reveal several forms of secondary stigma; these include (but are not limited to) verbal stigma and physical and social exclusion.

In sum, authors such as Herek, Mitnick, Burris, Chesney, Devine, Fullilove, Fullilove, Gunther, Levi, Michaels, Novick, Pryor, Snyder & Sweeney (1998) do not refer to finer categories of stigma but rather to other aspects that accompany stigma. They refer to personalized stigma, disclosure concerns, negative self-image, and concern with public prejudice. In addition, they comment on the discounting, discrediting, and discrimination that are directed at people perceived as having HIV and AIDS, and at individuals, groups and communities with which they are associated.

Stigma creates fear and consequently results in discrimination, which sometimes discourages individuals from getting the help they need. Despite the fact that stigma, including internal stigma, is prevalent in the lives of HIV-positive people, it does not always stop people from having aspirations. This positive orientation usually occurs when individuals accept their condition and themselves again, and in this context, the perspectives on resilience and agency described below are relevant.

2.5 Resilience and Agency: Perspectives, Debates, and Theorization

This section incorporates three related components. As already mentioned in the introduction to this study, this section was included when findings indicated that the adverse conditions, including stigma, experienced by the cohort of learners under study did not always constrain them but rather acted as a catalyst towards them implementing changes in their lives. The first part describes perspectives on agency and resilience, while the second focuses on literature that suggests how resilience might be built and sustained amongst children. I end this section with a brief critique of the literature that in my view, underplays agency as a factor in the lives of HIV-positive learners who are on ARVs and vulnerable to stigma.

2.5.1 Perspectives on Resilience

The growing number of children made vulnerable by HIV and AIDS threatens the achievement of Education for All (EFA) and the Millennium Development Goals. Policy recommendations assign schools key roles in meeting the needs of vulnerable children, but there is a lack of evidence on how vulnerable children and schools interact in AIDS-affected communities and what makes some of these children resilient. The construct of resilience has evolved and garnered great interest among scientists, practitioners, and government agencies over the past three decades, since it has far-reaching implications (economic as well as social) for research, intervention, and public policy in the spheres such as health and education..

Turner (2001:441) defines resilience "as the remarkable capacity of individuals to withstand considerable hardship, to bounce back in the face of adversity, and to go on to have functional lives with a sense of well-being", while Luthar, Cicchetti & Becker (2000:543) define resilience as a "dynamic process encompassing positive adaptation within the context of significant adversity." Both definitions acknowledge two critical aspects associated with resilience. The first is that individuals need to have been exposed to a significant threat or harsh difficulties to demonstrate resilience and the second, that resilience is the achievement of positive adaptation despite major problems in the developmental process. Put differently, resilience encompasses two components, namely, (a) exposure to or experience of a significant event that creates risk and vulnerability, and (b) the displaying of competence and successful adaptation. Implied in the above is the notion that resilience is fluid, dynamic, contextual and process orientated. Children made vulnerable and predisposed to stress at one age or stage in their lives may or may not remain so through later years as their life circumstances change (VanBreda, 2001).

Vaillant (2002) acknowledges that resilience might be both internal and external to the individual. He recognizes a combination of nature and nurture-related elements in which individual predisposition may play a role, acknowledging that the individual does not operate outside an influencing environment. He explains, "our ability to feel safe enough to deploy adaptive defences like humour and unselfishness is facilitated by our being among loving friends" (Vaillant, 2002:285).

Bonanno's (2004) definition of resilience, as people's capacity to combat and overcome debilitating experiences, assumes that resilience becomes assimilated into people's ways of being, thus becoming internal. In other words, Bonanno suggests that resilience assumes that people develop characteristics or attributes (e.g. toughness, self-enhancement, coping) that potentially become part of who they are.

Work by researchers in the field of vulnerability and resilience supports the notion that the latter is a vital construct as it helps researchers better identify and understand how people cope in certain situations despite the challenges they face. Walsh (2004) suggests that significant in descriptions of resilience is that it can be developed at any point over the course of a life cycle. Walsh (2004:14) extrapolates from Werner and Smith's research that ". . . unexpected events and new relationships can disrupt a negative chain and catalyze new growth". Favourable interactions with individuals, families, and elements in the contextual environmental might have the fundamental effect of shifting a negative series of events into a positive influence, thereby creating hope and aspiration, which might lead to resilience (Walsh, 2004).

I briefly describe some of the philosophical and ontological roots of the above in the following section.

2.5.2 Theorizing Resilience: Shifts and Debates

Resilience theory is a comprehensive field of study that has been addressed by psychologists, sociologists, educators and many others over the past few decades. VanBreda (2001) defines resilience theory as "... a theory that addresses the strengths that people and systems demonstrate that enable them to rise above adversity." Conceptions of resilience have roots more in psychology than sociology and education. The context of HIV and AIDS in South Africa in particular has necessitated a shift in which education gains a better understanding of the complex interplay between vulnerability and resilience. This will in turn enable a better understanding of children and their contextual realities. Emerging work in South Africa and elsewhere highlights gaps in the theorization of the concept of resilience - an area in which this study seeks to contribute.

Theron & Theron (2010), leading researchers in this field in South Africa, conducted a critical review of 23 articles focused on South African youth resilience, published in academic journals between 1990 and 2008. They also compare the South African findings to those of international studies. Their findings propose the need for more theorization of the concept. Important, though, is their call for an emphasis on resilience as socially and culturally situated, a move away from the emphasis in earlier research on resilience attributes of individuals, identified outside of the context in which resilience emerges and is located. This shift in emphasis highlights possibilities for support and sustainability. Thus, in an endeavour to explain how South African cultures and contexts shape youth resilience, Theron & Theron (2010) aim to contribute to the international discourse on resilience, which they also acknowledge is moving beyond an articulation of the factors and processes that anchor resilience, to a more focused enquiry into the dynamic, context-specific processes that fuel resilience.

An example of research that responds to the shift described above is the study undertaken by Theron, Cameron, Didkowsky, Lau, Liebenberg & Ungar (2011). It focuses on four impoverished, relocated youths (two Sesotho-speaking orphans in South Africa and two Mexican immigrants in Canada). They explore cultural factors as potential roots of resilience. They triangulate rich qualitative findings (visual, dialogical, and observational) to present results that speak to context-specific particularities, while at the same time acknowledging the universal aspects already articulated in previous research, nationally and internationally. Their findings reveal that there are common protective features, but that there are also elements unique to each cultural context. The protective themes that emerged include relatedness, a culture of sharing, religious affiliation, and mother tongue; mediated, as they found, by significant others (adults as cultural facilitators). They also found that a context with these protective features recognized or acknowledged the role of children as willing co-facilitators; thus the role of agentic action in becoming and being resilient was illuminated.

Similarly, Vaillant (2002) suggests that resiliency researchers who focus on risk factors and pathology suppose a predetermined picture and are often mistaken in believing that tragic events condemn disadvantaged children to miserable futures. Vaillant uses narrative data that he either collected or retrieved from archives holding 50 years of longitudinal data. He calls for research

that on the one hand contextualizes resilience, and on the other hand foregrounds the interplay between context and individual in the analysis. Such an orientation requires giving some consideration to the role of agency in resilience research.

2.5.3 Agency, Resilience, and Children

Agency, according to Barker (2005), refers to the capacity of individuals to act independently and to make their own choices. Barker posits that societal structures shape (that is, determine or limit) the level and scope of agency. These structures include (but are not limited to) social class, religion, gender, ethnicity, traditions, and customs. Barker (2005) asserts that agency might be shaped by the belief structure which individuals develop throughout their life experiences and the perceptions held by the society in which individuals make meaning of themselves and their experiences.

Children's agency and resilience is complex. According to Liebenberg & Ungar (2008:225), in harsh conditions, "resilience is both the capacity of individuals to navigate their way to health-sustaining resources, including opportunities to experience feelings of well-being, and a condition of the individual's family, community and culture to provide these health resources and experiences in culturally meaningful ways." This definition explains the need for children faced with hardship to find the way towards better living and wellbeing (Liebenberg & Ungar 2008).

2.5.4 Developing Child Resilience

According to Goldstein & Brooks (2005:3) child resilience is the capacity of a child to deal effectively with stress and pressure, to cope with everyday challenges, to rebound from disappointment, mistakes, trauma and adversity, to develop clear and realistic goals, to solve problems, to interact comfortably with others, and to treat oneself and others with respect and dignity.

The International Resilience Research Project was a study conducted by Grotberg (2000) in 14 countries in order to learn what different people or countries did to promote resiliency in children. The data for the study were gathered during September 1993 to August 1994. Five

hundred and eighty-nine children, randomly selected from the entire population, participated in the study, comprising 48% girls and 52% boys. Most of the children were aged 9 to 11 with the remainder being six years of age and under (Grotberg, 2000). The findings suggested that every country that took part had a common set of resilience factors. Those factors were then characterized under three headings: "I HAVE", "I AM", and "I CAN".

"I HAVE" factors featured support such as people who trust and love the child unconditionally, who establish protective parameters around the child, who act as role models, who encourage and teach the child to be self-sufficient, and who nurture the child when ill (Grotberg, 2000). Grotberg argues that the promotion of resilience in children depended heavily upon adult behaviour and that for example teachers, parents, pastors or counsellors contributed much more to promoting resilience in the lives of children than did the children promoting it on their own. Importantly, Grotberg (2000) suggests that child resiliency does not develop in a vacuum, but rather in a socio-cultural context.

"I AM" qualities include the child's respect for self and others, taking responsibility for actions, and being confident that life's journey will lead to a positive end (Grotberg, 2000). The "I AM" quality identified by Grotberg agrees with the propositions of Lin, Sandler, Ayers, Wolchik & Luecken (2004) that resilient children are those who have shown greater personal efficacy in coping with stress. They become positive about their lives and demonstrate the capacity to aspire and imagine a different future.

The "I CAN" traits encompass social/interpersonal skills that demonstrate children's ability to talk to someone when they feel threatened or troubled. It also demonstrates children's ability to solve problems, to show self-control when confronted with unpleasant situations, to determine when to seek help and when to take action, and to find someone to help when help is needed (Grotberg, 2000).

Gilligan (2000) suggests that there are five key functions or concepts for promoting resilience in children who are exposed to adverse conditions, namely: reducing the stockpile of problems; steering through the pathways and turning points in development; having a secure base;

promoting self-esteem/self-worth; and developing self-efficacy. He proposes that a small change within a child's life can positively influence that child to embrace life and become resilient (Gilligan, 2000).

Cohen, Lotan, Scarloss, & Arellano (1999) also report that children are more likely to prosper in environments where they feel accepted, appreciated, welcomed and connected. He suggests that school or home, as caring environments, are the key elements in increasing self-worth and encouragement and thereby reinforcing learners resilience (Cohen et al, 1999).

2.5.5 A Critique of Resilience Literature that underplays Agency

Many of the theorists and researchers who research resilience as a phenomenon primarily focus on how to provide care and support, create love and trust, and offer encouragement, both within and outside the family structure, with little attention to the agency children exert to determine their own realities and future.

Theorists like Werner (1995) have emphasized the protective factors in child resilience of which the family is the most enduring. She proposes that close bonds with at least one family member or an emotionally stable parent are critical not only for providing care and support, but also for facilitating resilience amongst children. She further argues that community support (for example from peers, teachers, or sports coaches) also offers the kinds of support to children that promote resilience. Werner also supports the notion that young children have the propensity to "… actively recruit informal support networks in their community. Among the most prominent examples were teachers, especially in the early grades" (1996:18-28).

Benard (1991), Higgins (1994) & Meier (1995) also found that caring relationships with significant others such as teachers creates resilience amongst children. In a school context, teachers who conveyed loving support to learners by listening and validating their feelings and by demonstrating kindness, compassion, and respect, created conditions in which learners displayed resilient behaviour and dispositions. These researchers found that teachers who developed resilience amongst learners withheld judgement, did not take student behaviour

personally and showed empathy. They recognized that the learners in question were doing the best they could, based on the way they perceived the world.

Cohen et al, (1999) reports that children are more likely to prosper in environments where they feel accepted, appreciated, welcomed and connected. He suggests that school or home, as caring environments, are among the key elements needed for increasing self-worth and encouragement and thereby reinforcing learners' resilience.

Grotberg (2000) also suggests that the promotion of resiliency in children depends more upon adult behaviours than on children themselves. Grotberg's study further suggests that adults (such as teachers, parents, pastors etc.) contribute more in promoting resiliency in the lives of children than the children contribute promoting it on their own. He argues that child resilience does not develop in a vacuum but in a socio-cultural context (Grotberg, 2000). The implication of this is that one cannot understand resilience outside the conditions that made the child vulnerable in the first place.

Walsh (2004) found that resilience could be developed at any point over the path of the life cycle of children when they have favourable interactions with significant individuals and families. She also stressed the social environment as an important factor in developing resilience amongst children.

The above researchers all place emphasis on the external factors that create and develop resilience amongst children, with few if any paying attention to the individual child and his/her agency. These researchers emphasize adult and/or external support as the primary way in which children develop resilience, an aspect that the data in this study also supports. However, as I show later on, child resilience is also determined by an internal drive, which is supported by external factors but is not always the result of external influence, or may occur in the absence of adult support.

Much of this work on resilience and children also emphasizes the structural support and role modelling that children need in order to become resilient. While researchers like Werner have

begun to recognize that support may come both from within and from outside family structures, he, too, underplays children's agency.

There is no agreement amongst researchers on how much agency can be exercised by children, with few, if any, acknowledging that children may potentially develop resiliency without external support in the way described above.

While the above work is important, much of this work pays attention to what children *need* in order to become resilient, without asking questions concerning what they have within themselves that may create resilience. Little if any of this work asks questions about what children may embody that predisposes them to become resilient. None of the literature draws attention to how children mediate structures and social and cultural conditions to develop resilience. My study contributes towards this gap. As my study demonstrates, and as I highlight later on in the analysis, it is the interplay between the environment and the child's own will to power that creates resilience.

CHAPTER 3 RESEARCH DESIGN

3.1 Introduction

In this chapter, I present the research design adopted by this study. I outline the methodology, sampling technique, methods of data gathering, ethical considerations, data management and analysis process. I end this chapter by describing the limitations of the study.

3.2 Methodological Orientation

This study investigated the school experiences of HIV-positive learners on ARV treatment. It posed questions on the extent to which taking ARVs shapes their experience of and in school. While not central, a secondary goal related to school responses (by teachers and school management) to HIV-positive learners on ARV treatment. As mention in Chapter 1, it was not possible to ignore the experiences outside of school that influenced learners' lives. Thus, I include a question on this aspect.

I used a qualitative orientation in the study. This involves taking a systematic approach to understanding qualities or the essential nature of a phenomenon within a specific context (Maxwell, 2004a). My decision was influenced by the compatibility of this orientation with my research goals, questions, and the actual research process. Maxwell (1992, 2004b) suggests that with qualitative research, the researcher aims to understand the meaning, events, situations, and actions they are involved with, and the accounts that participants give of their lives and experiences. In a qualitative study, the researcher is interested in the physical events and behaviour that takes place, as well as to paying attention to how participants make sense of these events and how this understanding influences their behaviour.

Qualitative research aims also to discover "patterns which emerge after interviews, close observation, careful documentation, and thoughtful analysis of the research topic" (Maykut & Morehouse 1994, p21). This kind of orientation allowed me to gather rich and detailed descriptions of situations and experiences from participants. It also helped me to understand how events, actions, and meanings are created by particular circumstances in which they occur. Qualitative research has the aim of understanding experiences from the perspectives of

participants. It not only focuses on what participants say about their experiences, but also on how they express the emotions and the non-verbal cues they express (Henning, Van Rensburg & Smit, 2004; Sherman & Webb, 1990).

Qualitative researchers see the world as socially constructed through individual perceptions. Their approach is not to believe that they understand and can identify reasons for behaviours. Rather, they are sceptical of providing possible explanations without carefully examining the process (Maykut & Morehouse, 1994). Warr (2004:578) echoes this sentiment, suggesting that qualitative research provides "researcher[s] with an opportunity to listen to people tell their life stories." In the case of this study and because of the sensitivity of the phenomenon, adopting such an orientation allowed me to hear "the voices of those who are silenced, 'othered', and marginalized by the dominant social order as the methods ask not only 'what is it?' and more importantly, for participants to 'explain to me – how, why, what's the process, what's the significance?" (Hesse-Biber & Leavy, 2005:28).

Within a qualitative methodology, I adopted an interpretive approach, with its goal of understanding "…the social world from the viewpoint of the actors within it". Further, an interpretive approach "…is oriented toward detailed description of the actors' cognitive and symbolic actions, that is, the meanings associated with observable behaviours" (Wildemuth, 1993:451). A central feature of interpretive research is the need to understand "the subjective world of human experience" (Cohen, Manion & Morrison, 2000:36). Interpretive research aims to characterize people's experience of the world, the ways they interact together, and the settings in which these interactions take place (Cohen et al, 2000). Cantrell adds, "... interpretive research emphasizes an understanding and interpretation of complex interrelations between social structures and the meanings people give to phenomena" (Cantrell, 1993:101).

I chose this approach because of my interest in understanding how being on ARV treatment shapes learner school experiences. It enabled me to focus on experiences, words, and points of view relating to the phenomenon. The process in this kind of research is inductive, meaning that, as Lincoln & Guba suggest, it "... has a design that emerges, develops and unfolds" (1985:225). Similarly, Henning, van Rensburg & Smit (2004:21) suggest "[the] interpretive approach focuses

on the understanding of individuals' day-to-day living and working environment, from the standpoint of their unique contexts and backgrounds."

I used a case study method to examine the school experiences of learners on ARV treatment. A case study is one that investigates an individual, group or a large-scale community to answer specific research questions. It is a descriptive or explanatory analysis of a human being, group or event. Yin (1994:13) defines a case study as an empirical enquiry that investigates contemporary phenomena within their real life context especially when the boundaries between phenomenon and context are not clearly evident. The case study is an ideal methodology when a holistic, in-depth investigation is needed (Baxter & Jack, 2008; Dul & Hak, 2008), as in this study.

Yin (2009) identifies different types of case studies; exploratory, explanatory, and descriptive. Exploratory cases are sometimes considered as a prelude to social research and may be used for doing causal investigations. Descriptive cases require a descriptive theory to be developed before starting the project. In all of the above types of case studies, there can be single-case or multiple-case applications. Case studies tend to be selective, focusing on one or two issues that are fundamental to understanding the system being examined.

Case studies typically examine the interplay of all variables in order to provide as complete an understanding of an event or situation as possible. This type of comprehensive understanding is arrived at during a process identified as 'thick description', which involves an in-depth description of the entity being evaluated, the circumstances under which it is examined, the characteristics of the people involved in it, and the nature of the community in which it is located. Thick description also involves interpreting the meaning of demographic and descriptive data such as cultural norms and mores, community values, ingrained attitudes, and motives (Yin 1994).

I chose to use a case study because it provided an opportunity for understanding the totality of the phenomenon under scrutiny. The case study gave me a chance to study one aspect of a real-world problem (school experiences of HIV-positive learners on ARV treatment) in detail from different viewpoints.

I adopted a descriptive case study as it allowed for me to obtain detailed information on this issue. Baxter & Jack (2008) suggest that a descriptive case study is one that is focused and detailed in which propositions and questions about a phenomenon are carefully scrutinized and expressed at the beginning.

I also realized that this type of case study would require a theory to point the data collection in the correct direction. Baxter & Jack (2008) suggest that descriptive theory helps to specify the boundaries of the case, and contributes significantly to the rigour of the finished case study. They further note that the power and promise of a descriptive case study lie in its potential for mining for abstract interpretations of data and theory development.

The case in this study is the phenomenon under examination rather than the site or number of participants. Put differently, the case was school experiences of learners on ARV treatment.

3.3 Research Site

I conducted the study at a school in Windhoek, Khomas Region. This school is located in Katutura suburb where many under-resourced and underperforming schools are situated. Learners at this school are from poor backgrounds. The area is characterized by a high number of HIV and AIDS cases, many patients on ARV treatment, high poverty, informal settlement houses, poor sanitation, and high rates of unemployment. This claim is supported by De la Torre, Khan, Eckert, Luna & Koppenhaver (2009) when they indicate that HIV prevalence in the Khomas region ranges from 9% to 21% among adult HIV patients and from 12% to 16% among children on ARV's. This is among the highest for urban regions in the country.[2] Apart from the prevalence rate, this site was appropriate since being my workplace it was easily accessible to me.

Originally, I had planned to carry out my study at two proposed schools in Katutura, Windhoek. However, I was advised by my university's higher degrees research committee to work only at

[2]The highest prevalence is reported to be at Katima Mulilo in the Caprivi region, with HIV prevalence rate of 39.4%.

my school because of the ethical issues concerning disclosure. This proved to be a wise decision given the sensitivity of the topic and the need to build trust in learners first. However, and as I outline later on, I selected to source data from school counsellors and Life Skills teachers in the wider region on their experiences and preparedness to work with HIV-positive learners on ARV treatment.

Having been a teacher-counsellor and a Life Skills teacher at the site for more than five years, I had experience of - and access to - the research site. The fact that I already worked with the children who became the focus in the study, increased the practicability of my study.

3.4 Sample

As advised by the research committee, I sampled teachers and learners, with the latter being the main participants. In the first instance, I selected learners and teachers from the site school. Life Skills teachers and/or counsellors were also sampled from schools in the region. I explain each sampling process below.

Sampling Learners

As mentioned before, I originally planned to carry out my study at two schools in order to gain insight into the experiences of more participant learners. In the end, I chose to sample learners from my school only. Eight learners on ARV treatment were sampled purposefully, based on my knowledge (as a school counsellor) of their HIV status. As suggested by Merriam (2009:77), purposeful sampling is "based on the assumption that the researcher wants to learn, understand, and gain insight and therefore must select a sample from which the most can be learned". It is used when the researcher requires respondents who are likely to be experiencing the phenomenon under focus. In other words, respondents are viewed as 'knowledgeable people', i.e. those who have in-depth knowledge about particular issues, such as role, power, and expertise or have relevant experience (Cohen, Manion & Morrison, 2007:115). As Creswell (1998) puts it, to select a purposive sample one must have a clear reason for the selection. The purpose is not to generalize across a whole population but to shed light on a range of issues relevant to the research questions. The selected learners had experience of the phenomenon and were known to have information relevant to the study. Learners were between the ages of 16 and

22. I sampled a group of six females and two males. Learners were given pseudonyms for use in their profiles, for confidentiality reasons. Learners were briefed on the research during a counselling session and they volunteered to participate. They were informed that they could withdraw at any time and that the research was confidential and would be used for research purposes only.

Sampling Teachers

The sampling of teachers took two forms; a group from the site school as well as a larger sample of Life Skills teachers/counsellors from the region.

Firstly, I sampled seven teachers and the principal from the site school – all people who teach and manage participating learners. I had initially approached 12 teachers to avoid being disappointed if some were to make excuses on the day and avoid participating in the study. As it turned out, four teachers did not participate, stating that they were not comfortable with talking about HIV/AIDS which had taken away their loved ones. The final group comprised four teachers in management positions at the school (including the principal), while the other four participated because they were directly involved with the sampled group of learners (either as class or subject teachers). Participation was voluntary and teachers were informed that they, like learners, could withdraw at any point in the research process.

Secondly, I sampled 27 Life Skills/counsellors/teachers from schools in the Khomas Region, whom I surveyed through a questionnaire. The Life Skills teachers were singled out to be part of the sample because of their experience in dealing with, counselling, and/or supporting learners who face problems at school, including problems related to their taking ARVs. This decision, as already indicated, was a recommendation by the faculty higher degrees committee.

Questionnaires were distributed at a Life Skills and counsellors' workshop, which not all schools attended. I personally distributed questionnaires to the schools that had not been present at the workshop (Appendix A). Twenty-five of 27 schools responded. The number of participant teachers (27) exceeded the number of schools (25) that participated because some schools have

two Life Skills teachers (having not yet implemented the 2012 government requirement that every school should have only one full time teacher responsible for the Life Skills subject.

Participation was voluntary. As with learners, teachers also signed consent forms (Appendix B).

3.5 Methods of Gathering Data

This study adopted a variety of strategies for gathering data. I used interviews, focus group discussion, observations, and document analysis to source information for the main component of the study; namely understanding school experiences of HIV-positive learners on ARV treatment. Interviews were held with learners and focus group discussion was used with the teachers from the participating school.

I used the questionnaire already mentioned (Appendix A) to gather information from Life Skills teachers/counsellors for the second component of the study. I describe each strategy in detail below.

3.5.1 Interviews

Interviews were the main source of data. Interviews are discussions, usually one-on-one, between an interviewer and an individual, meant to gather information on a specific set of topics. They can be conducted in person or over the phone. Interviews differ from surveys by the level of structure placed on the interaction. Interviews can be used as a primary data gathering method to collect information from individuals about their own practices, beliefs, or opinions. They can be used to gather information on past or present behaviours or experiences as indicated by Harrell & Bradley (2009).

According to Cohen et al. (2000), interviews are seen as expressively engaged social interaction about people's real experiences in constructing their personal accounts on a particular topic. They may be viewed as an exchange of "views between two or more people on a topic of mutual interest" (Cohen et al., 2007:349). Cohen and others argue further that interviews emphasize the social situations of research data (Cohen et al, 2007).

There are different types of interviews. Structured interviews are normally done in a face-to-face format using a standard set of questions. The same questions are usually posed to each participant with a view to obtaining data that can be aggregated because identical questions were asked. Questions are fixed, sequenced and standardized, with little or no probing. The researcher usually only repeats or clarifies instructions when applying a structured interview format (Taylor & Bogdan 1998).

At the other extreme, unstructured interviews are also usually conducted face-to-face but take on a very different format. In this case, the researcher starts from a position of wanting to be sensitive to how participants construct their views and perspectives of things. The aim is to allow the participant's structure to dominate and to get the participant to talk about a topic area. Normally, probing questions are not directed, but are rather asked to encourage the participant to keep talking or to get back to the subject of interest, as explained by Strauss & Corbin (1990).

A third format, applied in this study, is a semi-structured format. Such an interview structure offers flexibility while at the same time providing structure and consistency. This is the type of interview where, "... more or less open-ended questions are brought to the interview situation in the form of an interview guide" (Flick, 1998:94). From the beginning, the focus is on gaining an understanding based on textual information obtained. The level or depth of understanding that the researcher pursues is used to characterize this type of interview. Questions are mostly open-ended, yet directed at obtaining particular information (Gubrium & Holstein, 2003; Flick, 1998; Dillman, 2000; Kawana, 2007). The interviewer has some discretion about the order in which questions are asked; but the questions are standardized, and probes may be provided to ensure that the researcher covers the correct material. This kind of interview collects detailed information in a style that is somewhat conversational. Semi-structured interviews are often used when the researcher wants to delve deeply into a topic (Harrell & Bradley, 2009; Bernard**,** 1988; Cohen & Crabtree, 2006).

I used in-depth semi-structured interviews, which allowed me to ask in-depth questions as well as probe for clarity. The semi-structured interviews, which I applied, had some pre-set questions. However, I was able to deviate depending on participant responses. Semi-structured interviews

are useful when working with a sensitive topic in that they promote trust building and intimacy, important when gathering data from vulnerable people (Liamputtong, 2007).

I interviewed learners individually during counselling sessions, so as not to raise any alarm or create deeper isolation. I interviewed each learner more than once. Each interview lasted from 45 to 60 minutes, depending on the responses by learners.

I used a timeline to initiate the discussion with learners in the first interview. I realised that it would be a challenge for learners to discuss painful experiences or current events in their lives without a prompt. It is for this reason that I had asked the participants to draw a timeline (see Appendix C) that indicated significant events that happened in their lives. I probed my questions from the timeline; asking for explanations, feelings and perspectives on the events depicted. Learners had the choice to either write a word or phrase the event.

I conducted second interviews with all learners, where I focused primarily on learner school experiences. I had a third interview with some learners.

Before I started with the interviews, I realized that it was important for me as a researcher to develop empathy with the participants and win their confidence because of the sensitivity of the topic. Being a teacher-counsellor gave me the advantage of engaging with participants on a daily basis. This proved to be invaluable in that the interviews were perceived as part of the day-to-day interaction between the learners and me, even though they understood and had agreed to participate in the research process.

I made sure that I paid attention to the venue where the interview was held. In this regard, I chose the counselling room where I regularly meet with learners. Before the interview started, I made sure that the interviewee was comfortable by asking general questions about their well-being. I hoped that the introductory remarks would create a potentially stress-free environment. This, as I explain later on, proved to be a challenge.

All interviews were tape recorded and transcribed. Walford (2001:83) suggests that the use of a tape recorder allows the researcher to focus on asking questions and probing. It also allows researchers to use long quotes as evidence in the study. I also took great care to maintain confidentiality and ask questions which would not hurt respondents' sense of self, considering the sensitivity of the topic.

During the design phase of my study, the emotional well-being of the participants was my primary concern. While I had invited them to request support should they require it, I had not considered the impact of their life stories on me as the researcher. Young & Lee (1996) argue that the role of emotion in the research process is not accorded the recognition it deserves and this is endorsed by Hubbard, Backett-Milburn & Kemmer (2001) who address the need for research teams to develop strategies to 'manage' the emotions of researchers throughout a project. They suggest that while there is now a widely accepted understanding that participation as a respondent in research carries with it an emotional part and a consequent need for the researcher to be sensitive and aware of the ethical implications, there is little corresponding awareness of the emotional impact on the researcher.

I, too, was affected by the suffering and pain of the HIV-positive learners as they talked about the illness and in most cases the death of their parents and siblings. I was also affected by their experiences of rejection. As a researcher, their acceptance and resilience inspired me to want to help even more than I had already done as a counsellor.

3.5.2 Focus Group Discussions

Krueger & Casey (2009) argue that a focus group is a special kind of organized discussion or series of discussions. They propose that focus group discussions are guided by a few specific questions. The purpose of a focus group interview is to gain a deeper understanding of participants' views and experiences, their feelings, perceptions, beliefs, knowledge, and attitudes about the topic being investigated.

According to Lederman (see Krueger & Casey, 2009; Evans, 2007) a focus group is 'a technique involving the use of in-depth group interviews in which participants are selected because they are

a purposive, although not necessarily representative, sampling of a specific population, this group being 'focused' on a given topic'. Participants in this type of research are, therefore, selected on the criteria that they would have something to say on the topic, are within the age-range, have similar socio-characteristics, similar careers or interests and would be comfortable talking to the interviewer and to each other (Richardson & Rabiee, 2001; Smith 2009; Webb 2002).

Focus group discussions involve interviewing a number of people at the same time with the emphasis being on questions and responses between the researcher and participants. However, these groups also rely on interactions within the group based on topics that are supplied by the researcher (Smith 2009; Evans 2007).

Focus groups seek to bring intensely personal issues to the surface, to allow for divergence of perceptions, attitudes and opinions, and to allow respondents to interact so as to produce data that may be analyzed. The focus group interviews enable the researcher to tap into human dispositions and feelings on a given topic. It may be taken for granted that individuals influence each other with their comments during discussions and that in the course of a discussion, opinions of an individual might shift. The researcher is in a position to observe such shifts as well as the form of the influencing factors (Evans 2007; Krueger & Casey 2009; Mclafferty 2004).

Focus groups answer questions that the researcher is asking and can lead to new information and surprises (Mclafferty 2004; Webb 2002). They are particularly useful when there are power differences between the participants and decision-makers or professionals, when the everyday use of language and culture of particular groups is of interest, and when one wants to explore the degree of consensus on a given topic (Smith 2009; Krueger & Casey 2009; Mclafferty 2004). I chose teachers and management members to give me their opinions and views on HIV-positive learners' schooling and how the school manages and supports these learners. These teachers were comfortable talking about HIV issues with me and with the other participants.

The focus group session in this study concentrated on gathering opinions, beliefs, and attitudes about issues of the schooling experiences of HIV-positive learners on ARVs, testing the assumptions that I held concerning these experiences, and providing an opportunity to learn more about my topic from the perspectives of the school management and teachers.

I had two warm-up general questions to make participants comfortable before I got to the more substantive questions. My focus group questions (Appendix D) were open-ended and moved from the general to the specific. I selected a focus group facilitator who was knowledgeable about my study to mediate the process so that I could concentrate on responses and probe. The facilitator welcomed the group, introduced the topic and dealt tactfully with outspoken group members. She also kept the discussion on track and made sure every participant was heard.

The location was the counselling office at our school, which could accommodate the participants and where they felt comfortable expressing their opinions. This location was also easily accessible to participants because they all work at the school. I set out refreshments and arranged the seating in a U-shape so that all participants could have a full view of the others. I sought and obtained permission to tape-record the session, making sure that the technology would not fail.

In addition to the rationale already offered for using the focus group format, it was felt that while participant teacher attitudes, feelings and beliefs may be partially independent of a group or its social setting, they would more likely be revealed in the sociable and interactive context of a focus group than individual interviews. There is no doubt that one of the participants used the focus group discussion to have her opinions heard and, once this was done, she settled down and took part in the interview.

Two reasons accounted for all invited teachers not attending. First, teachers were reluctant to participate due to the sensitivity of the topic and the silence around HIV and ARVs in school and in the community. Second, the time schedule for the interview proved to be a challenge since I requested that it take place after school. Many teachers are not willing to stay for an extra hour after school and thus chose not to participate.

Focus group members were given the freedom to choose whether to participate in the study or not. They were given consent letters to sign as an ongoing part of the research process. The researcher not only discussed the consent form with participants, but also explained their right to refuse to participate or to withdraw any time during the research process.

It was the first time that, as a researcher, I experienced a sense of self-doubt and hesitation in part because I was a colleague and thus known to participants. The use of a facilitator eased any possible tension, enabling teachers to communicate well with me and with each other. There was no tendency for teachers to talk over each other, nor were there any disagreements that they were not able to resolve.

3.5.3 Observations

I included observations to provide me with insight into learner's lives at school. Observation means studying or watching with scrutiny. The difference between a simple action of seeing and observation as a research tool is the same as the difference between hearing and listening. In observing, the mind must be involved as it is involved when listening. The observer must try to assess, analyse, and study as he/she sees a particular object or person (Taylor-Powell & Steele 1996). Nieuwenhuis (2010:85) sums it up by defining observations as "a systematic process of looking at the behavioural patterns of participants, objects and occurrences without necessarily questioning or communicating with them."

Cohen et al, (2007:44) argues that observations "offer a researcher the opportunity to collect 'live' information from the natural setting and allow the investigator to look directly at what is taking place in situ rather than relying on second-hand accounts."

Observations can be direct or indirect and obtrusive or unobtrusive. Direct observation takes place when you watch interactions, processes, or behaviours as they happen; for example, observing a facilitator presenting a lesson with the task of determining whether that facilitator has delivered it with dedication. Indirect observation takes place when you watch the results of interactions, processes, or behaviours (Taylor-Powell & Steele, 1996). In seeking to look into the natural setting of my study, as a qualitative researcher, I aimed to be as unobtrusive as possible,

so that neither my research presence nor my methods would disturb learners or the day-to-day running of the school. I adopted a passive, non-intrusive role, merely noting down the incidence of the factors being studied as suggested by Cohen et al. (2007:398).

I asked permission from the principal (Appendix E) to observe learners. I observed situations of interest at the school: in particular, I observed the learners in the playground and their participation in certain classes. As a researcher, I adopted the 'fly on the wall' technique for observation. Although this technique lacks the advantages offered by participation, it allows things to flow without any disturbance caused by the observer's presence.

I chose to be the only person conducting observation because my topic was very sensitive. For the same reason, I did not have a structured timetable for observing learners, but rather took advantage of every chance that I got. I sometimes joined the learners on the field, or kept them company on behalf of other teachers who were supposed to be with them in the classroom, and on these occasions pretended to be busy with something else to avoid distracting them. I took field notes. Taylor-Powell & Steele (1996) point out that field notes are the least standardized way of collecting observation data and do not include pre-set questions or responses from participants.

My observations focused on learners who were taking ARVs, and looked at the following aspects: how these learners reacted to others in and outside the classroom; whether they participated in extra-mural activities; their interactions with others; and whether stigma or discrimination was being directed towards them. What and how I observed depended very much on the subjects of study. My task then was to capture as much of the detail as possible, through making notes, which I studied in detail later in the day at my convenience. Generally, observations (Appendix F) helped me to verify and complement some of the data generated through individual and focus group interviews. This method was very time-consuming compared to other data collection methods that I have used in this study, even though it was not the main technique.

3.5.4 Document Analysis

Heffernan (2001) argues that document analysis is a social research tool that is a helpful part of most schemes of triangulation. At school level, policy (and other) documents are a large source of knowledge about the school. To be able to use documents effectively, the information in the documents should be carefully planned, followed and implemented (Heffernan 2001). To understand how the schools are managing and supporting learners on ARVs, I analyzed documents that had allowed me access to subjects that may be difficult or impossible to research through direct or personal contact with learners who are on ARVs.

I analysed the schools' internal policy (Appendix G) to trace evidence for how HIV and AIDS was managed and the school's level of involvement in helping learners taking ARVs. In particular, looked at how they planned to help and manage these learners, whether they had guidelines on taking ARV medication and school policy on privacy, and the extent of psychological support learners could anticipate.

I also perused the attendance registers (Appendix H). I analysed the school attendance of these learners over the past two years. I looked at the days they had been absent to assess the consistency of their school attendance.

In addition, I analysed the transgression files to see if the learners under focus were reported to have absconded from school (or class); whether they had done homework consistently or not, and if any other types of transgression were recorded against their names (Appendix I).

Finally, I also screened the recreational books (sporting codebook, choir records) for various disciplines such as the soccer, netball, volleyball and rugby for the year to find out whether the participating learners had been involved in any sports or in the school choir.

Document analysis thus also provided me with a useful tool not only for collecting data but also for verifying information from the individual and focus group interviews and my observations. As with the observations, I took field notes during the document analysis.

3.5.5 Questionnaire

Before describing how I used the questionnaire, this introductory section provides some background information on questionnaires and their use.

Questionnaires are printed lists of questions used to find out what people think or feel about an issue, product or service. They can be filled in away from the researcher in the form of a self-administered, group-administered or postal questionnaire. The term questionnaire is also often used to describe a set of questions administered face-to-face or by telephone in the form of a structured interview (Rattray, Johnston & Wildsmith, 2004; Oppenheim, 1992; Brace, 2008). What questionnaires assess depends on the issues that are being investigated, the aims of the study, and the research design (Hannan & Anderson, 2007; Oppenheim, 1992).

There are different types of questionnaires. Questionnaires can provide quantitative data using closed questions, where the participants are given a choice of responses to a question and asked to tick the one that they think is most suitable (Brace, 2008; Oppenheim, 1992). In most cases, closed questions have been criticized for forcing participants to choose answers from the alternatives provided answers and not allowing respondents to use their own words (Converse & Presser, 1986; Hannan & Anderson, 2007). Another argument against closed questions is that they may fail to provide an appropriate set of responses that are worded meaningfully for respondents (Schuman & Presser, 1996; Hannan, 2007). On the other hand, closed questions are also perceived to be more specific than open ones, giving the same frame of reference to all respondents (Converse & Presser, 1986).

On the other hand, a questionnaire can be used to collect qualitative data, using open-ended questions to which participants are asked to write their own answers (Brace, 2008); Oppenheim, 1992). Babbie argues that open-ended questions are those that invite free ranging responses. Such responses are useful for obtaining a deep understanding of respondent views and behaviours, even though they are a challenge to capture precisely and are time-consuming to analyze (Babbie, 2009; Oppenheim, 1992).

In the case of this study, questionnaires were administered to 27 teachers with experience in teaching or counselling learners on ARVs, with a view to gaining insight into teacher beliefs, attitudes, and levels of preparedness in their work with learners on ARV treatment.

I used a semi-structured questionnaire (Appendix A), which consisted of both open-ended and closed questions. According to various sources (Babbie, 2009; Brace, 2008; Hannan & Anderson, 2007), this type of questionnaire is commonly used in social research where there is a need to accommodate a large range of different responses from communities. The use of semi-structured questionnaires enables a mix of qualitative and quantitative information to be gathered. I used this type of questionnaire to provide me with greater depth of response than is possible with a totally structured questionnaire. The questionnaire development was informed partly by learners' responses and behaviours already investigated, and partly by my knowledge of the field.

I focused on obtaining data from the region in which the site school was located so that I could situate the results from the case study school.

3.6 Reliability and Validity

To ensure the validity and reliability of my research, I used multiple data methods. This diminishes bias by increasing the wealth of information available to the study. The data gathering process took a period of six weeks. I used a number of methods to collect my data that is: interviews, focus group, questionnaires, observation and document analysis. I did this for triangulation purposes. According to Coleman & Briggs (2002:69), "triangulation techniques in the social sciences attempt to map out or explain more fully the richness and complexity of human behaviour by studying it from more than one standpoint", a process that increased the reliability and validity of the research.

3.7 Ethical Considerations

Soltis (1989:129) suggests that researchers should observe the 'non-negotiable' values of 'honesty, fairness, respect for persons and beneficence'. In practical terms, this means, for example, not harming the institution or the persons one is researching, if possible leaving them in

a better rather than a worse condition, protecting their identities in disseminating the research, and obtaining permission to view and film activities, record interviews, and to use documents owned by others.

The HIV and AIDS epidemic presents unique health challenges to learners, including ethical and moral issues related to their lives and dignity. In this study, I had to make sure that I did not expose the names and identities of the participant learners and teachers, given that learners might suffer increased stigma if they were to be identified as a result of the study. I realized that, despite assurances of confidentiality, participating learners and teachers could feel uncomfortable and conflicted about confidentiality when they revealed information to me as a researcher. Thus, the learners and teachers were given pseudonyms to ensure anonymity and confidentiality.

As a researcher, I also made every effort to ensure that privacy and confidentiality of participant learners was maintained by participant teachers in the focus group. I informed participant teachers of the importance of maintaining confidentiality and discussed how participation could put learners' privacy and confidentiality at risk, suggesting possible situations in which confidentiality might be breached inadvertently or unintentionally. I also set confidentiality protocols that would protect learners.

Confidentiality, anonymity, and respect were thus maintained, with careful consideration for the sensitivity of the topic. To avoid suspicion or raising alarm, I conducted learner interviews during the 'normal' counselling sessions at school as a way to protect the participants' identities.

In addition, I realized that any activity related to HIV and AIDS, which is culturally embedded in sexuality and shame, might create anxiety among the learners. As a Life Skills teacher and counsellor, I was aware that I needed to be sensitive to cues or signs of emotional trauma and accordingly stop the process to allow respondents the opportunity to withdraw at any time.

To ensure that ethical practices were followed in this study, I also sought permission from the principal of the school (APPENDIX E), the teachers and the learners (APPENDIX B).

Permission was also sought from the parents (and when parents were not available, guardians) because learners under the age of 16 are deemed not to be old enough to give consent, but can be informed. I made the purpose and outcome of the study clear to the principal, parents/guardians, teachers and learners. To reduce risk, I confirmed by indicating in the school letter (APPENDIX E) and also to the principal, that I would not discuss topics such as learners' sexual behaviour or how they contracted the disease. I proposed to discuss only their daily life experiences. However, although this was the plan, learners volunteered background information during the time-line discussions. I asked if they wanted me to use the information and all agreed.

Clearly, then, my relationship as researcher with the learners in the study was shaped extensively by the relationship I had already established with them as their teacher-counsellor. As a researcher, I recognized that trust is a cornerstone of the researcher and participant relationship. As a teacher-counsellor, on the other hand, I already knew that being fair means making unbiased decisions and not taking advantage of people just because they are in a weaker position. As a trained teacher-counsellor, I have always had the primary responsibility to support and understand my learners, respect their dignity and promote their welfare. In addition, I talk regularly with my learners about their worries and frustrations because I care. I had ensured my learners' trust and confidentiality through the years before this study was undertaken; this trust had already helped learners to open up to me freely and share their personal concerns rather than holding on to harmful secrets. When students have come to perceive me as approachable and trustworthy, many have taken steps to help me know them better.

My already existing relationship with the learners also shaped their decision to disclose voluntarily and take part in the study, without me forcing them. As a researcher, I was concerned that learners whom I already taught and counselled might be too nervous to refuse my request even if they preferred to do so. Therefore I made it clear to them that their decision on whether or not to participate in the research activities would not affect their academic standing, or their relationship with me as counsellor; they would be treated the same whether they participated in the study or not.

In conclusion, it is by now clear that the learners participating in the study did not experience me, the researcher, as a stranger: they trusted me because I had long-standing relationships with them. The culture of trust that my learners and I built up was promoted by good cooperation, commitment, extra effort, continuous improvement and information exchange, and proved invaluable in dealing with many of the ethical considerations of this study.

CHAPTER 4 EXPERIENCES OF HIV-POSITIVE LEARNERS ON ARV TREATMENT

4.1 Introduction

This study investigated the school experiences of HIV-positive learners on ARV medication. A secondary goal included examining school responses by eliciting information from teachers and school management on how HIV positive learners on ARV treatment were managed and supported.

While the above may have been the focus, I soon realized that learners' experiences in and out of school cannot be separated. Their out of school experiences impacted how they understood and viewed themselves as well as how they experienced school, as the data below will show. It is for this reason that this current chapter includes data on learner life experiences, their family and other aspects outside of school that shaped - and continue to shape - their daily experiences.

I present the results in two chapters. Chapter 4 presents results that focus on the primary component of the study, namely, experiences of HIV-positive learners on ARV medication; while Chapter 5 presents results from the questionnaire distributed to 27 Life Skills teachers and/or counsellors.

The current Chapter 4 is in four parts. I begin by profiling each participating learner in 4.2. These profiles were each derived from the initial time-line and life history interviews. While brief, they illustrate significant events, which learners reported, had shaped who they are (and which still have some influence over their lives).

I proceed in 4.3 with an analysis of experiences outside of school that have had (and continue to have) an influence on the day-to-day experiences of the learners. These include experiences of family, relationships, HIV status disclosure and responses to this, as well as support. These two initial components (the profiles and out-of-school experiences) form an important backdrop to the main component of the study, namely, learners' school experiences, that I report in 4.4. The final section, 4.5, describes school responses to HIV-positive learners on ARV treatment. These data were derived from the focus group discussion held with teachers at the site school.

4.2 Learner Profiles

The profiles that follow include stories from two males and six female HIV-positive learners on ARV treatment.

Name: Neville **Grade**: 10 **Age**: 16	**Parental Status**: lost both parents to AIDS **Born**: with the HI-Virus **Medication**: ARVs	**Date**: 06 February 2012 **Place**: Counselling Room at school **Time**: 13h30

Neville was born in Windhoek in 1995. He started his primary schooling in 2001 at one of the local schools. He has two siblings and is the second born in the family. He has an older and younger sibling and is the only boy. He currently lives with his grandmother.

Neville's father took ill and passed away in 2004 and after two years, his sister passed away. In 2007, his mother was very ill, causing them to lose the family home because she was unable to pay the bond. The most painful moment in his life as he recalls, was the moment when he lost his mother in 2008 and had to go and live with his grandmother. He tried to commit suicide in the year 2009 when he discovered that he was HIV positive. It was at this time that he went on ARV treatment.

Neville described 2010 as the most difficult year in his life; when he disclosed his status to his long-term girlfriend from primary school, she 'dumped' him because of this. She told others at school that he is HIV-positive and that he wanted to infect her. The next year (2011), his friends 'disappeared' because they heard about his status from his former girlfriend. They labelled him with different names such as 'the ghost' and 'the drinker'. This he said, made him hate school. He realized that life is unfair when he noticed that learners isolated him and preferred not to sit next to him in class. While 2010 was the most difficult, Neville describes 2011 as the most challenging and loneliest year in his life.

Neville reported that 2012 was an equally difficult year because he still felt lonely and left out. He said that he tried to be calm and happy but that did not always work for him. He often still feels rejected by his friends and reported that they were not available when he needed them. He blames his parents for infecting him and making his life hell. He described being HIV positive as not his fault and he did not understand why learners discriminated against him. He would have liked to move to a new school with the hope of meeting new friends. He expressed his anger toward some teachers, stating they were not only unhelpful, but also misunderstood his condition and in the process, made his life difficult at school. This notwithstanding, he singled out one teacher whom he trusted as his motivator who encouraged him to move on with his life.

He described his grandmother as his pillar of strength and support. He reported that she helps him through the difficulties he experiences at school. When he was absent for many days and wanted to quit school, it was the Christian counsellor from an NGO who helped him to go back to school and gave him hope to live again.

Name: Johanna **Grade**: 11 **Age**: 19	**Parental status**: lost her mother **Born**: with the HI-Virus **Medication**: ARVs	**Date**: 07 February 2012 **Place**: Counselling Room at school **Time**: 13h30

Johanna was born in 1992 at a farm outside Windhoek. She started her primary schooling in 1999 at a local school in Katutura. She is an only child. She has never met her father and does not even know his name.

Johanna's mother passed away in 2000. From 2001, she stayed with her grandmother, aunts, cousins and nieces. She reported to be always sad when she saw her nieces and cousins joking and laughing with their mothers; given that she no longer had one. In 2002, she became sick and was admitted to hospital several times. In 2003, her grandmother sent her to stay with the workers on the family farm away from Katutura because she was always ill. Her life at the farm was difficult, because most of the time, she had no one to care or cook for her. She was very upset about her move to the farm, interpreting this as her grandmother being tired of her and just wanting her to die. For this reason, she said, her grandmother sent her to the farm while she knew that Johanna was very ill.

Johanna described 2004 as the most difficult year of her life because it was when her uncle disclosed her HIV status (of which she was unaware) to her in the most painful way. He came to the farm in a drunken state and made

disparaging comments about her mother; saying she was a prostitute. He proceeded to disclose Johanna's status, likening her to her dead mother. Johanna described her family as uncaring. She reported not to have seen them since the day her mother passed away.

Hanna, a woman from a neighbouring farm, witnessed her plight and took her in when she was ill. At the beginning of 2005, Johanna was taken to hospital by Hanna. She was admitted and stayed in hospital for what she reports to be a long time. None of her family members visited her during this time. Johanna started taking ARV medication and returned to stay with Hanna who also ensured that she returned to school. Hanna sent Johanna back to Windhoek where she instructed her daughter to take care of Johanna and make sure that she completed her schooling.

In 2006, her cousin told others at school that Johanna was HIV-positive. Life started to be difficult for Johanna at school because of her status. She was treated badly by her fellow learners. She describes 2007 as a year of pain, loneliness, and embarrassment. Like Neville, she attempted suicide, by overdosing with tablets. In 2008, Johanna failed Grade 8 because of what she was going through at school.

In 2009, still lonely, she said she hated everyone around her. In 2010, she started attending a support group at the hospital where she gets ARVs. Life became better for Johanna because she heard testimonials from people who were facing similar challenges to those she faced. In 2011, Johanna met a fellow learner from her school at the support group and they became friends. Life became better because now she has someone that she can talk to at school.

Hanna and her daughter still support and keep Johanna in school and Johanna now also finds support through the social worker, school counsellor, and the support group at the hospital.

Johanna described 2012 as a better year; although not 100%. She reported that there are still some learners who don't want her at school. She made the point that some teachers don't even intervene when these learners taunt or jeer at her whenever she makes a point in class or tries to participate in activities in school. She described an incident when she used a cup to drink soup that she bought at school. She said that no one else wanted to use that cup after her. One of the learners suggested that the cup she used be thrown in the dustbin.

Name: La-Toya **Grade**: 12 **Age**: 20	**Parental status:** mother is alive **Born:** without HI-Virus **Medication**: ARVs	**Date**: 08 February 2012 **Place**: Counselling room at School **Time**: 13h30

La-Toya was born in 1991, in the Omaheke Region. She started primary school in 1997 in Omaheke until her Grade 3. In 2000, she went to Windhoek to live with her mother and her stepfather. La-Toya has an older sister.

In 2001, she was raped by her stepfather for the first time. For the whole year, she did not divulge this information to anyone because her stepfather threatened her with a gun. She decided to tell her mother about the rape in 2002; but the mother did not believe her. In 2003, she tried to kill herself because she was tired of the on-going rape and she thought life was very unfair. She moved out of the house in 2004 and went to live with her sister who had just bought a house.

In 2005, La-Toya got a boyfriend and by the end of that year, had fallen pregnant. She went for an antenatal check-up which is when she discovered that she was not only pregnant, but also HIV-positive. She decided to disclose her status to her sister, who chased her away from her house in 2006. La-Toya's sister said she needed to leave the house before she infected her too. She went to beg her mother to take her in, but her mother refused, saying that La-Toya was a curse to the family. She miscarried in the same year.

La-Toya described 2007 as the most difficult year in her life. Her boyfriend left her, her family rejected her, and she was homeless. She started abusing alcohol and drugs, sleeping under the bridge and in many instances, even looking for death. She was tired of living. She described how she wished someone could stab her or that she could be bumped by a car, but this did not happen. In 2008, she met someone she called a 'Good Samaritan'; a woman who took her to a children's home. This 'Good Samaritan' made sure that La-Toya returned to school.

In 2009, she started schooling again and life was good at the children's home; until she started getting seriously sick. The hospital that she was taken to discovered that she had tuberculosis. La-Toya started taking ARVs in 2010.

In 2011, fellow learners, who called her disparaging names and stigmatized her, treated her badly at school. She was afraid to raise the issue with her teachers or the principal.

La-Toya is currently in Grade 12. She reports to be at a loss on how to improve the current situation, because as she reports, the stigmatization continues. She is looking forward to passing Grade 12 and hopes that maybe things will change when she enters university. La-Toya's family did not support her during all the difficult times she experienced. The 'Good Samaritan' continues to support and motivate her to stay in school and to become someone in the future.

Name: Bertha **Grade**: 11 **Age**: 20	**Parental status**: lost both parents **Born**: with the HI-Virus **Medication**: ARVs	**Date**: 09 February 2012 **Place**: Counselling room at School **Time**: 13h30

Bertha was born in Windhoek in 1992. She started her primary schooling in Katutura in 1998. She comes from a family of six children and is the second last. She currently lives with her grandmother.

Bertha's father took ill and passed away in 1999. In 2000, she became sick and spent most of her time that year in hospital. She found out that she was HIV positive from her aunt in 2001, who divulged this information on Bertha's birthday. At the end of 2002, she dropped out of school because she was continually ill. In 2004, she started taking ARVs, which, she reports, gave her many side effects. She once told her mother that she would rather die than suffer the way she did. Her mother encouraged her to keep on taking her medication. Eventually, she started to have fewer side effects.

In 2005, she returned to school where she was promoted to the next grade. Her mother passed away in 2006. Her mother's death brought the fear of death to Bertha's mind. She found it difficult to reconcile to her mother's death. She said that she feels guilty and useless now that her mother has passed away. Bertha's guilt arises from her sense of helplessness during her mother's illness. She said she was unable to do anything for her mother, while her mother was always there for her when Bertha was sick. In 2007, her younger sister also passed away.

Bertha started secondary school in 2008. At first she was happy to come to a new school where people did not know her status. That year she failed Grade 8 because she was unable to concentrate on her schoolwork. She said that her focus was always on her family members who had passed on.

In 2009, a local newspaper wrote her story and disclosed her status without her consent. This was done by a woman she trusted, who had offered to help her. She felt betrayed and vulnerable because now peers and teachers at the school knew her status.

She described 2011 as a year of challenges because learners did not wanted her to use the toilet and kept calling her awful names. She joined a support group that year, which helped her to became strong and pass her Grade 10 very well. Bertha is currently in Grade 11. She is happy and healthy. She is looking forward to next year when she will be in her final year of high school. She gets support from her grandmother and the support at the church, as well as from the social worker and counsellor. She reports that the support group plays a vital role in her life.

Name: Salmi **Grade**: 11 **Age**: 18	**Parental status**: lost her mother **Born**: with the HI-Virus **Medication**: ARVs	**Date**: 13 February 2012 **Place**: Counselling room at School **Time**: 13h30

Salmi was born in Windhoek in 1995. She started her first primary school in 2001 in Katutura. She is the only child in her family. She has no idea where her other relatives are, not even her father. Her mother did not tell her anything about him. She doesn't know if her father is still alive.

In 2003, she became sick and she was in and out of the hospital several times. In 2004, her friend Maria told her

that her mother told her that Salmi has 'AIDS'. Maria's mother warned her to be careful because she might become infected by Salmi. Salmi confronted her mother and asked her if it were true. Salmi's mother apologized for keeping her HIV status as a secret for long time.

Salmi reported that school became hell for her in 2005. She was precluded from using the toilet. Peers would say about her, "the diarrhoea is here." They (learners) never wanted to share a joke with her or even to play with her. She could not take it anymore. She started to be absent for many days, thinking that they might forget about the issue.

She decided to drop out of school in 2006 because of pressure at school. She thought school was not meant for sick and dying people. However, she returned in 2007, but became very sick again. She started ARV treatment in the same year.

In 2008 she joined a youth club for people living with HIV/AIDS and in 2009 decided to talk openly about her status. She told herself that she will not go down again because of other learners.

She recalled how when she wanted to drop out of school, her Life Skills teacher followed her home and tried to convince her to come back to school. The social worker, who later referred her to a psychologist, made sure that Salmi met young people who had similar problems to her own with regard to her HIV status.

She reported 2010 as one of the most difficult years because her mother, who was always her support, passed away. In 2011, Life became too hard for her at school and at home. She said she had no mother, no family, no food, and no money. Even though Salmi is still in school this year (2012), she reports to not doing well.

Name: Monique	**Parental status**: lost both parents	**Date**: 13 February 2012
Grade: 12	**Born**: with the HI-Virus	**Place**: Counselling room at School
Age: 20	**Medication**: ARVs	**Time**: 13h30

Monique was born in Windhoek in 1992. She started her primary schooling in one of the Katutura schools in 1998. She is an only child but reports to have a large extended family.

Her parents passed away in 2000. Monique went to stay with her uncle in 2001. The following year she found out in a most cruel way from her uncle's wife that her parents died of AIDS-related diseases. Monique recalls how her aunt humiliated her and called her names, and said, "stupid girl that's why your parents died of AIDS." When she got ill, her aunt demanded an HIV test be done on Monique, which turned out positive. Monique fainted when the doctor disclosed her status. When she woke up she was admitted to hospital. She feared death and continually worried about when she would die and how. In 2004, her aunt chased her out of the house because of her status. Monique's uncle tried to convince his wife to let Monique stay in the house; this did not help, as the wife had made up her mind already. Monique got comfort in the neighbour's home; they accepted her and she currently lives there.

In 2006, Monique became very sick and people thought she would die soon. She started ARV treatment in 2007. That year of 2007, life at school became very tough for her. Learners knew that she was taking HIV/AIDS medication. Some learners confronted her and asked her to confirm if it is true that she was on ARV treatment. She decided to remain silent to avoid further embarrassment. She said that school became "hell" for her. She hated it so much because of the embarrassment and hurt that fellow learners put her through. Fortunately, Monique has a supportive friend who has not abandoned her despite knowing about her status. Her friend normally visits her at home when she is sick or absent from school. Her friend encourages her to live positively.

Monique said she developed hatred for people around her and she hated life itself. She started questioning her friend's loyalty and the authenticity of her empathy toward her. She said, "… my friend doesn't know how it feels to live with HIV. I wonder if she really feels sorry for me."

In 2008, the neighbour she stays with took her to the support group for people living with HIV/AIDS "Lironga Eparu" which means 'learn to survive'. She learned a lot and enjoyed listening to different testimonies by people living with HIV who are still going through a lot of problems because of their status. The following year, 2009, she

started to think about living positively and studying her grades. In 2010, she passed her Grade 10 and was the highest achiever at school.

Monique confirmed that she was looking forward to passing Grade 12 and would like to go to university. The woman (Maria) who took her in is still very supportive and inspires her a lot. The support group, together with her Life Skills teacher, helps her to decide to live positively and fight for her rights. She confirmed knowing her rights better now and can take a step forward and open a case if her rights are violated. She realizes that AIDS is not a death sentence; rather it is just a condition and a sickness like other diseases such as TB.

Name: Mercia **Grade**: 12 **Age**: 20	**Parental status**: don't know **Born**: without HI-Virus **Medication**: ARVs	**Date**: 13 February 2012 **Place**: Counselling room at School **Time**: 13h30

Mercia was born in 1992 at a farm outside Okahandja. She started her primary schooling in 1997 in Okahandja. In 2000, she moved to Windhoek to stay with her mother. She met a man in 2002 whom she became involved with at the age of 13.

Mercia recalls that from 2004, her mother was unemployed and they needed money. Her boyfriend took care of Mercia and her mother. Mercia fell pregnant and later discovered that she was HIV-positive when she visited the antenatal clinic. She decided to disclose her status to her boyfriend, knowing that he was the only man with whom she had slept. Her boyfriend responded with anger and accused her of wanting to infect him. He dumped her and disappeared. She lost her baby because she was very unhappy and also hungry.

Like others in this study, Mercia said she started abusing alcohol and drugs in 2007. She recalls hoping and waiting for death. She ran away from home in 2008, sleeping around with any men who offered her alcohol or drugs. This continued until at the end of that year when five men raped and stabbed her. She was admitted and stayed in hospital for a month; at which time no one visited her. A kind lady, she says, not only offered her a place in an orphanage, but also took her back to school in 2009.

The year she returned to school, she became sick. In 2010 she started taking ARV medication, which she says, made her to develop thrush and nausea; giving her no choice but to tell her teachers about her medication. She remembers how one teacher disclosed her status without her consent; to protect the boy that he saw getting close to Mercia. From there the whole school knew that she is HIV positive and taking ARVs.

She described 2011 as the worst year of her schooling, as she was treated badly. Boys always laughed when she walked past them. One of them said, "… someone, some people are so sick and they are dying" while another said "if we were teachers, we would not waste our efforts on teaching a dying learner." Peers refused to eat her food, thinking that she might have injected it with her infected blood so as to infect them. She confided in her Life Skills teacher who gave her hope.

Mercia is currently in Grade 12 and was looking forward to what was in store for her the following year. She decided to stick to her school, despite what she was going through. She blamed herself for messing up earlier on in her life and says she cannot risk anything anymore. She said, "[W]hatever the learners are saying will hurt, but not kill me." The woman at the orphanage continues to support and motivate her.

Name: Benzao **Grade**: 12 **Age**: 22	**Parental status**: lost his mother **Born**: without the HI-Virus **Medication**: ARVs	**Date**: 13 February 2012 **Place**: Counselling room at School **Time**: 13h30

Benzao was born in Windhoek in 1990. He started his primary schooling in 1996 in Katutura. He lives with his grandmother in Windhoek. His mother passed away when he was a baby.

His uncle started molesting and raping him in 2000. When he had the courage to tell his grandmother about the on-going rape in 2004, she told him to remain silent and keep it secret. The uncle who molested him passed away in 2006. Before his death and while he was very sick, he asked forgiveness from Benzao, who found it difficult to

forgive him. He hated him so much and says he was happy the day he passed on.

In 2007, he became sick and dropped out of school. In 2008, he found out that he is HIV-positive and later that year started taking ARV treatment. He also decided to return to school. In 2009 he wanted to die because when he returned to school, most of the boys knew that he was raped and is drinking HIV medication. They start calling him names such as, 'wife', 'gay', and 'AIDS monster'. He was hurt, and he told a teacher about the name-calling. The teacher, he says, showed no empathy. Instead he (teacher) just wanted to know the details of rape and was not interested in Benzao's feelings.

In 2010, his aunt took him to church, where the pastor asked him to stay with them for a week. Benzao recalled how he felt better when he was in the house of the Lord and how, often, he started to forget about his problems. After a week the pastor's wife asks him to stay for two more weeks, she was aware that he was not ready yet to face the world. He claimed that those two weeks changed his life forever and he became a 'born again' and decided to give his life to the Almighty. He said that he has now forgiven his uncle and fellow learners, who have abused him emotionally.

He is currently in Grade 12 and made a conscious decision to live. He wants to go to university and study to help others and bring change in the lives of those who are going through what he went through. He made the claim that his grandmother, aunt, and the church supported and helped him to develop strong self-esteem and to become resilient. He said that he also helped himself by developing power from within; not giving up on life.

He proposed that schools should start inviting churches to restore peace, morals and values amongst learners. He believed that was the only way learners who are taking ARV medication in school would not face many challenges such as rejection, a love-less life, sadness, and discrimination. He believed that the church changed him and that it could change other learners too, to treat others better.

4.3 Out of School Experiences

As indicated earlier on, this section provides more nuanced data on aspects in the lives of the participating learners that shape their day-to-day experiences. What follows, therefore, are four themes, comprising: HIV and status disclosure; family and HIV-positive learners on ARV treatment; community and HIV-positive learners on ARV treatment; HIV-positive learners on ARV treatment and intimate relationships.

4.3.1 HIV and Status Disclosure

This section includes two categories of discussion, namely status disclosure and helplessness, shock, pain, and disruption and HIV status, secrecy, and silence.

Status Disclosure and Helplessness, Shock, Pain, and Disruption

HIV status disclosure is a sensitive issue for many and no different for this cohort of learners in the study. All reported status disclosure, and how they came to know their HIV status, as significant events.

Five of the participants indicated that they found out about their HIV-positive status at health facilities when they were already sick, while family members or friends disclosed to the other three. Two of those who learnt their status from a health facility, discovered their status during an antenatal visit because they were pregnant..

Three participants heard their HIV status indirectly from family members and friends. Salmi learnt about her status from her friend at school. She said:

> *Then one day at break time, my classmate told me that her mother said I am HIV-positive and she must be careful because I might infect her. That was the shock of my life. I tried to concentrate but I could not. Then, I asked my class teacher to go home and told my mother about what I had just heard at school, which was not cool. She told me that she is so sorry, because I found out that way.*

Bertha experienced her status disclosure in a form that she reported changed her moments of happiness into moments of pain and hurt. She had this to say:

> *[I]t was on my ninth birthday. My mother made me a birthday party and invited some friends and family members. Although I was usually sick, at that time, I was better and even enjoyed my birthday. During the party, then my aunt called me and asked if I am drinking medicine for HIV. I was shocked and confused. I ask her, 'me'? Then she said, 'Yes I am asking you'. I told her that I don't know what she is talking about. Then from there I went to bed and started crying.*

Bertha recalled how she confronted her mother to tell her the truth about her status. She said, *"I asked my mother, 'am I drinking medicine for HIV'? My mother was shocked and disappointed in my aunt; however she explained that I was born with the virus and is not my fault. That is how I found out."[The learner was very sad and emotional when recalling this event]*.

Johanna on the other hand, heard about her status from her uncle in a painful and insulting way. She reports to have experienced pain, that she felt unwanted and that her character was defamed. She said:

> *One day my uncle who is a soldier in Okahandja just showed up at the farm where my grandmother had sent me to live. He was very drunk. He started saying bad things about my mother. He said she was a prostitute and that is why she died of AIDS. He also told me that I too have AIDS and for this reason, no one wants me in Windhoek. That's why they send me to the farm, he really sucks.*

Johanna did not take her disclosure lightly; she experienced a sense of helplessness and feared death. She said, *"I was feeling angry, Miss. and I was asking myself, 'Why me?' I ended up telling myself that, 'No… not me… it cannot be true.' Then again I was also thinking about, 'Who will love me since I am HIV-positive?' And I was also asking myself 'When will I die?' 'How will I die?'"*

Five of the eight participants indicated that they found out about their HIV-positive status directly at health facilities. Three (Neville, Monique and Benzao) learnt about their status when they were already sick, while two (Mercia and La-Toya) discovered their status during pregnancy, through antenatal medical testing.

Like the rest of the participants in the study, Neville experienced hurt when his status was revealed, and in what he reports as a callous manner. He said,

> *Miss, one day my grandmother took me to the doctor and the doctor just revealed the most painful information in my life. He said, '… you are HIV-positive hhh...! And the medication you are taking is ARVs. That will prolong your life and make you healthy'. The rest of the conversation I did not even hear.*

Neville described his feelings and reactions after the status disclosure as a moment of hurt and confusion. He said, "*I was just crying. We stayed long there, but I don't even remember what else the doctor told me or my grandmother. I was hurt, confused, I just wanted to die*."

Monique, who went to stay with her uncle and his wife after her parent's death, found out in the most hurtful manner from her aunt that her parents died of AIDS. She also recalled how her uncle's wife demanded that an HIV test be done on Monique, when she became ill. The test turned out to be positive.

Monique found out about her own HIV status from the medical practitioner. She reported, *"... when I became sick, my uncle's wife took me to the clinic and she demanded that I be tested for HIV. I was not worried about that. Then after three days, we came for the results. The doctor told me that I am also HIV-positive."*

She did not remember what happened after the news was broken to her because she fainted. She said, *"They told me that I just fainted there when I heard from the doctor that I am positive and the next day when I woke up, I was admitted in hospital. I could not stop thinking that I will also die like my parents, but then again I didn't want to remember that I can also die soon like my parents."*

Benzao, who was molested by his uncle, heard about his status from a medical doctor when his grandmother took him to the hospital because he was ill. He reported, *"... the whole 2007, I was not well. Then in 2008, my grandmother insisted that I must be tested for HIV. That's how I heard about my status."*

Benzao developed hatred for his dead uncle after he got the news of his HIV status. He said, "*I hated my uncle more even though he is dead now.*"

La-Toya, who was raped by her step-father, had her HIV status disclosed by the nurse when she went for an antenatal check-up. She described her experience by saying *"[I]n 2005, I met this guy and I fell pregnant. When I went to the clinic, I also found out that I am also HIV-positive. I don't know who infected me. Is it my stepfather or is it my boyfriend? I don't know'."*

Mercia's status was disclosed at the antenatal clinic in much the same way as La-Toya. She said,*"[W]hen I was five months pregnant, I went to the clinic for antenatal care. That is how I found out that I am HIV-positive."* Mercia expressed how she felt when she discovered her status, by saying, "… *I felt so bad that day when I found out that I am HIV-positive.*"

Feelings of helplessness, pain, and shock were pervasive amongst this cohort of participants when they learnt about their HIV status.

Neville said,

> *I was shocked, asking myself 'how will I drink these ARVs at school?' Will the learners want to be with me when they know that I am now drinking the medicine for four letters (another name for HIV)? It is not cool because now I know that I won't live long and I will die soon because there is no cure for AIDS.*

Salmi recalled her thoughts on that significant day. She said, *"I was just thinking about what my friends and classmates will say when they find out that I am also a drinker (name called for people taking ARVs). I ask myself 'when will I die, since there is no cure for this disease?'* Monique considered the potential lack of privacy and jeering that might occur because of her status. She said, "*.....I was just thinking about privacy at school and how learners and teachers will tease me and not wanting me. I ask myself 'where will I drink my medication'?"*

Johanna made the link between her status and the treatment by her family who laughed at her and eventually sent her to live on the family farm; all without the knowledge of her status. She said,*".....I told myself that 'they (grandmother and family members) knew that I am dying that's why they don't want to stay with me'."*Benzao on the other hand, described the emotional stress experienced as a result of the disclosure. He said, *"... I was suffering, stressed, my heart was jumping fast and I was just thinking about the terrible death that I will die because of AIDS."* Mercia stated that she thought of all the derogatory names people call those who are HIV-positive on ARV treatment in the community. She said, *" [M]any people in my community call people who are taking ARVs 'drinkers' or sometimes 'epango' (*meaning 'treatment' in Oshiwambo vernacular*). They say 'you are useless; walking corpses who are just waiting to be buried."* Such thoughts created anxiety and pain.

All participants had overwhelming experiences of their mortality and experienced disruption to their lives, materially and psychologically. It would seem too that their responses were directly shaped by how the community responded to HIV and AIDS. They had experience of how stigma and discrimination linked with discourses on HIV and AIDS in their community.

HIV Status, Secrecy, and Silence

Although five of the eight participants in this study indicated that they were born with the virus, all five knew nothing of their status for nine years or more, because their parents/guardians kept it as a secret.

Salmi was angry because her mother kept her status a secret. She experienced denial, saying, "*I didn't want to believe what I have just heard. 'Why did my mother hide it from me'? Now I have to hear it from a child at school."*

Benzao's grandmother responded with shock and warned him not to tell anyone about his status. He said, *"[M]y grandmother was shocked and started crying when she heard that I am HIV-positive. She said I must not tell anyone."*

Like Salmi and Benzao, Bertha's mother also kept Bertha's status a secret, until the day when Bertha confronted her. Bertha said, *"I asked my mother if I am drinking medicine for HIV and she was shocked to hear me asking her about that. She could not hide it or lie to me anymore, but only to explain to me that she is so sorry and that I was born with the virus and is not my fault. I must understand that she was just trying to protect me."*

4.3.2 Family and HIV-positive Learners on ARV Treatment

Individual learners in the study were overwhelmed by the loss of a number of family members, especially parents, as well as coping with their own HIV diagnosis. The death of parents shifted the primary care responsibilities to extended family members, mostly grandparents. In this study, the family responsibilities of taking care of three of theparticipants fell on the grandparents after the infected parents died.

This section includes data on the following: family responses to learners' status disclosure; family, loss and HIV status; family care and on-going support; and family relations.

Family Responses to Learner Status Disclosure

HIV status disclosure to family members in this study was associated with both positive and negative outcomes. Some family members responded in a positive way by showing empathy, and offering increased support, acceptance, and kindness. Some tried to decrease anxiety and depression among participants and to strengthen personal relationships. This was the case with Benzao, Neville and Bertha.

Benzao recalled how his grandmother's initial response was with emotional shock. He said, *"... my grandmother was shocked and started crying. She said I must not tell anyone."*

Neville reported that his grandmother was sad because of his status. He said, *"... on our way home my grandmother said, 'don't worry it will be ok'... but I [could] see that she was sad and her eyes [were] full of tears."*

Bertha reported how her mother was shocked when she confronted her about what her aunt had revealed. She said, *"I asked her, 'Mummy am I drinking HIV medicine?' My mother was shocked and she asked me why I am asking her that question. I told her that my aunt asked me the same question. My mother was shocked to hear my aunt's actions. I forced my mother to explain to me that I was born with the virus and [that] it is was not my fault."*

Not all families responded with empathy. Some chased learners away and blamed them for their status. Two participants' families responded with rejection. Monique recalled what happened after her extended family discovered she was HIV-positive. She said, *"[M]y uncle's wife chased me away from home after the doctor said I am HIV-positive. She said that she doesn't want me infect them. My uncle was trying to keep me but my aunt insisted that 'is either me or her who will leave this house'."* La-Toya experienced similar reactions from her family. She said, *"[W]hen I told my sister that I am pregnant and HIV-positive, she freaked out and threw me out of her house. 'Go and die somewhere else not in my house stupid girl'."*

While Mercia and Johanna were not chased away from the family home, they reported to have been neglected by family members. Mercia recounted, *"My mother did not come to visit me at the hospital when she heard that I am HIV-positive*." The same applied to Johanna who recalled that she was sent to the family farm when she became sick. She said, "[*M]y grandmother decided to send me to the family farm because I was sick and she knew that I have HIV*."

Teachers in the focus group discussion attested to some learners experiencing rejection and lack of empathy. Ms Alina reported,

> *These kids are emotionally hurt and rejected at their homes when family members discover their status and this has affected them. In most cases, a child's heart doesn't want to go home but because there is nowhere else to go, they will just go there. Most of them don't say anything about what is happening at their houses because they are threatened not to*.

Family, Loss and HIV Status

Only one of the eight learners has parents who are still alive. Six of the eight learners in this study experienced the loss of parents or family members fthrough HIV and AIDS. Three of these lost both parents, three lost only mothers, and one of the participants, Mercia, is unsure about her parents' existence or status.

Monique's experience of losing her parents was different to other participants as she still blamed her parents for infecting her. She said,

> *I was very young when I lost my parents. If I may recall very well, I was just 8 years. My parents passed away in the same year. First my mother then later on at the end of the year, my father also died. I am hurt but there is not much that I can remember about them. In fact, I don't want to remember anything about them as I am still blaming them for the virus that I am living with.*

For Benzao, who lost his uncle who was also his rapist, the experience of loss was liberating in that he did not have to deal with the perpetrator any longer. He said, *"[I]n 2006, my uncle passed away because he was very ill. His death hurt people in the family, but not me because of what he did to me, I was very happy the day he died."*

The other five learners experienced severe loss and a sense of hopelessness. For example, Neville who lost both his parents as well as a sister to HIV and AIDS, attested to how he felt when his family members died. He said, *"... I was very much disappointed because now I have to learn to live without my father and I was very much disappointed in myself Miss. I felt useless because there was nothing I can do, regardless of what we were going through."* Neville took the responsibility of the family upon himself and felt that he would be failing them due to his status.

Johanna and Salmi also experienced a sense of loss. The former moved to her grandmother's house after her mother's death. She said, "*I was always sad when the other kids of my two aunts were joking and laughing with their mothers, while mine is dead. There was time I was missing my mother so much and I felt lonely, Miss."* Salmi, who lost her mother, reported,

> *I was going through a lot. Life became a nightmare to me, Miss. I didn't know where to go or what to do next; it was crazy. My mother was my support, my love and my everything. She was the only person I had who really cared about me. 'Where to from here now'? I don't know. I never knew my father, not even in pictures. My mother never told me who he was.*

Not only did learners experience loss and a sense of hopelessness, but they also had disparate experiences with support from family. Most lacked family support, as the data below will show.

Family Care and On-going Support

Only three in this cohort received support from their families after their HIV status disclosure. Four experienced no family support, while one participant who lived alone at the time of disclosure after the mother died, did not know where her extended family lived.

Monique and La-Toya experienced stigma, rejection and abandonment. They were both rejected and chased away by their families after disclosure; finding comfort in neighbours' homes. Monique reported, "[*M]y uncle's wife chased me away from home after the doctor said I am HIV-positive. She said she did not want me to infect them. My uncle was trying to keep me, but she my aunt insisted that it is 'either me or who will leave'."*La-Toya was also equally rejected, and like Monique, was chased away. She said, "[*W]hen I told my sister that I am pregnant and HIV-positive she threw me out of her house. 'Go and die somewhere else not in my house stupid girl'*. Monique reports that her mother reacted in much the same way as her sister. She said*, "[M]y mother reacted also the same way as my sister when I went to her house. She told me that she regrets the day she gave birth to me. My mother shouted 'I don't want AIDS in my house, you are a curse to this family and I don't want to see you anymore in my life'."*

Mercia and Johanna were neglected and abandoned by family members, with the former now living at a children's home. These two participants experienced a sense of neglect from family members. Mercia's mother disappeared and abandoned her. She said this when she recalled what

happened that day, *"... after [I was] discharged from the hospital, one lady (Marie) offered me a place at the orphanage home since my mother was nowhere to be found."* [The learner was emotional and cried for a while].

Johanna felt helpless, sad, and anxious when her family neglected and did not support her. She said,

> *I became sick. I was in and out of the hospital many times, and then my grandmother decided to send me at the family farm. There were only workers at the farm and most of the time no one cooks. I was very upset about that. I think she was tired of me and maybe she just wanted me to die. I cried a lot Ms, I was very unhappy and I just wanted to die and follow my mother. After few months I was better and later on I was discharged from the hospital. No one from my family visited me, not even my grandmother.*

However, as already reported earlier, some participants' families responded positively and supported them. Benzao experienced emotional and psychological support because, he said, he was lucky to have a caring family. He tried to commit suicide when his found out about his status and recalls, "*After my suicide attempt, my aunt decided to help me. She took me to this born again church for spiritual support."*

Family Relations

One of the participants, Salmi, did not have any idea about the existence of her extended family and where they lived. She said,

> *I never knew my father, not even in pictures. I don't have extended family here in the city. My mother is from South Africa, but I don't even know the city or suburb where she came from. It is very painful to think that now I am alone. I wish I have family who might accept me and love me the way I am.*

Johanna was neglected and abandoned by her family. She recalled the incident of getting sick and being taken to hospital. She said, *"No one from my family visited me, not even my grandmother. I think they hated me, so I went with that woman (Marie) at her house."*

La-Toya experienced rejection from her family after she revealed her status. She said, *"I went to my mother's house and she yelled and told me that she regrets the day she gave birth to me. She said, 'I hate you and I don't want to see you."*

On the other hand, Neville and Bertha had different experiences to those of Johanna, Monique and La-Toya. They experienced a good relationship with their respective families. Neville reported, *"... the next day after my disclosure, my grandmother talked to me nicely; she told me that she loves me and she took me to a psychologist."*

Bertha explained the good relationships and support she got from her mother helped her cope with her illness. She said, *"...after the disclosure of my status, my mother encourage me to drink my ARVs and kept on reminding me that I will be healthy and happy again if I drink my medicine on time. After few months I started to gain weight and I was healthy again."*

4.3.3 Community and HIV-Positive Learners on ARV Treatment

In this study, I distinguish community from family and school for analytical purposes only. I define community as individuals, groups, institutions, and systems that fall outside family and school.

Community support in this study came in the form of individuals, NGOs, religious groups and social community institutions. Learners accessed help principally from churches, family, neighbours, support groups of people living with HIV and AIDS, social workers and counsellors.

I present data in this section by using the following categories; support and individual community members; community and support groups; and community and support systems.

Support and Individual Community Members

Neighbours were very active in providing a safety net in their homes to participant learners who were orphans, chased away or abandoned by families. Two participants in this study, Johanna and Monique, moved in with neighbours after being chased away and rejected by family members. Johanna, who found refuge in her neighbour's home, reported,

> *For almost a week, I could not eat food. I just laid down there or went to the riverbed the whole day. One day a woman, Hanna, who stays in the neighbourhood, saw me. She asked me what was going on, but I was very weak to talk. And then she decided to take me to the hospital. I was admitted in the hospital and then I started ARVs. So I went with*

that woman to her house, as no one from my family visited me in hospital. I started to gain weight again and Hanna decided to send me back to school. She asked her daughter to take care of me in Windhoek and made sure that I went back to school.

Monique recalled how she found herself finding shelter at her neighbour's home after being chased away by her aunt because of her status. She said, *"I went to stay with the neighbour. She took me in as her own child."*

Community and Support Groups

Some learners in this study were socially rejected by family, friends or peers. Four joined support groups to seek emotional and social support to cope or deal with stigma and give them hope to live again.

Bertha, Monique, Salmi and Johanna received comfort as well as emotional and social support when they joined support groups. Johanna said,

I learnt from the support group that it was not only me who was rejected by a family or fellow learners. It happens to a lot of kids. I also learnt that I can be strong and not allow others to break me and bring me down because of the virus that I am living with. I started feeling better in 2010 when I joined a support group. There, I felt I belong to a certain group of children who are having the same problems like me. They talk about what they are going through and how they are overcoming discrimination.

Bertha reported how the support group made her feel accepted and gave her a sense of belonging. She said:

The social worker introduced me to the support group of young people like me. They understand what I am going through and they face many challenges that I also face in life. I felt different as a person since I became a member of that support group, because we became a family and we help each other to face the problem we have in life.

Salmi recalled how the support group helped her to move on with her life.

She said,

I joined a group for young people living with HIV and AIDS called, "We are also human beings." There I learnt a lot about the virus itself and how I can cope with rejection and discrimination. That's how I returned to school. I told myself that I will not go down again because of other learners.

Monique reported how Marie, the woman who took her in, encouraged her to join a support group. She said,

> *The woman (Marie) I was staying with cares about me so much. She took me to a support group "Lironga Eparu" which means learn to survive. There I learn a lot. I enjoyed being there and listening to different testimonies of people living with HIV. I learnt that there are a lot of people who are still going through a lot of problems because of their status.*

Community and Support Systems

Professional associations were available in the community, where learners could go to a qualified person or organization for practical, emotional, moral and psychological support when needed. Supportive family members or those in the community who acted as support introduced participants to such facilities.

Neville recalled how a group of professionals played a vital role in his life at that stage of status reveal. He said,

> *The social worker referred me to a psychologist. The next day, my grandmother took me to a psychologist and in the afternoon, we went to see the Christian counsellor at an NGO. She is the only one who made me to feel better because all what I was thinking is just to take my life. I was seeing that counsellor three times per week for the whole month. She helped me a lot. She is the only one who gave me hope to live again and go back to school.*

Johanna reported on her experiences of how the social worker and counsellor changed her life. She said, "[*T]he social worker came to visit me always in the hospital and she referred me to a counsellor who helped me and made me feel better. Thanks to (Hanna), the woman who has taken me in her house and helps me with all my problems.*

Like Neville and Johanna, Salmi also recalled how the psychologist helped her to meet young people who have the same problems as hers. She said, *"I started to take ARVs in 2008. The psychologist made sure that I met young people who were having the same problems that I have and this has helped me."*

Orphanages or children's foster homes was the last resort for two learners in this study, which helped them to cope and convinced these learners to go back to school. La-Toya explained her journey to the children's foster home when Lerato embraced her and supported her. She said,

> *I met this Good Samaritan woman, Lerato, who gave me a shelter in the children home. That is where I am staying until now. She made sure that I went back to school and she was very good to me. The lady who took me in forced and motivated me to go to school every day.*

Mercia received shelter in a children's home after her family abandoned her. She said, "*[I] was admitted in the hospital and stayed there for a month without anyone visiting me. Then, I thought of seeking help. One lady, Mercy, came one day and offered me a place in an orphanage. I went with her since I had nowhere else to go.*

Some family members motivated learners living with HIV and taking ARVs to turn to God and seek spiritual support and pastoral care. Churches were helpful in some participant learners' lives and provided spiritual support and pastoral care. Two participants, Bertha and Benzao, revealed how they committed their lives to their religious faith and sought pastoral care in church. Bertha said, *"[A]fter a month, the church members came to visit me in hospital. A strong man of God encouraged me that God loves me and said that God would make me stand up and walk again. He gave me a Bible to read and I was happy. I got connected to God and that was cool."* Benzao recalled how his aunt took him to a church, which, he claimed, changed his life forever. He said,

> *My aunt took me to this born-again church. The pastor tried to talk to me that day but I did not care much about his preaching as I was very sad. The pastor asked me to stay with them for one week. I felt better when I was in the house of the Lord. Sometimes I forgot what my problems [were]. After a week, the pastor's wife asked me to stay again for two weeks. She said I was not ready yet to face the world. Those two weeks change my life forever. I decided to give my life to the Almighty, I became a born again. That's how I have forgiven my uncle and my fellow learners.*

Communities and families had their own ways of coping with the hardship experienced by the cohort of learners in the study. In particular, community members played a special role in some of these learners' lives by providing support structures.

Learners reported challenges in intimate relationships due to their HIV status, as I detail in the next section.

4.3.4 HIV-Positive Learners on ARV Treatment and Intimate Relationships

Living with HIV and AIDS is a challenge on its own to participants and disclosing status to their lovers or romantic partners is yet another challenge. This study revealed how romantic partners of participant learners reacted negatively because they were unable to deal with the situation and challenges that come with HIV as a disease and ARV taking as a permanent condition.

There was an expectation by learners in intimate relationships that things would remain the same after disclosure to partners. In this study, three participants in intimate relationships, took the risk and disclosed their status to their loved one; hoping that their partners would understand and support them. To their surprise, they were generally rejected and dumped. Neville described the moment he disclosed his status to his then girlfriend. He said,

> *That year, I told my girlfriend about my status and I also told her that I am taking ARVs. It was not easy to lie to her because we have been together since primary school, but we never got involved in sexual activity. We just kissed Miss, that's all. I thought she will understand and support me. But to my surprise, she dumped me.*

La-Toya and Mercia both experienced rejection, blame, and abusive language from their loved one. La-Toya recalled the incident saying, *"[M]y boyfriend left me, insulting me and accusing me of wanting to infect him."*

When Mercia fell pregnant at the age of 15 and was told her HIV status at the antenatal clinic, she decided to tell her boyfriend, reporting the following,

> *I decided that I will tell him that I was told that I am HIV-positive. After all, he was the only man I knew in my life and must be the only one who has infected me. I called him to come home [so that I could] tell him the news. He started insulting me and accusing me of infecting him. He said that the pregnancy was not his. That was the last day I saw him. He dumped me and just disappeared.* [The learner started to cry and kept quiet for a while.]

The majority of the out of school experiences may be described as negative, with family members demonstrating the least empathy and support. Even though the literature in Chapter 2 suggests adverse experiences and responses from communities, support and acceptance for learners in this study came mostly from community members and support groups. The data

shows that decisions to continue with school were directly impacted by what was happening in the learner's lives outside of school.

The next section presents data on the main focus of the study, namely the school experiences of the participating learners.

4.4 School Experiences of HIV-Positive Learners on ARV Treatment

The previous section presented data on learners' life experiences out of school that shaped their day-to-day experiences out of school. The above also showed the integral link between out of school experiences and decisions about school. This section is looking at the data related to schooling experiences of HIV-positive learners on ARV - experiences that further shape their day-to-day experiences in school.

Schooling is often a good experience with good memories for many people. But this was not always the case for the learners who participated in this study. These learners encountered many challenges at school, which became a frightening place in some learners' memories.

All participant learners in this study faced many issues that were linked to stigma from their fellow learners and teachers, who often were not even aware of the impact of their remarks, actions or attitudes.

I present data in five themes of description in this section, namely: teacher insensitivity and learner relations; teachers and learner trust; medication-taking and staying in school; stigmatisation in school; and motivation, aspirations, and hope.

4.4.1 Teacher Insensitivity and Learner Relations

In this study, the relationship between HIV-positive learners on ARVs and teachers had implications for learners' schooling and their social development, as the results below reveal.

Teaching can be a challenge to many teachers who don't have background knowledge in teaching sensitive topics such as HIV and ARV medication-taking. Not all teachers might be

aware of what learners are going through in relation to HIV and ARV medication, given the disclosure policies that regulate institutions like schools and health facilities. Some might be aware of HIV-positive learners (and some on ARV treatment in their class), but might not be sensitive or aware of insensitivity in their teaching. Insensitivity, as the data shows, brought about mistrust and adversely affected teacher-learner relationships.

Johanna summed up a characteristic response by learners who indicated how insensitive teachers were when they discussed HIV and AIDS in class. She said,

> *....And the teachers don't understand. They are making everything difficult for me. Maybe they don't know or they are just doing it on purpose, I don't know. I was happy for a certain time, until one day when a teacher was talking about HIV/AIDS in a class. My classmates started to accuse people who are living with HIV. One boy even suggested that 'all the HIV people must be killed'. What hurt me is that the teacher was also enjoying it. Now I also just remembered what happened to me at my former school. Then, the teacher asked me '... if you were a minister of health, what would you do with people, who are HIV-positive?' I just started crying.*

Teachers also confirmed that some teachers were insensitive in dealing with HIV related matters in the classroom. Ms Kasata from the teacher focus group said,

> *I remember during my teaching practice here at this school, I had to help my support teacher to invigilate a test and one of the questions that she asked was that a learner should imagine that she just finds out that she was HIV-positive and she must write down her reaction toward that. One of the learners started crying and yah, that's how we discovered that she was HIV-positive... because she was crying. And the teacher asked her what's wrong and she said, 'no, I am crying because I am really HIV-positive and if people start talking about it, I think everyone knows. It is like it is written on my forehead that I am HIV-positive'.*

Ms Dolly from the focus group said, *"Learners on ARVs are very sensitive and sometimes they don't participate on class activities because teachers are not sensitive enough when they are teaching HIV and ARVs."*

4.4.2 Teachers and Learner Trust

Degrees of trust towards others can shape the decisions learners make. In this study, lack of trust in teachers prevented some participants from seeking help at school. This group of participants revealed how the degree of trust - particularly trust in teachers - shaped their decision making to

go and seek help. Not all teachers responded positively; five learners indicated this to be the case. Sometimes, teacher responses reflected a lack of knowledge about particular learner needs (such as ARV medication-taking) and other times, lack of empathy and insensitivity.

La-Toya made the point that teachers could not be trusted because they might breach confidentiality. She said, *"I did not tell any teacher. You never know, some teachers might tell other learners about my status and the medication I am taking. I don't trust some of my teachers."*Mercia also distrusted teachers because one had disclosed her status to other learners. She said,

> *I had no choice but to tell my teachers that I am on ARVs medication, because of the rash they gave me. Then one teacher told a boy about my status to protect him because he saw how the boy was getting close to me. From there the whole school knew that I am HIV-positive and taking ARVs and I lost trust in my teacher, he revealed my status.*

Another learner, Benzao, was also disappointed and lost trust in one of his teachers whom he said was more interested in how he became infected than in offering him support and empathy. He said, *"[I] told one of my teachers about my status and to him, he was just more interested to find out if I was really raped and have AIDS. He never cared about how I feel; he just wanted to hear the details of the incident. He is not cool and I lost trust in him."*

Johanna revealed how teachers turned a 'blind eye' to jeers by learners. She said, "[*S]ome teachers don't even interfere when learners are making fun of me or when they are laughing and calling me 'drinker'* (colloquial name for someone taking ARVs) *whenever I want to make comments in class."*

Bertha experienced similar negative responses and a cold shoulder from teachers. She said, *"I wanted to kill myself because my teacher doesn't understand why I don't want to come to school. I told her what was happening at school and how learners treat me and call me names of medication I take, but she did not care much."*

Fear of being labelled and stigmatized meant that learners required privacy when taking medication. However, teachers were not always accommodating in this regard. Monique said,

"....It was very difficult for me because I have to take my tablets at 10h00, and sometimes the teachers don't want to allow me to go outside and drink my medicine."

The data reveals that teachers who foster positive relationships with their learners create conducive learning environments and respond positively to ARV medication-taking. Some learners were able to confide in teachers, thus building trust relationships. For example, Neville reported to have been able to build a relationship with a teacher. He said, *"Yes, I shared my problems with one of my teachers that I trusted and she motivated me to go on with my life and ignore them (learners)."* Salmi also experienced positive responses from her teacher when she confided in her. She said, *"I told my Life Skills teacher about discrimination, hurt, and rejection even blame that I was going through at school because of the medication I am taking and she was very helpful."*

Teachers confirmed learner claims as they explained that there is lack of trust sometimes between the teachers and learners. Ms Ivy reported, "[*S]ome of these learners on ARVs don't trust teachers and is not easy to gain trust from all the learners taking ARVs as they are very sensitive and secretive.* She acknowledged the tension between disclosure of learner status and potential support that teachers might be able to provide. She said, "… c*onfidentiality is an issue sometimes at school; that's why some of these learners don't open up to their teacher."*

Teacher insensitivity and lack of trust of teachers by learners were only a part of the experiences that negatively influenced learners' school experiences. The act of taking ARV medication posed yet another layer of threats to the well-being of learners in this study, as I outline in the next section.

4.4.3 Medication-taking and Staying in School

Some types of medication must be taken at regular times, while in the case of others; timing is important but not always critical. In most instances, medication should be taken before, during or after a meal or snack. In all cases, medication comes with instructions that explain the correct dosage and use. ARV medication requires a strict regimen with timing as an important aspect.

Once on a particular regimen, medication has to be taken with food and on time. Failure has consequences that might be life threatening for the individual.

In Chapter 2, I outlined the differences between general medication-taking and taking ARV medication, and the challenges involved. There is no doubt that taking ARV medication indicates someone's HIV-positive status, which often carries stigma. Thus, medication-taking for the learners in this study was an experience that had implications for how they made meaning of the school experience and how they participated in it. I describe experiences in the following categories: initial responses to ARV medication; medication-taking, side effects, and nutrition; secrecy, privacy and ARV medication-taking; ARV-taking, guilt and blame; ARVs and fear of death; ARV medication-taking and suicide; and support for medication-taking at school.

Initial Responses to ARV Medication

Some in the cohort who did not want to disclose their status avoided taking medication during school hours, and those who did take it conducted this in secret. None of the learners enjoyed taking ARV medication but they acknowledged its health benefits. Neville said, *"[W]henI started the medication, it was not easy for me to take ARVs every day at school. I didn't like them, but they make me healthy*. La-Toya said this about ARVs, *"In 2010 I started taking ARVs because my CD4 count was very low, and they helped me a lot. That is why I came back to school, but I never enjoyed taking them."* Benzao said, *"[T]he same year I started to take ARVs and after two months they made me feel better and I went back to school; but I didn't like taking this medication."*

Six of the eight teachers in the focus group discussion confirmed being aware of learners on ARVs. Mr Petrus said,

> *Yah, I am aware of learners on ARVs. In fact, recently last week, the mother of one of my learners from last year ... we build up a good relationship and she told me that her daughter is taking ARVs and that they helped her to be healthy and to come to school although she don't like to take them.*

Medication-taking, Side Effects, and Nutrition

Reasons given by learners for their dislike of the ARV medication included the negative side effects they experienced. In this study, all participants experienced side effects, which included rashes, dizziness, nausea, stomach cramps, and fatigue. Neville explained how the side effects made things difficult for him at school. He said,

> *I was feeling dizzy for almost a month. I started to have a rash on my body and it was very itching. It was difficult for me when I was at school because I was very shy to scratch myself in front of my fellow learners. I suffered a lot Miss because of that medication. There was a time I just want to give up and die because of this medication problem.*

La-Toya and Bertha both explained their experience of taking ARVs in the following way. Latoya said, *"I had problems with ARVs because when I started drinking them, I experienced tiredness, dizziness, and stomach cramps for almost two months. I suffered a lot especially at school where I [could] not go somewhere to lie down to feel better"* while Bertha said, *"[W]hen I started drinking those tablets, they [made] me dizzy and I would fall even when I was at school. I told my mother that 'may be is better to die instead of being embarrassed at school'."*

Salmi and Monique faced similar side effects as La-Toya and Bertha. Salmi said, *"[W]hen I started ARVs, I developed a lot of big pimples on my face. These tablets made me feel uncomfortable and unhappy at school because I thought everyone at school can see that I am on ARVs."* Monique said, "[*A]t the beginning, the tablets gave me certain skin for almost six months. This rash came and went. I was not at ease to wear short sleeve shirts at school because teachers and learners were always asking me what is happening to me and I felt bad."*

Side effects were not the only negative consequence of taking ARV medication. Access to food and importantly, to a balanced diet, posed a challenge to most participants. Two of the eight participants encapsulated the experiences of most of the learners by explaining how taking medication was a problem when they were hungry or when they took it on an empty stomach. Neville and Salmi were often unable to take their ARV medication on a regular basis because taking the drugs on an empty stomach left them feeling sick. Neville said, *"... if I did not eat, then I cannot drink that medication; because they will make me feel sick and sometimes there is no food at home."* Salmi said, "[*T]he other problem with this medicine is that when I am hungry,*

I cannot drink them." Lack of access to food, together with the challenges of when and how to take medication during school hours, affected adherence; an issue that might have long-term effects on the health and well-being of some in this cohort.

Three teachers confirmed learner claims concerning nutrition. Ms Dolly said, *"I think one of the challenges is lack of right nutrition or a balanced diet, which can help them to live longer. Medication alone is not enough for them if they are not eating well."* Mr Petrus also reported on how learners on ARVs suffer because of lack of food. He said, *"Most of the time these learners on ARVs are orphans and vulnerable children whose parents passed away because of the disease and they got nothing to eat at home which makes it difficult for them to take their ARVs."* Ms Ivy shared similar sentiments by stating, "*I am aware that learners on ARVs sometimes don't have food to eat. As a Life Skills teacher, they will come to me sometimes and tell me that they have nothing to eat and cannot take their medication; then I will offer them something to eat if I have."*

Yet another challenge faced by learners was where to take medication given the silence around the pandemic as well as confidentiality and secrecy as I detail below.

Secrecy, Privacy and ARV Medication-taking

Shame, taboo, embarrassment and fear of ridicule made it difficult for learners to take this medication openly or in public. All participant learners admitted that they needed privacy and would hide when they were taking their medication. Salmi and La-Toya hid when taking medication at school. Latoya said, *"[A]nother problem with these tablets is that I have to go in a toilet or somewhere where there are no other learners to take them. I know that if they see me taking these tablets, they will tease me."* Salmi had the following to say,

> *I always make sure that I hide my medication when I go to school, because learners will make fun of me if they saw me [taking them] or saw them [the medication]. It was not easy for me to drink the tablets at 08:00 every day. Right now, I don't feel dizzy anymore, but I still have to hide when I drink them.*

Other participants singled out privacy at school as the biggest challenge. Neville said, *"[A]nother embarrassing problem is, when I am at school I cannot drink my medication because there is no private place or room at school where I can take my medication and that is still a*

challenge for me." Johanna said, *"I just feel pity for those kids who are taking medication, no privacy at school and once you choose the time you take them, you have to stick to that time every day."*

Teachers acknowledged that lack of privacy (and the attendant stigma) poses a challenge to learners. Ms Ivy said,

> *There are many challenges, especially when these learners are taking their ARVs, and privacy is one of those big challenges because there is no specific space or place where these learners have to take their medication. They have to sneak away from their friends if they are having friends, and then they hide somewhere so that they can take their ARVs because they know that if the others see that they are taking ARVs they won't keep quiet. They will start teasing them and make fun of them and call them those names that they are always calling them.*

Guilt and blame posed yet another layer in the challenges learners faced.

ARV-taking, Guilt and Blame

Seven participants blamed either others or themselves, with some experiencing guilt or remorse. Neville, Johanna and Monique blamed their parents for challenges they faced at school, because they were born with the virus. Neville blamed his parents for being HIV-positive and claimed that they infected him, causing him to suffer at school. He said, *"[If] my parents did not infect me, my life would be very different from the life I have now. No one [would] tease me at school if they did not infect me."*Johanna said, *"then, I am blamed my mother for what I am going through at school; it is because of her I have AIDS."* Monique said, *"...in fact, I don't want to remember anything about my parents. I still blame them about the virus that I am living with and the embarrassment that I am facing at school."*

Mercia on the other hand blamed herself for her current situation. She fell pregnant and was infected by her boyfriend. Feeling remorseful and guilty, she said*, "I also blame myself about everything that is happening to me now at school. If I was a committed girl, I suppose not ending up like this. I messed up my life."*

ARVs and Fear of Death

Many of the learners questioned the effectiveness of ARVs; bringing about a fear of death among them. Death seemed to be present in all the discussions, given their experiences in the community. Stigma and its consequences created increased fear, hopelessness, and self-doubt concerning their mortality, as the following learners highlight. Johanna said, *"And I was also asking myself 'How long will this medication help me, when will I die? How will I die? What about my school and my future?' I am scared to die."* Bertha said, *"My mother was also on ARVs and she died. Her death has brought fear of death in me. I can't believe that my life is still going on. I started to fear to die especially at school because learners will still laugh at me even though I am died."* Salmi put it this way:

> *I was feeling that death is just close to me and I don't know how long the ARVs will help me. It has taken away my mother who was a strong woman. It can also take me anytime. I lost hope and decided to give up. It was not worth to fight the disease, while I know that I will die soon.*

While many learners suffered the consequences of stigma such as hopelessness, loneliness, rejection, isolation (and self-imposed isolation), as well as name-calling, four of them also attempted suicide: a drastic and nearly fatal consequence as I detail below.

ARV Medication-taking and Suicide

Many learners reported that the negative experiences sometimes overshadowed the health benefits of ARV treatment. Four (Johanna, La-Toya, Bertha and Benzao) attempted suicide because of challenges they faced at school. Of this experience, Johanna said, *"[W]hen I arrived home from school, I drank a lot of tablets, because I just wanted to die. Learners drive me crazy. I told myself that...'Life is very unfair. Why is this happening to me'?"* La-Toya said, *"I tried to kill myself. There was time I was looking for death, [for] someone must bump me with the car or just stab me with a knife. I was desperate and unhappy at school and at the same time also sick and tired of ARVs."*

Teachers confirmed suicide attempts amongst learners on ARV treatments due to stigma and discrimination. Mr Michael said,

> *My experience is a little bit worrying because the other kids are not behaving properly. They discriminate and make fun of this kid who is taking ARVs; later on this child tried to*

commit suicide, I spoke to her personally, and it was difficult for me because we are not trained well in this situation. But, at least we managed to sort of put her off not to commit suicide. (Others agreed by nodding or saying "yes").

Support for Medication-taking at School

People living with HIV and taking ARV medication need support. The same goes for the learners in this study, who reported to need emotional and material support. Tension between disclosure and confidentiality on the one hand and the need to seek support on the other hand, created challenges for this cohort of learners. While all needed support, many hesitated to disclose their status because of fear, stigma, and discrimination.

Not all learners voluntarily disclosed their status or their medication-taking. Shock and disbelief expressed by friends, family members, and peers followed disclosure. In some instances, the HIV or ARV treatment status was revealed by others; creating undue pain and suffering on the part of the learner.

The above notwithstanding, some learners were able to develop trust relationships with a teacher, friend or peer with whom they could share experiences about the need for support. Two participants reported to have good relationships and support from friends at school. These friends did not withdraw even after learners revealed to them that they were taking ARV medication. When they were stigmatized, these friends supported them, as revealed by some participants below.

Johanna was lucky to have a friend who also takes ARV medication. This enabled them to talk about what they were going through. They also reminded each other to take medication. Having a friend eased the pain and made the burden of by an HIV-positive learner on treatment as Johanna indicates. She said,

> *My life at school became better and simple because I [had] someone that I [could] talk to openly to, without fear of being discriminated, rejected or even labelled by [being] called scary names. We reminded each other about time we supposed to take our ARVs and [discussed] what helps me to feel better and to pass my Grade 10 ... it is a true friend that I have at school.*

Monique also reported to have a faithful friend who did not abandon her. However, Monique's friend was HIV negative, sometimes making it difficult for Monique to trust her because she was not always empathetic. Monique said,

> *I was very lucky because my friend supported me at school; she never left me. Whenever I was sick and absent, she [would] come and visit me and always reminded me not mind whatever people [said] at home or at school. But, there was a time I questioned her support [because I asked myself]… 'What does she know about HIV and ARVs? She doesn't know how it feels, man'.*

Only one learner experienced family support in relation to ARV treatment and staying in school, Bertha said, *"[M]y mother encouraged me to drink my ARVs and kept on reminding me that I will be healthy and [that I would] go back to school. After few months, I started to gain weight and I was healthy again. Then I was missing school, so I went back to school*."

Support from peers or friends eased the experience of taking medication at school. However, learners reported that teachers were not always aware, and if they were, not sensitive or empathetic to that learner's needs for privacy and adherence to the time regimen. Monique revealed a consistent concern amongst this cohort of learners when she said, *"...It was very difficult for me because I have to take my tablets at 10h00, and sometimes the teachers don't want to allow me to go outside [meaning in private] and drink my medicine."*

Stigma and discrimination shaped the school experiences associated with HIV status and ARV medication-taking. All participants lived in the same community and experienced similar socio-economic conditions. Similarities in economic status and the lack of a larger sample of males meant that I was not able to critically examine and deconstruct differences in discriminatory practices that privileged or constrained some more than others in the study, even though the theoretical frameworks adopted in the study provided analytic tools to do so. The data that follows, therefore, illustrates prevailing stigma and discriminatory practices that were consistent amongst this cohort. I provide data on the forms of stigma that were evident, its sources and also the consequences experienced. I also present data that illustrates some discriminatory practices learners experienced.

4.4.4 Stigmatisation and Discrimination in School

Stigma was a pervasive concern to all the participants. Often, the learner population and some teachers at school were not aware of (or empathetic to) the impact of stigma and discrimination in the lives of learners living with HIV who were also on ARV medication. Nor did they appear to grasp the serious suffering and mental anguish that stigma caused.

All eight participants experienced stigmatization and discrimination in one way or another at school. Six participants from the teacher focus group also singled out stigma and discrimination toward learners on ARVs as a major challenge experienced at their school.

All the learners reported feelings and experiences of different forms of stigma at school (and at home), which affected their schooling in negative ways. Participants indicated stigma emanating from their HIV status as well as from taking ARV medication. Stigma originated from different sources and took different forms. It resulted in name-calling, isolation, and discriminatory practices that affected participants' self-esteem, self-worth, and confidence.

Some described stigma resulting from their HIV status. Peers, loved ones, and people close to them stigmatized them, resulting in them being isolated, rejected, or called derogatory names.

Neville, for example, explained his experience of stigma at school after his former girlfriend revealed his HIV status to his peers. She also revealed that he was taking ARV medication. He said,

> *All my friends disappeared, just in one day. No one wanted me; no one wanted to greet me. So, I decided to quit school, 'maybe it is better'. I could not look at them when they passed by because they told me not to look at them. I did not understand why the learners were discriminating and hated me. I could not believe that my buddies changed so much towards me. 'Those were my man, man'.*

Name-calling was a manifestation of stigma in school. Learners reported to feel shame and embarrassment. Seven of the eight participants experienced name-calling. Neville said, *"[T]hey started calling me the AIDS boy and labelled me with different names, such as 'the ghost' or 'the drinker'."*Mercia also experienced name-calling and said, *"I was called any type of name that came on their minds that time. There was a group of four girls who didn't stop laughing when*

they saw me and [they showed] four fingers (which represents the four letters of AIDS). They really suck."

Benzao said, *"[W]hen I went back to school, most of the boys knew that I was raped and [that] I am drinking HIV medication. They started to call me names like 'wife', 'gay' and 'AIDS monster'. It hurt me so much because I did not get AIDS because I wanted it but because someone raped me."*

La-Toya recalled how the boys made schooling difficult for her after they knew her status. She said, *"[T]he boys started to say that they are scared to be in the class with a ghost. They said I am already dead, but not buried yet."*

Johanna recalled how bad it was in her case when fellow learners learnt about her status. She said, *"... most of the time they will start laughing and pointing at me and shouting 'go away AIDS'."* [The learner cried when she recalled this incident]

Teachers confirmed that name-calling on school grounds was common. Mr. Petrus said, *"[T]hey call them 'drinkers'; they don't mention the name of the tablets but they just say someone is a drinker then they know already that he/she is on medication."*

Stigma did not only result in name-calling, but also in learners having difficulty in using school facilities. Bertha, Latoya and Salmi experienced similar problems with the use of toilets at school, where peers refused to use the toilet after one of them had been in. La-Toya said,

> *My fellow learners did not want me at all; especially after they found out about my medication ... they suck. When I use a toilet, no one will want to enter that toilet anymore. One day, one of the Learners Representative Council members (LRC) called me and told me that learners don't want me to use the toilet because I have a dangerous infectious disease. I was very disappointed in our leader who supposed to serve all of the learners, but she is also discriminating against me.*

Bertha who experience the same problem as Latoya said,

> *Life at school was not easy for me. I wanted to move to another school where people don't know me. My friends don't have anything to do with me. I concluded that it is because I am taking ARVs. Life is very unfair, when I am at school learners' start teasing*

me. They accused me of wanting to pass the virus to them. They even said I must stop using the school's toilet.

Salmi's experience was no different to those of her peers in the study. She too experienced discrimination due to her status. She said, *"[M]y life at school became hell. The whole of 2005 was not cool. I was going through a lot, especially at school. The toilet became a problem because whenever I went in, they [peers] would start saying 'the diarrhoea is here'."*

Monique recalled her experience in this way,

Life at school became very tough for me when I started taking ARVs. Learners knew that I was taking AIDS medication and some asked me if it was true. I didn't know what to say; I thought if I denied it they might laugh at me again. So, I kept quiet. Now I am very sure that they know that I am drinking ARVs. School became hell for me; I hated it so much, because of how learners treated me.

Mercia reported her painful emotional school experience after other learners learn about her taking ARVs. She said,

2011 became the worst year of my schooling. The boys laughed when I am passing by and said 'some people are so sick and they are dying.' Some even proposed that if they were teachers, they would not waste their efforts on teaching a dying learner. No one wanted to eat my food Miss; they thought I injected it with my infected blood. They made me feel that I am a 'moggoe' (meaning useless or stupid). [The learner cried when she recalled this incident]

Teachers were also aware of the name-calling that occurred in school, but seemed unable or unwilling to intervene. They were aware of the consequences of stigma, recognising that affected learners felt rejected and isolated. Miss Ivy said,

Most of the learners on ARV medication share with me their experience of pain, trauma, and rejection especially when fellow learners find out about their status. There are some learners at our school who came with their medication to school and they have to take them at a specific time. Now the difficult part is that they have to ask from a teacher to go out of class and take their medication and some learners would like to follow them and monitor the process so that they can start making fun of them.

The consequences of stigma extended beyond name-calling and challenges about the use of resources, to learners experiencing isolation, rejection, and loss of self-worth. Learners were not always isolated by peers, but often imposed self-isolation due to fear and shame. The

consequence was loneliness, a sense of despair, and a feeling that their experiences were unique. Four of the eight participants experienced isolation and a loneliness at school after the disclosure of their status. In this regard, Neville said,

> *In 2011, my life was so lonely; all my friends disappeared just in one day and no one wanted to socialize with me. The learners looked at me and started to disappear. 'Why me?' That is the question, which was in my mind always. Some learners preferred to sit far from me when we are in class or just stand up and go and sit somewhere else. That was hell.*

Johanna, Bertha, Salmi and La-Toya suffered the same isolation as Neville. Johanna said,*"I felt that no one wants me, I was just alone. I can still hear their voices now, when they were telling me to go away with my AIDS."* Bertha has this to say, *"HIV made life difficult for me at school. I was just alone and even wanted to make few friends, but no one wanted me. I felt lonely and unwanted. That was just too much for me"* while Salmi said, *"I was just alone at school" a*nd La-Toya said,*"*[*T]he learners in my class did not even want to come close to me because I have HIV."*

Four teachers confirmed learners' claims and recognized isolation as a challenge. Miss Elina said, *"[I]solation is one of the aspects that normally chase those particular learners out of the school."*

The data did not reveal practices that discriminated one group of learners over another. Put differently, this cohort experienced similar discrimination resulting in similar outcomes, mainly associated with their status rather than also with medication-taking.

The evidence attests to the pain and emotional stress caused by stigma and discrimination caused amongst this cohort. Interestingly and as I show in 4.5.5 below, stigma and discrimination resulted in learners deciding to take control of their own lives; leading them to find ways to cope and become self-reliant. Put differently, stigma and discrimination became the enabling conditions for agency and resilience amongst this cohort.

4.4.5 Motivation, Aspiration and Hope

This study revealed that all HIV-positive learners on ARVs were stigmatized in one way or another and that they all experienced deep anxiety, pain and a sense of hopelessness. They became vulnerable to emotional and even physical abuse by others. Despite these circumstances, all in this cohort made a conscious decision to turn the negative circumstances to their advantage. In contrast to the studies I reported on in Chapter 2 that posit external support structures as a critical ingredient in the development of resilience amongst learners, , in this study learner agency was also a key factor. The learner cohort exercised agency in ways not always reported in this body of literature. While many report on the importance of external support from friends, peers and sometimes, family members, their ability to take control and make decisions demonstrates individual agency, showing the development of a resilience that does not always only rely on external support. In all cases, self-acceptance was the precondition for agency and resilience to emerge. In the case of all learners, self-acceptance was contextual and dependent on others' acceptance of the individual. Thus, agency and resilience emanated from external support but was not exclusively the result of that support.

While I acknowledge the relativity of resilience and agentic action and that both are dynamic and subject to change (sometimes causing vulnerability and loss of agency), for analytic purposes, I present data to illustrate both aspects. Indeed, a participant, Salmi, illustrated the former point when she said, *"For a while I told myself that I will not go down because of other learners; but later on after the challenges that I encountered again in my life, I just realize …"* [She became quiet and looked down]*."* After a long silence Salmi said, *"[F]or a while I was strong and refused to give up; then in 2010, my mother got sick just for two days and she passed away. I was going thr ough a lot, Miss and I felt useless and worthless again."*

Learners not only reported to have developed self-acceptance, but also self-worth, hope and motivation to stay alive and healthy and to live a successful life; aspects I put forward below as evidence that illustrates the development of agency and resilience. The development of agency and resilience occurs in a continuum over time. It is for this reason that I present a tabulated series of events across a period of time to illustrate development, rather than a narrative as I have

done in the presentation thus far. While it was possible to trace agency and resilience development amongst all participants, I only present four examples in this section.

I present a series of experiences (of one learner each time) from learner data to show experiences depicting the shift from despair and hopelessness towards the development of agency and resilience. In the words of participants, such examples illustrate the move from an experience as a constraint to it becoming a condition from which children made different choices and developed motivation to live a healthy and successful life, hope, and future aspirations, aspects I put forward as illustrations of the development of resilience.

Self-Acceptance, Hope, and Aspirations

BERTHA	
2001	**Finds out about her HIV status**, of which she said: *"It was on my 9th birthday. My mother makes me a birthday party and she was, she invited some friends and family members. At that time I was better and I even enjoyed my birthday. Then my aunt called me and asks me if I am drinking medicine for HIV. I was shocked and confuse. I ask her, 'me'? Then she said, "Yes I am asking you". I told her that I don't know what she is talking about. Then from there I went to bed and started crying."* *"I felt angry for everyone. I chased my mother out of my room and I told her that I hate her. I locked my room and I wanted to die that day. I had a lot of questions and I asked myself why this is happening to me. I was telling myself that 'if my friends find out at school that I was HIV, I am HIV-positive, they will hate me'."*
2002	**Suicide attempt, dropped out of school because she was always sick**, of which she said: *"I was very sick, I even tried to kill myself by drinking a lot of tablets at the same time. I did that because I was so desperate and unhappy, at the same time I was also very sick. I dropped out of school because I was always sick. I will never forget those days in my life.*
2006	**Her mother and younger sister passed away.** She reported: *"...then my mother died and the year after, my younger sister died. My mother's death brought a fear of death in me. I can't believe that my life is still going on. I also feel guilty and useless. She was always there for me when I was sick and then what did I do for her? ... nothing."* *"...life in school was not easy for me. I wanted to move to another school where people don't know me. My friends were in higher grades and they did not want to have anything to do with me. I concluded that is because I am HI- positive. I was just alone, but I decided to stay in school.*
2009	**Betrayed by the donor and the local newspaper wrote about her HIV status**.She said, *"I was very much disappointed in her. She published my story in the local newspaper and even put my photos of me wearing my school uniform. So for me, I learnt and I decided not to trust anyone in my in my life anymore. I will only trust myself."*
2010	**Stigmatized and discriminated against at school,** of which she said,*"Life is very unfair, everyone at school knew about me, so when I was at school, learners started teasing me. They started calling me awful names that I don't want to repeat. They accused me of wanting to pass the virus to them. They even said I must stop using the school's toilet. The learners called me the 'AIDS girl' and they were just waiting for me to die. I felt lonely and*

	unwanted." *"I wanted to kill myself because my grandmother didn't understand why I don't want to go to school. I told her what was happening at school, but she did not care much. It was only until that day when Miss talked to me and referred me to the social worker that my life became better. I realized that there is still a person who cares about me. Then because of that I make a choice to live again, I know that is possible for me to live again."*
2012	**Currently in Grade 11, happy and healthy,** she said*, "I am currently in Grade 11 this year. I feel happy and healthy. There are so many things that I am always thinking that I want to happen for me. One of them is to get the cure for HIV and AIDS and then I will stop drinking ARVs."* *"I know that I have AIDS, but I now have faith in my future and I just want to finish my high school one day and became a doctor to help those who are sick. There are still, there are still some people at my school who don't want to be friends with me or to share a table with me or a chair with me. It hurts me, but it is not serious anymore the way it was last year when I didn't even wanted to live. Now I live with hope. "*

Agency, Resilience,and Rights

MONIQUE	
2000	**Parents passed away,** she said*, "My parents passed on when I was just eight year. I don't remember anything much about them. In fact, I don't want to remember anything about them because I still blame them for the virus that I am living with."*
2001	**Went to stay with her uncle**, she said *"In 2001, I went to stay with my uncle. He is my father's younger's brother and he promise to take care of me, but he did not keep his promise."*
2002	**Found out that her parents died of HIV/AIDS,** she said, *"Life was ok so far, until one day when my uncle's wife told me that I am stupid that's why my parents died of AIDS. I did not know what killed my parents. It was the first time I heard about it. I was crying the whole day."*
2003	**Found out that she was HIV-positive,** of which she said, *"The doctor told me that I am HIV-positive. They said I fainted there and the next day, when I woke up, I was in the hospital. I didn't want to die soon like my parents. I was very unhappy. I did not want to eat. I kept on asking myself why I am so bad luck. I was crying, sad and felt useless."*
2004	**Uncle's wife chased her out of the house:** she said, "*...after my status disclosure, my uncle's wife chased me out of the house. She said, she did not want me to infect them, my uncle was trying to keep me, but she did not she said is either me or her. I was very sad, scared and lost hope as I have nowhere else to go, but I decided to look for help."*
2005	**Stayed with neighbours:** she said, "*... I went to stay with the neighbour. She took me in as her own child."*
2006	**Became very sick this year and people said she would die soon.** She said, "*Later on I became very sick and people thought I will die. But I told myself that I will not die, I have to fight to live."*
2007	**Started taking ARVs medication,** she said, "*I started taking ARVs in 2007. Life at school became very tough for me. Learners knew that I am taking HIV/AIDS medication. Some even came and asked me if I am really drinking AIDS medication. Then I did not know what to say. If I deny, they might laugh at me again. So, I kept quiet. Now I am very sure that they know that I am drinking ARVs. But I was very lucky because my friend supported me."*
2008	**School became hell for her:** she said, *"School became hell to me, I hated it so much. I didn't want to be asked if I am taking my ARVs by people who just want to laugh at me."* **Neighbour took her to support group:** she said, *"The woman I was staying with cared about me so much. She*

	took me to a support group of "Lironga Eparu" which means 'learn to survive'. There I learnt a lot. I enjoyed [being] there and listened to different testimonials of people living with HIV. I learnt that there are a lot of people who is still going through a lot of problems because of their status."
2009	**Started to think about living positively and studying:** she said, *"In 2009, I decided to live positively and move on with my life. I will not giving up my life because of HIV or because of those people who are putting me down."*
2010	**Passed grade ten as the best achiever at school:** she said, "*I started to study hard to prove that even HIV-positive people can pass well. In 2010, I passed my Grade 10 with flying colours, Miss. I was the best achiever in that grade. Some of the kids who were always teasing me started to keep quiet and just look at me."*
2011	**Decided to live positively and fight for my rights:** she said, *"I decided to live and fight for my rights. Now I even know that if someone is hurting me, I can open a case and sue them. I know my rights better now."*
2012	**Currently in Grade 12 and wants to go to university:** she said, "*I passed my Grade 1, and this year I am in Grade 12. I am looking forward to passing and going to university. I realize that AIDS is not a death sentence; but is just a condition and a sickness like other clinical disease such as TB."*

Agency, Resilience, and Aspirations

MERCIA	
2004	**Met an Angolan man and fell in love:** she said, "I met an Angolan man and fell in love with him at the age of 14."
2005	**Fell pregnant and discovered that she was HIV-positive,** *she said, "I fell pregnant at the age of 15. My boyfriend was the happiest man on this world when he learnt about the pregnancy. He promised to marry me. When the pregnancy became five months, I went to the clinic for an antenatal test. That is how I found out that I am HIV-positive. I felt so bad, shocked, and betrayed by my boyfriend that day."*
2006	**Boyfriend dumped her and disappeared:** she said, "*I decided that I will tell him mmm .... After all ... mmm... he was the only man I knew in my life mmm ..... I was convinced that he must be the one who has infected me. I called him to come home and told him the news. He started insulting me and accusing me of infecting him. He said that the pregnancy was not his. That was the last day I saw him. He disappeared."*
2007	**Started abusing alcohol and drugs:** she said, "*I was very unhappy, I lost the baby. Life without my boyfriend was not easy at all. He was the breadwinner for me and my mother. We didn't know what to do anymore. I started drinking alcohol and abusing drugs. My life was not a life anymore; I was just waiting for my death anytime."*
2008	**Ran away from home:** she said, "*Later on I just ran away from home in 2008. I started sleeping around with anyone who could offer me alcohol or drugs. I didn't care because I thought I will just die anytime."*
2009	**Returned to school and got sick:** she said, "*One day, five men raped and stabbed me with knives and I stayed in hospital for a month without anyone visiting me. Then, I thought of seeking help because I saw that this is not the life that I want to live for ever. One lady (Marie), offered me a place in an orphanage since she heard that my mother was nowhere to be found. The lady took me back to school in 2009."*
2010	**Started taking ARV medication:** she said, *"I became very sick and I started taking ARVs in 2010. Life with AIDS medication was not easy for me. They made me to develop a rash and vomit even at school. I had no choice but to tell my teachers that I am on ARV medication."*
2011	**Was treated badly at school:** she said, *"Then one teacher told a boy about my status to protect the boy because, he saw how the boy was getting closer to me. From there, the whole school knew that I was HIV-positive and that I was taking ARVs***.** *They started to treat me badly."*

	Worst year:she said, "*2011 became the worst year of my schooling. The boys just laughed when I passed by and said 'some people are so sick and they are dying' Some even said if they were teachers, they would not waste their efforts on teaching a dying learner. I was called any type of name that came to mind at that time. I also blamed myself about everything that is happening to me. If I was a committed girl, I suppose not ending up like this. I messed up my life. However, I realized that I have to do something for myself if I want to have a better life. I decided to ignore those people who are teasing me and also to move on with my life."*
2012	**Currently in Grade 12:** she said, *"I decided to stick to my school, despite what I was going through. I messed up already and I cannot risk anything anymore. Enough is enough. Whatever the learners were saying to me I decided would hurt me, but it will never kill me. I went up and down looking for a better life and I did not get anything. All what I got is only pain, hurt, rejection, unhappiness, discrimination. I decided to study and pass my Grade 12 and see what I will do next after that*. I told myself that '*My live has to go on.'*

Agency, Hope, Aspirations, and Living Positively

BENZAO	
2000	**Him uncle molested him;** he said, *"...that day my uncle raped me. I was feeling sick, angry and betrayed. I started hating him. I did not like what he just did to me"*
2004	**Told his grandmother about the rape and she advised him to keep it as a secret:** he said, *"...when I told my grandmother about the rape, she started crying. She said I must not tell anyone because her child would go to jail."*
2007	**He was sick and dropped out of school:** he said, "*I became very sick. I couldn't attend classes anymore, so I dropped out of school.*
2008	**HIV status disclosure**: he said, *"...when I found out, I hated my uncle more even though he is dead now. I was shocked, hurt and disappointed; I just wanted to die."*
2009	**Just wanted to die**: he said, *"When my friends found out, they called me names like' wife', 'gay' and' AIDS monster'; that was not cool. It hurt me and I just wanted to die."*
2010	**Told the teacher, but the teacher did not show empathy:** he said, **"***He never cared about how I felt. I decided not to come to school anymore, because I was very unhappy at school. I couldn't take the hurt anymore and I was feeling ashamed and unwanted. I tried to kill myself with a rope in my room. I just wanted to die, Miss. Then the rope just broke and I fell and I fell ... that's how people in the house found out about my suicide attempt.*
2011	**Became a born again**: he said *"my aunt took me to this born again church and I became a born again Christian."*
2012	**He decided to live positively:** he said, *"I have learnt to accept that I am HIV-positive and [that] I [can] still live a normal life like other kids. I decided to live positively."* **He also said,** *"This year 2012, I just want to pass my Grade 12 and study further to be a pastor. That is what I am aiming for, because I want to change people's lives and attitudes towards people living with HIV/AIDS."*

The four examples above show the complex interrelationship between external support and agency towards building resilience. In the lives of this cohort, external support was the precondition and not the only feature in the emergence of agency and resilience.

The final section below in this chapter draws on data from the documentary analysis and focus group discussion with a select group of teachers, including the principal, to present school responses to HIV-positive learners on ARV medication.

4.5 School Responses: The Case Study School

In this theme, I present data on structures and systems available to children in this cohort in school. I begin with a brief profile of the case study school and thereafter present results on policies, school support, training, teacher experiences and learners on ARV medication, and suggestions put forward to improve support for learners.

The School

This Senior Secondary School (Grades 8-12) comprises 990 learners with a staff complement of 32 teachers and four administrative and support staff. The senior management consisting of the principal and four heads of department oversee the day-to-day operations of the school, which include staff supervision, policy implementation, academics, spiritual oversight, program development, instructional supervision, and operational functions. The principal reports to the inspector and updates the chairperson of the school board. The principal is a member of the school board, which consist of six parents and three teachers.

School Structures and Teacher Responses

Policies

Because of the increasing number of learners taking ARVs in Namibia, the Ministry of Education established the National Policy on HIV/AIDS for the Education Sector to ensure learners taking ARV medication receive care and support and access to education. I provide parts of the policy relevant to the study in APPENDIX J.

Four teachers of the eight teachers in the focus group were not aware of any policies at their school, and three were aware. These three stated that while national policy exists, there is no internal school policy. One participant indicated that the school had a Life Skills (but not HIV and AIDS policy) internal policy, which does not articulate anything about HIV-positive learners or supporting learners on ARV medication. Mr Michael encapsulated the general sentiment

concerning policies at the school level. He said, *"Mhh ... there are some policies in place, but is more from the Ministry and we don't have them here at school, I think we need to work on our internal policy."* Largely, this result highlights the challenge of ensuring support for HIV-positive learners, especially those on ARV treatment, at the systemic and structural levels of the school system.

School Support

Two teachers talked about non-governmental organizations that obtain names of HIV-positive learners from school to help in paying school fees and stationery. Mr Michael, the principal of the school, explained that non-governmental organizations allowed the school to apply for HIV-positive learners to obtain grants. He said, *"The school is in partnership with a certain group FAWENA (a non-governmental organization) and Catholic AIDS Action that gives the school permission to apply for uniforms and stationery for some of these kids."*

Two teachers discussed emotional support from teachers. For example, Mr Petrus, He said *"[T]eachers feed these kids with whatever they have, give emotional support and educate other learners to avoid stigmatizing learners on ARVs."*

One of the teachers stated that the school offers food on certain days to learners in need, a practice that sometimes identifies and distinguishes learners on ARV treatment from those in need. Miss Ivy said,

> *There is a school programme at the moment working with a certain society that gives our learners soup and fat cakes on Mondays and Wednesdays. Tuesdays and Thursdays another volunteer gave us maize meal and soup. That was brought in specifically when I realized that there are learners who are using the medicine here at school and sometimes they come from home without having anything to eat. So there the school is doing something already.*

Teacher Training and Learner Support

In Namibia, the region and school recruit Life Skills teachers and teacher counsellors, the majority of which are not trained in the relevant knowledge and skills, as data in Chapter 5 will show. Teachers in the case study school were no different, as they too indicated that they were not trained in the subject area or as teacher counsellors.

Teachers were quick to point to the need for training, given not only the policy imperative, but also the presence of HIV-positive learners on ARV treatment in school. Teachers also offered suggestions on how schools might address the issue. For example, Ms Jacqueline said:

> *I think training will help teachers and learners on ARVs. The school, together with the Ministry of Education, must invite someone to come and do the training on how teachers can handle HIV-positive learners and other sensitive issues in a professional way; to avoid hurting them and to keep the learners in school. Sometimes learners quit school if teachers did not act fast or if they were not sensitive enough.*

Ms Dolly, from the teachers' focus group, suggested that the school must involve non-governmental organization in training teachers. She said:

> *I think what the school can do is maybe also consult non-governmental organizations which deal with people living with HIV/AIDS and with people who take ARVs. These organizations can send someone who has experience of ARVs treatment to come and train teachers and make them aware on how to handle learners who are drinking this medication.*

Teacher Experiences and Learners on ARVs

Disclosure is complex. Learners are not expected or required to disclose their HIV status, without which schools cannot act to support. Two teacher participants at the school had no idea that the school had learners on ARV treatment, while the other six did. Five of the teachers described this group of learners as shy, sensitive, and disassociated. They also said learners did not fully participate in the full life of the classroom or school and (as the learners themselves indicated) lacked trust in teachers. Teachers were aware of absenteeism and dropout amongst this group of learners, as well as illness related to their HIV status and stigmatization. Ms Ivy explained lack of trust, saying, *"[S]ome of these learners don't trust teachers and it is not easy to gain trust from all of them."* Mr Petrus explained how shy they were, saying, *"... most of them are shy and oversensitive and don't say much in class."*Mr. Michael said, *"So far, I did not experience any problems with those ones I know, only absenteeism and drop-out due to HIV illness or stigma."*Important in his observation was his mention of absenteeism resulting from stigmatization.

Participating teachers in this study were articulate in proposing ways schools could respond and better support learners on ARV medication in the school environment. All eight teachers

suggested training on how to be around, respond to, and work with learners on ARV treatment as the main area that teachers needed to know more about.

Some suggested that the school should assist this group of learners with economic, emotional, and nutritional support, as well address stigma and discrimination in the school context. Ms Kasata said, *"[T]he school must approach donors to help them with tools and equipments to start the school vegetable garden that will sustain the feeding scheme at school."* Mr. Michael suggested obtaining fund-raising assistance from the sister school in Europe. He said, *"[S]ince the school has a sister school overseas, I think we can try to set up a fund that can assist. It will be better to help these 'kids'."* Ms Ivy suggested that teachers should reconsider their roles to include becoming parents too. She said, *"I would love to suggest that all the teachers must not be teachers only, they must change to be parents too at the school, if teachers have good hearts then learners will be open because of the trust they have in their teachers."*

In summary, teachers in the case study school were aware that they needed to give better support to learners on ARV treatment, but recognized their own constraints. These included school structures as well as individual limitations such as lack of training and lack of knowledge about the policy and the scope of the phenomenon at school. These findings corroborated with those from the questionnaire implemented with a larger population of Life Skills teachers and teacher counsellors that I present in the next chapter.

CHAPTER 5 SCHOOL CONTEXTS AND LEARNERS ON ARV MEDICATION

5.1 Participating Teachers

Data generated for the teacher profile that follows below were derived from a questionnaire (Appendix A) distributed to 27 secondary schools in the Khomas Region.

I begin with a brief demographic profile that includes the designation, age, gender and years of teaching experience in general, and experience in teaching Life Skills and/or counselling in particular. I follow this with results on the nature, form, duration and institutions of training.

Participant Demographics

Table 1 below categorizes participants into those who are Life Skills teachers only versus those who identified themselves as Life Skills teachers as well as being a counsellor at their school.

Table 1: Sample of Participants

Participants	
Designation	**Number**
Life Skills teachers only	9
Life skills and counsellors	18
Total	27

Nine teachers identified as Life Skills teachers only while the majority are Life Skills teacher as well as a counsellor at the school. As will become clearer in the analysis later on, this distinction is important in this study because of its focus on experiences in mediation, treatment and care of the school-going HIV-positive youth.

Table 2 below indicates the gender and age of participants.

Table 2: Gender and Age of Participants

Gender	**Age**				
	Under 25	**26-35**	**36-45**	**46-55**	**Over 55**
Male			2	2	
Female		5	10	6	2
Total		5	12	8	2

Out of 27 participants in the study, 4 were males and 23 were females. As Table 2 indicates, the majority were 36 years or older.

When teachers were asked about their general teaching experience, it emerged that, 17 had more than 10 years of general teaching experience, as Table 3 below indicates.

Table 3: Years of General Teaching Experience

Years of General Teaching Experience	Numbers of Teachers
Below 5	2
6-10	8
11-15	10
16-20	3
More than 21	4

Table 4 below indicates the number of years' experience as Life Skills teachers and/or counsellors. The results show that more than half of this cohort has five years or less experience in their current positions.

Table 4: Years of Teaching Experience as Teacher and/or Counsellor

Years of experience in Life Skills Teaching and/or Counselling	Number of Teachers
0-5	16
6-10	8
More than 11	3

It therefore emerges that the general teaching experience amongst this cohort is longer than their experience as either Life Skills teachers or counsellors. This relative inexperience may have consequences for their manner of dealing with HIV-positive learners in general and those on ARV treatment in particular.

The next section highlights the nature, form, duration and institutions of training reported by participants. It distinguishes between those who are Life Skills teachers only and those who are Life Skills with counselling, for the purposes of discussing the training.

5.2 Nature, Duration, and Institutions of Training

Thirteen of the 27 teachers did not receive any training either at the pre- or in-service levels as Tables 5a, and 6a below reveals. Tables 5b and 6b indicate the nature, duration and institution where training was obtained. Table 5a below indicates that seven of the nine teachers who only teach Life Skills, were not trained. One was trained during pre-service for one year. This teacher

received additional in-service training for a week. The second teacher obtained in-service training for four weeks only as Table 5b indicates.

Table 5a: Training Levels of Life Skills Teachers only

Training Levels	Number
In-service	1
Pre-service	1
Untrained	7
TOTAL	9

Training at the pre-service level included basic information on HIV/AIDS, counselling, bereavement and working with HIV-positive people. Interestingly, the teacher who had this training reported not to be doing any counselling even though she was trained for this purpose. On the other hand, training by the MoE focused on the role of the Life Skills teacher and sexuality education, with no training in counselling, even when the teacher in question assumed that role in school.

Table 5b: Duration, Institution and Content of Training for Life Skills Teachers

Teachers	Institution	Year of training	Duration	Content
Pre- and in-service	a. MoE b. UNAM	2010 & 2006	a.1 week b.1 year	a. Basic counselling, bereavement b. Basic counselling, bereavement, working with HIV patients
In-service	MoE	2008	4 weeks	Sexual reproductive health, characteristics of a Life Skills teacher, behaviour change

Table 6a below presents results from a group of Life Skills teachers who are also counsellors. Six amongst this cohort have not received any training for their current positions, while four had pre-service training. The rest attended in-service training organized by the MoE.

Table 6a: Life Skills and Counsellor Training

Training Levels	Number
Pre-service	4
In-service	8
Untrained	6
TOTAL	18

While 18 teachers reported to be working as Life Skills teacher and counsellor

, only 12 were trained. Table 6b below indicates the nature, duration, and content of those who were trained.

Table 6b: Duration, Institution and Content of Life Skills with Counsellor Training

Category of Teacher	No. of Teachers	Institution	Years of Training	Duration	Content
LifeSkills & Counselling	4	MoE	2008, 2009	3 weeks	Basic counselling, first aid, HIV/AIDS, suicide, different policies, bereavement
		MoE	2011	4 weeks	Sexual reproduction, HIV/AIDS
		MoE	2009-2012	3 weeks	General Life issues, HIV/AIDS, basic counselling
		Stellenbosch University	2009, 2010	2 years	Curriculum of business and life skills, managing a classroom, research, curriculum development, basic counselling, counselling practice, learning support, psychometric assessment, career guidance
Life Skills only	1	MoE	2007, 2010 2011	4 weeks	Syllabus, subject related training
Counsellor only	7	UNAM	2007	1 year	Basic counselling, fear of dying, HIV/AIDS
		UNAM	2010	1 year	Fundamental counselling, HIV/AIDS, death, bereavement
		UNAM	2010	1 year	Counselling, counselling support, bereavement, HIV/AIDS
		MoE	2010	1 week	Basic counselling, bereavement
		Life Line Namibia	2009	1 year	HIV/AIDS, gender issues, loss, fundamental counselling
		Life Line Namibia	2010	6 months	Basic counselling, HIV/AIDS, emotional behaviour
		Phillip Trust Namibia	2008	2 years	Fundamental of counselling, bereavement, HIV/AIDS counselling, self development and growth
Total	**12**				

Seven teachers trained as counsellors only, while four trained as Life Skills teacher and counsellor. Training by the latter group was of short duration, while counsellor only training lasted between six months and two years, with four of the 7 counsellors receiving training for a year. Training by institutions was part of initial or post graduate studies rather than in-service training. For the most part, training focused on the fundamentals of counselling with little or no focus on HIV and AIDS.

5.3 Training, HIV and ARV Medication

Still focusing on the question of training, only five of the 27 teachers indicated to have received training on how to work with HIV-positive learners. Importantly for this study, none obtained training to work with children on ARV treatment or to handle this type of medication in school.

5.4 Awareness of HIV-positive Learners and Policies

Twenty of the 27 teachers were aware of HIV-positive learners on ARV treatment at their respective schools. Participants who were aware of the phenomenon indicated the number of learners on ARVs at their schools, shown in Table 7 below.

Table 7: Number of Teachers and Number of Learners on ARVs

No. of Learners on ARV	No. of Participants
0-5	19
6-10	8
11-15	0

The majority indicated five or less learners on ARV treatment at the school.

Fifteen of the 20 participants who were aware of learners taking ARVs at their schools found out from learners themselves, while two found out from parents and two from learners' peers.

Only one participant indicated the availability of an HIV and AIDS policy at her school and none of the participants had any knowledge about ARV medication policy at their schools. All the participants indicated that they did not have policies on managing learners on ARVs at school.

CHAPTER 6 DISCUSSION AND ANALYSIS

6.1 Introduction

In the previous two chapters (Chapters 4 and 5), I presented the data generated from the teacher and student respondents. I gathered data as follows: through individual interviews with eight learners in the school who were not only HIV-positive, but also on ARV treatment; through focus group interviews with eight teachers in the case school; and through a questionnaire distributed to 29 Life Skills teachers in the region and returned by 27 teachers.. Data gathering also included observations of the eight participant learners in their school setting as well as document analysis of policies, class attendance registers and school recreation activities.

In this chapter, I make sense of the data and interpret them in terms of the main research questions. In so doing I make use of the theoretical and conceptual tools described in Chapter 2.

I summarize the main findings below and thereafter elaborate on each theme.

6.2 Summary of Main Findings

The discussion of my research data is framed by the following main findings emerging from the study:

Stigma, Context, Medication-taking, and Sexuality Discourses

- A typical pattern was secrecy and lengthy delay in disclosure of the child's HIV and AIDS status by adults who were aware of it.
- Of the eight participants, five had their status disclosed by professional medical staff on a medical visit for other reasons; three had their status disclosed by relatives or friends.
- When relatives or friends disclosed the HIV status to the child, it was done in a vicious and deliberately painful manner.
- Moments of shock, pain, betrayal and fear of death characterized the feelings of all participant learners when they heard about their HIV-positive status for the first time.
- Fear, delay, denial and lack of trust characterize the feelings of all the children in disclosing their status to almost anyone.

- Disclosure to a girlfriend or boyfriend resulted in 'disastrous' outcomes for the children.
- Of eight children in the sample, only three received family support after disclosure.
- People take medication with the purpose of getting better or staying healthy. The findings reveal that all participating learners opt not to adhere to the consistency of taking ARVs at some point, because they did not want to give signals of being HIV-positive or be reminded by people about their status.
- All the learner respondents revealed that ARV treatment exposed them to stigma of some form or another, as I elaborate later on.
- The findings reveal that ARV medication-taking and individual identity linked in complex ways to produce particular experiences amongst the cohort of learners. The associated HIV status created another layer of complexity since it is embedded in sex, sexuality, shame, and blame discourses.
- The findings revealed that ARV medication-taking brought fear of death on the part of participant learners, with the experience a constant reminder of their proximity to death.
- All participant learners pointed out that the most critical issue for them when they are taking ARV medication at school is privacy.

Trust, Confidentiality, and Support

- The need for support to deal with emotional, psychological trauma, fear of death and stigmatization around HIV illness was a compelling feature in the results amongst all learners.
- To varying degrees, schools, churches, psychologists, social workers and teacher counsellors have been professionally active in the lives of most of the participants.

Coping Mechanisms, Resilience, and Agency

- All participants developed coping mechanisms to protect themselves and try to cope despite challenges facing them.
- Most participant learners experienced extreme despair; but over time and with support they resolved this, accepted their condition and their circumstances, drew strength from their inner resources, and developed their own realistic goals.

School Responses

- Absence of ARV-related components in the national and internal school policies made it difficult for schools to manage and support learners on ARVs. All teacher participants indicated the need to include ARV management and support in the policies.
- All teachers suggested that training is a necessity to help them to deal with challenges facing learners on ARV treatment in school.

6.3 Discussion of Findings

The findings reveal that schools face educational and social challenges as a result of an increase in the number of learners taking ARVs; a reality many schools have yet to confront. Learners are infected either from maternal transmission, sexual abuse or through intimate sexual relationships. Their journeys, as the data reveals, depict shifts from moments of deep despair to a state of resilience that was only possible through complex interaction between social support and learner agency.

The themes outlined in the summary are explored in more detail below.

6.3.1 Stigma, Context, and Medication-taking, and Sexuality Discourses

The findings reveal that stigma severely affected participant learners in this study. Among the varied approaches to understanding stigma, it has been conceptualised as a combination of interrelated components, such that it occurs when differences are labelled andlinked to negative stereotypes, and people are categorized as separate, so that discrimination results (Link & Phelan, 2001; Parker & Aggleton, 2003).

Goffman's (1963) distinction between two levels of stigma (felt and enacted), combined with Deacon's theory of stigma (instrumental, symbolic and resource) were useful for understanding and analysing learner experiences in this study. Felt stigma (Goffman, 1963) is the feelings that individuals harbour about their condition and the likely reactions of others. Felt stigma happens inside the heads and imaginations of the individual. Goffman (1963) describes enacted stigma as the actual experiences and outcomes of stigmatization.

Deacon's (2006) explanation of instrumental and symbolic stigma provided a framework for understanding the roots of stigma that leads to 'felt' stigma, which she refers to as instrumental and symbolic stigma. Resource-related stigma (Deacon, 2006) is an example of Goffman's concept of enacted stigma, whereby people are discriminated against or stigmatized because of particular positions they hold in society. Interestingly, though, I found that one cannot separate the two forms or the three types of stigma, since felt stigma itself results in enactments and vice versa. Instrumental, symbolic or resource stigma can be the cause or effect of stigma; a reciprocity that is underplayed and not always acknowledged in current literature.

Deacon (2006) also calls for a distinction between stigma and discrimination for analytic purposes so that their interrelationship may be examined. To her, discrimination caused by stigma is "only one element of stigma-related disadvantage" (Deacon 2006:418).

Deacon argues that there is a difference between stigma and discrimination. She calls for analyses that examine both psychological and social dimensions of the stigmatizing process, without conflating stigma with discrimination. Deacon (2006) explains that separating stigma from discrimination is important in that while the result of the former may be blame, shame and status loss for the stigmatized person or group, the effects do not necessarily always lead to discrimination having a negative effect.

Stigma is dynamic and occurs to varying degrees across a range of experiences, with consequences more pronounced at particular moments. In other words, while stigma was always present in learner experiences reported in this study, the way they responded changed as they gained control of their circumstances and better understood their role in creating a future for themselves.

While I analyse the type, form, and outcomes/consequences of stigma below, I also show through a discussion of resilience and agency that as learners gained control of their lives, the impact of stigma and discrimination on their sense of self was lessened. Even though the effects of stigma remained hurtful, and were expressed in various discriminatory practices, learners exhibited control over their lives and acknowledged that the impact of stigma and

discriminationwas no longer as debilitating for them as when they had first confronted their HIV status.

Types of Stigma, Discrimination, Status Disclosure, and Self-Worth

Felt stigma manifested in how learners understood themselves, particularly soon after disclosure. Learners harboured beliefs and perspectives of themselves and of how others perceived them because of their HIV status and medication-taking. Negative beliefs and perspectives of the 'self' led to low self-worth and feelings of hopelessness. In some cases, beliefs of worthlessness led to suicide attempts amongst learners. Thus, low self-esteem, low self-worth and even ideas about death as an escape resulted from what Goffman (1963) describes as 'felt' stigma, which itself led to fear and secrecy. The effect was learners isolating themselves for fear of being 'caught out' or 'called out'. Stigma was found to have complex elements of cause and effect, with learners caught in the double bind of fearing both the cause and the discriminatory consequences or effects. In the same way, relationships and interactions between individuals produced and reproduced experiences that offered little hope for a different way of being for learners. Learners feared the stigmatization, isolation and rejection that disclosure would bring but at the same time needed the support that would only come with disclosure.

Enactment occurred on two levels: firstly, experiences by the learners on ARVs and secondly, discriminatory responses to them. Thus at one level, learner-enacted stigma was expressed as experiences of isolation, rejection, character defamation, blame, and name-calling. At another level, the outcomes or discriminatory practices included learners not having friends, being chased away or displaced by family, getting little or no support from family, and (at school in particular), being told not to use the same toilet facilities, not to be touched or sat next to. All learners, irrespective of gender, reported similar experiences of felt and enacted stigma.

Instrumental and symbolic stigma manifested amongst those closest to learners; family members in particular. Partners and peers also responded negatively and wanted to have little to do with learners once they disclosed their status. Fear of being associated with an infected person had major consequences for this cohort of learners. Family members said that infected learners brought shame to the family, were the cause of their own infection (although all but one of the

learners had become infected in circumstances beyond their control). Responses by family members led to learners feeling worse about themselves.

In addition, family members feared the social stigma the family might suffer. In most instances, rather than supporting the infected learner, family members responded in ways that increased that learner's isolation and emotional trauma as well as their feelings and experiences of rejection.

Friends and fellow learners considered learners taking ARVs as shameful, and like family members feared infection and/or social stigma. Fearing secondary stigma, they also displayed instrumental stigma by distancing themselves.

Discrimination took the form of social isolation and displacement for most learners in this cohort.. Not only did they suffer emotionally from the trauma associated with mourning the loss of parents and/or siblings but were also traumatized by being removed from familiar environments where they lived with parents.

The implication here is that stigma can arise from different sources; family, fellow learners or even friends. In most cases, families placed the protection of family status above support for the infected member, in the present study. The results present a different picture from that depicted in current studies that highlight the importance of family support both in treatment and care of the ill and in creating conditions that promote and support resiliency. That body of literature highlights the importance of parents and (in the absence of parents) extended family members in caring for ill or vulnerable children. Few if any studies pay attention to three important factors: firstly, contexts where parents are absent or deceased; secondly, differences between family responses to general illness and their responses to illness associated with the HI-Virus; and thirdly, those effects of HIV infection that create social and individual stigma. Results in this study bring all three aspects to bear. The majority of learners suffered the death of parents, had little or no support from extended family, and were offered support by community members, often strangers.

An examination of the moral aspect of HIV and AIDS reveals symbolic stigma, as outlined by Deacon (2006). Learners in this study were judged and blamed for perceived immoral actions, with people (friends, teachers, and peers) questioning their morality and moral behaviour. Although most of these learners contracted the HI-Virus in circumstances beyond their control, people stigmatized and blamed them. Some studies highlight the distinctions arising from symbolic stigma. Fish & Rye (1991) and Crandall et al, (1997) found that people distinguish between what they call 'innocent victims' (for example, babies born with HIV) and those infected through so-called 'voluntary' sexual or other 'immoral' behaviours. In contrast, five of the eight learners in this study were born with the virus, yet suffered similar effects to those who contracted it from others.. The findings do indicate, however, that some people perceived some of the learners in this cohort (Neville, Benzao, Bertha and Salmi) as innocent victims, and others (such as Mercia and La-Toya) as so-called voluntary victims. While all experienced discrimination, treatment differed somewhat according to the nature of HIV contraction.

The findings reveal that symbolic stigma played out to produce different experiences for learners. Sometimes it served simply to distance individual learners from peers, friends and/or family members as a result of the fear of becoming infected. Yet in other instances, those uninfected positioned themselves as superior morally. In other words, symbolic stigma gave the uninfected a false sense of security, to protect themselves from fear and anxiety in this instance rather than from being infected.

Instrumental stigma, which arises from the perception that interacting with infected persons, poses a direct threat to one's own physical well-being, manifests in the results. It may well be an incorrect perception, as family member, friends and fellow learners of participants might know very well how HIV is transmitted and therefore be aware that one cannot become infected through casual contact, but even so refrained from showing affection (for example, hugging HIV-positive learners).

Resource-related stigma was evident in the way learners were restricted or monitored when they used facilities. They were refused the use of certain services such as toilet facilities, taps (for drinking) or soup utensils. Some eventually isolated themselves to avoid pain and rejection.

These learner reports were supported by the teacher responses derived from the focus group and also from the researcher's observations. In school settings, participants from the teacher focus group described specific instances of discrimination related to HIV and ARV stigma - behaviours from fellow learners that included unwanted looks from fellow learners, insulting questions, humiliating exchanges of words and refusal to share utensils or facilities.

Resource-related stigma also linked to lack of nutrition amongst learners. Learners singled out nutritional needs and lack of food as debilitating at a material level and in terms of their experience of school. Learners could not take ARV medication on an empty stomach. Lack of food sometimes meant that they did not adhere to the strict regime of taking ARV medication at the same time daily. Some report to defaulting due to lack of food and because of the side effects experienced if they took medication on an empty stomach. The findings reveal that lack of nutrition is embedded in poverty, which can lead to stigma. As Deacon (2006) suggests, poverty can fuel stigma, as poor people are perceived as highly stigmatized in their own right. The implication here is that if participants do not have food or do not have money to buy food at school, they feel shy to be with other learners who have food; yet another reason why learners isolated themselves.

These findings are supported by researchers such as Fitzgerald & Simon (2001) who found that in rural Haiti, being infected with HIV and AIDS and taking ARV treatment can result in ostracism, people blaming the victim for the disease, withholding of food, social isolation, and denial of human dignity. Liechty & Bangsberg (2003) found that HIV-infected children in resource-poor settings may face a significant degree of discrimination in being denied the use of certain services. Such results are evident in this study.

It is difficult to separate or distinguish between in- and out-of-school experiences of stigma in this study, given that it was learner status (as HIV-positive learners on ARV treatment) rather than the particular location (community or school) that had consequences for their experiences. Even though this was the case, the impact of isolation and discrimination by peers during adolescence, which was concentrated in the in-school experience, cannot be underestimated.

The results reveal that different forms of stigma had different outcomes, thus particular discriminatory practices. These included amongst others: verbal and physical abuse; social exclusion at home and at school; loss of identity, rights and status; and loss of access to school resources. The majority of participant learners, if not all, indicated that verbal abuse exceeded other forms of discrimination, leading to self-isolation or social exclusion in school, in the family or community. Learners experienced gossip, rumours, labelling and 'shaming and blaming', insult, curses, and scolding; and people openly discussing punitive measures for learners living with HIV and taking ARV medication. The outcome was that learners believed themselves to be worthless and thus isolated themselves.

These findings concur with Gilborn, Nyonyintono, Kabumbuli & Jagwe-Wadda (2001:33) when they argue "in many countries, stigma has led to teasing by classmates of HIV-positive school children or children associated with HIV."

The findings reveal that age plays a protective role or provides coping mechanisms in dealing with the stress of HIV and ARV medication-taking, as older learners tended to deal better with stigma and discrimination than younger learners did. However, discourses around HIV, which involves sexual activities, disadvantage these mature or adolescent learners as they are thereby associated with sex and immorality (Campbell, Foulis, Maimane, & Sibiya, 2005). That study suggests that stigma or gossip around HIV is used by others as a way of socially policing and punishing transgressive adolescent sexuality. People make the assumption that adolescents or mature learners contracted HIV through sexual activities. Similarly, Ogden & Nyblade (2005) agree with Campbell et al. when they suggest that younger children who have contracted HIV through birth or blood transfusion might not be blamed for having the disease, while adolescents on the other hand might be blamed for engaging in sexual intercourse and thus bringing the disease upon themselves through immoral actions. That study also found that boys were less discriminated against than girls and did not suffer the same kinds of stigma and discrimination as girls.

Deacon (2006) and Goffman (1963) suggest that stigma can also be self-imposed and thus internalized. Self-stigmatization is the shame that learners living with HIV and AIDS and taking

ARVs experience when they internalize the negative responses and reactions of others. In this study, self-stigmatization led to depression, withdrawal and low self-worth, with learners blaming themselves for their condition. These findings go along with Banteyerga, Miz-Hasab, Nyblade, MacQuarrie & Pande (2004) who suggest that HIV-positive people experience internal stigma as they accept and internalize society's stigmatizing attitudes toward them by believing that they deserve the bad treatment they get from others.

Deacon (2006) suggests that health-related stigma can be associated with other features of a person's identity such as ethnicity, sexual preference, or socioeconomic status, which can result in limited access to health services. She highlights that the consequence for marginalized or vulnerable groups is discrimination and prejudice, which in turn has consequences for their health and well-being. The findings in this study concur with Deacon in revealing that stigma sometimes could lead to discrimination.

The findings revealed that stigma was a persistent concern to all the participants. All participant learners on ARVs reported feelings and experiences of various forms of stigma at home and at school, which affected their schooling in many negative ways. Participants expressed their frustration on how to deal with stigma at school, which sometimes led to them staying away from school. Some failed and had to repeat the same grade, while others dropped out of school.

The study also found that stigmatizing and discriminatory environments had different effects on different learners taking ARVs, depending on their levels of maturity, emotional trauma and helplessness (or hopefulness) and indicating the link between agency and resilience described later on. Learner experiences were not universally negative. Accepting their diagnosis was a major step in learners shifting from deep hopelessness towards hope and resilient dispositions and behaviour. Those who did, developed voice and were better able to exercise agency, speaking out and becoming stronger advocates for themselves and others in similar circumstances. Agency and resilient dispositions, though, always emanated from conditions where learners received affirmation and support. In this case study for the most part support came from community (neighbours, church, HIV support groups) rather than family support, a

finding that contrasts with findings in current literature on the role of family in developing resiliency.

HIV, Medication-Taking, Sex and Sexuality

Shoemaker & de Oliveira (2007) assert that taking medication is a normalized practice in many societies and in most cases, health practitioners, family members, friends or community members encourage patients to take medication with the hope that they will feel better or be cured. They also suggest that medication experiences differ and depend on the type of medication and its purpose, as well as the type of disease. The findings show that learners in this study were no different from patients generally in their reliance on medication to prevent hospitalization and improve their quality of life. The differences lay in the attendant meanings, experiences and feelings associated with ARV medication-taking.

The findings reveal that ARV medication-taking is different from taking other medication because it raises questions about the individual's identity and sexual practices and because it is embedded is discourses of sex and sexuality, and thus linked with immorality, shame, taboo and silence. For these reasons, participant learners taking ARVs kept medication-taking personal and secretive. The consequences of this were three-fold for learners in this study.

Firstly, fear of disclosure of HIV status overlaid with secrecy in taking ARV medication carried health risks, in that learners opted not to adhere consistently to taking ARVs because of the attendant consequences of stigma, isolation and rejection.

Secondly, fear of the social consequences of isolation, labelling, and rejection inhibited possibilities for learners not only to disclose their status, but also to establish and sustain help-seeking behaviour.

Thirdly, learners experienced deep emotional trauma resulting from the nature of disclosure to loved ones and the subsequent behaviour of loved ones. Not only did this influence when they commenced with medication, but also how they understood and responded to their condition and to others.

Context and Medication-taking

The physical and discursive context posed challenges for this cohort of learners. Stark in this analysis is the complex interplay between space, context, and stigma. The physical context of schools and classrooms posed a serious challenge, which resulted in secrecy and change in health behaviour that had implications for learners' health and emotional wellbeing.

There are serious medical implications to not taking ARVs at the prescribed times. When learners on ARVs start to skip or ignore taking their medication at the prescribed time, this easily develops into full-scale non-adherence to a principled ARV medication regimen. As a result, some learners ended up being seriously sick and hospitalized. In extreme cases, it led to school dropout.

Lack of privacy at school placed learners on ARVs in the uncomfortable position of choosing to be alive by taking ARVs or choosing to be at school but not to adhere to the rules of taking ARV medication at specific times every day as required. Analysis of the daily class registers revealed that such circumstances forced some learners to be absent for long periods of time, with some opting to drop out for a year or two before being encouraged by a supportive friend, counsellor or family member to return. During the interviews, the majority of learners requested for the intervention of a special room or facility at school where they could take medication freely without fear of teasing or other discrimination.

Absenteeism and drop-out amongst this cohort of learners also resulted from HIV-related illness, lack of parental reinforcement to attend school, trauma related to HIV status disclosure and side effects of ARVs.

A consequence of absenteeism or patterns of drop-out and return was that learners were older relative to the grade average. Some remained absent for long periods of time due to illness, while others stayed away because of stigma and discrimination. The fact that some HIV-positive children progress slowly in school and are older than other children in the class may thus be due

in part to them frequently being unwell, or having to attend clinics for treatment purposes, so that they have difficulty in keeping up with schoolwork (UNESCO 2009).

Non-disclosure resulted in some teachers being unaware of learners' condition and thus perceived by learners to be insensitive to their physical and emotional needs. The findings revealed that some teachers refused to allow learners to leave the room for various reasons (e.g. to take medication), while the lesson was in progress.

The health side effects of ARV medication created yet another challenge in that some learners developed visible manifestations that included itches, sores, runny stomachs, vomiting and/or dizziness,. Learners suffered individual and social discomfort as a result. First, constant physical discomfort had a detrimental effect on learner school attendance as well as participation and concentration in class. Second, jeering, insensitivity of peers and teachers, isolation, rejection, and lack of support resulted. While such experiences do persist, learners (interestingly) described these mostly in the past tense and acknowledged how they had developed coping mechanisms, acceptance and agency to act differently. Thus, in the face of continuing stigma (and its effects) and fear of death, this cohort exercised agency not only to develop a different self, but also to change contextual realities - contradicting the expected.

Lack of clear school policy guidelines (concerned with disclosure, privacy, and support) also posed a challenge to the school experiences of this group of learners. One the one hand, learners had the right not to disclose, yet on the other hand, non-disclosure minimized the possibility of help-seeking behaviour and obtaining support. Tension caused by this became clear in results from both learners and teachers.

6.3.2 Trust, Confidentiality and Support

The findings revealed that some participant learners on ARVs did not want to disclose their status to teachers or school management because they lacked trust in teacher behaviour and capacity to maintain confidentiality. The implication here is that learners who did not disclose their status at school were potentially unable to seek help and support from teachers or school management. More serious was that teachers responded insensitively when dealing with HIV-

related material or when learners requested to be excused from class when they needed to take medication. Learners also reported staying absent because of the effects of the medication (dizziness, nausea, fatigue); they said teachers did not understand these side effects or empathize with learners' experience.

The findings indicated that communities play a special role by providing supportive structures like health services, support groups, and religious groups. For the most part, schools had not yet actively engaged with the form and level of support needed by HIV-positive learners on ARV treatment. This was evident in teacher and learner interviews. In the case study school, support for learners came mostly from the teacher-counsellor. It was ad hoc, unsystematic and only upon request from learners. Such an approach to learner support reflects inconsistency in the nature and level of support from schools and compromises learners' school experiences, especially in the face of their fear of seeking help and support openly.

In this study, some peers responded positively and provided some participant learners with vital support in times of difficulty at school. Significant in this finding, is that such support came mostly from other HIV-positive learners, who understood and could empathize. Thus, learners exercised agency in seeking support from informal rather than formalised structures in school. While important, they were insufficient to assist learners to deal with the pervasive stigma and discrimination. A study by UNICEF et al. (2007) found that informal support from peers and teachers does help learners to recover from their distress at home and to regain a sense of normality; but I argue that this is an insufficient response to learners' needs in terms of their overall school experience.

School is the place where learners spend most of their time. As such, it ought to provide not only knowledge, but also a sense of belongingness for ll learners, including those on ARV treatment. Irrespective of the nature or severity of the problem, most schools referred learners who needed support to the Life Skills teacher or teacher-counsellor, with few mechanisms involved. Thus, this is where the principal and other teachers referred children with problems or issues concerning ARVs. The study revealed that some schools involved non-governmental organizations that help in paying school fees and buying stationery for learners on ARV

treatment. This, however, was ad hoc, and was not formalized either in the case study school or in the larger sample of schools.

It is recognized that schools play an important role in providing protection and support for children affected by HIV and AIDS (UNICEF et al, 2007). For example, education in literacy, numeracy, vocational skills and other life skills can equip children to cope better with their future lives (Carr-Hill, Katabaro, Katahoire, & Oulai, 2002). Schools might also be an important entry point for children to receive social welfare and health services and food. This is difficult to sustain in the absence of formalized policies and structures that create environments to support learners, while at the same time attempting to reduce stigma and discriminatory practices in school (Coombe, 2004). Learners in this sample did not experience school as a safe and inclusive space and thus made decisions and choices that adversely affected their school experiences, their futures, and also their health and wellbeing.

Teachers in the study expressed a sense of being overwhelmed by the needs of learners on ARV treatment since on the one hand, they did not feel equipped to deal with these needs, and on the other hand, felt that the situation of these learners animated their own vulnerability. Many had HIV- positive family members themselves or had experienced death resulting from the pandemic, and therefore felt that dealing with HIV-positive learners on ARV treatment was simply too much to handle. Especially, teachers articulated a great concern about their ability and training to deal with the emotional and psychosocial needs of learners on ARV medication. Then also, ome teachers had lost someone in their immediate family, so that facing the epidemic's effects on their learners also meant attending to their own situations. This finding raises questions on the current conditions in schools and the role of teachers in helping learners when the former might not be comfortable or might themselves be in need of help and support regarding HIV and ARV treatment. Little if any research pays attention to the psychological needs of teachers when helping learners on ARV treatment.

The tension here might relate to the need for training in how to deal with learners or it might be that teachers also need counselling which will help them to deal with their own personal

problems while at the same time equipping them to support HIV-positive learners on ARV medication.

In addition, UNESCO (2009) draws attention to the necessary consistency of the medication regime: a potentially difficult responsibility for a child. Teachers have to support the process tacitly, without drawing attention to it, if they are aware that the child is on a daily regime of medication. This also implies the need for sensitivity to the associated needs of the child, and assurance of confidentiality and support. However, conditions in many affected education systems suggest that many teachers may not have the capacity, skills, time or personal inclination to assume this role as part of their classroom responsibilities (UNESCO 2009), a finding that this study confirms.

6.3.3 Coping Mechanisms, Resilience, and Agency

I have already indicated that stigma operates as a continuum and that it is dynamic. In the main, learner participants had challenging experiences in and out of school that (initially) negatively affected their sense of self and changed how they perceived and positioned themselves. Instructive in these narratives, though, is the extent to which all learners told stories that had a consistent pattern of shifts from disbelief, deep despair, anger, and pain, to eventual acceptance. While many still displayed evidence of the continued pain and suffering caused by stigma, discrimination and recollection of significant events, all decided to create a different life trajectory. The decision to change led to learners developing voice, seeking and receiving help and support and developing coping mechanisms that support resilient behaviours.

When individuals possess traits that damage their identity permanently and prevent their full participation in society, they carry a stigma (Goffman, 1963). Because stigma always carries negative connotations, stigmatized individuals develop coping strategies to protect themselves when dealing with ‘normal’ people. They also attempt to normalize situations by developing coping mechanisms. Sometimes individuals may be able to disguise the impact of stigma but may not be able to if they have physical manifestations that might cause stigma. One coping strategy may be withdrawal by limiting one’s participation in society. Another consists of creating a social structure to fight the negative stigma.

Learners in the study not only confronted stigma from being HIV-positive or on ARV medication, but also because of the physical manifestations of their illness (rashes, sores, and other illnesses associated with HIV-positive people). Initial coping strategies included withdrawal and isolation. The implication of this is that learners internalized their problems most of the time and became depressed, which led to withdrawal from class activities or participation in school. I observed learners sitting on their own during interval. Analysis of the recreational books also revealed that participating learners withdrew from sports activities.

With time, learners developed support structures or sought help from individuals. The latter though, always occurred after initial intervention by a significant other (most often a community member and seldom a family member). The results reveal that for the most part, developing coping strategies, agency, and resiliency after a traumatic event such as disclosure of HIV status requires initial intervention and support from a significant other, not necessarily always a family member.

Participant learners in this study were all vulnerable at one point or another because the majority had lost one or both parents or been taken away/chased/involuntarily removed from familiar environments. Their material conditions (e.g. displacement, poor nutrition) exacerbated their vulnerability; sometimes with life-threatening consequences. This though became the condition through which learners developed voice and resilience. Luthar, Cicchetti & Becker (2000:543) define the development of resilience as a dynamic process encompassing positive adaptation within the context of a significant adversity. They contend that there are two critical notions associated with resilience: firstly, individuals need to be exposed to a significant threat or severe adversity to demonstrate resilience and secondly, resilience is the achievement of positive adaptation despite major assaults on the developmental process.

My findings revealed that learners in this study showed remarkable capacity as individuals that helped them withstand considerable hardship at home and school. Despite deep suffering and pain that was still very palpable in interviews, learners were able to pull themselves together and

bounce back in the face of adversity, and go on to have functional lives with a sense of well-being.

Resilience research is about identifying the strengths of individuals and communities in order to replicate what is working in the lives of those who cope successfully, helping others who are equally vulnerable to change the odds stacked against them (Liebenberg & Ungar, 2009; Goldstein & Brooks, 2005).

I tend to agree with Liebenberg et al, (2009) because my findings reveal how some learners cope with life in general and with their schooling. The findings also reveal that some participant learners have become very strong in the process, being able to withstand negative comment, exercise agency by standing up for themselves and (even now) help other learners who have had experiences similar to their own.

While recognising that resilience, like stigma and vulnerability, occurs in a continuum, one can assert that all learners showed evidence of resilience; with some better able to cope than others. This condition of resilience was always accompanied by learners' ability to understand and make meaning of their own experiences and emotions, as well as their ability to express these in words or in actions. While many cried in recalling significant events in their lives, all had developed a way of bracketing negative experiences so that they could get on with their lives.

The findings reveal that most of the participant learners drew strength from their inner resources. This, however, did not occur in isolation from the initial and continued support from sources external to the individual. Put differently, resiliency and agency was noticeable in circumstances where learners felt supported, accepted and encouraged. Many described that they developed positive behaviour and refused to give up on life despite stigma and discrimination. They developed strong coping mechanisms by having friends with the same status at school or through joining support groups. All but one displayed self-confidence and had developed realistic goals for their lives, which in this study was a manifestation of resilient dispositions and behaviour. Many were not only hopeful but also excited about their future.

Early studies tended to focus on individual traits presumed to communicate 'toughness', giving rise to such conceptions as the 'invulnerable child'- a youth considered impervious to stress due to inner fortitude or to such characteristics as high creativity and competence (Anthony, 1987). Studies that are more recent acknowledge the complex interplay between internal/external forces (or between structure and agency) (Raveis, Selwyn, & Frederickson, 2008; Layne et al., 2007). Raveis et al, (2008) studied resilience among young and older minority patients with advanced HIV disease. They suggest that there is some evidence that youth living with the HI-Virus exhibit resilience in their ability to adapt to their condition over time, enhancing their quality of life and achieving a level of success in their lives. . They found in particular that the majority of mature youths felt good about themselves, emphasized the importance of being at peace with themselves, found meaning in their life, and shared their feelings with family.

Interesting in the results of the present study was how learners moved from dependency to some level of independence and from over-reliance on external support to acknowledging their own agency in changing their circumstances in and out of school. They recognized the inner strength they possessed – strength that helped them to create conditions, which would in turn support them and build their capacity and skills for dealing with HIV and AIDS. Some learners gained more knowledge on how the virus works, while others developed inclusive support networks to help themselves and others in similar circumstances.

6.3.4 School Responses

The findings reveal that schools face educational and social challenges due to an increase in the number of learners taking ARVs. Learners on ARV treatment need support from schools, fellow learners, and teachers to deal with emotional stress and psychological trauma related to their HIV status, as well as support with ARV medication-taking. The case study school, as well as responses from the teacher counsellors and Life Skills teachers in the region, showed that schools were neither prepared nor perceived as places where learners obtained support. The school system did not always guarantee support for learners in that they did not have policies in place in this regard.

Learners needed emotional, psychological, material and nutritional support, which was sometimes available when they disclosed their status to teacher counsellors or Life Skills teachers. Responses were ad hoc rather than systemic and depended on individual teachers rather than stemming also from policy and a collective effort at the regional and school levels.

Learners also needed support in the form of structures, such as a room in which to take medication.

Kirp & Bayer (1992) as well as Manuel, Enel, Charrel, Reviron, Larher, Thirion & Sanmarco (1990) agree that HIV and AIDS-related stigma and discrimination in society is commonly manifested in the form of laws, policies, and administrative procedures, which are often justified as necessary to protect the 'general population'. From the documents analysed in this study, it emerged that guidelines on implementing support for learners on ARVs are absent in the HIV national policy. All participant teachers from the focus group and questionnaire indicated the absence of policies or guidelines on how to deal with learners on ARVs at schools. In fact, they acknowledged that there are no policies or guidelines at national or at school level. While many teachers who responded to the survey were aware of the National HIV Policy of the Education Sector, they acknowledged not having policies at the school level. Where policies existed, they were silent on treatment, support and care for HIV-positive learners in general and those on ARV treatment in particular.

The majority of secondary schools in Khomas Region did not have a copy of the HIV national policy at school either. Where available, national policies or guidelines for dealing with HIV-positive people were found to be broad – that is, non-specific to the school environment. The majority of schools had not realized the goal of developing internal policies. The absence of policies at schools made it difficult for schools and teachers to protect and support HIV-positive learners; let alone those taking ARV medication.

The implication here is that, teachers and school management might easily react or do things wrongly given the lack of policies and guidelines at school. Some of them might even choose to ignore these learners because of lack of know-how on dealing with them. The study revealed that

there is a need for schools to develop internal policies and guidelines for dealing with stigma and discrimination of learners on ARVs, and for support of these learners However, the findings revealed that even where supportive HIV policy or guidelines existed in the country, it was not always enforced in schools. Having the necessary national and internal policies available and in use shows that the school protects the legal rights of learners on ARVs and supports, them by enforcing the existing legislation where necessary. Failure to have these structural measures in place has been described as a form of discrimination by neglect by Daniel & Parker (1993) and Watney (2000).

The national HIV educational policy in Namibia, recommends the principle of confidentiality as essential to respecting learner rights. However, the findings revealed that some teachers did not apply this principle as they revealed learners, status without their consent. Furthermore, the findings revealed that there is still silence around HIV and lack of confidentiality is one of the contributing factors. Participant learners revealed that assurance of confidentiality at school would break the silence around HIV-related issues at school, and restore and build trust between teachers and learners. The findings revealed also that confidentiality would also boost the numbers of learners seeking support and HIV-related counselling at school.

Internal policy at the case school was silent on supporting and managing learners on ARV treatment. In fact, the internal guidelines did not even mention ARV medication (Appendix G). Life Skills teacher and counsellor responses also mentioned this omission.

It has emerged from the findings that teachers assumed it to be the responsibility of parents to inform teachers and the school about learner HIV status. Many of the learners in this study did not have parents, and where they did, parents opted not to inform teachers or schools about their children's status for fear this revelation might reflect and link to their own status as parents. Some feared that their children would become victim of stigma at school.

The implications here are that teachers and schools need to be informed about learner status so that they can respond sensitively to needs and incidents related to HIV and ARVs, a result supported by UNESCO (2009).

The Namibian government has mandated that each school employ at least one Life Skills teacher or a teacher-counsellor, to deal with learners' day-to-day challenges. Teachers are required to upgrade their skills and knowledge in order to provide quality Life Skills education. This implies that teachers should be trained continuously throughout their teaching career so that they can respond to the changing school environment, a claim supported by Graczewski, Knudson & Holtzman (2009).

The study revealed that school management and teachers in general require further training to help them improve their teaching and support of learners taking ARVs. Training would help teachers towards understanding how to deal effectively and sensitively with the emotional trauma and stress experienced by these learners at school. However, training needs to be extended beyond Life Skills teachers and teacher counsellors to include all teachers, school management, and learners, particularly in the area of reducing stigma. Some participants articulated that their circumstances were not their fault, a perspective that needs to emerge through strengthened awareness at school. Teachers in particular expressed a need for the school community to be better educated and trained on how to deal with HIV-positive learners, including those on ARV medication. While not every teacher may feel capable of performing the function of active support to learners, it would be important that every school has someone who is well informed about HIV and ARV medication, trained in how to approach HIV-positive learners on ARVs over sensitive matters, and motivated to help them find assistance as and when needed.

The next chapter concludes this study, and also recommends and discusses further research.

CHAPTER 7 CONCLUSIONS AND RECOMMENDATIONS

7.1 Conclusions

Only a handful of learners taking ARV medication are living openly with HIV and AIDS in Khomas Region secondary schools. Learners experience different forms of stigma, each with different consequences.

Stigma and discrimination continue to be prevalent in school settings. This affects the school experiences and wellbeing of HIV-positive learners on ARV treatment. HIV and AIDS and stigma are embedded in discourses of sex and sexuality, which leads to silence, denial, and fear as a result of the taboo associated with sex.

Stigma and discrimination thus promoted fear, which in turn led to the isolation and rejection of these learners. The consequences for their schooling were inconsistent school attendance, prolonged absenteeism, grade repetition, and dropout.

Teachers were uneasy, uncomfortable and often unable to handle learners on ARV treatment. This was partly the result of their lack of training or knowledge on how to deal with learners. However, dealing with these learners also animated teachers' own vulnerability as people infected and affected by the pandemic. As a result, they referred learners to Life Skills teachers or teacher-counsellors where possible.

The rate of disclosure of learners' HIV-positive status was low at high school, because there was low trust felt towards teachers, as well as fear of stigma. There is urgent need for training to skill teachers in handling sensitive topics in the classroom and in supporting learners who are taking ARV medication in school.

There is a pressing need for favourable school climates in which stigma and discrimination are no longer tolerated;however, creating such a climate is not an easy task. It requires interventions in the school community as well as mobilization and empowerment of learners on ARVs to resist

stigma and discrimination. Structural interventions are needed, too, such as school rules and internal policies that will protect and support the rights of learners on ARVs.

HIV and stigma can create conditions where all learners became vulnerable but they can and do bounce back, become flexible and begin to cope with the harsh conditions at school. Thus, individuals are not always determined by current circumstances; they have potential to become resilient and triumph over their circumstances.

It emerged from this study that even when laws exist to protect PLWH rights and confidentiality, only few individuals are willing to litigate or speak out if their rights are compromised. The findings revealed that participant learners could not take action against the discriminators or stigmatizers, as they feared that this would result in disclosure of their identity and HIV status. Similarly, because of widespread negative responses from the community, family and fellow learners,, participant learners chose not to reveal their HIV status, in order to avoid stigmatization and discrimination. The overall findings thus illustrate the complex interplay between cause and effect of stigma.

Furthermore, the findings indicate that all participant learners experienced similar stages in the journey from disclosure. They all went through deep pain, anger, blame (directed to themselves and others) and shame, and moved toward some level of acceptance. While they remained vulnerable, with support all eventually bounced back and returned to school. They found coping mechanisms to overcome the continuing harsh conditions at home and school. Acceptance and external support were key features on this journey towards agency and resilience.

The findings also revealed that efforts to tackle HIV and AIDS-related stigma and discrimination at school level have been constrained by the complexity and deep-rooted nature of the problem. More specifically, the inadequate school response reflects an absence of effective internal policies together with insufficient training to skill teachers who might develop guidelines for supporting and managing learners on ARVs. Teachers' discomfort around dealing with matters that involve HIV and ARVs was another challenge schools faced. Teachers are unwilling or

unable to talk about HIV or help in solving related issues, for personal reasons as well as their lack of training.

The findings revealed that most of the schools in Khomas Region have no internal school policies that clearly stipulate support and non-discrimination towards learners on ARVs.

7.2 Recommendations

The study made known some strong issues and challenges that shape the day-to-day life experiences and schooling of HIV-positive learners on ARVs. Much needs to be structured if schools are to actively respond and support HIV-positive learners on ARV treatment. Therefore, I recommend the following:

- Schools should design and develop internal guidelines or policies and procedures for action on HIV-related issues at school level. Many teachers and members of school management do not recognize the implications of classroom practices for the school experiences of learners on ARV treatment. Such policies should take account of both implicit and explicit stigmatising and discriminatory practices.
- Teachers need guidance on how to deal with and respond to cases concerning HIV-`positive learners on ARVs.
- The school should come up with strategies to actively combat stigmatization of HIV-positive learners on ARVs and develop codes of conduct and guidelines on confidentiality and non-discrimination that protect their rights and well-being.
- Schools should consider training teachers in counselling to support HIV-positive learners on medication. While specialized and advanced training might be limited to teacher counsellors and Life Skills teachers, minimum counselling should be made available to all teachers.
- Schools should develop well-organized strategic response systems such as referral networks, to ensure medical and other support for learners living with HIV and AIDS and on medication.
- School management and teachers should think about ways that can reduce or remove obstacles to continued education of infected learners on ARVs.

- Teachers should be trained in communication strategies to help them develop confidence with managing issues related to infected learners on ARVs.
- Schools need to provide support in the broadest sense by designing and implementing internal policiesfor handling ARV medication and supporting learners on ARVs. Such policies need to consider issues of confidentiality and privacy.
- Schools need to be aware that future guidelines for accommodating and supporting HIV disclosure and ARV medication-taking at school need to be flexible, so that relevant new information can be included with the ultimate goal of improving the lives of learners taking ARVs at schools.

7.3 Suggestions for Further Research

- Many studies in Namibia have mostly examined adults' HIV-related experiences. The school experiences of HIV-positive learners on ARVs are one of the many under-researched areas in Namibian schools, and indeed elsewhere in sub-Saharan Africa, where pandemic rates persist. Future research should include a larger sample, also a sample or samples that could consider experiences in relation to gender, the rural/urban divide, and younger learners.
- Resilience is an under-researched phenomenon amongst learners on ARV treatment. More research is needed to understand the conditions that create and sustain resilient behaviour. Such research should pay attention to agency of learners in the development and maintenance of resilient behaviours.
- Future research can examine the range of possible mechanism or ways that can be put in place to improve the schooling experiences of HIV-positive learners on ARVs..

7.4 Afterword

The whole process of research, from research design to the process of data collection and through to analysis of the data, has been an eye-opener for me. as it has given me the opportunity to learn how to conduct research. As a researcher, I at first experienced a sense of self-doubt and hesitation, in part because I was a colleague to participant teachers and a teacher to participant learners, thus known to all participants. Through interaction with the participant learners and teachers, I learned that there are many complex issues around HIV and ARVs. This study was

very sensitive and had emotional impact on myself as a teacher, a person, a mother to teenagers, and also as a counsellor. In the process, I was affected by the suffering and pain of the HIV-positive learners as they talked about the illness and, in most cases, the death of their parents and siblings. I was also affected by the experiences of rejection that they faced - from their families (especially mothers and sisters), fellow learners and even from their romantic partners. As a researcher, I found that their acceptance and resilience inspired me to want to help even more than I had done previously as a counsellor.

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APPENDICES

APPENDIX A: QUESTIONNAIRE FOR TEACHERS AND COUNSELLORS

QUESTIONNAIRE

Introduction

My name is Emilie Haipinge, a master's student from Rhodes University in South Africa, a Life Skills teacher and a teacher counsellor at one of the secondary school in Khomas region, Namibia. This questionnaire will gather information on school experiences of HIV-positive high school learners on ARV medication and how the school manages and supports these learners. The researcher is **NOT** interested in the incidents that resulted in learners becoming infected nor is she interested in their personal life outside school. The research focuses on the school experiences of HIV-positive high school learners on ARV treatment only. The researcher will make sure not to expose the names and identities of the learners and teachers in the study.

In Namibia, the HIV incidence rate is increasing among learners and the numbers of learners who are taking antiretroviral drugs has increased. This questionnaire has been developed specifically for counsellors to help the researcher to achieve her goal of finding out and understanding:

- **What are the school experiences of HIV positive learners on ARVs?**
- **What are the experiences of learners on ARV treatment?**
- **What are the school experiences of learners on ARVs?**
- **What are school responses to learners on ARVs?**

The information that you will provide will be used for my master's research only and will be kept ***confidential.*** *No names of schools, Life Skills teachers or counsellors will be mentioned.*

School	Teachers	Code
		Red
	Life skills teacher	Green
	Counsellor	Yellow

PART A

*Check **only one each time under each question**:*

A1. Gender

Male ☐ Female ☐

A2. Marital Status

Single ☐

Married ☐

Widowed ☐

Divorced ☐

Separated ☐

A3. Age

Under 25 ☐ 26 –35 ☐ 36 –45 ☐ 46 –55 ☐ Over 55 ☐

A4. Which grades do you teach *mostly*?

Grade 8 ☐ 9 ☐ 10 ☐ 11 ☐ 12 ☐

A5. How long have you been a *teacher*?

0-5 years ☐

6-10 years ☐

11-15 years ☐

16-20 years ☐

More than 21 years ☐

A6. Are you?

Life Skills teacher only ☐ Life Skills teacher and counselor ☐

A7. How long have you been in the position in 6?

0-5 years ☐

6-10 years ☐

More than 11 years ☐

A8. Have you been trained as a Life Skills teacher?

Yes ☐ No ☐

If ***YES***, please specify

When:

_____

By who:

_____

_____

Duration of Training:

_____

The Content of the Training:

_____

_____

_____

_____

A9. Have you been trained as a counsellor?

YES ☐ NO ☐

If ***YES***, please specify

When:

_____

By who:

_____

_____

Duration of Training:

_____

The Content of the Training:

_____

_____

_____

_____

10. Have you been trained to work with HIV positive learners or learners on ARVs?

Yes ☐ No ☐

If ***YES***, please specify

When:

_____

By who:

_____

_____

Duration of Training:

_____

The Content of the Training:

_____

_____

_____

_____

PART B

Please check only one

B1. Do you have HIV positive learners at your school that you are aware of?

Yes ☐ No ☐

B2. Do you know of any learners at the school who are on ARVs medication?

Yes ☐ No ☐

B3. How many learners are you aware of that are on ARV medication at your school?

0-5 ☐ 6-10 ☐ More than 11 ☐

B4. How did you find out about learners on ARV's?

From learners themselves ☐ parents ☐ school ☐

School board ☐ clinic ☐ friends ☐

PART C

C1. Do you have an HIV/AIDS policy?

Yes ☐ NO ☐

C2. Do you have a policy for handling ARV medication in schools?

Yes ☐ NO ☐

If ***YES,*** briefly describe it

.....

.....

.....

.....

If ***NO***, what kind of guidelines do you think will help you to manage or support these learners?

.....

.....

.....

.....

C3. Do you have a policy on managing HIV positive children in school?

Yes ☐ No ☐

If ***YES,*** briefly describe it

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.....

.....

.....

If ***NO***, what kind of guidelines do you think will help you to manage or support these learners?

.....

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.....

C4. Do you have a policy on managing children on ARV medication at your school?

Yes ☐ No ☐

If ***YES,*** briefly describe it

.....

.....

.....

.....

If ***NO***, what kind of guidelines do you think will help you to manage or support these learners?

.....

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PART D

D1. In your view, what are the most difficult challenges faced by HIV positive learners in or out of school?

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D2. In your view, what are the most difficult challenges faced by HIV positive learners on ARV medication in school?

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D3. What are the challenges you face in working with learners on ARV medication as a life skills teacher or teacher counsellor?

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D4. What kind of help do you provide to learners on ARVs as a Life Skills teacher or a teacher counsellor?

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D5. What kind of help does the school provide to learners on ARV medication?

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D6. In your view, what support should learners on ARV medication receive from schools?

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D7. Are there aspects not asked above that you would like to comment on regarding learners on ARV medication at schools?

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.....

Thank you for your time and help!

The information provided shall remain confidential.

APPENDIX B: CONSENT FORMS

Oral Informed Consent for Interviews

Title of study: **An investigation into the school experiences of HIV-positive high school learners on ARV treatment**

Principal Investigator: Emilie Haipinge

This interview is for a study that is being done by **Emilie Haipinge**.

This study will gather information on school experience of HIV-positive high school learners on ARVs and how the school manage and support these learners. The researcher is **not** interested in learners' sexual behaviours or how they get infected or contracted the disease. **Nor** is she interested in their personal life outside school. She will only discuss their experiences and will also make sure that she gains and maintains trust. The researcher will make sure that she will not expose the names and identities of the learners and teachers in the study given that learners may suffer increased stigma if they were to be identified as a result of the study.

The interview will include questions on teachers and learners towards learners living with HIV/AIDS. It will take most people about **45 minutes** to answer the questions.

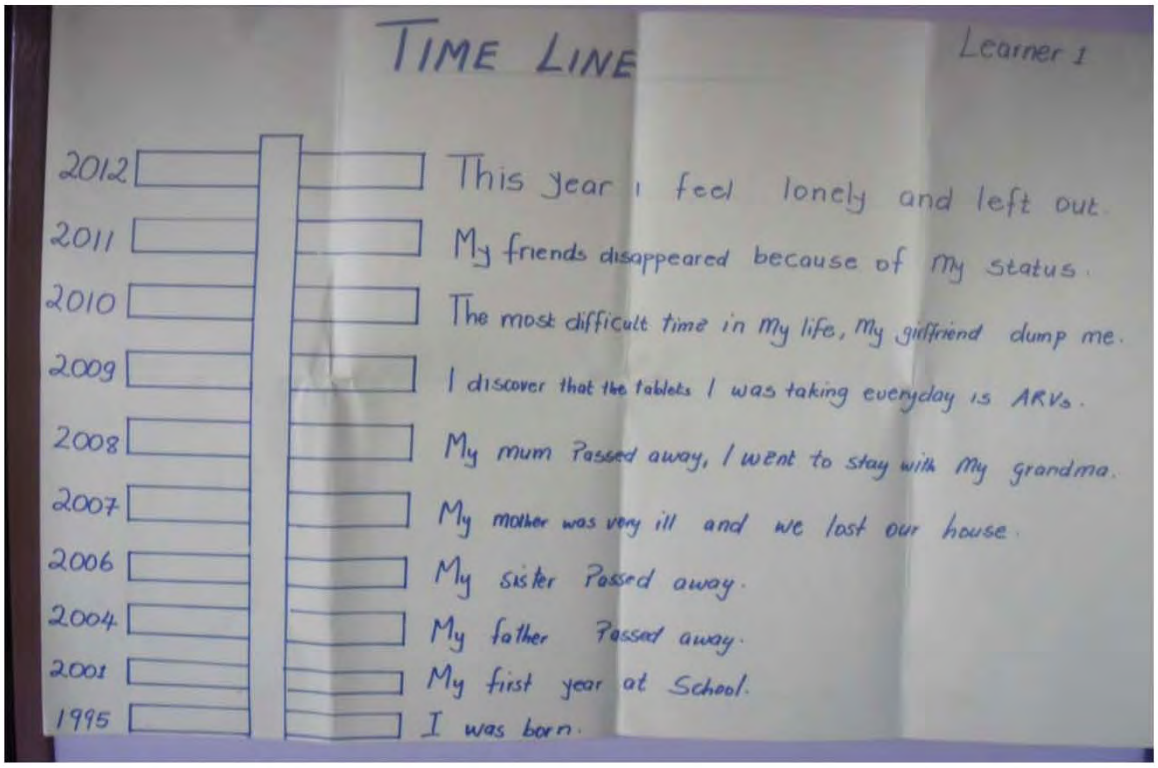
The names of people who agree to participate will not be recorded without their permission.
Your participation is voluntary and there is no penalty for refusing to take part. If you do not take part, it will not affect you in any certain way. You may refuse to answer any question in the interview or stop the interview at any time. The information gathered will be kept **confidential**.

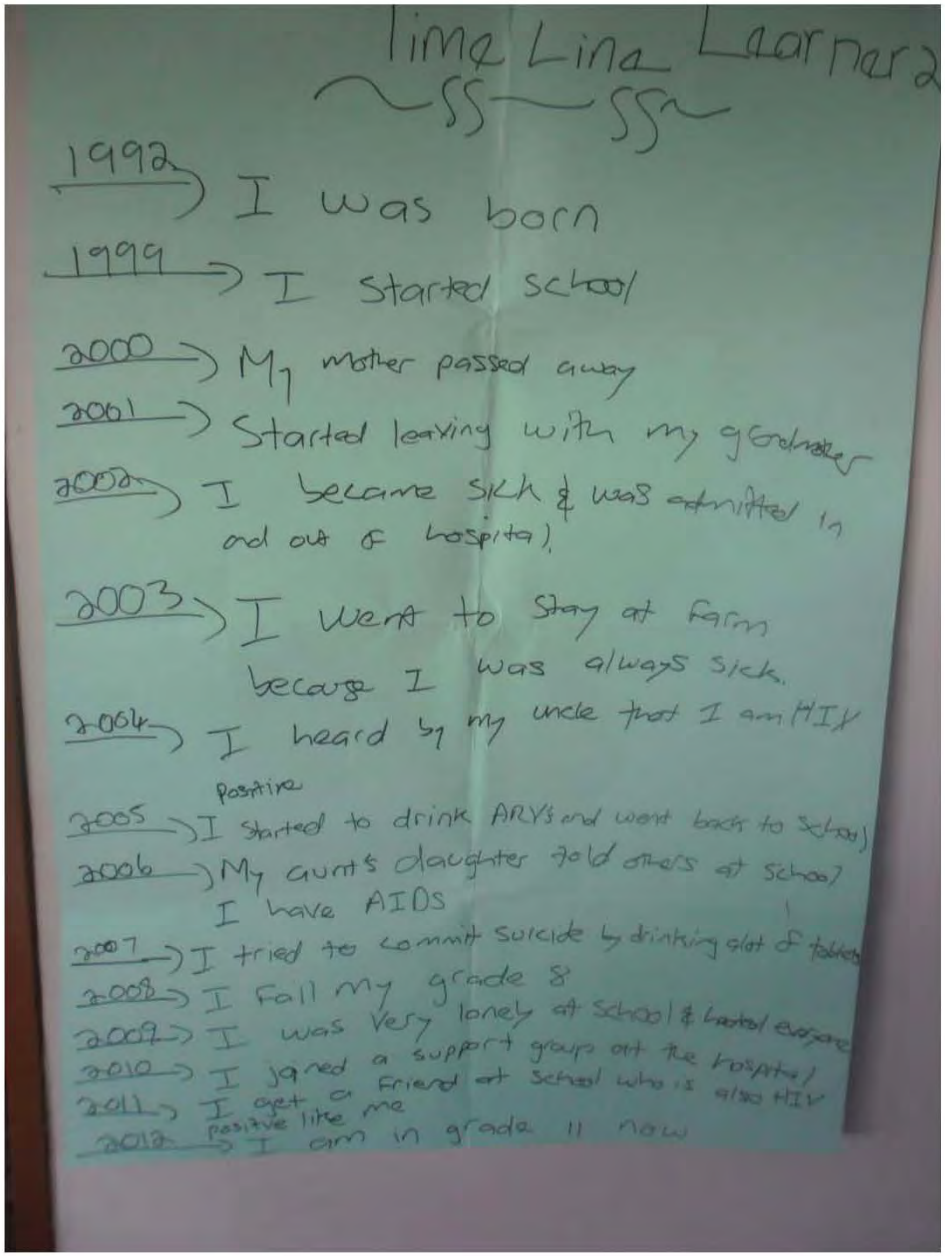
I..... certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this study have been explained to the volunteer.

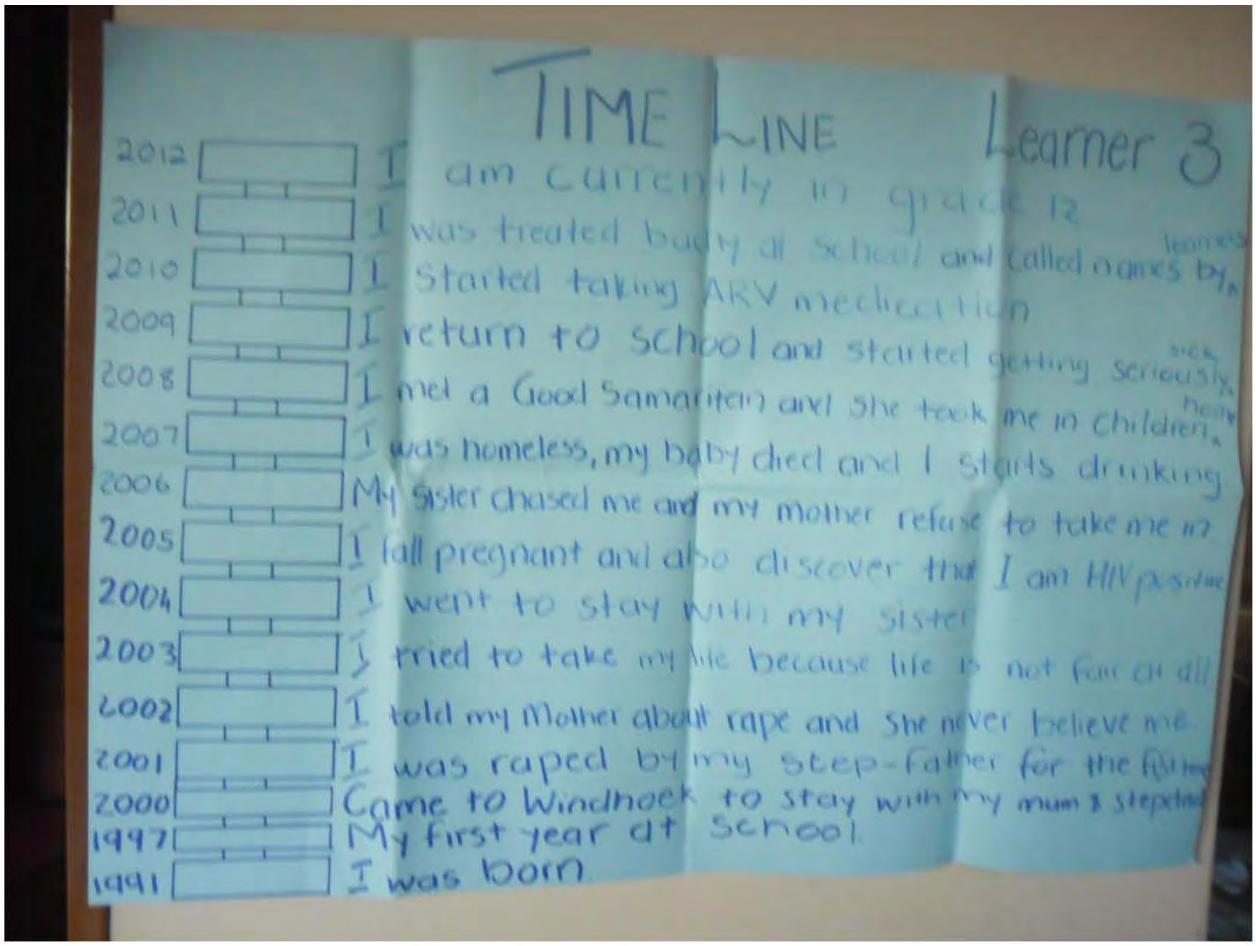
....

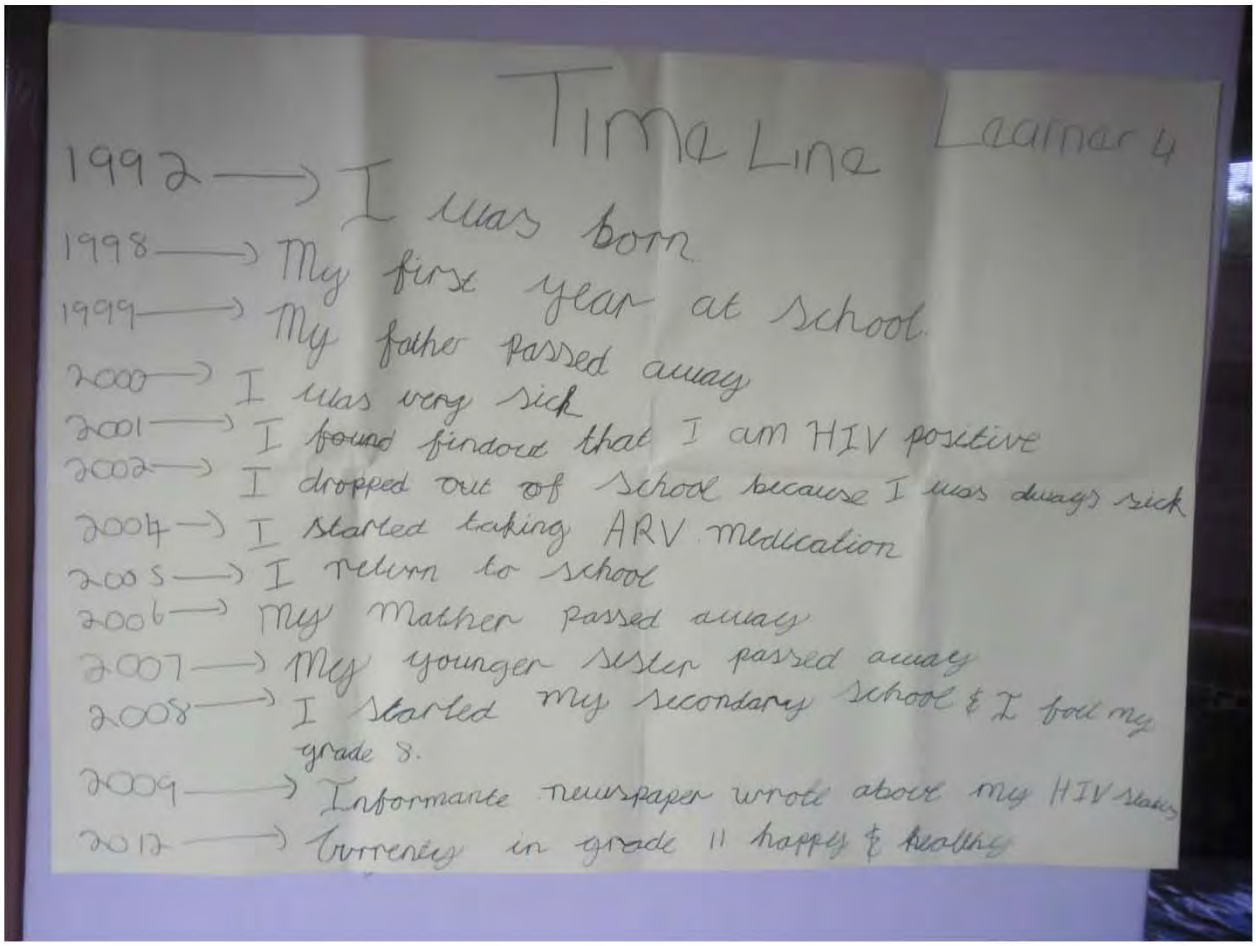
Signature of Person Obtaining Consent

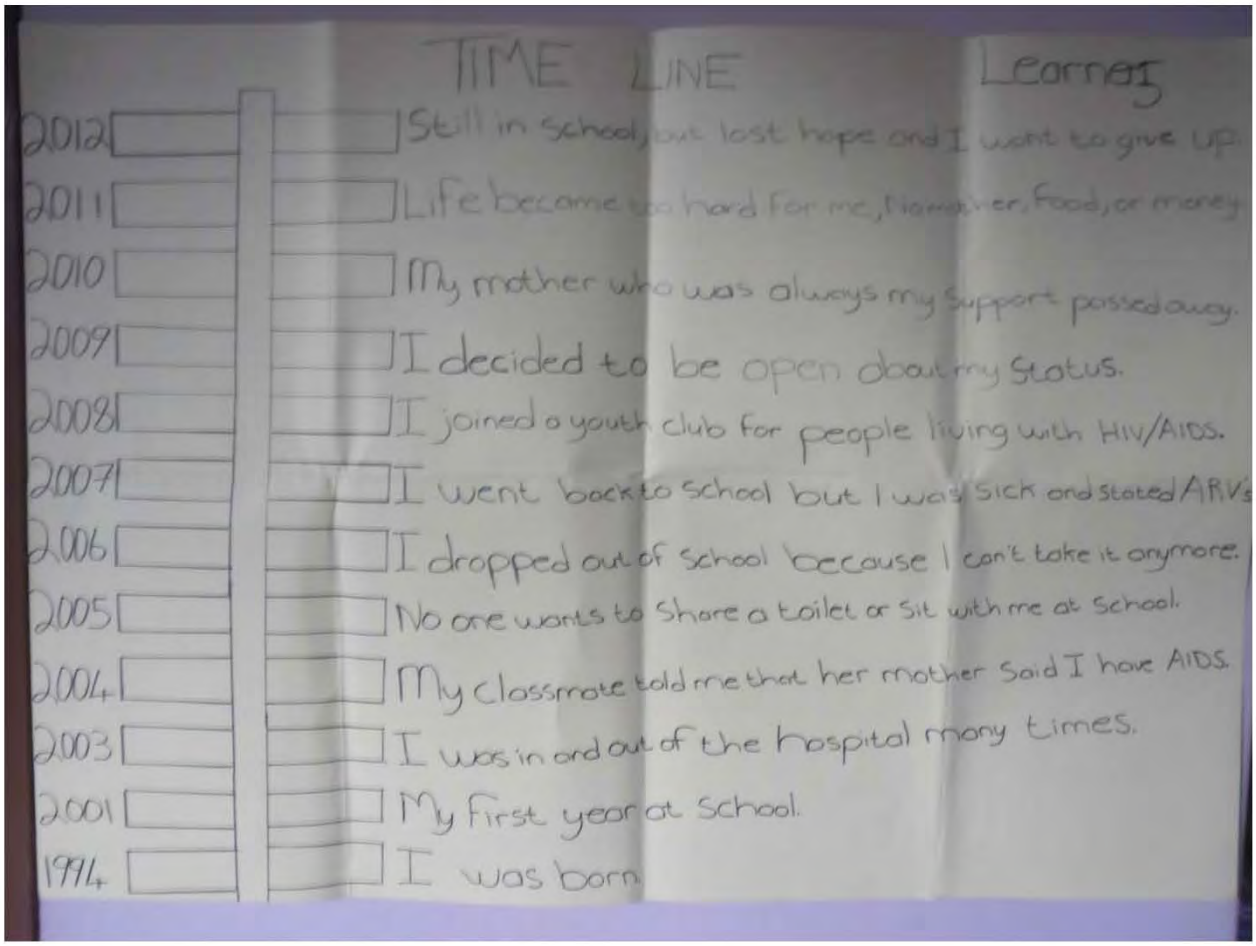
APPENDIX C: TIME LINES

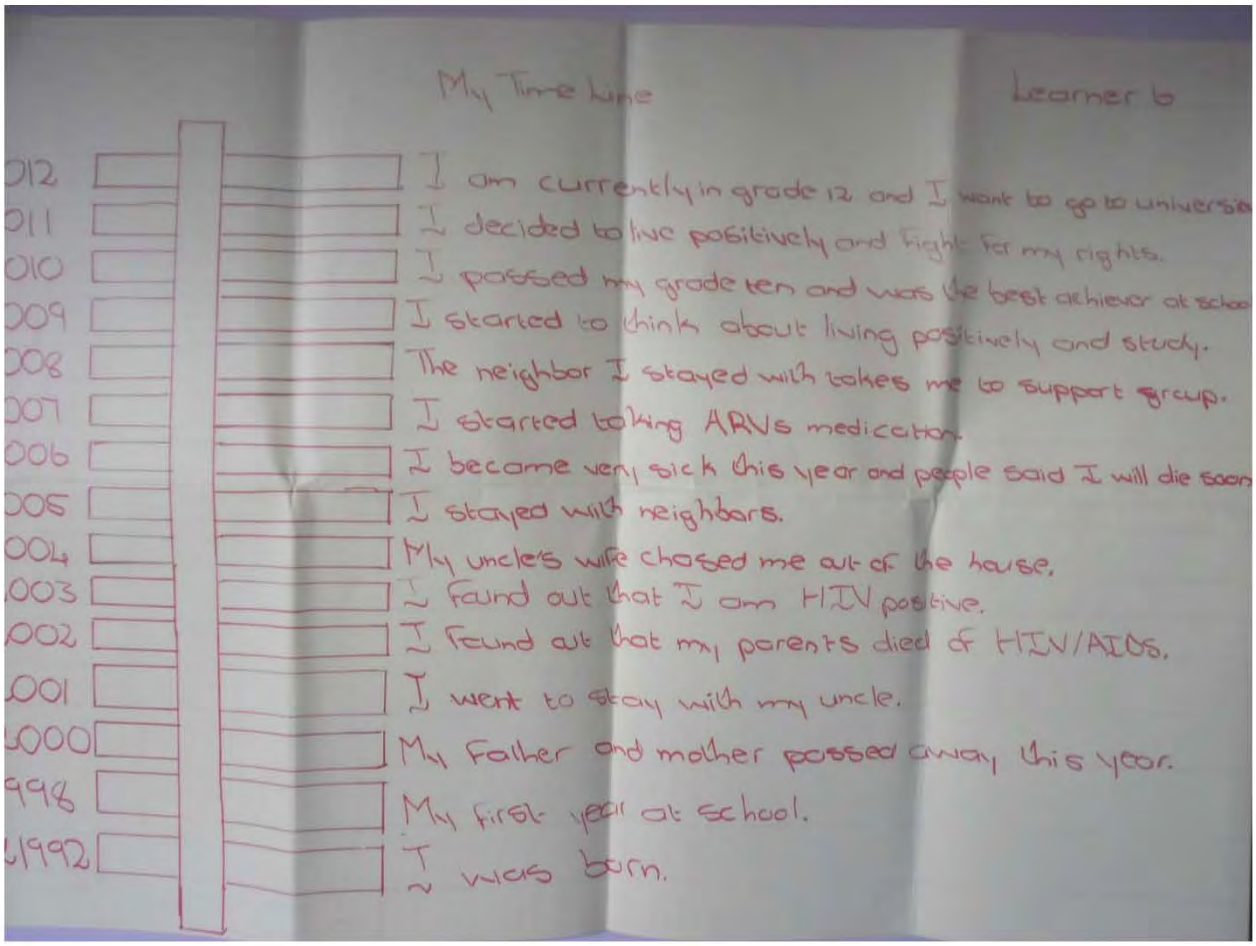


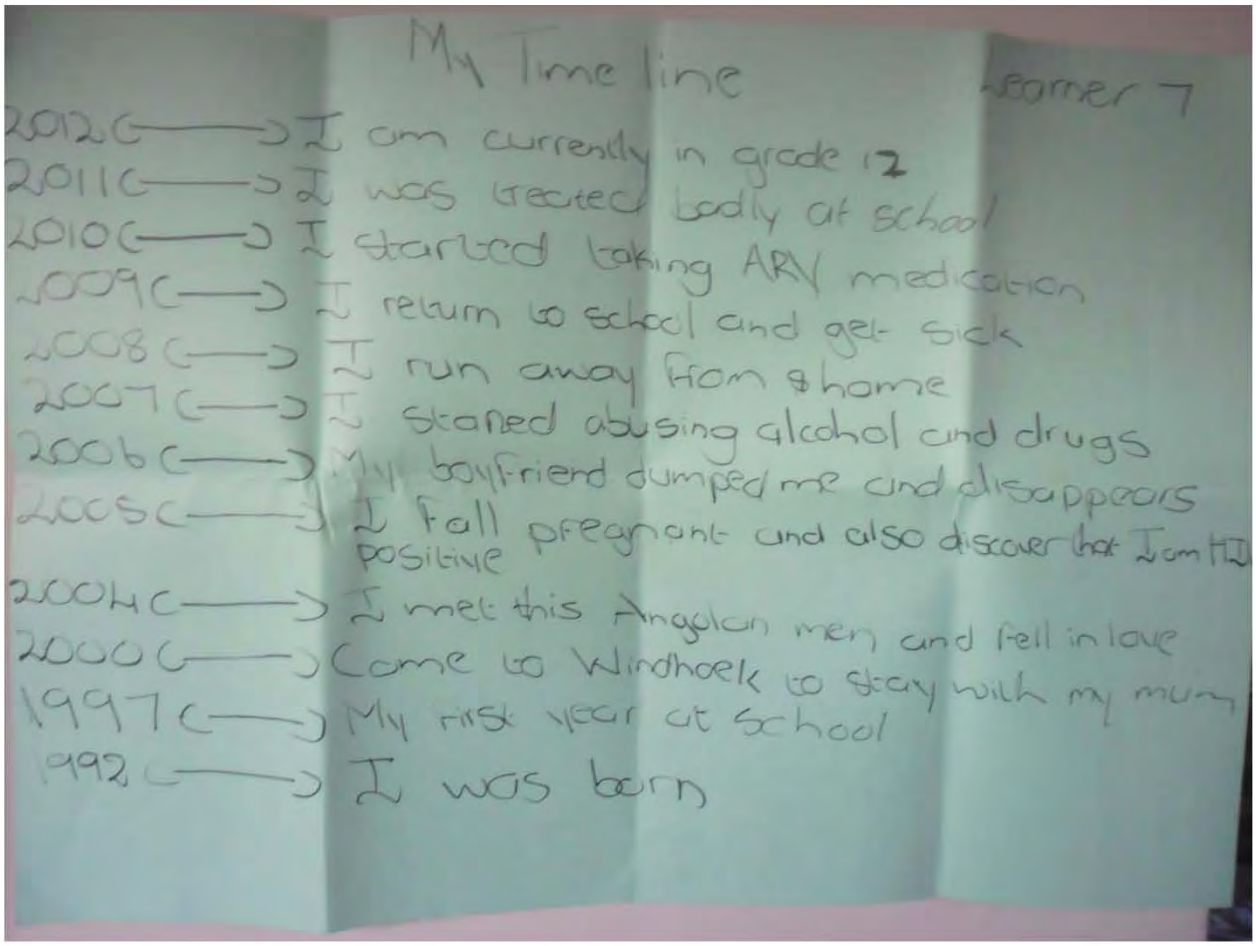

Time Line Learner 2
1992 I was born
1999 I started school
2000 My mother passed away
2001 Started leaving with my grandmother
2002 I became sick & was admitted in and out of hospital
2003 I went to stay at farm because I was always sick.
2004 I heard by my uncle that I am HIV Positive
2005 I started to drink ARV's and went back to school
2006 My aunt's daughter told others at school I have AIDS
2007 I tried to commit suicide by drinking alot of tablets
2008 I Fail my grade 8
2009 I was very lonely at school & hated everyone
2010 I joined a support group at the hospital
2011 I get a friend at school who is also HIV positive like me
2012 I am in grade 11 now

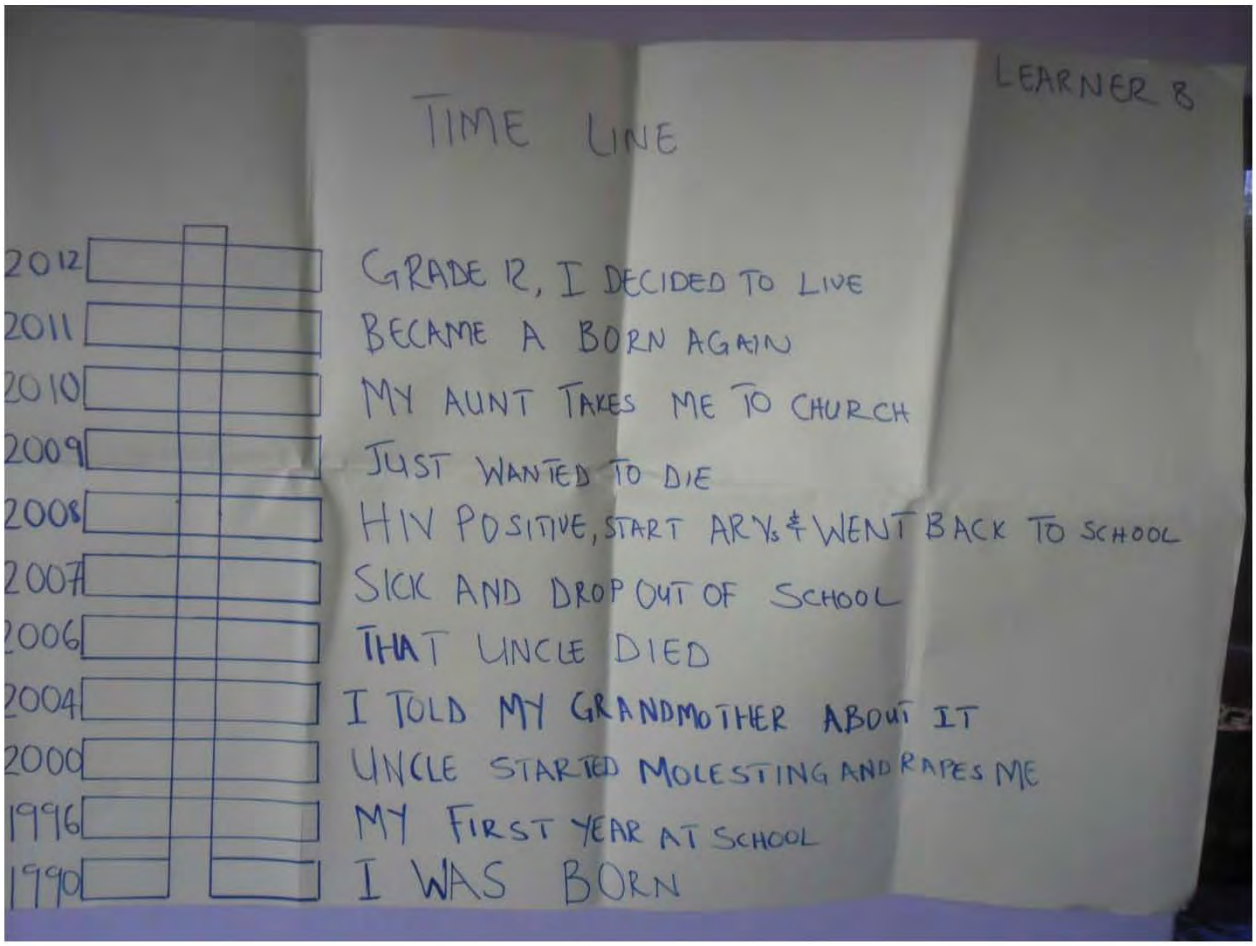

TIME LINE Learner 3
2012 I am currently in grade 12
2011 I was treated badly at school and called names by learners
2010 I started taking ARV medication
2009 I return to school and started getting seriously sick
2008 I met a Good Samaritan and she took me in Children home
2007 I was homeless, my baby died and I starts drinking.
2006 My sister chased me and my mother refuse to take me in.
2005 I fall pregnant and also discover that I am HIV positive
2004 I went to stay with my sister
2003 I tried to take my life because life is not fair at all
2002 I told my Mother about rape and she never believe me.
2001 I was raped by my step-father for the first
2000 Came to Windhoek to stay with my mum & stepdad
1997 My first year at school.
1991 I was born.


Time Line Learner 4
1992 → I was born
1998 → My first year at school
1999 → My father passed away
2000 → I was very sick
2001 → I found findout that I am HIV positive
2002 → I dropped out of school because I was always sick
2004 → I started taking ARV medication
2005 → I return to school
2006 → My Mather passed away
2007 → My younger sister passed away
2008 → I started my secondary school & I fail my grade 8.
2009 → Informanie newspaper wrote about my HIV status
2012 → Currently in grade 11 happy & healthy


TIME LINE Learner
2012 Still in school, but lost hope and I want to give up.
2011 Life became so hard for me, Nowadays, Food, or money
2010 My mother who was always my support passed away.
2009 I decided to be open about my status.
2008 I joined a youth club for people living with HIV/AIDS.
2007 I went back to school but I was sick and stated ARV's
2006 I dropped out of school because I can't take it anymore.
2005 No one wants to share a toilet or sit with me at school.
2004 My classmate told me that her mother said I have AIDS.
2003 I was in and out of the hospital many times.
2001 My first year at school.
1994 I was born.


My Time line
Learner b
012
011
010
009
008
007
006
005
004
003
002
001
000
998
1992
I am currently in grade 12 and I want to go to universit
I decided to live positively and fight for my rights.
I passed my grade ten and was the best achiever at schoo
I started to think about living positively and study.
The neighbor I stayed with takes me to support group.
I started taking ARVs medication.
I became very sick this year and people said I will die soon
I stayed with neighbors.
My uncle's wife chased me out of the house.
I found out that I am HIV positive.
I found out that my parents died of HIV/AIDS.
I went to stay with my uncle.
My Father and mother passed away this year.
My first year at school.
I was born.


My Time line
learner 7
2012 → I am currently in grade 12
2011 → I was treated badly at school
2010 → I started taking ARV medication
2009 → I return to school and get sick
2008 → I run away from home
2007 → I stared abusing alcohol and drugs
2006 → My boyfriend dumped me and disappears
2005 → I fall pregnant and also discover that I am HI positive
2004 → I met this Angolan men and fell in love
2000 → Come to Windhoek to stay with my mum
1997 → My first year at school
1992 → I was born


LEARNER 8
TIME LINE
2012
2011
2010
2009
2008
2007
2006
2004
2000
1996
1990
GRADE 12, I DECIDED TO LIVE
BECAME A BORN AGAIN
MY AUNT TAKES ME TO CHURCH
JUST WANTED TO DIE
HIV POSITIVE, START ARVs & WENT BACK TO SCHOOL
SICK AND DROP OUT OF SCHOOL
THAT UNCLE DIED
I TOLD MY GRANDMOTHER ABOUT IT
UNCLE STARTED MOLESTING AND RAPES ME
MY FIRST YEAR AT SCHOOL
I WAS BORN

APPENDIX D: FOCUS GROUP INTERVIEW SCHEDULE

Focus Group Interview Schedule

Introduction

Good afternoon ladies and gentlemen. Thank you very much for availing yourself for this interview. My name is Emilie Haipinge and I am here for the interview as agreed upon. I would like to reaffirm as I mentioned in the letter, that the information that I will gather from this process will only be used for my master degree and will be kept confidential. I will give you a chance to check on the information after it has been transcribed and before I use it in the thesis. You will have an opportunity to read the transcript and withdraw any information you are not comfortable revealing. Before we start the interview, I would like you to complete a brief profile of yourself.

FOCUS GROUP INTERVIEW SCHEDULE

1. What do people in your community say about HIV/AIDS?
2. What is your experience with HIV/AIDS in the community?
3. What is the school's experience with HIV/AIDS?
4. Are you aware of HIV positive learners in the school?
5. Are you aware of any HIV positive learners at the school that take medication? (probe what they know and how they came to have the information)
6. Does your school have a policy or guidelines of how to work with children on ARV treatment?
7. What are your experiences in dealing with these learners?
8. What does the school do to help children who are on treatment?
9. What problems or challenges in your experience do these children experience at home?
10. What problems or challenges in your experience do these children experience in the community?
11. What problems or challenges, in your experience, do these children experience at school?
12. What would help you better deal with such learners in the school context?
13. What in your view is the role of schools in this regard?
14. What is your suggestion on how the school should assist these learners?

Thank you for your participation in this study.

APPENDIX E: LETTERS RELATING TO PERMISSION/CONFIRMATION

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

EDUCATION DEPARTMENT
Tel: +27 (0) 46 603 8383
Fax: +27 (0) 46 622 8028
PO Box 94, Grahamstown, 6140
E-mail: education@ru.ac.za

10 November 2011

To whom it may concern,

Dear Sir / Madam

PERMISSION TO CONDUCT RESEARCH

CANDIDATE: **EMILIE HAIPINGE**
STUDENT NUMBER: **609H6228**

This letter is to confirm that Emilie Haipinge is a registered student with the Education Department at Rhodes University. She has been registered for a Masters in Education.

Emilie Haipinge will be required to conduct research for her thesis. This letter serves to request permission for Ms Haipinge to conduct research in your school for this purpose.

Her proposal was approved by the Education Higher Degrees Committee. Her proposal complied with the ethical clearance requirements of the Faculty of Education. I trust that her application for leave meets the necessary requirements.

Yours Sincerely

Dr Bruce Brown
Head of Department

[redacted]

High School

[redacted] Street

Tel: [redacted] Fax: [redacted] P.O. Box [redacted] Katutura Windhoek Namibia.

18 January 2011

This letter serves to confirm that Mrs. Emilie Haipinge has been granted permission to conduct her research at [redacted] High School in relations to the requirements to complete her Master's degree in Education.

Mrs. Haipinge's research must not interrupt our teaching and learning process. She have to adhere to all the agreement that we have came up with, that teaching and learning must go on as usual and under no circumstance must she try to disrupt it.

We hope that her study will benefit our school and be helpful to the Namibian child's education.

Yours in Education

[redacted]

.....

PRINCIPAL

[redacted] School

201[redacted]

Tel: [redacted]

Fax [redacted]

APPENDIX F: OBSERVATION SCHEDULE

As a researcher I used non-participant observation. I took the position of an outside observer and interacted very little with the learners that I was researching, to avoid influencing the way they behaved.

I observed all eight participants who had taken part in the main individual interviews with HIV-positive learners who are on ARVs. For these case studies I also took notes of what I saw or heard from the people around these learners.

I used observation as an additional data-collection tool in order to examine and understand more deeply what these learners were experiencing at school. It also served to verify what the learners had said in their individual interviews and what the teachers had said in the teacher focus group, enabling me to identify differences or connections.

I observed the grade 12 learners together on one day and the grade 11 together on another day, for 45 minutes per grade group. Only one learner who is in grade 10 was observed by himself for 45 minutes too.

I observed the grade 11 learners at the school field during a physical education period which they normally spend at the school field getting involved in various activities and in the care of one teacher. I asked the teacher who is responsible for that subject to give me a chance to be with the learners on his behalf.

To avoid suspicion and curiosity from learners and teachers, I made sure to use this routine before with other grades too, especially when I had free periods. I always pretended to be busy writing or doing something important to avoid disturbing or being disturbed by learners. For all the six sessions that were devoted to this, I allowed learners to do whatever they wanted to do and gave them space. However, I used only three of the sessions for actual observation and at that time I took my field notes.

There were certain categories that I set out to observe, but other categories come up in the process. The categories come into view in table 1 below.

Table 1: *Participants' names and categories*

Neville	Johanna	La-Toya	Bertha	Salmi	Monique	Mercia	Benzao	Categories
						✓	✓	*Learner participation*
✓			✓					*Verbal comments from others*
							✓	*Interaction occurs*
			✓		✓			*Eye contact with others*
								Body language
✓	✓			✓		✓		*Teased*
✓	✓						✓	*Called names*
		✓						*Alone at the edge of the field*
✓		✓		✓	✓			*Silence*
			✓				✓	*Making jokes, laughing*
								Sad
	✓	✓						*Change seating or standing positions*
						✓		*Sharing food*
			✓		✓	✓	✓	*Happy or showed enjoyment*
✓	✓	✓		✓				*L ack of interest in others*

Four participants showed lack of interest in interacting with others and were very quiet; the rest appeared happy and enjoying themselves.

Only two learners participated fully and made jokes with others. Of the cohort of eight, four were teased by others and three of those four were called names.

Two of the participants changed their positions when others came near them and one out of those two went to sit alone at the edge of the field. Only one participant shared food with other learners.

These results confirm that some of the HIV positive learners seemed happy despite the HIV and the stigma they were going through: that is, they chose to be happy, since of those four, two were teased and one was called names but that did not stop them smiling and enjoying themselves. They had become resilient and had chosen to live positively. The findings confirm also that four learners were still finding it hard to cope with stigma and would keep quiet and withdraw themselves from the others – notably, two of them kept changing positions if others come closer to them.

APPENDIX G: LIFE SKILLS SUBJECT POLICY (INTERNAL)

INTERNAL SUBJECT POLICY

[redacted]

LIFE SKILLS

1. AIMS

This document is the official subject policy for **Life Skills** at [redacted] **School** and this policy is aiming to:

- List roles and responsibilities of teachers and subjects' heads of Life Skills
- Help teachers on how to: **Plan**, **Organize**, **Supervise, control and Manage** Their teaching and learning activities and meet the expectations of Ministry of Education
- To provide guidance for teachers and subjects heads on assessments on learners work
- To guide new teachers on the way forward in teaching and learning Life Skills
- To make teaching and learning effective and efficiently
- To guide teacher counselors on the way forward

2. Subject Specific issues

2.1 The curriculum for Basic education

Subjects' teachers need to consult this document frequently to make sure that they are teaching within the ministry guidelines.

2.2 Time tabling

The timetable of Life Skills subjet at [redacted] as provision for 1 period in the 7 days cycle for grade 8-10, and 2 period for grade 11-12 per cycle.

2.3 Syllabus

The syllabuses of these two subjects is the property of the school and they are available in the subject files in the HOD office, and one copy remains in the preparation files.

LIFE SKILLS MOTIVATE, HEAL , BUILD AND TURN OUR LEARNERS INTO RESPONSIBLE CITIZENS

2.4 In service –training

Workshops materials and handouts will be kept in the subject files and they are school's properties if they are available.

2.5 Scheme of work

Every subject teacher must draw up their own scheme of work and there must be a copy in the preparation file together with the year plan.

2.6 Written preparation

Every teacher should have a written preparation irrespective of experience they have. The lesson plan should have date, theme, topic, objectives and teaching and learning materials.

2.7 Teaching and learning materials in the subjects

Teachers should have prescribed text books for each grade and teachers must be creative and innovate their teaching and learning materials relevant to the topics.

2.8 Assessment

There following documents will guide teachers in assessing Business Studies and Economics subjects:

- The subject syllabus
- Guidelines in the teachers guide
- Guidelines for teachers setting and marking assessments
- Towards improving continuous assessments
- DNEA directives

2.9 Forms of assessments applicable at [redacted]

(a) Tests or examination

- No tests or examination are written by the learners
- Learners are assessed according to the Subject policy, using different activities

NB: Marks must be kept in the subject teachers' administration file.

2.10 Learner Centered Education (LCE)

The teachers should encourage learner to participate to ensure sufficient time for LCE to take place.

2.11 Life Skills teachers should:

- make the classrooms conducive for every learner
- Inclusive education must be implemented in their classrooms
- Encourage learners to have positive attitudes towards these two subjects
- Attend cluster meetings
- Involve parents in monitoring the works of the learners

2.12 Subject meetings

Teachers should attend the subjects meetings always when they are invited to attend by the Head of Department, subject advisor or by the subject head.

2.13 Learners

- Must respect their fellow classmates, respect their teachers and adhere to the rules in the classrooms.
- Should be active and involved in classroom activities
- Should punctual and always present in the class
- Learners should be given counseling when ever is needed
- Learners should be given moral support by the subject teacher

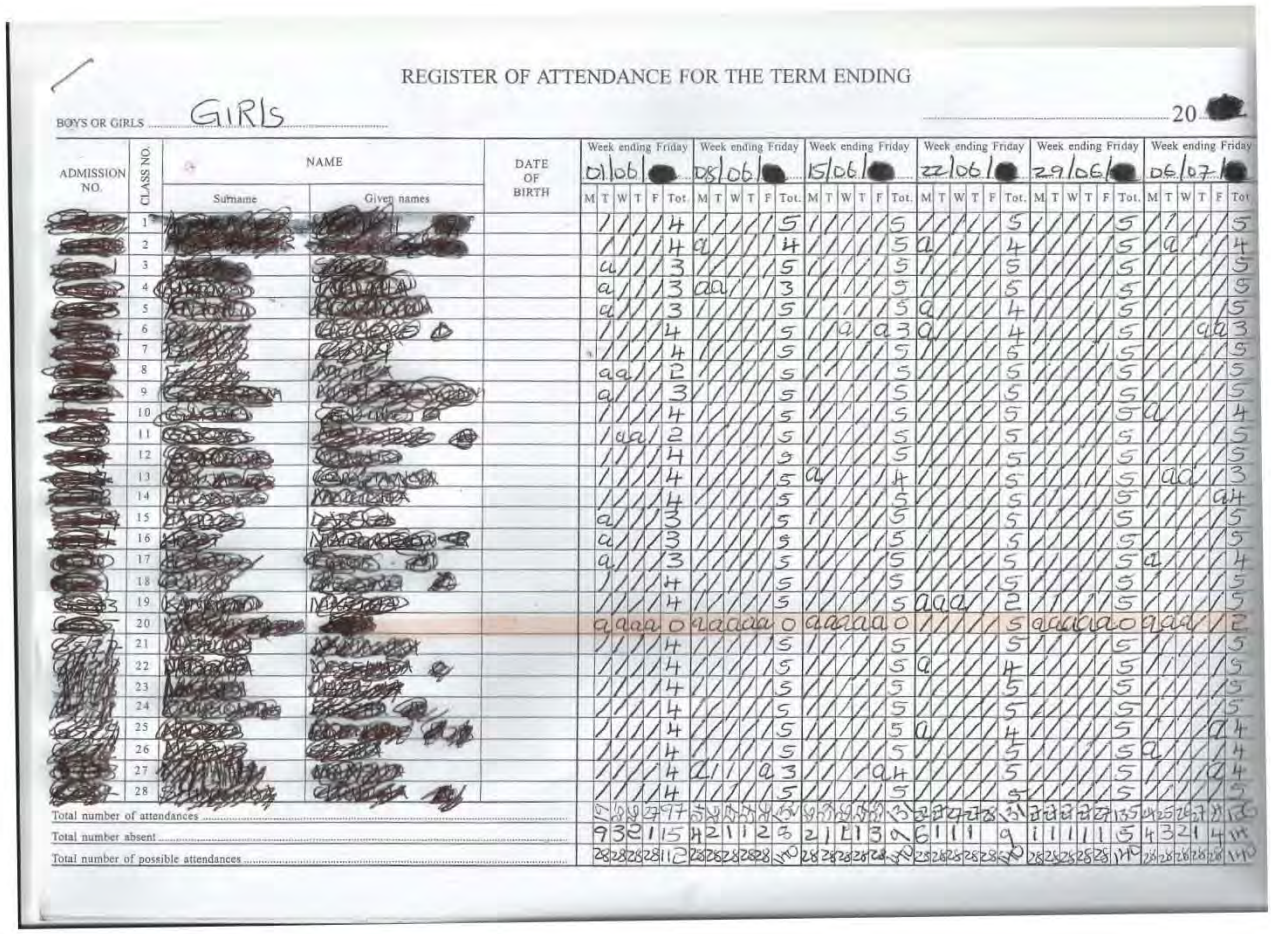
2.14 Commitments and hard work

Teachers should be committed, responsible, handworkers and having passion for the subjects they teach.

2.15 Cluster subject meetings

Play a positive role and help the teacher to have more skills, learning from each other, and create mutual relationships between subjects teachers.

APPENDIX H: ATTENDANCE REGISTERS



REGISTER OF ATTENDANCE FOR THE TERM ENDING

BOYS OR GIRLS GIRLS ..... 20[redacted]

ADMISSION NO.	CLASS NO.	NAME		DATE OF BIRTH	Week ending Friday 01/06/[redacted]						Week ending Friday 08/06/[redacted]						Week ending Friday 15/06/[redacted]						Week ending Friday 22/06/[redacted]						Week ending Friday 29/06/[redacted]						Week ending Friday 06/07/[redacted]					
		Surname	Given names		M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.
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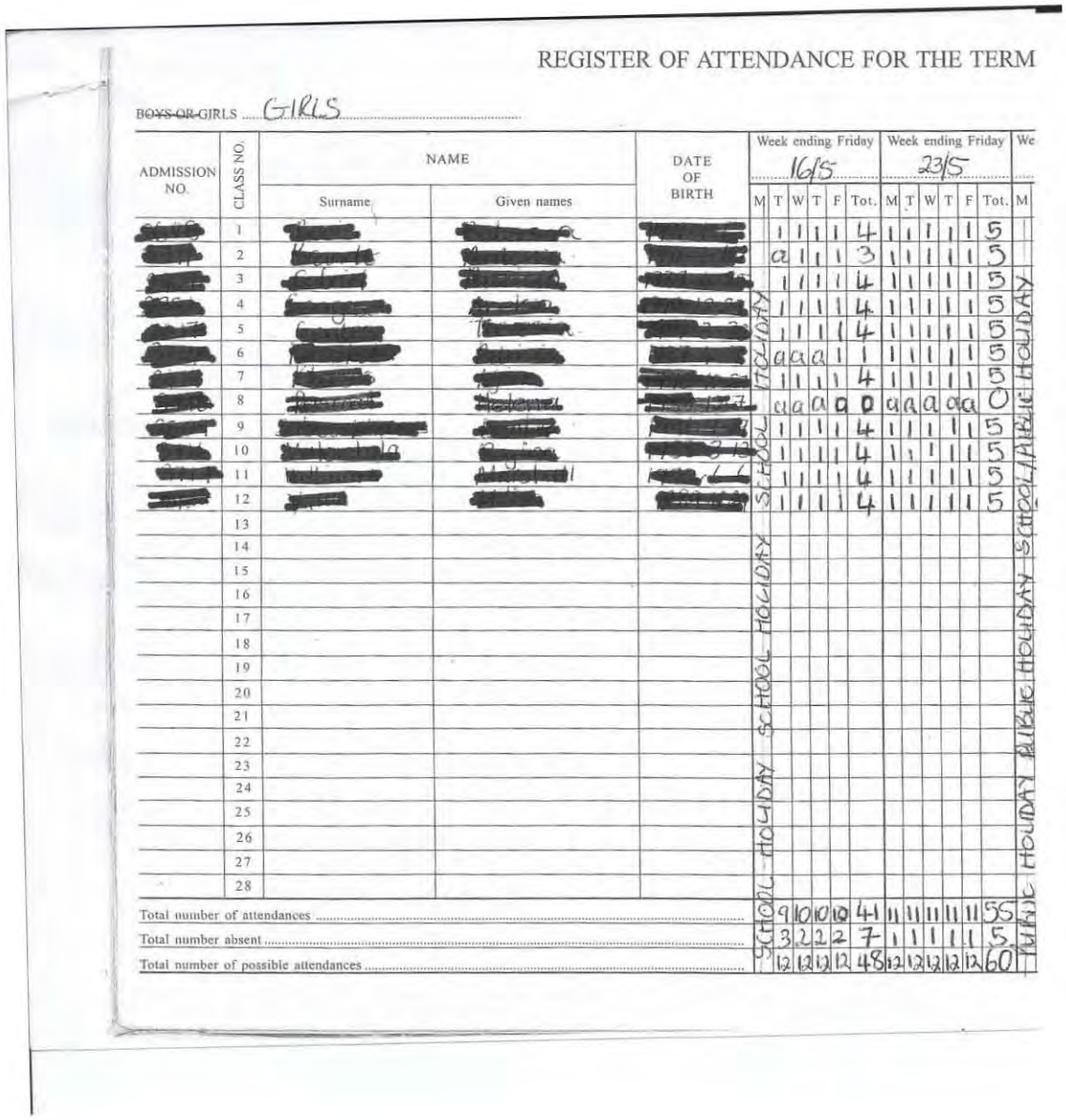
Total number of attendances					27	28	28	27	27		25	28	28	28	28		28	28	28	28	24		25	28	28	28	28		28	25	25	25	25		28	28	28	28	28	
Total number absent					9	3	2	1	5		4	2	1	1	2	3	2	1	4	1	3	0	6	1	1	1		9	1	1	1	1	1	5	4	3	2	1	4	
Total number of possible attendances					28	28	28	28	28		28	28	28	28	28		28	28	28	28	28		28	28	28	28	28		28	25	25	25	25		28	28	28	28	28	



REGISTER OF ATTENDANCE FOR THE TERM

BOYS OR GIRLS GIRLS

ADMISSION NO.	CLASS NO.	NAME: Surname	NAME: Given names	DATE OF BIRTH	Week ending Friday 16/5: M	T	W	T	F	Tot.	Week ending Friday 23/5: M	T	W	T	F	Tot.	We: M
[redacted]	1	[redacted]	[redacted]	[redacted]		1	1	1	1	4	1	1	1	1	1	5	
[redacted]	2	[redacted]	[redacted]	[redacted]		a	1	1	1	3	1	1	1	1	1	5	
[redacted]	3	[redacted]	[redacted]	[redacted]		1	1	1	1	4	1	1	1	1	1	5	
[redacted]	4	[redacted]	[redacted]	[redacted]		1	1	1	1	4	1	1	1	1	1	5	
[redacted]	5	[redacted]	[redacted]	[redacted]		1	1	1	1	4	1	1	1	1	1	5	
[redacted]	6	[redacted]	[redacted]	[redacted]		a	a	a	1	1	1	1	1	1	1	5	
[redacted]	7	[redacted]	[redacted]	[redacted]		1	1	1	1	4	1	1	1	1	1	5	
[redacted]	8	[redacted]	[redacted]	[redacted]		a	a	a	a	a	a	a	a	a	a	0	
[redacted]	9	[redacted]	[redacted]	[redacted]		1	1	1	1	4	1	1	1	1	1	5	
[redacted]	10	[redacted]	[redacted]	[redacted]		1	1	1	1	4	1	1	1	1	1	5	
[redacted]	11	[redacted]	[redacted]	[redacted]		1	1	1	1	4	1	1	1	1	1	5	
[redacted]	12	[redacted]	[redacted]	[redacted]		1	1	1	1	4	1	1	1	1	1	5	
	13																
	14																
	15																
	16																
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	20																
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	24																
	25																
	26																
	27																
	28																
Total number of attendances						9	10	10	10	41	11	11	11	11	11	55	
Total number absent						3	2	2	2	7	1	1	1	1	1	5	
Total number of possible attendances						12	12	12	12	48	12	12	12	12	12	60	

SCHOOL HOLIDAY SCHOOL HOLIDAY SCHOOL HOLIDAY PUBLIC HOLIDAY SCHOOL HOLIDAY PUBLIC HOLIDAY

REGISTER OF ATTENDANCE FOR THE TERM ENDING .... 20[redacted]

BOYS OR GIRLS Boys

ADMISSION NO.	CLASS NO.	NAME		DATE OF BIRTH	Week ending Friday 7/09/[redacted]						Week ending Friday 14/09/[redacted]						Week ending Friday 21/09/[redacted]						Week ending Friday 28/09/[redacted]						Week ending Friday 5/10/[redacted]						Week ending Friday 12/10/[redacted]					
		Surname	Given names		M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.
[redacted]	1	[redacted]	[redacted]				/	/	/	3	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/		4	/	/	/	/	/	5
[redacted]	2	[redacted]	[redacted]				/	/	/	3	/	/	/	a	/	4	a	/	a	/	a	2	/	/	a	/	/	4	/	/	/	/		4	a	/	/	/	/	4
[redacted]	3	[redacted]	[redacted]				/	/	/	3	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/		4	/	/	/	/	/	5
[redacted]	4	[redacted]	[redacted]				a	/	a	1	a	a	/	a	/	2	a	/	/	a	a	2	a	/	a	a	/	2	a	/	a	/		2	a	/	a	a	a	1
[redacted]	5	[redacted]	[redacted]				/	/	/	3	/	/	/	/	/	5	a	a	a	a	a	0	a	a	a	a	a	0	a	a	a	a		0	a	a	a	a	a	0
[redacted]	6	[redacted]	[redacted]				/	/	/	3	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/		4	/	/	/	/	/	5
[redacted]	7	[redacted]	[redacted]				/	/	a	2	a	a	a	a	a	0	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/		4	/	/	/	/	/	5
[redacted]	8	[redacted]	[redacted]				/	/	/	3	A	/	/	a	/	3	a	a	/	a	a	1	/	a	a	a	a	1	a	a	a	/		1	a	/	a	a	a	1
[redacted]	9	[redacted]	[redacted]				/	/	a	2	a	a	a	a	a	0	a	a	a	a	a	0	a	a	a	a	a	0	a	a	a	a		0	a	a	a	a	a	0
[redacted]	10	[redacted]	[redacted]				/	/	/	3	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/		4	/	/	/	/	/	5
[redacted]	11	[redacted]	[redacted]				/	/	/	3	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/		4	/	/	/	/	/	5
[redacted]	12	[redacted]	[redacted]				a	a	a	0	/	a	a	a	a	4	a	a	a	a	a	0	/	/	a	a	a	2	a	a	a	a		0	a	a	a	a	a	0
[redacted]	13	[redacted]	[redacted]				/	/	/	3	a	a	a	/	/	2	a	a	a	/	/	2	/	/	/	/	/	5	/	/	/	/		4	/	/	/	/	a	4
[redacted]	14	[redacted]	[redacted]				/	/	/	3	/	/	/	/	/	5	/	/	/	/	a	4	/	/	/	/	/	5	/	/	/	/		4	/	/	/	/	/	5
[redacted]	15	[redacted]	[redacted]				/	/	a	2	/	/	/	/	/	5	/	/	a	/	/	4	/	/	/	/	a	4	/	/	/	a		3	/	/	/	/	a	4
[redacted]	16	[redacted]	[redacted]				/	/	/	3	a	a	a	a	a	0	a	a	/	a	a	1	a	a	a	a	/	1	/	/	a	a		2	/	/	a	/	/	4
[redacted]	17	[redacted]	[redacted]				/	/	/	3	/	/	/	/	/	5	a	/	/	a	/	3	a	a	a	/	/	2	/	/	/	/		4	/	/	/	/	/	5
[redacted]	18	[redacted]	[redacted]				/	/	/	3	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	a		3	/	/	/	/	/	5
[redacted]	19	[redacted]	[redacted]				/	/	/	3	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/		4	/	/	/	/	/	5
[redacted]	20	[redacted]	[redacted]				/	/	a	2	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/	/	5	/	/	/	/		4	/	/	/	/	a	4
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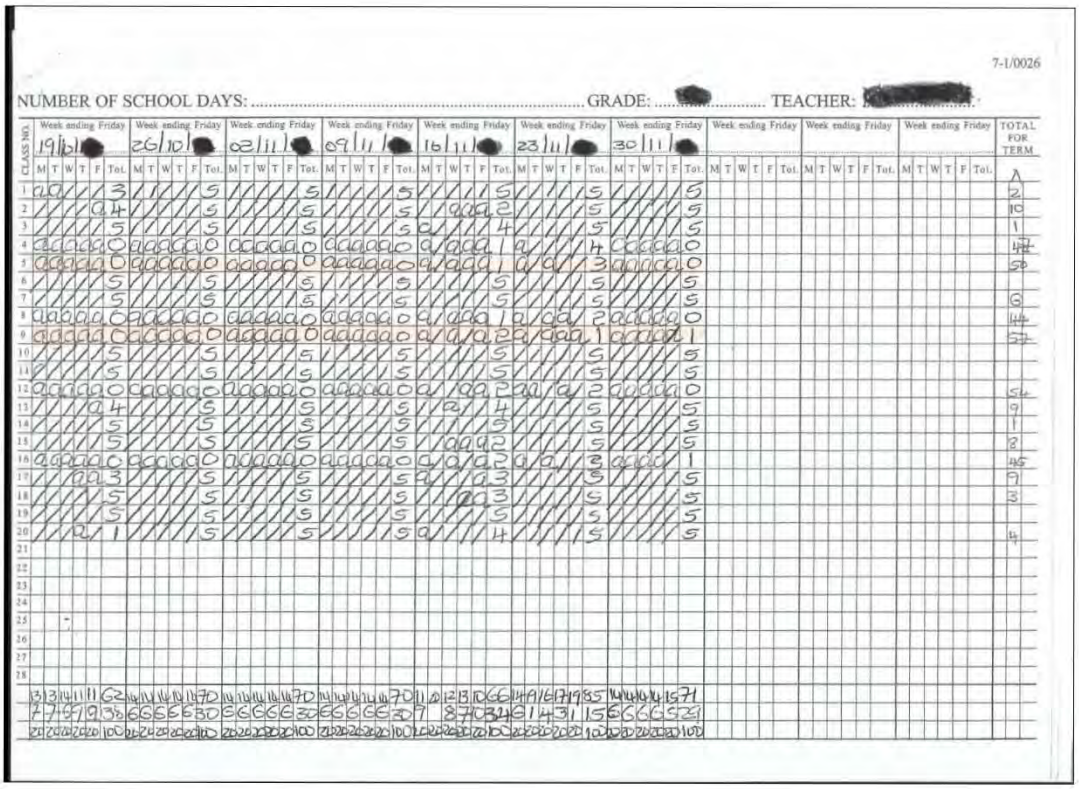
	28																																							
Total number of attendances							18	19	14	51	15	14	15	13	16	73	11	13	14	13	12	63	15	15	12	14	15	71	15	16	14	14		59	14	17	14	15	12	72
Total number absent							2	1	6	9	5	6	5	7	4	27	9	7	6	7	8	37	5	5	8	6	5	29	5	4	6	6		21	6	3	6	5	8	28
Total number of possible attendances							20	20	20	60	20	20	20	20	20	100	20	20	20	20	20	100	20	20	20	20	20	100	20	20	20	20		80	20	20	20	20	20	100



7-1/0026

NUMBER OF SCHOOL DAYS: ..... GRADE: [redacted] TEACHER: [redacted]

CLASS NO.	Week ending Friday 19/10						Week ending Friday 26/10						Week ending Friday 02/11						Week ending Friday 09/11						Week ending Friday 16/11						Week ending Friday 23/11						Week ending Friday 30/11						Week ending Friday						Week ending Friday						Week ending Friday						TOTAL FOR TERM
	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	
1					3						5						5						5						5						5						5																			A
2					4						5						5						5						5						5						5																			2
3					5						5						5						5						5						4						5																			10
4					0						0						0						0						0						1						4																			1
5					0						0						0						0						0						0						3																			42
6					5						5						5						5						5						5						5																			50
7					5						5						5						5						5						5						5																			6
8					0						0						0						0						0						2						0																			44
9					0						0						0						0						0						1						1																			52
10					5						5						5						5						5						5						5																			
11					5						5						5						5						5						5						5																			
12					0						0						0						0						0						2						0																			54
13					4						5						5						5						4						5						5																			9
14					5						5						5						5						5						5						5																			1
15					5						5						5						5						2						5						5																			2
16					0						0						0						0						2						3						1																			45
17					3						5						5						5						3						5						5																			7
18					5						5						5						5						3						5						5																			3
19					5						5						5						5						5						5						5																			
20					1						5						5						5						4						5						5																			4
21																																																													
22																																																											
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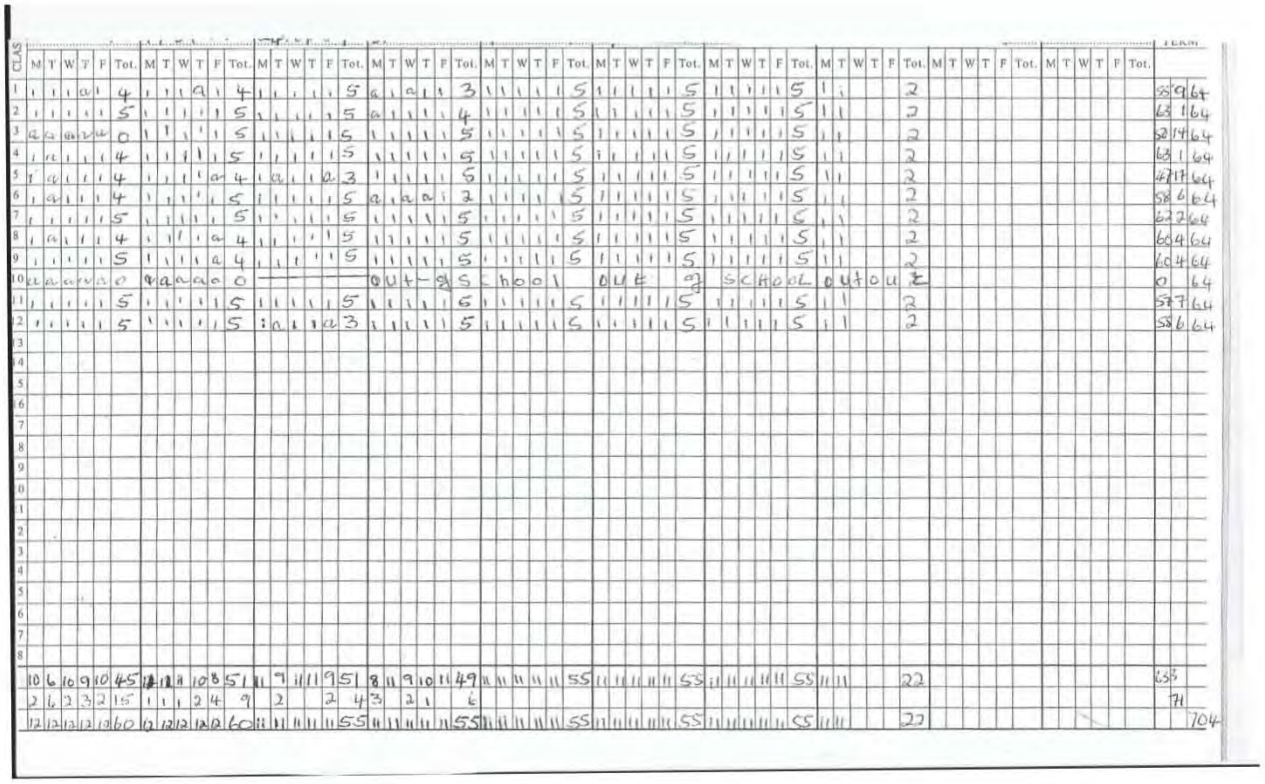
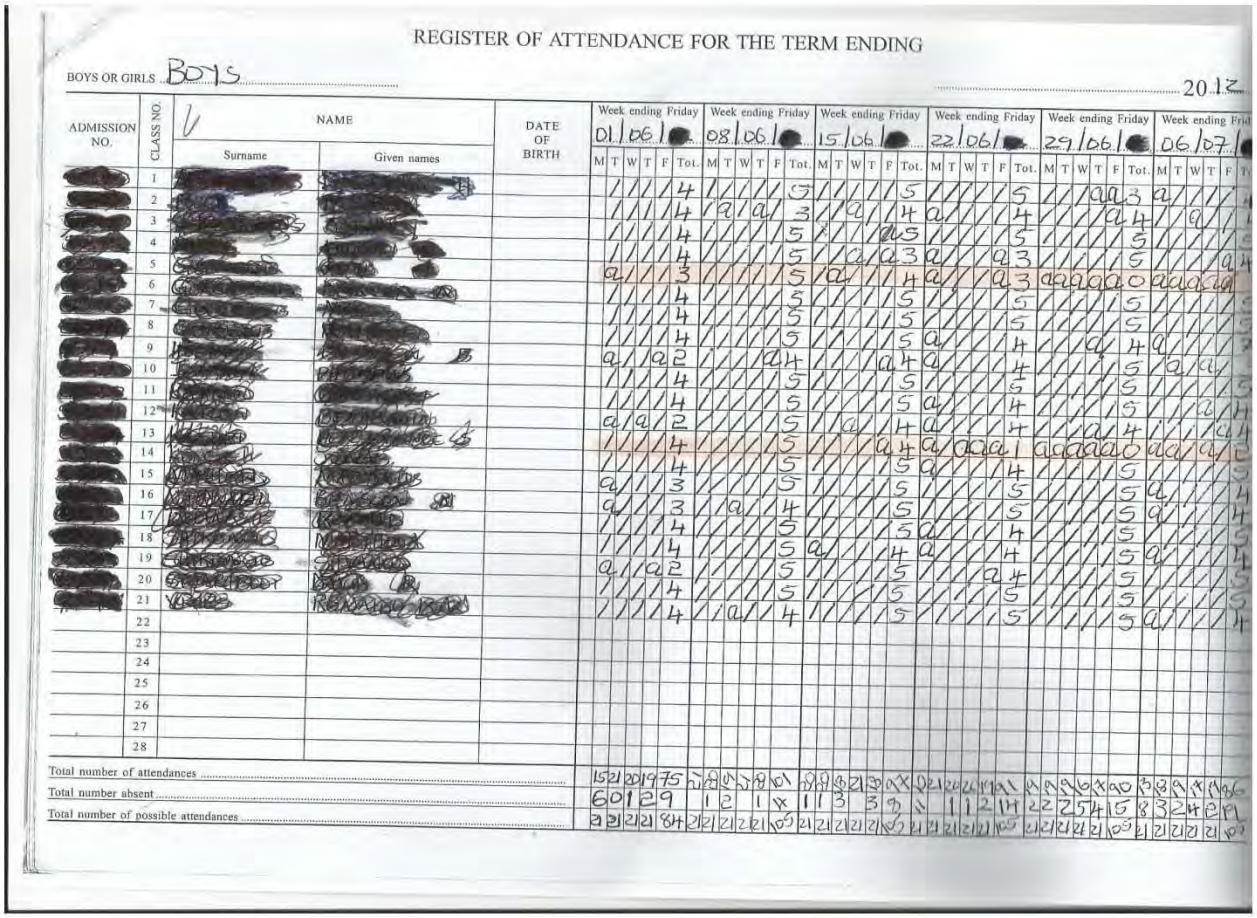
28																																																											
	13	14	11	11	62		14	14	14	14	70		14	14	14	14	70		14	14	14	14	70		10	12	13	10	66		14	9	16	7	19	85		14	14	14	14	56																	
	17	19	13	16	66	55	16	16	16	16	80	55	16	16	16	16	80	55	16	16	16	16	80	55	17	18	13	14	82	55	16	14	13	15	16	74	55	16	16	16	16	64	55						55						55	1571
	20	20	20	20	100	20	20	20	20	20	100	20	20	20	20	20	100	20	20	20	20	20	100	20	20	20	20	20	100	20	20	20	20	20	20	100	20	20	20	20	20	100	20						20						20	1100

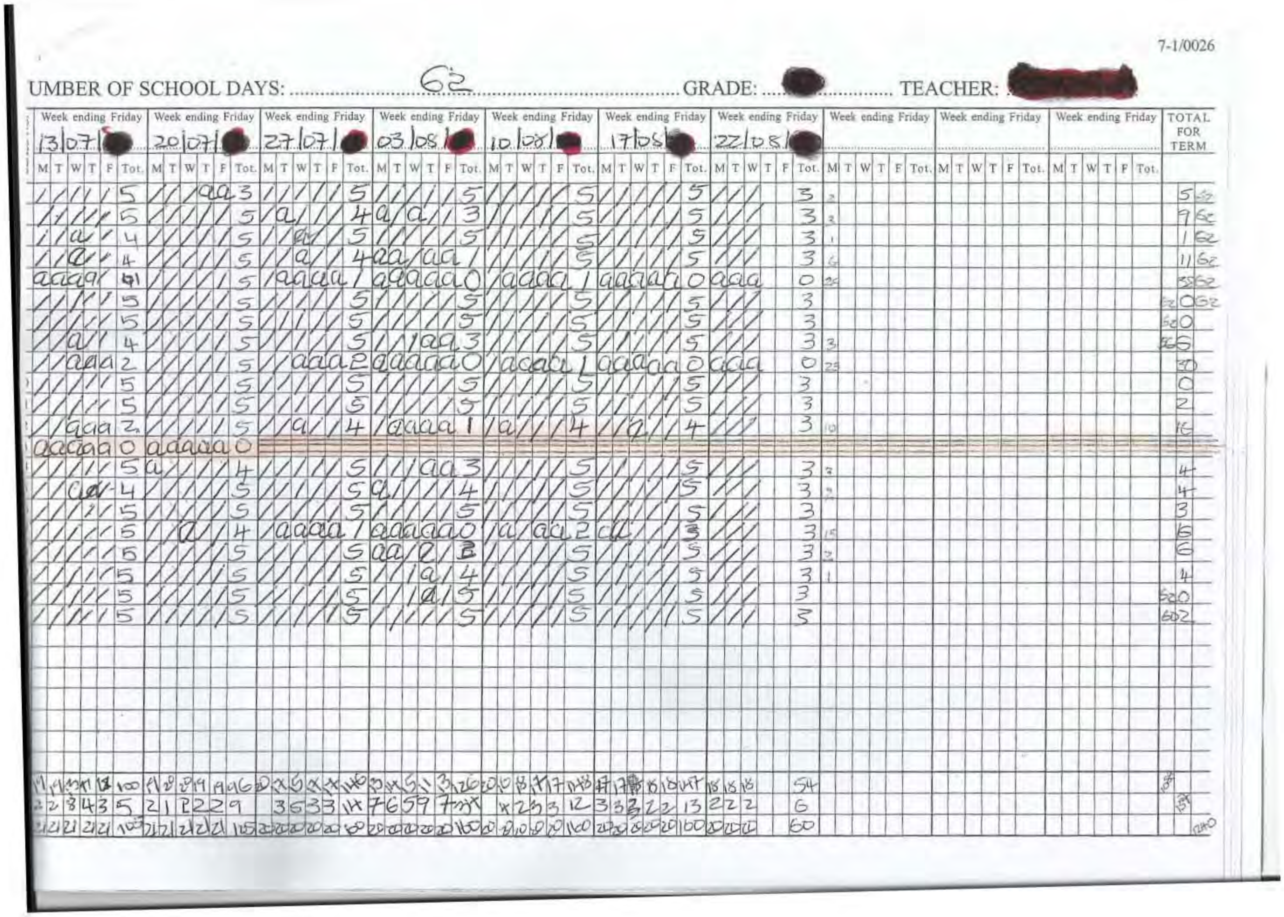




REGISTER OF ATTENDANCE FOR THE TERM ENDING

BOYS OR GIRLS Boys 20 17

ADMISSION NO.	CLASS NO.	NAME		DATE OF BIRTH	Week ending Friday 01/06/[redacted]						Week ending Friday 08/06/[redacted]						Week ending Friday 15/06/[redacted]						Week ending Friday 22/06/[redacted]						Week ending Friday 29/06/[redacted]						Week ending Friday 06/07/[redacted]					
		Surname	Given names		M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.	M	T	W	T	F	Tot.
[redacted]	1	[redacted]	[redacted]		/	/	/	/	4		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5		/	/	a	a	3		a	/	/	/	4
	2				/	/	/	/	4		/	a	/	a	3		/	a	/	/	4		a	/	/	/	4		/	/	/	a	4		/	a	/	/	4
	3				/	/	/	/	4		/	/	/	/	5		/	/	a	a	3		a	/	/	/	4		/	/	/	/	5		/	/	/	/	5
	4				/	/	/	/	4		/	/	/	/	5		/	a	/	a	3		a	/	/	a	3		/	/	/	/	5		/	/	/	a	4
	5				a	/	/	/	3		/	/	/	/	5		a	/	/	/	4		a	/	/	/	4		a	a	a	a	a		a	a	a	a	a
	6				/	/	/	/	4		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5
	7				/	/	/	/	4		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5
	8				/	/	/	/	4		/	/	/	/	5		/	/	/	/	5		a	/	/	/	4		/	/	/	a	4		a	/	/	/	4
	9				a	/	a	2			/	/	/	a	4		/	/	/	a	4		a	/	/	/	4		/	/	/	/	5		a	/	a	/	4
	10				/	/	/	/	4		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5
	11				/	/	/	/	4		/	/	/	/	5		/	/	/	/	5		a	/	/	/	4		/	/	/	/	5		/	/	/	a	4
	12				a	/	a	2			/	/	/	/	5		/	a	/	/	4		a	/	/	/	4		/	/	/	/	5		/	/	a	/	4
	13				/	/	/	/	4		/	/	/	/	5		/	/	/	a	4		a	a	a	a	4		a	a	a	a	a		a	a	/	a	4
	14				/	/	/	/	4		/	/	/	/	5		/	/	/	/	5		a	/	/	/	4		/	/	/	/	5		/	/	/	/	5
	15				a	/	/	/	3		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5		a	/	/	/	4
	16				a	/	/	/	3		/	a	/	/	4		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5		a	/	/	/	4
	17				/	/	/	/	4		/	/	/	/	5		/	/	/	/	5		a	/	/	/	4		/	/	/	/	5		/	/	/	/	5
	18				/	/	/	/	4		/	/	/	/	5		a	/	/	/	4		a	/	/	/	4		/	/	/	/	5		a	/	/	/	4
	19				a	/	/	a	2		/	/	/	/	5		/	/	/	/	5		/	/	/	a	4		/	/	/	/	5		/	/	/	/	5
	20				/	/	/	/	4		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5
	21				/	/	/	/	4		/	a	/	/	4		/	/	/	/	5		/	/	/	/	5		/	/	/	/	5		a	/	/	/	4
	22																																					
	23																																					
	24																																					
	25																																					
	26																																					
	27																																					
	28																																					
Total number of attendances					15	21	20	19	7	5	[illegible]						[illegible]						[illegible]						[illegible]						[illegible]					
Total number absent					6	0	1	2	9		1	2		1	[illegible]		1	1	3		3	[illegible]		1	1	2	1	[illegible]		2	2	2	5	4	1	5		8	3	2	[illegible]	[illegible]
Total number of possible attendances					21	21	21	21	84		21	21	21	21	21	[illegible]	21	21	21	21	21	[illegible]	21	21	21	21	21	[illegible]	21	21	21	21	21	[illegible]	21	21	21	21	21	[illegible]



7-1/0026
UMBER OF SCHOOL DAYS: 62 GRADE: [redacted] TEACHER: [redacted]
Week ending Friday 13/07/[redacted]
Week ending Friday 20/07/[redacted]
Week ending Friday 27/07/[redacted]
Week ending Friday 03/08/[redacted]
Week ending Friday 10/08/[redacted]
Week ending Friday 17/08/[redacted]
Week ending Friday 22/08/[redacted]
Week ending Friday
Week ending Friday
Week ending Friday
TOTAL FOR TERM
M T W T F Tot.

APPENDIX I: TRANSGRESSION FILE

RECORD OF BEHAVIOUR OF LEARNERS

TEACHER:..... **GRADE**.....

DATE	NAME OF LEARNER	GRADE	TRANSGRESSION	SIGNATURE LEARNER	SIGNATURE TEACHER

APPENDIX J: NATIONAL POLICY ON HIV/AIDS FOR THE EDUCATION SECTOR IN NAMIBIA, 2003, p3-7.

This national policy shall be applicable to all government and private education institutions in Namibia.

This policy formalizes the rights and responsibilities of every person involved, directly or indirectly, in the education sector with regard to HIV/AIDS: the learners, their parents and caretakers, teachers, administrators, ancillary staff, planners, in fact the whole of civil society. It underscores the dignity of all affected and infected by the disease and the respect that is their due. The policy provides guidelines to ensure that all in the education sector are fully informed about the disease, the way it is transmitted, the consequences and living positively with it. Below are some parts of the policy that focus on learners.

- Appropriate course content should be included in the pre-service and in-service training of educators to enable them to adequately respond to HIV/AIDS in schools.
- The purpose of education about HIV/AIDS is to prevent the spread of HIV infection, to reduce excessive fears about the epidemic, to reduce the stigma and discrimination associated with HIV/AIDS, and to foster non-discriminatory attitudes towards persons with HIV/AIDS.
- All educators should be trained to give to guidance on sexuality, sexual health and HIV/AIDS. Educators should respect their position of trust and the rights of all learners and students in the context of HIV/AIDS.
- This national policy is intended as a broad framework on which individual educational institutions may build. It has been kept broad in order to meet the wide variety of circumstances that exist in Namibia and in recognition of the importance of governing bodies, parents and caregivers in the education partnership. Heads of educational institutions are responsible for giving operational effect to this policy by developing an HIV implementation plan in consultation with governing bodies and parents or caregivers. Within the framework of the national policy, such plans should reflect the needs and values of their specific educational institution and its community.
- People living with HIV or AIDS in Namibia face discrimination and stigma on a daily basis. In the home environment they face rejection by family members, friends and parents.
- No learner or student living with HIV or AIDS may be unfairly discriminated against directly or indirectly only on the basis of his or her HIV status.
- No learner or student may be stopped from attending an educational institution or from participating in sports or play activities, only on the basis of his or her HIV status.
- Learners and students living with HIV/AIDS should be treated in a just, humane and life-affirming way and provided with support and counselling.
- Consultative mechanisms must be put in place in educational institutions to ensure that learners and students can effectively participate in the decision making and solution-seeking process concerning HIV/AIDS in those institutions.
- Any special measures put in place concerning a learner or student living with HIV or AIDS should be fair and justifiable in the light of current medical facts and knowledge and established legal, ethical and human rights principles.

- All learners and students should be educated about the fundamental human rights and freedoms contained in the Constitution of the Republic of Namibia. In particular, they should learn about the basic rights and freedoms of learners, students and education sector employees living with HIV/AIDS and the need for a human rights based response to HIV/AIDS.
- Learners and students living with HIV or AIDS have the same right as all other learners and students to attend any school or other educational institution. The needs of learners and students living with HIVIAIDS with regard to their right to basic education should be accommodated in the educational institution as far as is reasonably practicable.
- Learners and students living with HIV/AIDS are expected to attend classes in accordance with legal requirements for as long as they are able to do so effectively.
- No learner or student (or parent, caregiver or guardian on behalf of a learner or student) shall be required to disclose his or her HIV status to an educational institution.
- Voluntary disclosure of a learner or student's HIV status to the educational institution attended by him or her should be encouraged. An enabling environment should be developed in which the confidentiality of such information is ensured and in which unfair discrimination on the basis of HIV or AIDS is not tolerated.
- The Ministries shall appoint and train enough education sector employees as are needed to ensure that adequate attention is given to the teaching of life skills, sexual health and HIV/AIDS education at each educational institution.
- All learners, students and education sector employees should respect the rights of others regardless of their HIV status.
- The Code of Conduct adopted for learners or students at an educational institution should include provisions about the unacceptability of behaviour that discriminates against others with HIV/AIDS or that may create the risk of HIV transmission.
- Learners and students may not refuse to study with a fellow learner or student living with or perceived to be living with HIV or AIDS.