

The Lives and Experiences of HIV Positive Teenage
Learners: A Case Study of Intshanga Schools of KwaZulu-
Natal

By

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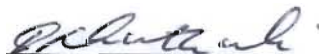
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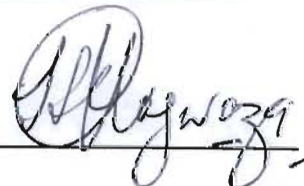
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Declaration

I declare that "The Lives and Experiences of HIV positive teenage learners, a case study of Intshanga schools in KwaZulu-Natal" is my own work. All the resources that I have used or quoted have been indicated and acknowledged by means of complete references. This study has not been submitted for any degree or examination in any university.

Signature: (student): 

Signature: (supervisor): 

Date: 18/04/08

Dedication

To all stakeholders that put an extra effort in fighting HIV/AIDS as a pandemic and the stigma around it.

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Glossary of Terms

- ARV's - Anti Retrovirals
- Umufi - The deceased
- Ukuthakatha - Witchcraft
- HIV - Human Immuno Deficiency Virus
- AIDS - Acquired Immuno Deficiency Syndrome
- T.V. - Television
- T.B. - Tuberculosis
- Teenagers - Young people clique between 15-19 years old
- Imbiza - A traditional herbal mixture/ medicine.
- Ubhejane - A rhino, a name for an Herbal mixture.

Abstract

The HIV/AIDS pandemic is acknowledged as a disease that has harmful impacts on the social and economic development of developing countries. Much of the research on the pandemic has not, until recently concentrated on its impact on the education sector and on teenagers as people living with HIV. This study investigates the lives and experiences of HIV positive teenage learners (main participants) in some Intshanga schools in KwaZulu-Natal. As teenagers are essentially minors, and would be under the care of parents or other caregivers, it was necessary to learn more about the lives of the teenagers from caregivers in the community and from family members within families where there are individuals living with HIV. The study provides some insight into how other people like family members and caregivers understand the pandemic as well as the role they play in the lives of those infected by the HIV virus.

Empirical data was collected over a period of a year (2004-2005) and yielded the following main findings:

- Fear about disclosing one's status: HIV and AIDS are still not accepted as one of the significant realities of the lives of learners. It is regarded as a shameful disease which most members of the community prefer not to talk openly about.
- Effects on affected learners: Social, economic and cultural circumstances and perspectives impact negatively on relationships in general and on relationships significant to learners themselves, i.e. parent-child and adult-adult.
- Persons living with HIV are called names by those who are seemingly not affected.
- Teenagers report that they avoid using local healthcare services because they have on occasion experienced being verbally abused at these health care centres.
- Teenagers are not assisted in dealing with peer pressure.
- Teenagers are vulnerable to making disastrous choices.

Chapter 1

1.1. Introduction

HIV and AIDS have proven to be one of the biggest challenges that nations have ever had to face. The impact of HIV and AIDS in South Africa has become so immense that no individual or sector can afford to ignore it, or work in isolation in trying to combat the disease. HIV and AIDS continue to have major effects on the lives of South Africans, especially children¹ who have been orphaned or made vulnerable by the pandemic. We have had numerous HIV/AIDS statistics and literature that concern the children. For instance; UNAIDS, 2004 estimates that 1.1 million children under the age of 18 years have lost one or both parents to AIDS and it will increase to approximately 3 million orphans by 2015. Of note is the fact that there is little literature on the direct impact of the pandemic on the lives of children. The literature deals mostly with the impact of the HIV/AIDS status of adults on their children. There is a distinct gap in the literature on how HIV impacts directly on youth and children. It is therefore crucial to have studies that seek to understand and present data on how being HIV positive impacts on the lives of young people.

Compared to other research fields, the education sector has received minimal attention and in particular young people attending school, who are living with

¹This study regards school learners as children hence the inclusion of this term in the narration.

HIV. According to the UNAIDS reports of 2003 and 2004, AIDS has overtaken malaria as the leading cause of death in Africa. These reports note that HIV infection is high in young people especially between 15 and 25 years of age. In this age group, more females are affected than males. There is a need to focus on the different manner in which HIV and AIDS affects females. Several scholars (Richardson, 1994; Gupta & Weiss, 1996; Tallis, 1997 and Tallis, 1998) have expressed concern that AIDS is a crisis for women given the greater vulnerability of women to HIV infection. Their arguments can be used to explain girls' greater vulnerability to HIV and AIDS.

The United Nations developed a Task Force to study the intersections of HIV and gender, following a planning meeting that was held in Johannesburg, South Africa. The meeting brought together global, regional and country level representatives from the United Nations. The meeting resulted in Terms of Reference for a study of the intersections of HIV & gender - focusing on six issues within a broad gender framework:

- Prevention of HIV/AIDS among young women and girls
- Girls' education
- Violence against women and girls
- Property & inheritance rights of women and girls
- The role of women and girls in caring for those infected and affected by HIV/AIDS

- Access to HIV/AIDS care and treatment for women and girls

Some of these issues were found to be of significance for the infected female learners in my study. The ensuing discussion will make reference to some of these issues. Female learner participants were asked related questions, such as:

- Have you ever been in a sexual relationship?
- Have you ever been forced to have sex?
- How old were you when this happened?
- Did you know about condoms?
- Where could you have known or have got access to condoms?
- How is your life generally?

1.2. Background and Geographical Location

This dissertation is based on an empirical study conducted at a semi-rural area called Intshanga, but represented as Intshanga in official documents. The latter representation is a corruption of the Zulu word, dating back from the colonial period. In this dissertation I opt to use the Zulu word Intshanga. This area is between the two main cities of KwaZulu-Natal, Durban and Pietermaritzburg. The focus is on Senior Secondary schools in the area, as this study focuses largely on teenage learners. Non-teenage respondents from Intshanga participated in

the study because of their potential role in deepening understanding of the teenagers in the study. These non-teenage respondents were either family members of the learners who live with HIV or people who were regarded as caregivers for the respondents. Although the empirical data was collected from 2004-2005, respondents who studied at Intshanga schools and were teenagers between the years 1996 and 2005 formed part of the study.

1.3. Statement of the Problem

In South Africa the HIV statistics is high as indicated below.

Fig. 1:

HIV and AIDS estimates for South Africa in 2005
Source: Department of Health 2006

Parameter	Estimate
HIV Prevalence (%)	18.78
Number Living with HIV (millions)	
Total	5.30
Men	2.19
Women	3.12
Adults age 15+ years	
HIV Prevalence (%)	16.25
Number Living with HIV (millions)	
Total	5.30
Men	2.19
Women	3.12
Total population	
Number living with HIV (millions)	5.54

Anne Ren (2006) points out that the magnitude of the global AIDS crisis is hard to grasp. It is estimated that AIDS deaths will reach 35 million by the end of 2010. These statistics do not account for all of those affected by the pandemic, that is, the children of those who have died or who are themselves dying of

AIDS or AIDS-related complications and the young people who are HIV positive. These children are among humanity's most vulnerable, helpless, and invisible persons affected by the pandemic. The generations of children who are infected and affected with HIV are creating a massive global humanitarian crisis.² Although this information is not directly linked to teenagers, its concepts and the scale of the problem is related to my area of study.

Similarly, there is an unusually high rate of absenteeism from school and a few deaths of past learners at Intshanga have been reported. The decision to include as respondents past learners who were teenagers between the years 1996 and 2003 stemmed from this observation. As I have been a pastoral-care teacher and life orientation educator at one of the schools for over a decade, I have been privileged to know, observe and record the situation. This situation affects the schools in the area and in particular, the secondary schools. Between 2003 and 2005 Intshanga schools have had about eight HIV/AIDS related deaths each year. The source of this information is anecdotal. The deaths are of former higher grades learners. It may be assumed that some of the learners may have acquired HIV through possibly having been raped at an earlier age.

Besides the enormous challenges presented by HIV, being a teenager is in itself, extremely difficult, as observed by Naicker (2006) in a study entitled

² <http://www.hampshire.edu/cms/index.php?id=8308>).

“HIV/AIDS as a Barrier to Learning: Exploring the Lives of Affected Children in the Richmond District”. As the adolescent stage is a time of experimentation, severe social and psychological pressures drive adolescents to seek to break free from parents and to succumb to temptations like sex, alcohol and drugs (Aggleton, 2006). For teens with HIV, the journey can be even more problematic as they face the challenge of preparing for “an adulthood they were never expected to reach”. This is a statement that was made by one of the participants, a past learner, who asserts that this is what she was told by a public health practitioner when she was diagnosed as being HIV positive. Helen Jackson points to the difficulties HIV/AIDS affected young people are likely to face noting that “children and youth face an increasingly insecure future” (2002: 23). She emphasizes that the disease is “indeed a tragedy in Africa, having surpassed any other major killer on the continent” (2002: 35).

Further, this study arises out of recognition that despite a number of efforts by government departments and non-governmental organisations to address HIV/AIDS in schools, learners continue to contract HIV and risk a possibility of later dying in isolation due to a prevalent tendency of abandoning AIDS patients. The lives of many learners continue to be at risk. Learners take longer to test because they fear to find out about their status and the resultant possible negative reactions from people in their community. The study revealed that fear is based on the knowledge that people with HIV/AIDS are stigmatised, and the existence of related recurrent myths (e.g. most condoms have the HIV virus,

virgin girls have a potential to cure AIDS and that drinking Coke with aspirin tablets immediately after sex prevents HIV). Due to misconceptions on how one may acquire or prevent HIV, teenagers are sometimes unable to distinguish between the facts and the myths about HIV and AIDS.

Alongside the main problem of this study, were the following problematic issues that presented themselves for the Intshanga schools:

- Ongoing stigma towards HIV and AIDS affected persons leads to discrimination or alienation of learners resulting in them having difficulty with accessing schooling. Although this factor was not found to be a rampant problem, one respondent reported that; he knows of a friend who decided to abandon school following a 'leak about his HIV positive status'.
- A reluctance to test for the HIV virus despite programmes that encourage individuals and families to do so resulting in teenagers not being diagnosed early.
- Most parents do not stay with their children due to jobs away from home, leading to minimal or nil parental guidance. This factor was cited by respondents as one of the reasons that make school learners more vulnerable to HIV infection. With parents away from home it more likely for adolescents to experiment with drugs, alcohol and sex, as well as making them more vulnerable to coercion to sex for financial gains.

1.4. Objectives and Significance of the Study

Having been a teacher at one of the schools in Intshanga for the past sixteen years, I have observed dramatic changes among the learners. There is less and less eagerness to play in the playgrounds and more caucus groups that seem to be involved in serious discussions. It has been found that the health state of some learners form part of the content of the serious discussions. The learners report that the discussions would constitute fear of shame and stigma that could result due to a possibility of contracting HIV; fear of being excluded from school as well as concerns of not 'reaching adulthood' as *siphila esikhathini sengculazi* (*we live in a period of AIDS*) as one participant expressed the concern.

Also, being involved in life orientation teaching I have been very close to the problem. I have learnt that learners are eager for knowledge and complain about the fact that parents communicate about everything except HIV and AIDS. Young people are eager for knowledge and without parents' open dialogue and guidance they 'feed on misconceptions' (see 1.3 above). Prior to conducting this study, the experiences of some teenage adolescent learners that confided in me, contributed to the need for this study.

The study therefore set out to;

- Learn about the impact of the HIV/AIDS pandemic on the lives and experiences of school learners of Intshanga.
- Highlight and analyse HIV positive learners' life experiences, as well as the experiences of individuals who come into contact with the learners. As teenagers often live with and depend on other people (i.e. parents, family members, health practitioners, teachers, pastors etc.); it was necessary to learn more about their lives from such people. In turn the study sought to find out how other people understand HIV as well as what role they play in the lives of those infected by the HIV virus.
- Find out who supports them and cares for them as well as their experience of such support and care
- Raise awareness in the community of the need for support and care for infected learners.
- Raise awareness in the community of the need to avoid stigmatisation.
- Suggest how schools, families and health care centres at Intshanga could be more supportive and foster hope in teenagers.
- To challenge all stakeholders including the government to take care for AIDS patients.

1.5. Focus of the Study

The HIV/AIDS pandemic is widely known as a disease that has a devastating impact on the social and economic development of developing countries. Much focus has been on orphans; that is, children who have lost parents to AIDS (Grainger, et al. 2001 and Louw, et al. 2001). According to UNICEF's "Children on the Brink" 2004 report, an estimated 16 million children aged 18 or younger are orphans. By 2010 this number is expected to increase to over 25 million. We have been exposed through academic, governmental, non-governmental and media resources to a number of stories featuring children orphaned by AIDS. However, details and reports about high school teenage children who are HIV positive or terminally ill due to Aids are sketchy. Of note is Nomkhosi Khuzwayo's 2003 master's degree study on high school students' sexual practices and their knowledge and attitudes regarding HIV/AIDS. Statistics and reports of teenage learners who live with HIV have been clumped into a generic 'young people' reference, that is, age 15-25. Studies have been done and some are underway - that look at the state of HIV/ AIDS at KZN schools (Balfour 2004, et al. and Majeke, 2004). These studies largely examine and report on teacher development and its impact on learners' perspectives on HIV/AIDS. It is therefore the intention of this study to isolate a certain 'young people' clique within the 15-19 year old teenage group; that is, Zulu speaking, school going, semi-rural residents, who are HIV positive. These reports note that HIV infection is high in young people, especially between 15 and 25 years of age. UNAIDS

(2002) attest that the vast majority of young people of this age group, living with HIV/AIDS in South Africa are female. My study takes into account the gender of the infected learners.

In conducting this study it became evident that South African teenagers in particular, are not viewed as a priority in the campaign against HIV/AIDS. The literature and programmes that do focus on youth seem to be biased towards the age group of 18-25 years. The study submits and recommends that it is crucial that teenagers below this age group receive appropriate attention as well. This arose out of the study's finding that teenage youth are sexually active, largely through coercion. One teenage girl learner related how she has had to repeatedly succumb to providing sexual favours to a male adult neighbour in order to pay for extra needs that most girls of her age have; i.e. airtime, make-up kits and costs for a hair salon.

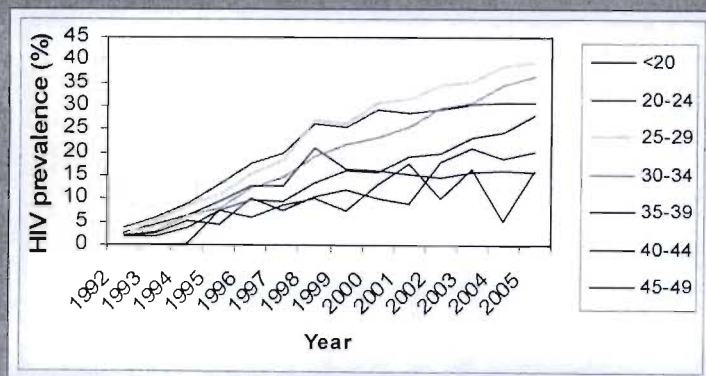
Education continues to be the most effective tool to fight HIV/AIDS. Observation of and conversations with learners prior to conducting this study signified that the effect of learning about one's HIV status was obvious at the school level. Learners said they found it difficult to think about school once diagnosed as HIV positive. This study was partially prompted by this observation. Due to fear of stigmatisation, teenagers reported getting distressed if they had a sense that they would not be accepted at school or by their peers. According to the Metro beat magazine, March 2005 issue, apart from the devastating effects this has on

youngsters' hopes for a brighter future, the latest surveys (see fig. 2 below) show that there has been an increase in the incidence of HIV infection among teenagers. The magazine asserts that the worst affected are girls who become sexually active between thirteen and nineteen years of age. Previous research studies report that relative to boys, girls become sexually active at an earlier age (Mok & Newell, 1995; Moohead & Gardner Huber 1997 and Helman, 2001).

Fig. 2:

HIV prevalence by age group among antenatal clinic attendees in South Africa, 1992-2005

Source: Human Sciences Research Council, 2005



1.6. Structure of the Dissertation

Chapter 1 is an introduction wherein I have discussed the key issues related to HIV/AIDS and teenage learners. Chapter 2 presents a review of published literature. Chapter 3 explains the research methodology and the limitations of this study. Chapter 4 presents and analyses the data where my respondents speak for themselves, and Chapter 5, contains the summary, conclusion and recommendations for policy as well as future research studies.

Chapter 2: Literature Review

2.1. Introduction and Extent of HIV/AIDS

As the province of KwaZulu-Natal (KZN) is amongst the key areas that face the greatest challenge of dealing with the HIV/AIDS pandemic, it does not come as a surprise that it is active in the production of knowledge in the area of HIV and AIDS. Although the following statistics (figures 3 & 4) are based on antenatal clinic results, they indicate the extent of the problem and have been applied in most discussions to understand the HIV prevalence of the general South African population.

Fig. 3: Estimated HIV prevalence among antenatal clinic attendees, by province

Source: <http://www.avert.org/safricastats.htm>

Province	2001 prevalence %	2002 prevalence %	2003 prevalence %	2004 prevalence %	2005 prevalence %	2006 prevalence %
KwaZulu-Natal	33.5	36.5	37.5	40.7	39.1	39.1
Mpumalanga	29.2	28.6	32.6	30.8	34.8	32.1
Free State	30.1	28.8	30.1	29.5	30.3	31.1
Gauteng	29.8	31.6	29.6	33.1	32.4	30.8
North West	25.2	26.2	29.9	26.7	31.8	29.0
Eastern Cape	21.7	23.6	27.1	28.0	29.5	29.0
Limpopo	14.5	15.6	17.5	19.3	21.5	20.7
Northern Cape	15.9	15.1	16.7	17.6	18.5	15.6
Western Cape	8.6	12.4	13.1	15.4	15.7	15.2
National	24.8	26.5	27.9	29.5	30.2	29.1

Fig. 4: Estimated HIV prevalence among antenatal clinic attendees, by age

Source: <http://www.avert.org/safricastats.htm>

Age group (years)	2001 prevalence %	2002 prevalence %	2003 prevalence %	2004 prevalence %	2005 prevalence %	2006 prevalence %
<20	15.4	14.8	15.8	16.1	15.9	13.7
20-24	28.4	29.1	30.3	30.8	30.6	28.0
25-29	31.4	34.5	35.4	38.5	39.5	38.7
30-34	25.6	29.5	30.9	34.4	36.4	37.0
35-39	19.3	19.8	23.4	24.5	28.0	29.6
40+	9.8	17.2	15.8	17.5	19.8	21.3

Medical researchers' recent reports provide statistics that is more alarming than the above figures. They assert that the rates of HIV and Aids infection among women in several parts of KwaZulu-Natal have provincial prevalence levels varying between 38 and 50 percent (*The Mercury* newspaper, 07 September 2007). In an article of the newspaper entitled 'KZN's shocking HIV rates' Professor Gita Ramjee, of the Medical Research Council in Durban, said that in one area of the South Coast the HIV prevalence level in women was as high at 70%. In Intshanga, my study area, the prevalence was found to be at 55%. The new HIV prevalence statistics came out during clinical trials by the council, which is testing the effectiveness of a variety of vaginal microbicides at eight test sites around the KZN province.

To conceptualise the study and gain enhanced insight in the field, various literature was consulted. Literature that is non-academic and informal has had a huge role in providing information that often takes long to get to academic publishing arenas. There is a dearth of academic information on teenagers

and HIV and AIDS – with a specific focus on their lives and experiences. In order to gain a deeper understanding of the problem, I relied heavily on information from newspapers, South African national television programmes, magazines, and to a limited extent internet sources. Relatively speaking these sources of information have proven to have more empirical data, practical cases and updated information about HIV and AIDS. It is for this reason that this literature review section appears biased against non-academic and research based sources of data than may be expected of a master degree mini dissertation.

It is essential to note that some of the literature survey presented hereunder is not related to teenagers or the HIV and AIDS field per se. The survey and use of such literature was necessitated by the complex nature of the subject of HIV and AIDS, specifically in relation to teenagers. I therefore make reference to literature on teachers, families, communities as well as literature that can be regarded as "recommendation-based". Furthermore, reference is also made to literature on 'care' with regard to HIV and AIDS affected teenagers and my view that 'caring for' goes beyond the act of clinical care. It is worth noting a few key sources that deal mainly with teenagers and their life experiences. These are: van Dyk's (2001) *HIV/AIDS Care and Counselling*; Treadwell's (1988) *The Problems of Adolescent*; Noller and Callan's (1991) *The Adolescence in the Family*; Coleman and Hendry's (1999) *The Nature of Adolescence*; Claxton and Harrison's (1991) *Caring for Children with*

HIV/AIDS and Christie-Dever's (1996) *AIDS, What Teens Need to Know*. This set of literature deals with teenagers' experiences in general, conflicts (internal and between teenagers & family members) that happen before and after teenagers have been either directly or indirectly infected by the HI virus, counselling methods for the young people, and essential information that teenagers ought to have in order to deal with the challenges that they often face. It is apparent that this set of research literature has limitations in particular in relation to the subject of my study.

The discussion of the ensuing literature takes into cognisance the fact that the challenge of the teenagers impacted by HIV and AIDS is complex. Hence, I take into account other literature that was found to have a positive effect in bringing about an enhanced understanding of the problem at hand.

Also, included in the discussion are instances and case studies³ that I believe, are crucial in gaining an enhanced understanding of my area of study. Some of the data used to elucidate points of discussion are from the mass media as well as from empirical studies. Such a literature survey responds to feminist practice of using personal narratives, embedded in the principle of 'relating and contextualising abstract information to the personal – as the *person is*

³ In an attempt to make this literature survey speak to the area of my study, I include the actual voices of some of the participants – a practice that is encouraged by feminist research scholars like Stanley and Wise, 1983.

political'.⁴ The complex nature of teenagers affected by the pandemic necessitates my option to categorise my discussion into various titled themes:

2.2. Kinds of Family

Greathead (1998) describes types of families and maintains that family forms impact the health of children as well as contribute to their existence or nil thereof of their wellness. There is a nuclear family which consists of a mother, father and children. It is the modern family typical in Western Culture. The extended family includes grandparents, uncles, cousins and in-laws. This is the traditional family found in Africa especially in KwaZulu-Natal. The single-parent family is becoming common and may consist of an unmarried man/ woman with illegitimate child or a divorced man or woman with custody of the child or a widow or widower. The step family is where a mother and father have remarried. Such a family sometimes includes children from both previous and new marriages. The children can be referred to as 'his, hers and ours'.

The foster family is where children are placed in the care of a suitable family with no biological relationship. Children are removed from parental care for various reasons such as neglect, abuse or drug and alcohol abuse. There is also child-headed family where both parents may have died. For some girls, there is a great need to be loved and cared for, particularly if they come from a

⁴ See Weedon, 1987 and Stanley and Wise, 1983.

neglected home. Marriage for them is a way of escaping to the romantic ideal of living 'happily ever after'. Unfortunately all too often the problems they are running away from are carried with them into the marriage, with history repeating itself. For others, the romantic illusion of marriage allows the teenager to avoid planning for the future and no longer having schooling and careers to worry about.

2.3. HIV/AIDS and Youth

The HIV/AIDS pandemic continues to constitute a global crisis of unprecedented proportions. Although HIV/AIDS affects all sectors of the population, it has had a particularly dominant effect on young Africans. Approximately 50% of Africans are less than 18 years old. This statistics indicate Africa as the most "youthful" continent in the world (CODESRIA, 2005). Evidently, greater knowledge and understanding of the lives and experiences of young Africans is required in order to examine the course of the HIV/AIDS pandemic among them.

According to Coombe (2000: 3) many adolescents are sexually active at the age of 12, but note with disdain that few practice safe sex. Concurring, Badcock-Walters (2002) posits that one third of all HIV infected South Africans are infected during their school years. He advances this argument and notes that schools are "a high risk environment but also suggests that it is the key strategic

ground on which the battle to mitigate the impact will be won or lost". (Badcock-Walters, 2002: 95)

Significant literature on the status quo of HIV and AIDS within the schools is recorded in a journal (*Agenda no. 53*) that emanated from a 2002 colloquium entitled "Instituting Gender Equality in Schools: Working in an HIV/AIDS Environment". The focus of the meeting was a discussion on intervention strategies within the schools. Burns (2002:9) admonishes that 'the current HIV/AIDS crisis calls for simultaneous deep and long-term as well as rapid and imaginative programmatic development' for achievements to be realised in schools in the fight against the pandemic. In the same vein, Morrell et al. (2002) advise that schools are a good forum for campaigns aimed to promote gender equity and reduce HIV transmission as they are institutions aimed for children between the ages of six and 16. Seeming to respond to this call; Harrison (2002) reports on a research she led that sought to design an intervention based on examining social factors that put youth in rural KwaZulu-Natal at risk. She decries the fact that few interventions address the needs of rural youth but quickly points out the need to have interventions that 'emphasise the acquisition of skills related to decision-making and negotiation for young women' (Harrison 2002: 50).

Potsonen et al. (1999:480) and Kelly (in Baxen et al, 2004) in agreement with Morrell et al. (2002) and Harrison (2002) assert that schools are among the best sites for educational efforts for adolescents about HIV/AIDS.

2.4. Challenges and Complex Nature of Teenagers

Developing the argument of the complex nature of teenagers and the difficulty for adults to deal with related challenges, Amit-Talai and Wulff (1995) caution adults who deal with teenagers. According to Amit-Talai and Wulff (1995: 178), a sense of deprivation or an unfulfilable dream of teenagers constructs one's behaviour, so it is important for us to be careful when dealing with teenagers. Freeman (1983: 105) states that in the past, society did not appear to have been troubled by its maltreatment of children. He was particularly mindful of the universality of cruelty to children, hence the necessity of my study. The parents, Freeman (1983) noted, were often of lower intelligence, immature; self-centred and quick to react with poorly controlled aggression. Freeman (1983) also points to alcoholism, sexual promiscuity, unstable marriages and minor criminal activities as common characteristics that add to challenges that teenagers have to deal with.

Teenagers' delinquency is also associated with some parents who divorce and ignore their children's needs. On the other hand some authors (Coleman & Hendry, 1999 and Crainger) say it is not uncommon for teenagers with health

problems to blame themselves for their parents' separation or divorce. According to Wyn and White (1997), the idea of risky behaviour and of risk-taking is also central to the discourse of youth development. The idea that adolescence is a time of stress remains very popular. Although citizenship is frequently mentioned with regard to young people in terms of young people's responsibilities, society also has a responsibility to recognize and take care of young people as citizens. On television E news 01 July 2005, a KwaZulu Natal teenage girl gets three years house arrest for murdering her four year old step-sister in a jealous rage. This shows how stressed teenagers can be and this leads them to have hatred and uncontrollable anger. They need to be taken care of and be given love and support they deserve even if they have lost their parents.

2.5. Risks Confronting Teenage Learners and Related Impact of HIV

Data from some mass media show that it is important for parents, teachers and peers to consider the stage of adolescence and understand teenagers and their peculiar behaviours. Lack of understanding may lead to conflict which may be very difficult to resolve. It has been observed that, once there is conflict, teenagers are often short-tempered, may feel that they are over-controlled and subsequently resort to disastrous choices. According to the *Daily Sun*⁵

⁵ 14 October 2005, article by Ntebatse Masipa.

newspaper, a girl aged 19 who had run away from home due to a fight with her parents was raped by a policeman. She had gone to the policeman for help in an attempt to reconcile her with her parents but the policeman raped her instead. It is not uncommon for teenagers to make disastrous choices which they may later regret. A female teenage participant in one of the schools at Intshanga reported of being exposed to a similar case which unfortunately led her being infected with HIV. The impact of HIV positive young people can be enormous and disastrous for both girls and boys. In the Witness Newspaper, Tuesday 26 July 2005, a boy aged 14 kills his sister. The reason for the murder is that his sister is well-behaved and loved by her parents whereas he is HIV positive and is not on good terms with his parents.

Incidents cited above are made reference to by Treadwell (1988) when he infers that teenagers do develop hatred for their parents and wish to leave them. Often when they leave homes, they also do not want to go to school. Treadwell asserts that such cases can be prevented, and says teenagers need to be properly guided in order to make appropriate decision. In support of Treadwell's assertion, van Dyk (2001) and Noller & Callan (1991) posit that parents must develop an ability to communicate with teenagers' sensitive behaviour both in and out of school. Failure to find appropriate strategies to communicate with teenagers may end up putting more pressure on them, and they are likely to develop hatred even towards themselves and subsequently make wrong choices (Claxton and Harrison, 1991; Christie-Dever, 1996 and Treadwell,

1998). Amongst the choices that teenagers may make could be to find comfort in 'sugar-daddies' who have been reported to be more likely to infect them with HIV⁶ In the Intshanga study some teenage respondents reported having had such kinds of relationships (see the testimony in 1.5 above) which expose them to HIV. This is evident in how girls as opposed to boys may acquire the virus – which explains higher statistics of infections amongst girls⁷ One 16 year old respondent was impregnated by a 'sugar-daddy'.

Incidents of being treated bad due to a pregnancy were reported in this study. According to the Metro Beat (March 2005), a Durban based magazine, most pregnant teenagers face alienation by their peers and sometimes even by their educators if they try to continue their schooling. In recent times there has also been an assumption that pregnant school girls are already infected by HIV or carry the disease. In one of the schools studied, it was found that some pregnant learners were forced to leave school due to pressure by teachers and schoolmates, as well as nasty verbal utterances.⁸ Such attitudes and practices are related to stigma that continues to be attached to people living with the HIV virus. This situation is to be discussed later on in the dissertation. However, in summary this discussion highlights the importance of caring. An approach that displays comprehensive care can prevent teenagers from being unfairly treated

⁶ UN Report, by United Nations Secretary General's Task Force on Women, Girls and HIV/AIDS in Southern Africa, 2005.

⁷ UNAIDS, 2004.

⁸ This is in violation of *The Declaration of the Rights of the Child* which South Africa is a signatory of.

and resorting to estranged behaviours– that can, as argued above, may result in teenagers contracting diseases, becoming ill and eventually dying (Treadwell, 1988; Foss & Farine 2000 and van Dyk, 2001).

“The Declaration of the Rights of the Child”,⁹ requires communities and adults in general to provide care for teenagers. Certain sections bind the country as follows:

- “The child shall in all circumstances be among the first to receive protection and relief.”¹⁰
- “The child shall be protected against all forms of neglect, cruelty and exploitation.”¹¹

In the declaration of the Rights of the Child of 20 November 1959; children must enjoy special protection and be given opportunities and facilities to enable them to develop physically, mentally, socially and spiritually. The child needs love, understanding and should grow up in the care of parents. Parental rights can be restricted or even terminated if it endangers the health, security or moral welfare of the child. Many of the obligations that adults have towards children are supported by legal regulation. Parents’ conduct towards their children can be

⁹ Proclaimed by the General Assembly, Resolution 1386 (XIV) of 20 November 1959.

¹⁰ 8th Principle.

¹¹ Ibid, the 9th principle.

scrutinized by state agencies to determine whether they are taking care of their children properly.

Parents and teachers need to be encouraged to adhere to these principles irrespective of the health status of a child. The alarming suicide statistics that 1 in 10 teenagers in South Africa commit suicide every hour, every day is a worrying reality (SABC television news, 13 September 2005), and should prompt a number of research projects into the causes of this serious situation. This is also the situation in Intshanga and needs urgent attention by parents, teachers and the community at large. The study found that HIV was a cause of some of the Intshanga suicide cases. It is in such situations that Claxton & Harrison (1991) and Leininger (1988) recommend that teenage learners be afforded attention that is cognisant of their unique needs.

Julie Bettie's book "Women without Class" analyses high school teenage behaviour and identities. Bettie's (2003) discussion, though referring to a US situation is found applicable to Intshanga schools. She refers to what she calls 'youth crisis', i.e. too much sex and violence which makes youth a threatening enemy to be feared. At Intshanga violence on girls by boys and between girls was cited as an emerging problem with a potential to impact negatively on HIV positive learners. A participant referred to a fight that developed out of an allegation that a learner who had confided about her positive status to a friend was a then a school talk. This is an indication that contemporary teenagers'

lives are impacted with different pressures that teenagers of a decade or two ago due to HIV. In an article 'Hitting Hard: HIV and Violence' Zierler (1997) alludes to the fact that violence within a context infested with HIV challenges is a reality.

For girls the challenges are reported to be intense due to their reproductive capabilities (Tallis, 1998). Teenage girls' pregnancies and HIV infection has been linked to pressure imposed on them by boys and adult males - to have sex when they are not yet ready (Brookes et al, 2004). From the study, it was reported that one teenage female respondent, reported that her pregnancy a year earlier was due to coercion and threats from a fellow male learner.

O'Donnell and Sharpe say official school policy on gender equality is a significant factor in the attitude formation of many of the boys (2000:16) as well as in instilling a culture of responsibility and respect for girls. The challenge is that schools at Intshanga do not have such policies and boys are not shaped to be good supporters. O'Donnell and Sharpe (2000: 38) believe that "the gap between what teachers are trying to achieve with 15 and 16 year olds and what some boys would rather be doing can create an air of non-communication and a sense of cross purpose in the classroom. Matters can deteriorate in all sorts of ways, sometimes into substantial disorder but more characteristically into student boredom and teacher frustration. The schools' responsibilities and policies need to be scrutinised as these are imperfect situations which need to

be taken care of. It is inevitable for 'uncared for' and bored school children to engage in unprotected sex which can lead to contracting HIV and drug abuse.

2.6. Educators, Parents & Caregivers' Obligations and Support

Claxton and Harrison (1991) say teenagers are unique in their attitudes, emotions, presentation in illness and their nursing care needs. For the purpose of this study the necessary care is assumed to be beyond that of just 'nursing' In the context of this study, subsequently, these authors infer the importance for teachers to have a manageable number of learners in classes so that they can have time to attend to learners individually, and be in a better position to identify learners' problems earlier. Unfortunately the reality in Intshanga schools is that school teachers have big classes and are therefore challenged to realise such an ideal.

Some AIDS scholars like Campbell and Foulis (2002) argue that there is a need to get health practitioners and educationists who are appropriately trained and qualified so as to reduce the reported high rate of deaths. Although there are no researched statistics on the death rate in Intshanga, anecdotal reports infer the rate of 6-8 deaths a year (from ill health and suicide) is related to HIV and AIDS. The high death rate of teenagers does not only affect families of Intshanga, it also affects the educators of schools because, and as asserted by some respondents the deaths retard the progress of schools. According to Lovell

(2002), AIDS is also blamed for shortages of skilled workers and teachers. Although it cannot be confirmed that the ensuing expression of fear is based on teenage deaths, it however is worth mentioning – as in turn the teachers' reaction and attitude towards teenagers living with HIV is likely to be a burden on the teenagers (refer to the reference to nasty verbal utterances in 2.2. above). This factor was cited by one of the adult participants in this study. She noted;

We as teachers find ourselves somehow unstable in our jobs as we are faced with the process of right-sizing and a threat of being redeployed elsewhere, even in far away places. This (referring to teenage deaths) makes the teachers' future to be unclear and they are even hesitant to further their studies to get higher academic degrees.

A factor pointed out by Cashmore (1984) is worth noting. Cashmore says education cannot fulfil its promises of good qualifications and work with decent pay and job satisfaction. The fact that there are also teachers at Intshanga who are infected and intensely affected by HIV cannot be ignored as it does impact the lives of HIV positive learners as well. AIDS impacts negatively on these teachers because they absent themselves from school and others become alcoholics and they frequently become ill. The escalation of the number of teachers' absence disturbs school schedules and can be regarded as one of the reason that children also absent themselves from school. Whilst away from school they become vulnerable to HIV, as they may engage in unprotected sex during school time. A conversation with two learners inferred this possibility, as learners are exposed to unprotected sex and drugs.

Reflecting on what is ideal; Lee (2001) says the school was a place in which skills and information were conveyed from teacher to learner. The school also produced day-to-day performance and general standards of competence. Although these ideals are of the old model, at Intshanga schools they are spoken of and recorded in some school codes as principles teachers should work towards. Furthermore, Lee points out that it is important for a teacher to behave well because he/she becomes a mentor and role model to learners. This is in line with what is traditionally expected of a community and schools that subscribe to good Zulu cultural values, as in Intshanga schools. Misbehaviour ranging from distracting learners by engaging with them in activities that are not expected of teachers ought to be prevented for the schools' clear educational objectives to be met. Teachers are therefore expected to be good guides and guards (Bockneck, 1986). All forms of conduct that learners could undertake in independence of the teachers' intentions and commands have a potential to be problematic. Rather than seeing the roots of this problem in social deprivation or poverty, and instead of questioning their ideals of childhood, adults have tended to see the children themselves as the location of the problem in the community. This study found that the discussion of this literature ring true for Intshanga schools and that accessibility, exemplary behaviour and good attitudes of teachers contribute in assisting learners deal better with personal challenges including health issues. Some teenagers reported finding some teachers inaccessible and therefore unable to talk to them about their health conditions.

As the family and the school are the centres of learning, it is their responsibility to take note of what is important about development and fulfilment of the potential of teenagers (<http://www.esrnational.org/home.htm>). If the parents, teachers and learners were to work together, most of the problems encountered by teenagers could be resolved.

It ought to be the schools' responsibility to provide educational experiences that improve young people's functioning in psychological domains such as self-esteem, self-awareness, expression of feelings, clarification of values and decision making (Aggleton, 2006). Boys and girls' behaviours ought to be monitored carefully as risky behaviours are likely to crop up (Schaefer and Hamm, 1994).

Reflecting on the adolescent, Coleman and Hendry (1999) say it is at teenage stage that young people are most in need of establishing their right to freedom, while at the same time it is the stage for parents when they least wish to lose control. It is more a matter of who has the authority than who is right. If young people and their parents define daily issues differently, then it may be that the resolution of conflicts will be difficult. They admonish guardians (parents and teachers) not neglect their children or be too harsh on them because this affects children negatively and further confuse their growing and complex stage.

At teenager stage there is a tendency for children to rely more on information given by friends and peers than that given by adults. According to Bocknek (1986: 70), the attitudes and values of peers not only replace the temporarily rejected family values, but also reflect more closely the existing psychological needs of the adolescent. To parents on the one hand the teenager is caught up in running around in frenzy and often wasting time. Peers on the other hand, are better able to recognise the need to burn off great surges of energy (Bocknek, 1986). He further asserts that parents may have difficulty in adjusting to the adolescent impracticality and radical shifts in attitude. This may be the period which may lead to a breakdown in family relationships and the start of problems which needs to be carefully handled (ibid.).

Some scholars' views on how to deal with teenagers call for teenagers' guardians to be careful in their choice for solutions. According to Kitwood (1980), adolescence is a period of moving away from parents both physically and psychologically. From a social - psychological point of view, adolescence arrives when boys and girls reach total independence from adults in certain areas of their lives; their projects begin to take on distinctive form; they move into social life-worlds which are evidently not childish and whose control at least in an immediate sense is in their own hands. I do not agree with these statements because it is always necessary for teenagers to be under their parents' care and control and they must not perceive home rules as unreasonable parental demands.

2. 7. Stigma and Discrimination: Impact of HIV on Teenagers

HIV/AIDS-related stigma has been recognised as a key problem that needs to be addressed in HIV/AIDS interventions. Most literature on HIV/AIDS and stigma indicates the extent of the problem acknowledging that stigma increase vulnerability of people living and affected by HIV/ AIDS (Chase & Aggleton, 2001; Dane & Levine 2005 and Deacon et al, 2005). The literature refers to psychosocial effects of the Aids pandemic on children, stigma as well as means employed by families and to deal and cope with stigma.

Chase & Aggleton (2001) report about the seriousness of the HIV/AIDS related stigma noting that it reduces access to treatment. Campbell validates this factor and posits that stigma robs many people access to treatment and the right to live a healthy, happy life (Campbell, 2005). This was found to be the case in Intshanga, learners reported difficulty in either starting or continuing with treatment due to fears of being the 'talk of the town' and the resultant stigma that both the infected and their family members endure. Due to fearing stigma the study found out that it was uncommon for members of the Intshanga community to live openly with the disease. Disclosing one's HIV status cited as a huge challenge. Brown, Macintyre & Trujillo (2003) mention that people who are infected and affected by HIV/ AIDS prefer to keep their problems secrete. A drama series in a South African Broadcast Corporation television alludes to a similar problem.

Burnard (1992) says friends and families respond and react in various ways to the knowledge that one of them has AIDS. Not all are supportive, and sometimes the person with AIDS has to face rejection by those he or she has loved. Sipho of *Soul Buddyz* (Television Drama series) is ashamed of his twin sister Thandi, who is HIV positive. He does not want his sister to disclose her HIV status at school fearing that his home will be stigmatized as they fear they will be discriminated by teachers and schoolmates. Issues of discrimination exist in areas that are least expected. During a visit to the 2004 Gender and Health class of the University of KwaZulu-Natal excursion at the Sinikithemba Clinic on the 16 September 2004, in Durban McCord Hospital, we were told that nurses have problems with HIV/AIDS issues. Nurses are afraid to disclose their HIV status fearing discrimination by doctors as well as patients. The McCord Hospital has had to open a voluntary testing centre for nurses but they are afraid that they will be stigmatised and discriminated. Such treatment of nurses can be largely attributed to their female gender. Despite statements by *The AIDS Epidemic Update* (December 2003) that the law can be a powerful tool against stigma and discrimination, instances as quoted above are a gender challenge. It is crucial to advance recommendations that the law and the caring ethic gets enforced as HIV/AIDS impacts on the most vulnerable – including young children and teenagers.

Some research report that some parents may unknowingly contribute to their children's inability to deal with pressure (Saunders, 1981). Noller and Callan (1991) state that adolescents whose parents are authoritarian and coercive in their relationships with them are likely to have lower self-confidence and self-esteem and likely to have problems in using their own judgment as a guide to behaviour. In turn they may find themselves vulnerable to be assertive.

Teenagers with HIV experience guilt, grief, loss of power and loss of control (Rathus & Boughn, 1994). That is why most people [teenagers] do not want to disclose their HIV status and maintaining secrecy becomes a huge burden (Naicker, 2006 and Schonnesson, 1999). The constant fear that people will find out, hinders access to health care, emotional support and basic rights.

The article by Pat Hlongwane in the Informer News, Volume 2, Edition 6 reports that the youth are forced out of their comfortable homes by unbearable and very harsh conditions because of hunger or abuse and also because they are HIV positive. This is a reality that the youth living with HIV have to deal with.

On the other hand, notes Hlongwane, HIV positive youth that have a good support base deal better with the pandemic. At a personal level, even with existence of personal challenges, the existence of support help with personal growth, clarify values and goals; offer an opportunity for self-definition, as well as to improve self-esteem, skills and knowledge acquisition. This was confirmed

by an HIV positive AIDS activist, Zandi (pseudonym) enrolled in the Women's Leadership Program run by Gender AIDS Forum (The Gender Aids Forum Power Talk Magazine, 2006), who experienced a lot of painful things like rape; teenage pregnancy and HIV infection. She says these experiences made her have a very strong backbone and she is now able to overcome whatever problem that comes her way as long as she is still alive. Teenagers are also at high risk for sexual violence both as victims and victimizers. Zandi started as a victim but ended up victimizing others by demanding school boys to have sex with her. My study highlights the vulnerability of both boys and girls to sexually coercive or exploitative situations.

According to Burnard (1992: 7) friends and families respond and react in various ways to the knowledge that one of them is HIV positive or has AIDS. Not all are supportive and sometimes the person with AIDS has to face rejection by those he/she loved. Silver and Caldarola (1989) as cited in Burnard (1992), state that this may be coupled with the fact that facing AIDS can lead to psychological problems and feelings of dispiritedness and meaninglessness.

Corbett (1989) says that distress and suffering caused by ill health of loved ones and related experiences of being stigmatised results in the suffering of the whole family, especially if the sick person is a breadwinner.

2. 8. HIV/ AIDS Counselling

According to Bender et al. (1998), there are no “quick-fixes” to the problems of accessibility to effective counselling and to adequate follow-up care. There is need for early intervention services especially for children. Bender also states that a policy on mandatory HIV testing for patients and health care workers violate their rights to privacy and self determination and cannot be justified because it could lead to discrimination against those who test HIV positive.

According to Soul City magazine, we can all support one another by helping each other to cope with the disease and to live with it positively. We can also help teenagers by joining support group circles. Those infected with HIV have the same needs, wants and rights as other people do. Counselling is the most useful approach to psychological and psychiatric manifestations of HIV disease. Youle et al. (1988) believe that it is essential that the counsellor has a thorough understanding of the different life-styles of people who might be affected by HIV infection, thereby avoiding unnecessary moral judgments. During counselling sessions patients are helped to work through the grief phase and often reach acceptance of the infection and its possible consequences.

Acknowledging the need to provide help to people who counsel and care for the sick and HIV infected; UNAIDS (2004) states that individual 'carers' need information and training on what to expect from AIDS, how to care for a patient and where to receive counselling for their own emotional needs.

2.9. Poverty as a Social Challenge in the Context of HIV/AIDS

Informed by the relevant literature, this section describes how poverty affects teenagers until they are driven to unacceptable behaviour. There are painful experiences and hardships facing teenagers and its root cause is poverty (Oyen, et al. 2002). Some experiences are painful and beyond human comprehension. Confirming Plant's (1990) assertions on prostitution a shocking story appeared in *The True Love Magazine*, February (2005: 82): it says child prostitution is alive and thriving all over the world including South Africa, where kids as young as eight years old can be found and forced selling their bodies on the streets. It says Sthembile (pseudonym) started selling sex at the age of 8 to get money to help her mother who had cancer. Her father knew what she was doing and he was happy when she brings money home. Some teenagers have become breadwinners by selling sex (Sweetman, 2002).

In South Africa poverty affects girls in a more intense way than boys (Walker, 1993, Walker, et al, 2004 and Budlender, 2005) and in turn exposes them to HIV infection. The Head of the South African Child Protection Unit, Andre

Neethling told True Love Magazine (2005) that some of the girls, most in their teenage stage had been kidnapped while others had been sold to the criminals by their parents. It is difficult to stop child prostitution because the child receives rewards for their services and the parents also benefit financially. Children are particularly vulnerable to HIV/AIDS because they cannot tell men to practice safe sex (Rotmann, 2005).

Walker's (1993) book "Managing Poverty" gives insight into the negative effect of poverty and unemployment. She says unemployment is seen as a threat to the moral behaviour because it becomes easy even to commit suicide. Teenagers could be drawn into stealing, selling drugs and selling sex (Walker, 1993). At Intshanga the study found a few instances of parents who, due to being unemployed encourage their teenage daughters to 'sell sex' – by setting them up for relationships with older men. These are situations that make Intshanga teenagers more vulnerable to the disease. Similar unfavourable circumstances have been reported elsewhere in South Africa. The Bona Magazine, January 2005 reveals that a study carried out in an informal settlement North of Johannesburg reveals that 40 parents of girls below age 16 are involved in prostitution and one in every five is HIV positive. Sexually exploited children face serious, life-long and life-threatening consequences. They are also more vulnerable to sexually transmitted diseases as their body tissues are more easily damaged (Harrison, 2002; Seabrook, 2003).

Noting the existence of poverty even amongst the employed, Dudwick et al. (2003: 3) state that poverty and unemployment are correlated more weakly than one would expect because much of the labour force remains employed but receive very low wages. In turn exposure to HIV infection and a resolve (discussed above) to sell sex may be a reality for females that are unemployed on starvation wages (Webb, 1997). Dudwick et al. (2003: 4) says the hardships of poverty have been accompanied by symptoms of enormous social distress which include suicide, drug abuse, violence, the breakdown of families and the abandonment of children and stress and trauma related illness that have contributed to heightened mortality rate. These circumstances were found to resonate in Intshanga.

Jackson (2002) draws parallels between HIV/AIDS and poverty, asserts that HIV impacts on the most vulnerable and has devastating effects on communities, contributing to a rise in poverty which reduces the ability to cope with the disease. Developing Jackson's assertion Lovell (2002) argues that HIV generates new poverty as people lose jobs due to absenteeism and spend more money on medical bills and funerals. Corbett's (1989) discussion is within the same wave length as it highlights the fact that poverty leads to depression and loss of hope which can result in teenagers developing negative attitude towards life. Further, Corbett notes that sickness leads to the further impoverishment of already resource-poor households which is difficult to reverse.

Konopka, 1966 and Osmani, 1992 believe that nutrition and poverty are very closely related and many aspects of being poor such as hunger, inadequate health care and the stress and strain of living, always means being deprived of full nutritional status. Osmani (1992: 70) is of the opinion that the adverse effects of diet and infectious diseases during early life exert a lasting influence on subsequent growth.

According to Christie-Dever (1996), for people living a poor, harsh and short existence without prospects for the future, the risk of HIV/AIDS infection matters little, as it is merely an additional threat to their lives. This is another angle that draws a correlation between HIV/AIDS and poverty. Poverty has made people engage in unprotected sex as their only way of entertainment because they cannot afford any other thing (UNAIDS, 2004). Bettie (2003: 46) says teenage pregnancy does not cause poverty but vice versa; girls who become pregnant early and especially those who go ahead and give birth are more often than not poor to begin with. In addition, Noller and Callan (1991) and McRobbie (2000) mention the fact that teenage mothers are a stigmatized female group. They have a lot to contend with and all this leaves young single mothers disadvantaged. This is what the some HIV positive teenagers of Intshanga reported as part of what they experience.

For poor families it is a challenge to provide basic like shelter and food (Griffith, 1994; Wilkinson, 1998). This is because if you are poor you cannot afford to buy

healthy food and effective immune system boosters. Noting the gender dynamic for providing food, South African National Guidelines of Nutrition (2001) say it becomes a duty of a woman to provide a patient with a balanced diet but it becomes difficult where there is no money to buy nutritious food. Pietermaritzburg Agency for Christian Social Awareness (PACSA) Fact sheet number 52, August 2004 - an article by Daniel Genrich states that many social ills such as crime; violence and drug abuse can often be tracked back to the dehumanising effect of prolonged poverty and unemployment. This report cites the fact that children and the youth are adversely affected by such conditions, the circumstances that Adams & He, 1995; White & Killick, 2001 concur with.

There is a group of authors who hold that AIDS causes devastations and worsens conditions of poverty and social ill; i.e. Seabrooke, (2003) Hagenars, (1986) and Schoub (2000). O'connor (1991) concurs with these authors but extends his argument to look into the impact poverty in the context of HIV/AIDS has on the youth. He says the incidence of most forms of malnutrition is far higher among children than among adults and that many diseases cause far more child deaths than adult deaths. Non-academic literature (Drum magazine & Informer News) has featured stories that relate similar effects of AIDS and poverty on children and school learners.

According to Wilkinson (1998: 79), a third of the children on the African soil come from homes below the poverty line where teaching and learning become

more difficult. In a context where HIV/AIDS is rife like at Intshanga parents battle to raise their children well. It is in such contexts that Wilkinson says children brought up by parents coping with increased stress of caring for HIV infected or affected children are more likely to have challenges of emotional and behavioural problems.

2.10. Gender Inequality Implications

A number of scholars have discussed HIV/AIDS and its impact on women. The category, 'women' is understood by this study to refer to young women as well. UNAIDS (1999) reports on findings of the United Nation's General's task force on girls and HIV/AIDS in Southern Africa, that reflect that gender inequality fuels infection because many girls cannot negotiate safer sex or turn down unwanted sex. These findings demonstrate that HIV/AIDS deepens and exacerbates women's poverty and inequality. The UN report further notes that AIDS burdens women and girls with care responsibilities, taking them away from school and productive income producing activities. This assertion is supported by the PACSA information sheet (1999).

According to South African Cities: HIV/AIDS Challenges and Responses (2004), poverty and gender discrimination often combine to deny access to drug services that can effectively treat HIV/AIDS; and poverty also limits access to services, appropriate housing and sufficient nutrition. The growth of informal

settlement appears to provide a favourable environment for the spread of diseases including HIV/AIDS. For Griffith (1994) and Corbett (1989) it is in such communities that the female, who is often the head of the family get exposed to harsh living conditions.

According to Jo Manchester (2004) women and girls with HIV are often trapped in cycles of poverty as their income diminishes and their day to day expenses rise. Manchester makes reference to effects on women (and their children) who have been divorced or abandoned due to HIV – who are often left homeless with no proper way of caring for their children.

Analysing the relationship between gender, HIV/AIDS and poverty, Kabeer (1996: 17) says poverty is often associated with forcing women and children to seek work, so that poorer women are most likely to have longer working days and less attention given to their children. Kaberr advances the discussion to emphasize that conventional conceptualizations of poverty are implicitly male-centred, and this means that monetary resources are not equally shared.

There are socio-cultural expectations that are expected from parents in raising children and giving guidance in particular to teenagers. These expectations are somehow gendered because they expect more from one gender than another (Bettie, 2003). It is important to evaluate and appreciate good work done by whatever gender, since dealing with teenagers is not an easy task. According to

the then Anglican Bishop Njongonkulu Ndungane, "women's work is invisible." (30 June 2005, Researchers' Forum, University of KwaZulu-Natal Medical School).

Watstein and Laurich (1991) say social issues raised by the HIV epidemic in Africa affect the female folk the worst. Richardson cited in Watstein and Laurich (1991) discusses women's role as caregivers, nurses and attendants of people with AIDS. In agreement with this impression; Aggleton et al. (1991) and Sims and Moss (1991) say women and girls are most likely to take up the caring roles within the domestic context and become involved in caring roles in the face of HIV/AIDS. At Intshanga some HIV infected suspected they got infected from long hours spent with sick family members. Taylor and Field's (2003) work confirm that women and girls are more likely to be the sole 'carers' who spend many hours caring and to receive less outside help with their caring. Magwaza (2003), in agreement; says that all these duties and physical contact with children are expectations imposed on mothers and girls rather than fathers and boys. The government of South Africa must provide training and information to 'carers' and ensure that they get remuneration for their caring job. It is unfair to expect women and girls to provide free caring services for HIV/AIDS patients whilst they expose themselves to the pandemic.

Coleman and Hendry (1999) say parenting practices may hold the key to the problematic or anti-social behaviour of young people. They further advise that

parents of teenagers should be involved in meeting the basic needs of young people, in guiding and supporting development, in providing protection and in acting as advocates for young people. At Intshanga it was reported that there is a tendency for fathers to shift the blame onto mothers when there are problems in raising teenagers – an unnecessary burden on women.

Compass and Vagner (1991) cited in Coleman and Hendry (1999) reported that females appear to find family friendships and sexual relationships more stressful than males during adolescence. Adults who have low control may become depressed and develop a sense of helplessness about their roles as parents (Frydenberg, 1999). In such situations fathers rather than mothers are more likely to give up and do not support teenagers (ibid). Girls see setbacks and difficulties as more threatening than boys and are more likely to expect the worst in stressful situations (McRobbie, 2000 and Annandale, 2000).

According to White and Killick (2001), it is important to state that women and girls face constraints that derive from cultural attitudes and religious values that give them low status in society and relegate their work and needs to second place. Goosen (1996) holds that the females have a right to be treated with love and respect.

According to Hagennars, 1986; Sherwin, 1998 and Seabrook 2003 it is common for female breadwinners have a higher probability of being poor. Their earnings

are considerably lower than the income of working men. Though they earn lower, they are expected to consider all the family needs because most men are irresponsible (ibid). Kabeer (1996) and Raikes (1992) say a widely prevalent constraint that women face is about making a living and caring for the family. Most teenagers at Intshanga reported being raised in similar family conditions that are infest with gender inequality. In addition, as alluded to in the above discussion, women carry out the extra health related tasks while men are only involved in the decision making processes in relation to any aspects of financing health care services (Raikes, 1992; Scott, 1996). Some of these tasks are related to caring for people affected by HIV/AIDS.

Moaning further the reality of gender inequalities, Act Now (2002) point out that the already threatened health of women as they face AIDS, rape and forced marriages has worsened; young girls are not fully informed and well-trained to fight the disease. Advancing this argument, Baxen et al. (2004:21) assert that issues of power, gender and sexuality are deeply connected to the construction of safe sex negotiation within relationships, and note with disdain that they are however largely neglected.

Chapter 3: Theoretical Framework

Theories do not only operate and are understood as the origin of ideas; they also help to facilitate the “connection of ideas”, as Albrow (1999: 41) notes. This connection of ideas concerns itself with facilitating and consolidating the link between a researcher’s concerns, aims and objectives with particular aspects of the tangible realities of their studies.

Theories serve as an ideological foundation that enables researchers to “connect ideas of unity, identity, repetition and sequence” (ibid). Within feminist research circles, any ensuing critiques and grounded theoretical frameworks have “highlighted the gendered nature of social relations in all spheres of public and private life” (Dominelli, 2002: 5). Most feminist theory and practice decry “men [as] privileged at the expense of women in many dimensions of social existence” (ibid).

This brief chapter discusses two fundamentals that I used as frameworks within which the study was conducted, its data gathered as well as the structure within which the data was analysed. The two theoretical fundamentals are:

- a. Grounded Theory
- b. Feminist Perspective and Rights Based Theory

According to Hughes (2002: 6) any text is built on some kind of theoretical or conceptual framework that may or may not be made explicit. Nonetheless, the importance or benefit of working within the confines of a theoretical framework “places the knowledge presented in a broader epistemological and ontological field” (ibid). Bertrand and Hughes (2005: 262) appropriately describe a theory as a “set of concepts, derived from and contributing to a model, which together explain a phenomenon or practice”. The purpose of a theory therefore is to carry forward the various structured ideas within this research whilst at the same time work as a point of origin for the ideas and views contained in the discussion of the dissertation. This section therefore captures the theories that underpin my investigation of the lives and experiences of HIV positive learners. It is significant in clarifying arguments I discuss in the dissertation as well as my analysis of the learners’ experiences.

3.1. Grounded Theory

A qualitative research methodology and ideological underpinning was used to examine the experiences and reality that face teenage learners who live with HIV. It is obvious that they face challenges and as minors they live in the company of other people, often adults who play a guardian role – i.e. parents care givers or teachers. Subsequently, other people's opinions other than the affected learners were sought. The Grounded theory was decided upon as a

suitable ideology to employ in understanding and analysing the lives of the learners and opinions (about the learners) of other people who often feature in the teenage learners' lives. Grounded theory techniques are useful in contributing to a knowledge base that has not been subjected to much formal inquiry and about which little is known. Although studies (see chapter 2) have been conducted on adolescents and their sexuality, at the time of conducting my research I was not aware of any study done with a specific focus on HIV teenage learners' experiences and in particular conducted in my area of focus, Intshanga. As such, the Grounded Theory is a method that allows for flexibility which was required for the exploratory nature of this study. As Glaser and Strauss (1967: 32) point out, it is a method that frees one to "discover what is going on, rather than assuming what should be going on". Accordingly, the qualitative holistic approach of ground theory served as a valuable heuristic in understanding and explaining what teenage learners go through in their efforts of dealing with the knowledge that they are HIV positive.

Corbin and Strauss (1990) define the elements of grounded theory thus:

- Incidents, events, and stories that make up people's lives are taken as, or analysed as, potential indicators of phenomena they deal with (in the case of the Intshanga learners the study was an attempt of listening to and understanding the day-to-day reality that face HIV positive learners).

- The researcher's task is to relate the incidents listed by research participants to the objective of her study. My task was in turn to relate the stories told by both the learners and other people in their lives to the holistic life experiences and strategies of the learners in dealing with the HIV/AIDS pandemic
- The other element of grounded theory is defined by Corbin and Strauss (1990: 7) thus:
- "Categories are higher in level and more abstract than the concepts they represent. They are generated through the same analytic process of making comparisons to highlight similarities and differences that is used to produce lower level concepts."

In the context of the Intshanga study this element was understood as the need for me as a researcher to understand various details that are given by research participants and categorise them into chunks of shared experiences; e.g. a resolve not to disclose one's HIV status due fear of being stigmatised, dropping out of school out of a misconception that once HIV status is established it is a declaration of a death sentence, etc.

3.2. Feminist Perspectives and Rights Based Theory

Feminist theory aims to understand the nature of gender inequality and focuses on gender politics, power relations and sexuality. While generally providing a critique of social relations, much of feminist theory also focuses on analyzing gender inequality and the promotion of women's rights, interests, and issues. Themes explored in feminism include discrimination, objectification (especially sexual objectification, oppression, and patriarchy. In the Intshanga study data was analysed to understand how these aspects impact both boys and girls that get affected by HIV. The general finding was that girls, relative to boys are intensely exposed and affected by HIV/AIDS due to their gender (see chapter 2 discussion). In the context of this study there is a need to highlight gender imbalances in the manner advocated by some key feminist activists and scholars listed below.

The struggle against gender inequality has a long history – it dates back from early feminist struggles as borne by the likes of Betty Friedan of the first wave whose bone of contention was the suffragette cause and women exclusion from the vote to Mary Wollstonecraft's (2nd wave) main charge of women's exclusion from the public, political, social and economic domain and relegation to the private sphere and agitation for their sexual freedoms, to modern discourses in the 21st century that include ecofeminism and earth democracy as articulated by the likes of Vandana Shiva (3rd wave). Nonetheless, in all this re-structuring,

women's insubordination has been shrouded in patriarchy. Spender (1982: 5) equates it to a question of men always being in charge saying:

Men are in charge in our society, not only do they hold the most influential positions and own and control most of the resources, but their positions and resources enables them to ... make pronouncements on what makes sense in society and what is to be valued.

Feminists subsequently began challenging sex roles and gendered identities that defined men as superior and women as subordinate. Their point of reference was that "male-identified roles were frequently seen to be more important and deserving of greater social rewards than female-identified roles" (Steans, 1998: 11). It was realised that the status accorded to both sexes was not equal. What had seemed to be natural in terms of men being more "aggressive, objective and logical [as opposed to women being] more passive, emotional and sensitive" (ibid) was queried. It was concluded that such illogical gender apportioning had been used to justify women's insubordination over the years. At Intshanga, the listed imbalances were found recurrent and in turn more repressive to girl teenagers and their mothers than is the case with boy teenagers.

The struggle against gender imbalances has been informed by the knowledge that hierarchies established within pronounced masculine and feminine roles helped to consolidate the imbalanced status by way of rewards or societal

affirmation and approval. Patriarchal systems impressed upon women that “a good woman cooks and does laundry for her husband, she sees it as her husband’s right to make major family decisions, she may not argue with him, nor want access to the kind of benefits or pleasures he does” (Ngcongco, 1993: 6). In this (mis)construed way, women strove to stay in their ‘place’ in respect to the phallic superiority and in turn unconsciously pass on a trend to be followed by their girls. At Intshanga girls seem to extend this misconception about females to an act of using their bodies for male sexual pleasures and in turn become vulnerable to HIV.

Cognisant of the existence of a new global wave of attempts to accord girls and women the human rights they deserve, the study found and critiques the fact that at Intshanga young women are discouraged to stand up for their rights – a factors that further exposes them to sexual abuse. Feminists have been disparaged about such drives and in turn acknowledge that within the feminist struggle, there are those that view the entrenchment of patriarchy by methods of divide and rule amongst women organising to challenge the imbalanced status quo as having worked to propagate patriarchal agendas. Spender (1998: 24) notes:

I am going to suggest that patriarchy has found it profitable to turn us away from the intellectual. We have been discouraged from formulating and building theories, for patriarchy finds this a dangerous activity on the part of women. This is why the theories we have constructed, again and again, and which show many similar features, have so effectively disappeared.

Chapter 4: Research Methodology

4.1. Research Methodology Overview

In this section I will discuss methodology of data collection and the details of the respondents that have made this research a success. Although the main focus of the dissertation is on HIV positive learners, interviews were held with other relevant people who are outside of this definition but who impact the lives of the main research participants. Mann (1985) defines research as a systematic investigation to find answers to a problem. Taking this broad definition into consideration, and a need to have a deeper understanding of the lives and experiences of the identified HIV positive learners; other people's experiences with HIV positive teenagers were deemed significant to form part of this study.

HIV positive learners were easy to identify given my status as a life orientation teacher, pastoral care tutor for some learners and the fact that I have taught at one of the schools for a considerable length of time. A number of learners confided with me about their health status whilst others – on learning from their peers that I was 'listening to HIV positive learners' stories' – requested to talk with me.

At Intshanga there are more than two secondary schools, but in an attempt to conceal the identities of HIV positive learners of the study I decided to concentrate on only two schools without mentioning the schools' names or the learners' names. Subsequently the study concentrates mainly on learners from two secondary schools who enrolled at Intshanga between 1996 and 2005 and were HIV positive during this period. I believe this is a realistic delimitation as it was during the time of the study (2004-2005) feasible to trace the whereabouts of learners who had recently graduated or left the schools. Concentrating on this period also enabled the study to include current Intshanga teenagers into the sample.

At the time of the study I had been a teacher at Intshanga for 16 years and – within the context of my duties it was imperative to spend most of my time getting to know learners and people who are part of their lives. My job and position requires that my life orientation duties extend outside the school at which I am employed. It necessitates that I conduct workshops for and with teachers of my subject area as well including learners outside my school. Subsequently I established friendship with various learners, teachers as well as the community members. As a researcher my teacher-status quo allowed me into the lives and experiences I would not otherwise been able to access. I visited some homes and was even invited for weddings, traditional ceremonies and/ or graduation ceremonies.

Mann (1985) describes the basic characteristics of research as being planned, systematic and reliable. Although I enjoy easy access to people's lives, I had to conduct research in accordance with good research practice, and within the context, regulations and permission afforded to me by the schools, parents, Intshanga institutions as well my University's ethics committee. In the process I am learning about what constitutes good or ill-health from the Intshanga point of view and plan to employ lessons learnt from the study to contribute towards a better understanding and subsequently improved life of the affected learners.

In practice, I collected data from HIV infected and affected teenagers at the two schools, the staff and patients (ex-learners at the schools dating back to 1996) of Intshanga Hospice, some community members as well as the staff of Intshanga clinic. The interviews I conducted with these people made me realise that there are many questions that need to be answered. To gain more information, I decided to ask open-ended and probing questions to 30 families. Bailey (1982: 106) states that the advantage of open-ended questions is that it is useful when all the possible answer categories are not known, which help to get findings not anticipated in addition to expected ones. They also allow the patient to respond adequately and in detail thus clarifying and qualifying their answers and giving the participant an opportunity for creativity and self-expression. It is also an advantageous method as there are too many potential answer categories anticipated. In order to fully understand the teenagers' experiences I also asked them about their family composition and marriage. See

Greathead (1998) for an in-depth description of the types of families in different cultures. The kinds of families into which teenagers belong have an impact in the manner in which they deal with the challenges of being young, HIV positive and still at school.

I also asked the respondents questions about illness and death – variables that had been raised by them in earlier conversations. Ngubane (1977) believes that in regarding nature as the factor in causation of illness, Zulus see natural forces as separating at two levels. The first is concerned with the body itself as a natural biological entity that presents somatic symptoms to indicate illness. The second is much more concerned with the role of ecological factors on health. Zulus believe and understand that there are notions of health and diseases that are based on Zulu cosmology. Diseases of this category are referred to as 'ukufa kwabantu' (diseases of African people). Ngubane (1977) says death is sometimes symbolically represented in the treatment of certain types of diseases by administering 'black' medicines. The relevance of this treatment here is that during the period when the patients are thus treated, they withdraw from society and behave like bereaved people (*ukuzila*) – a tendency that was observed in the Intshanga study. This data enabled me to check my understanding and theoretical hypothesis which is that HIV positive teenagers absent themselves from school out of a conviction (that may be subconscious) that they are going to die soon.

Therefore, as one respondent confided,

Ngempela kuba nzima ukuya esikoleni – isikhathi esiningi ngigcina ngizibuza, 'ukuthi ngiyokwenzani khona ngoba ngisendleleni yokufa'.
(In fact it is hard to attend school – often I ask myself “what is really the point of going to school as I am on a journey to death)

Such a testimony has been useful in an attempt to determine and understand various types of causes to which death and illness are caused or attributed. It was found that some HIV positive learners opt not to eat or take medication thereby further weakening their immune system as they believe they are on the death bed.

4.2. Qualitative Research

A qualitative research approach is used in this study. Qualitative implies a direct connection with experience i.e. ‘lived’ or ‘felt’. Neuman (1997: 144-146) writes that qualitative researchers discuss cases in their social context and show how people attach meaning to events. He notes that qualitative data are empirical in that they involve documenting real events, what people say and observing specific behaviours. Punch (2005) state that as qualitative techniques describe people’s representations and constructions of what is occurring in their world; it proves more useful for this research and will be utilised. Qualitative research depends on spoken and observed data or behaviour. Neuman (1997) states that a further consideration of qualitative research is that the researchers must

remain open to the unexpected, and are willing to change the direction or focus of the study.

The empirical data I got from the Intshanga study was mainly qualitative in nature. In accordance with the main feminist research principle of putting forward the 'people's voice' and emphasize their participation as active agents of their own lives, the study used narratives and meanings approach for analysing the collected data. Punch (2005: 217) encourages the use of this technique as an advantageous way of studying lives and lived experiences of research participants and submits; "Contemporary anthropology and feminism often emphasise the study of lives from the narrator's viewpoint, with data seen as a shared production with the researcher". I therefore used verbatim wording from the participants coupled with my interpretations grounded in the theoretical framework used in chapter 3 that propound that data collected from participants should speak for itself, inform interpretation and analysis; as well as unearth the nature of inequalities that exist in a study context. True to feminist forms of presenting data the study reports the research participants' voices verbatim.

4.3. Method of Data Collection and Analysis

This study utilises unstructured face-to-face interviews which allows for probing in order to gain further insight. Encouraging the use of this kind of interviewing technique Bilton *et al.* (1996: 117) says face-to-face interviews provide a richer

data based as they allow the researcher to “clarify meaning, can probe for additional information on an unexpected issue that emerges during interviews, and can ensure that all the dimensions of the research are properly covered”. Appendix 3 is a list of structured questions I prepared in advance and used as a guide. Further probing questions formulated during the actual interviews, were used to elaborate on the discussion points that emerged during the interview sessions.

The interviews were conducted in both English and Zulu; depending on respondents’ grasp of the English language. In private interviews it was much easier to make written notes as a person speaks. In the two focus groups I had, I tried to memorise what they said, recalled it later and documented it. I did not want group members to become tense once they realised that their responses were being documented. I created a relaxed atmosphere so that my respondents could give honest answers.

At the studied schools I had private interviews with teenage learners who are infected and affected by HIV/AIDS. The interviews were held at a place most preferred by each participant, i.e. either at school or their homes. I visited Intshanga clinic where I spoke to the HIV/AIDS counsellors, a male and a female. I wanted to hear their views and experiences as counsellors dealing with HIV positive teenagers. I was interested in finding out how infected teenagers behave and how difficult, as attested by the literature reviewed in the

previous chapter, it is to deal with them. I wanted to get views from both genders. I wanted to know what treatment they have us or have tried before and what they really think is wrong with them. I also visited patients and staff of Intshanga Hospice. Some of the patients at the hospice were relevant for the study as they had been learners at Intshanga schools.

4.4. Ethical Considerations¹²

It is imperative for all social research to adhere to ethical issues, in order to respect moral guidelines concerned with research conducted under my university's auspices. The Oxford English Dictionary describes ethics as the moral principles by which a person is guided or rules of conduct recognised in society. I informed my respondents that I will not use their real names in my research report. They will be given pseudonyms and the information will remain confidential and will be used strictly for academic purposes only. Verbal and written permission to conduct the interviews were received from the schools, clinic, hospice, individuals and parents.

As the discussion of chapter two infers, i.e. the literature review; young people grow up in incredibly varied circumstances with different priorities and perspectives. There is need for understanding what is happening in young people's lives generally. How young men and women negotiate their future

¹² See the appendices which indicate some of the permission granted to collect data.

varies, depending on cultural and national context. In conducting the interviews and analysing the data I took cognisant of the arguments, advice and ideologies put forward by some the literature I present in chapter two.

Youth as an age category, for institutional policy purpose generally starts at age 13 and continues until age 25. The research was conducted over one year, October 2004 to October 2005 with a specific focus on learners who enrolled at the studied between 1996 and 2005. In total, taking into account individual and focus group interviews I managed to source out views of 22 families about teenage HIV positive learners. The views came out of structured interviews, non-structured interviews and casual conversations.

As a researcher, and a mother and teacher of teenagers, I feel the pain that my respondents felt and believe that my study can make a contribution towards helping these vulnerable children. Given the fact that I strongly identified with the respondents the data that I collected, its analysis and presentation may reflect a more emotive tone.

4.5. Key Respondents¹³

Respondents were drawn mainly from two Intshanga secondary schools, Intshanga Clinic, Intshanga Hospice, and some relevant members of the Intshanga community. I interviewed a total of 31 individuals but for the purpose of this dissertation I am restricting my discussion to 11 respondents. The 31 individuals were made up of 21 learners from two single sex focus groups;¹⁴ seven boys in one group and fourteen girls in another, three learners interviewed individually, two patients (20 and 25 years respectively) who were learners at Intshanga schools and were HIV positive and teenagers whilst at school, one parent, one manager from the hospice, two caregivers and one counsellor. Hereunder I give details of the key respondents.

Nganele

Gender: Female

Age: 17

Lives at: Intshanga

Occupation: Grade 11 learner

D.D.K

Gender: Female

Age: 18

Lives at: Intshanga

Occupation: Grade 12 learner

¹³ See appendix 3, a list of questions posed to interviewees.

¹⁴ Of the 21 learners only three female and one male teenage-learner were HIV positive. I later had face-to-face in-depth interviews with each one of them

Ngenzeni

Gender: Female

Age: 19

Lives at: Intshanga

Occupation: Grade 12 learner

Sipho, also a parent of an HIV positive learner

Gender: Male

Age: 35

Lives at: Intshanga

Occupation: Community member

Simo

Gender: Male

Age: 18

Lives at: Intshanga

Occupation: Grade 11 learner

Mhambi

Gender: Male

Age: 20

Originally from: Zimbabwe, studied at Intshanga as a HIV positive teenager

Occupation: Patient of Intshanga Hospice

Melusi

Gender: Male

Age: 25

Originally from: Bhobhonono, studied at Intshanga as a HIV positive teenager

Occupation: Patient of Intshanga Hospice

Sister Nkosana

Gender: Female

Age: 43

Lives at: Pietermaritzburg

Occupation: Manager at Intshanga Hospice

Nomthandazo

Gender: Female

Age: 45

Lives at: Intshanga

Occupation: Carer at Intshanga Hospice

Buhle

Gender: Female

Age: 24

Lives at: Intshanga

Occupation: Carer at Intshanga Hospice

Thandiwe

Gender: Female

Age: 30

Lives at: Pinetown

Occupation: HIV/AIDS Counsellor, Intshanga Clinic

4.6. Limitations of the Study

In the course of this research there were a few limitations that were unavoidable.

Time was a major limitation. A number of interviews took place at school with limited time and at hospice and clinic the carers did not have enough time to

spend. They were involved in their daily tasks which I interrupted. Time constraints in the working environment also made it difficult to probe respondents for information other than their initial responses. Sometimes I had to wait patiently for respondents who were late for appointments.

Some respondents did not answer some questions fully or give replies to those that probed for further responses. In the case of the hospice, the carers/ staff feared that they will lose their jobs if they provided details which may jeopardize the reputation of the hospice. In the case of community members, it is still difficult to talk freely about HIV/AIDS issues. Talking about sex-related issues is still a taboo. Explaining such a conditioning in *The History of Sexuality* Foucault (1991) argues that because sex has been kept secret, there has been a struggle against this secrecy towards greater freedom of expression. In turn this results in a reduction of factors which constrain expression of sexuality. Foucault (1991:5) states,

We are informed that if repression has indeed been the fundamental link between power, knowledge, and sexuality... we will not be able to free ourselves from it except at a considerable cost: nothing less than a transgression of laws..., a reinstating of pleasure within reality... will be required.

In the case of teenagers when they told me their experiences, they became emotional and burst into tears. Some had fears of stigmatization and discrimination.

Having limited training in counselling, I counselled the participants and also referred them to people with advanced counselling skills. This study required me to make contact with many social workers and counsellors who could assist these vulnerable teenagers. Below is a list of some of useful helpline numbers I gave to the participants:

AIDS HELPLINE	0800012322
CHILDLINE	0800055555
DOMESTIC VIOLENCE	0800150150
CHILD EMERGENCY SERVICE	0800123321
CRIME STOP	086001011
RAPE CRISIS CENTRE	031-394 4444
FAMILY LIFE CENTRE	031-701 3953
FIRE and AMBULANCE	10177
POWA (People Opposing Women Abuse)	011-642 4345/6
SANCA (South African National Council on Alcoholism and Drug Dependence)	031-708 1520
AA (Alcoholics Anonymous)	031- 301 4959

Chapter 5: Data Presentation and Analysis

In this chapter I give an analysis of the data from interviews that were carried out with the research participants. Its discussion is informed by thematic ideas voiced by the participants and reported in verbatim as well as my interpretation of the participants' voices. Although the data and discussed is presented under set heading HIV/AIDS related issues are hard to discuss in strict isolation. Therefore the subheadings of the ensuing discussion interlock with each other. The discussion takes into account the theoretical framework adopted by the study as well as ideologies highlighted in the reviewed literature section, presented in chapter 2 of the dissertation.

This study explores a number of HIV/AIDS related issues as lived and understood by the research participants. Feminist principles and scholars say it is important for researchers to 'listen to the voices of the participants' (Dominelli, 2002: 22) and present them as 'true and real a manner' (Stanley & Wise, 1983) as they were presented during the research process. Based on gathered data I have decided to categorize this data in the following way – to reflect the experiences that HIV learners go through:

1. HIV testing
2. The effects on Affected and Infected learners

3. Treatment and care
4. Coping strategies

5.1. The Respondents

In total the narration of the study is informed by a total of 31 interviewees. The following selected list of respondents is used to illustrate in some detail interviewees' categories and presents key respondents (refer to the discussion in 4.5 above for more details). Although this chapter presents much of the collected data, some of the findings are highlighted in the previous chapter.

- 21 learners from two focus groups (girls and boys, HIV + & HIV -)
- 2 hospice male patients, former school learners
- 2 hospice caregivers
- 1 hospice management member
- 1 Intshanga Clinic Counsellor
- 1 community member
- 1 parent

In this section I will describe the interviews conducted, the findings and the recommendations made by some of the respondents. The names used in this section are not their real names. I have used pseudonyms for the purpose of confidentiality.

5.2 HIV Testing

20th March 2005: Interview with Ngenzeni, 29 year old grade 12 learner

My going public about my HIV status cost me the father of my child. He left me after I disclosed that I'm HIV positive. Though it is painful but I do not regret my decision. I want to prove that testing HIV positive does not mean being disabled. I found out about my status after giving birth to my first baby on the 20th of April 2004; and from that day on wards I never looked back. I am determined to educate the public about the dangers of HIV/AIDS. I conducted motivational talks at the church but I am still afraid of conducting HIV/AIDS awareness campaigns at local schools. The reason is that my school mates know my boyfriend and they also know that I have infected him [the suspicion comes out of a thinking that she got infected by her earlier boyfriend, a married man 'sugar daddy' about 20 years older than her] and they will think that I have another boyfriend who forced the father of my child to leave me. His parents died of AIDS and I think he decided to leave me because he feared death after seeing his both parents suffer. I am still very strong and living positively with HIV though I am not accepted by most of friends and family members. My parents are ignoring me and whenever we talk about my status they always change the topic and want to shift the blame to ancestors or witches.

Testing and disclosing your status is a good thing which needs to be encouraged because it makes people living with a disease informed of their status and be able to manage it – thus live 'positively'. Furthermore, if the disease is detected early, the relevant treatment can be administered (Paine & Tjam, 1988). People react in different ways when one discloses that one is HIV positive. For women and girls as was the case with Ngenzeni, it is common for women to take self blame (Epstein, et al, 2004) the fact that she infected a man. Epstein et al. rightly note that the incidences of HIV/ IDS cannot be separated from social relationships, assumptions and identities. Form this testimony it is

apparent that people need to be educated so that they do not react negatively as did the father of Ngenzeni's child. Peer pressure has negative effects because it suppressed Ngenzeni's ego to disclose her status to her classmates. She had fears of being stigmatised¹⁵ and discriminated against, one negative consequence for disclosing one's HIV status (Naicker, 2006).

Witnessing an AIDS patient suffer makes one lose hope (Rathus & Boughn, 1994), resulting in low self-esteem and incorrect decision-making. The father of Ngenzeni's father obviously feared death and forgot about his obligation of taking care of his new born child. The person who had discloses her status suffered rejection and non-acceptance, (Sims & Moss, 1995). For Ngenzeni it was even more painful because she did not expect that reaction from her real parents. The parents accused the ancestors as Ngubane (1977:73) say it is in the interest of the living to satisfy the ancestors by fulfilling the marriage obligations. From the interview it transpired that the parents are guilty of the fact that they did not slaughter the goats and oxes that were necessary in their marriage. Ngenzeni's mother did not give bridal gifts (umabo) to the family and she thinks that this may be the cause of the wrath of the ancestors. Ngenzeni is just a teenager and she is not yet married but the effects of their parent's marriage obligations, they think, may harmed their daughter, hence the HIV infection. These are traditional cultural notions that are held by some contemporary Zulu speaking people.

¹⁵ A report on SAFM, 30 Nov 2006 stated that there was a huge reduction of the stigma against people living with HIV. This was in relation to attitudes that prevailed a decade ago.

Sontag, (1988) in the book, 'Illness as Metaphor' alludes to the existence of such beliefs as represented in Ngenzeni's thinking and (re)actions.

According to Act Now, 2002, a resource guide for HIV/AIDS for young women, if you are in a safe environment, disclosing to family members and loved ones that you are HIV positive and being accepted and cared for, helps you to live a healthier and fuller life. People with HIV/AIDS are often thought to be 'responsible' for contracting the disease and they are seen to deserve some form of punishment. For women, stigma takes on harsh forms. Agenda, a feminist media journal dedicated the entire journal to unearth, decry and present evidence to this effect (*Agenda* 39, 1998). The journal was guest edited by Vicci Tallis, a prominent feminist and AIDS activist. Vibrant discussions of the journal express anger at the fact that many women are seen as 'carriers' of HIV/AIDS and are assumed to have brought AIDS into the family. Beyond the stigma attached to testing HIV positive and coming into open about it, stigma result in discrimination in a wide range of areas including housing, employment, access to health care, education and access to public services. Within households and community, women are often subject to emotional harassment, thrown out of their homes or physically abused for their HIV positive status. HIV- related stigma refers to all unfavourable attitudes and beliefs directed towards people perceived to have HIV/AIDS. People infected with HIV are often blamed for their condition and many people believe HIV could be avoided if individuals made better moral decisions.

28 October 2004: Interviewed D.D.K; 18 year old Grade 12 learner

Instead of answering my questions, D.D.K chose to express the questions that she asked herself after finding out that she was HIV positive.

Why is this happening to me? What have I done to my God and my ancestors? Do I deserve this? Am I that bad to get such a punishment? I blame myself because I saw the symptoms that there is something wrong in my life and I also thought of AIDS but ignored the signs because I wanted to keep and maintain the relationship with my boyfriend. I did not ever think that I could get HIV/AIDS because I have only one partner who is my very first boyfriend. I have fear of rejection and fear of death. I fear disclosing to my parents and my classmates. Sometimes I feel like dying and committing suicide comes as the first option. I now hate my boyfriend and I do not think that I will ever be involved in a relationship again. I do not have sexual desire ever since I knew that I am HIV positive.

The mental dilemma that D.D.K has undergone, reflect that she has not accepted the fact that she is HIV positive and she blames herself. She regards herself as a curse to God and to ancestors. The fact that I documented in the introduction; that Intshanga teenagers do not disclose their HIV status early enough is confirmed by the fact that D.D.K saw all the symptoms of HIV/AIDS but she decided to remain silent and do nothing about it in order to keep her relationship with her boyfriend. This is ignorance which must be avoided as it does not help the patient; an advice put forward by Webb, 1997. D.D.K feels accountable for her actions and she cannot face the world and she thinks the only way out is to die. This teenager suffered from self-stigma and expressed

needs to be loved, cared for and supported. She needs to be encouraged to disclose her status, at least to close people that can help, so as to receive treatment and the support she deserves.

It was apparent from this study that teenagers are affected by stigma and tend to keep their problems secret until it is too late. A caregiver noted:

Discrimination has destroyed families. At this place children and women are still experiencing the effects of stigma in our communities despite the reports we have on the news that stigma against HIV and AIDS patients and families is declining.

14 & 16 May, 2005: Interview with Simo

Simo, a grade 11, 18 year old boy approached me at school at the end of January 2005. I asked him whether he was coming back to our school or not. He said that he wanted a donation. He handed me an envelope. Upon opening it, I saw a report from King Albert Luthuli Hospital which confirmed that Simo was HIV positive. As expected, I was shocked and told him to be positive. He said he will always be drunk so as to avoid thinking about his status. I told him that, that was not the right way. I referred him to the AIDS counsellors at St. Mary's Hospital in Marianhill. I asked him whether he had told his parents or not. He said he was afraid and could not face them. I offered to accompany him to inform his parents. In 2006 he decided to go to enrol for grade 12 at another school because he could not face his school friends. The last time I saw him he had sores on his face, and was under heavy alcohol influence. Simo's behaviour

has been eloquently described by Aggleton (2006), a condition of adolescents succumbing to drugs and alcohol due to a severe social pressure. The ensuing discussion further develops this discussion.

High stress together with low levels of protective factors, have been reported to lead Intshanga teenagers to turn to alcohol and irresponsible sex (ibid). On sobering up, - as reported by two HIV positive girls, they discovered that they were HIV positive. They end up not having stable relationships and this is a major source of unhappiness and depression.

5.3 Social and Psychological Effects of HIV AIDS on Learners

18 October 2004: Interview with Nganele, a 17 year old Grade 11 learner

I started having sex at the age of 17 and fell pregnant. My parents were very angry at me and my father chased me away from home. I went to live with my grandparent who is a pensioner. I was also expelled from school. This became my problem and I suffered all the consequences alone and the man who impregnated me who was five years older than me was free while I was having stigma and discrimination by my family and by the teachers at school. I was also discriminated in the church of God for falling pregnant. I was suspended and not allowed to take the Holy Communion. I had to wait until a new born baby is six months old before I ask for forgiveness and repentance. The process of asking for forgiveness in a church is a very humiliating one. I had to stand in front of the whole congregation and confess that I did something wrong and I promise never to do it again. It was only me and the father of my child was free out there. Above all the suffering with the baby I later discovered that I am HIV positive. The father of my child is nowhere to be found. He did not tell me of his status and I only discovered that I am HIV positive after I became ill in January 2004 and I went to the clinic. They took a

blood test and told me my status (HIV & pregnancy). I did not tell anyone because my grandmother will die and my parents will kill me.

This confession clearly shows that men cannot be trusted because Nganele's boyfriend did not respect her virginity and did not provide care and support for her and the baby. Instead of loving and supporting this young mother he also infected her with HIV. This man caused Nganele double pain because he left her with a fatherless baby and an incurable disease, a common problem decried by a special focus *Agenda* journal (1998). The parents also added to Nganele's problems by chasing her away. She feels rejected by her boyfriend and by her real parents. She feels that she is adding an extra burden to her old grandmother who also depends only on a government pension. The interview revealed that Nganele is suffering from depression and stress and that she needs care and support so as to realize that there is still life ahead. Parents need to have an understanding of how teenagers suffer and they need to be empathetic so that they could offer fair and constructive punishment if necessary (Coleman and Hendry, 1999). The schools should also not discriminate against teenagers who are pregnant or HIV positive (Lee, 2001) as was found to be the case with some learners' experiences. According to the Constitution of South Africa (1996), every child has a right to learn and expelling a learner for being HIV positive is illegal. At the church Nganele should not have suffered because church members are not expected to be judgmental or react adversely since God is the only judge. Goosen (1996) says all women have a right to be treated with love and respect -including Nganele.

The responsibility lies with families, communities and the schools that learners are enrolled in (Campbell and Foulis, 2002). The Intshanga schools' study found that young mothers often do not have male support as they strive on their own to support themselves and their babies. Coupled with this reality is that some parents abdicate their responsibilities (Magwaza, 2003). Young HIV positive mothers ultimately suffer because they do not get help or support from parents and partners.

15 June 2005: Interview with a hospice patient; Mhambi, 20 years ex-Intshanga Grade 12 learner for a brief period

I know little of IsiZulu and I am trying hard to learn it. My parents are both still alive but divorced. I have 3 brothers and 4 sisters and they are all employed in Zimbabwe. I am the last born and I am the youngest of us all. I was at school doing grade 12 when I started being sick. I had 1 child and he died in 2004 when he was 3 years old. He was also diagnosed to have AIDS. I knew in 2003 that I am HIV positive. The doctor in Zimbabwe told me after giving me a pre-test counselling and he also gave me a post-test counselling. I started having sex when I was 17 years old with a 15 year old girl. I think I was infected by my girlfriend from Empangeni [not in South Africa] who is five years older than me. I caught her with another boyfriend and I did not trust her any longer. I disclosed my HIV status to her and her family. They told me that she is also ill. My family isolated and discriminated against me. I felt so lonely and I went to church. As a Catholic, I confessed and disclosed my HIV status to a Catholic Priest in Zimbabwe. He recommended that I should go to a hospice but there are no hospices at Zimbabwe. Fortunately for me the priest had the contact details for the Intshanga Roman Catholic Mission. He phoned the Intshanga Priest and they arranged for me to be admitted at Intshanga Hospice. I arrived at Intshanga Hospice on the 30 May 2004. I was admitted for free of charge and I get food and pills for free. I do not get social grant and I do not know how and where to apply for it. I do not blame anyone for my illness because it is useless blaming. I was once employed but was fired after an illness, but by then I was not aware that I am suffering from AIDS. I thank Intshanga Hospice for taking care of me

because if I am home in Zimbabwe, I would be dead by now. In Zimbabwe you cannot find even painkillers due to poverty.

Stigma is again coming up as a contributor in making HIV positive people's lives difficult. Lack of good communication is another challenge inferred by Mhambi's experience with his parents. A 16 year old girl from an Intshanga focus group session stated the following:

If avenues of communication can be kept open, conversation and laughter between teenagers and parents may make any conflict easier to resolve. Parents need to apply a fair discipline so that teenagers can develop a sense of moral responsibility, respect for the rights of others or self-confidence.

Poverty as discussed in chapter 2 is another contributor to this regard. From this interview, in line with Crainger's (2001) assertion, we find Mhambi, though intent on not blaming anyone for his HIV condition said his parents got divorced because of his embarrassing AIDS condition. Some of the literature in chapter 2 also explains situations similar to the one that Mhambi faced i.e. an AIDS related illness of a worker that forces the worker out of his job and into poverty. Mhambi is reported to have been forced out of school and his country because of the illness and poverty. At Intshanga some learners gave similar testimonies of 'being forced out of a normal/ ideal life' as well as 'forced into an unfavourable condition due to HIV/AIDS. Some girls reported being forced into having sexual relations with older men in order to have money for school fees. Others reported being forced to seek constant remunerated work in order to get money to pay for nutritious food which is advised by care workers to eat.

Despite the enormous social and psychological effects of being a HIV positive learner, it is worth to note that at Intshanga it is not all gloom and doom. There were reports of some few family members who are living positively with HIV/AIDS and share their experiences with the infected and affected students. This is a valued involvement. Revealing one's HIV status makes one feel free and strong because the stress of keeping it a secret makes one feel ill (van Dyk, 2001 and Noller & Callan, 1991). As it is the case with Mhambi, disclosure at times does assist a patient in accessing care and treat.

Although the ideal, as indicated by Bender et al, 1998, is for patients to test for HIV in order to be treated earlier; accessing treatment and care continues to be a challenge in some rural areas – including Intshanga which does enjoy a satisfactory health care centre like its hospice. This study highlighted that there are challenges to the provision of easy access to affordable medical treatment, rehabilitation and other forms of support for people living with HIV/AIDS. The major challenge is to help reshape society and the mindset, so that together we can confront and reduce the HIV/AIDS pandemic.

5.4 Treatment and Care

19 October 2004: Interview with Sipho (35); parent and Intshanga community member

The community of Intshanga is enraged about the number of people losing their lives because of a lack of health facilities in the area, including children who are still at school. We have a clinic but it does not have enough resources and is "literally" not working. The nearest hospital is about 40 km away in Marianhill. Ambulances take about five hours to arrive to help and it is usually too late for patients. We have a serious problem because our people are dying. When somebody falls ill, we have to go around, hiring cars to rush the patient to the hospital. We know that some of these people in the ambulance are not qualified to take care of the patients - along the way they do not care and usually by the time they get to hospital, the patients are dead. AIDS is killing a lot of young people and it is getting worse. Sometimes when a sick person is taken to Pietermaritzburg hospitals, he/she is sent back and they say Intshanga people must go either to Marianhill or R.K Khan Hospital

These words from a parent of an HIV positive female teenage learner reveal that the Intshanga community has a lot of problems some of which can be solved if things can be done correctly, like proper training for volunteers. According to Frohlich (1999) cited in Van Dyk (2001), many of the perceived disadvantages of using volunteers can be overcome if the volunteers are recognized as key workers in the programme; if they are chosen by members of the community, and if they are properly trained in basic home care. There are factors that need to be considered when selecting caregivers who take care of teenagers. Besides age and gender, willingness, commitment, and the ability to relate well with people together with the necessary integrity to respect confidentiality and people's basic rights (Lovell, 2002), are important factors to

be used in selection criteria. People directly involved in patients care should have an interest in basic nursing care and they should possess good interpersonal and communication skills. There is no need for patients to be chased away when they are already in the hospital. The AIDS Epidemic Update, December 2003 report that people seeking care or counselling may be rejected by the very services that should help them. Those living with HIV can therefore be left isolated and deprived of care and support that could lessen dealing with the epidemic's impact. At Intshanga the learners did make reference to this problem as one of the difficulties they experience.

One focus group participant with profuse anger said,

The government does not consider people's needs, when it makes decisions which are unfavourable to some people. I blame the government for most teenage deaths, especially in rural areas where it is not easy for patients to get treatment.

Added to this is the fact that anti-retro virals (ARVs) are only available at selected clinics and poor people do not have money to go there. According to the Daily Sun, 17 March 2004, the government took an initiative to support the ailing father of Black theatre Gibson Kente after he disclosed his HIV positive status. This followed Kente's complaints about his lack of income, inability to meet his medical costs and the threat of his house being repossessed. If such a prominent and once successful person can battle with accessing ARVs, for the poor rural people the challenge is insurmountable.

The government negotiated with the bank to save Kente's house from repossession and to generate a sustainable income rather than depending on a grant. This government's gesture is appreciated but we see no support for people in rural areas. This was done because Kente was a famous person. The Intshanga AIDS patients, including teenagers suffer until they die (some from suicide than direct HIV/AIDS) without government intervention. The reason for highlighting these issues in my study is significant.

Weedon (1987), a feminist post structuralism analyst posit that it is necessary to challenge inequalities. She holds that the agency should be conducted taking into account that there are differences among people, i.e. along the divide of class, poverty line, race and gender. We are not all the same and the treatment we get will not be the same. While men and women alike are at risk of infection from HIV/AIDS, in many ways women are particularly vulnerable. Women continue with their daily lives working, caring for their sick children and husbands unaware that in many ways they are at risk for infection. Negative attitude by health providers, laws and policies preventing young people from accessing services is a problem. The government must develop youth oriented prevention and care facilities that offer a full range of service; encouraging the involvement of men and boys towards caring for the sick.

**15 June 2005: Interview with Melusi (25) male patient & ex-learner at
Intshanga**

At home I live with my father who is a pensioner aged 80 years and mother died in the year 2001 and she was 75 years old. I have one brother who is a taxi driver at Hammarsdale. I am not working and I depend on my father's pension fund. Whilst at high school I had a very bad cough and I went to Intshanga clinic for an HIV test in 2000, the results came out positive. I was so afraid. Three years later I started having diarrhoea and tuberculosis. At home there is only my father and he is too old to take care of me. My legs are sore and I cannot walk. The neighbours phoned my brother that he must come and take me to Intshanga Hospice, so that I can get help. I belong to a Nazareth church but now I am here at a Catholic Hospice and I am taking medication once a day. I did not tell anyone about my status but the family can see the symptoms of AIDS that I have. I do not get a social grant because I cannot access it. I was employed by a factory called Ipop in New Germany and I was fired in 2003 due to absenteeism caused by illness. I have Ingoduso (bride-to-be) and I started paying Ilobola (bride-price) when I was still employed and now I cannot continue because I do not have an income. I had a lot of girlfriends, young and old from early teenage stage and I do not know who may have infected me because I did not suspect anything wrong from them. I do not blame anyone for my condition but I do not want my father to know about this. I have been here at a Hospice for six weeks now and I can feel a little difference.

This story reflects how poverty devastates most families. It is not healthy to depend on only the elder's pension fund. You cannot get nutritious food with pension fund only. If you are malnourished, it becomes easy for you to be attacked by diseases. He opted for a Roman Catholic Hospice where they only depend on prayer and western medication as opposed to Nazareth where they depend on traditional herbs. Focusing on herbs and traditional healers make one forget about taking tests until a disease advances and it is too late for treatment. Being reluctant or not willing to disclose HIV status hinders one from getting certain benefits like social grants, treatment and care timeously. Keeping

it a secret also causes more stress which can complicate the illness. Similar discussion ensued with focus group sessions with teenagers and one note,

One tends to lie and pretend to people that everything is fine knowing clearly that is not true and the body itself tells a story by its symptoms. It may be worth to bring the naked truth to the fore.

This comment resulted into a lot of debate if it is worth telling the 'naked truth' given the stigma and fear that most people experience.

On the 26 February 2005 I visited a home of a 19 year old ex-Grade 10 pupil, Thulani. When I got there the boy was alone in the house. He was lying on the sofa. When I asked him where the other family members are, he said his mother lives in Pinetown, where she is a domestic worker. His grandfather was at the sheebeen and his grandmother was at a nearby school where she sells some chips and sweets to earn a living. This was a sad poverty situation, discussed (see chapter 2) as a factor that exacerbates the conditions of people living with HIV. The boy was swollen all over the body especially his feet. I asked the boy what was wrong with him. He said:

Ngiyasha lapha esifubeni kanti nezinyawo ziyahlaba futhi ngiyashiselwa futhi ngiyakhwehlela.
(I am burning in the chest and my feet are itching and I have hot flushes and coughing.)

He said he went to Edendale Hospital and he was admitted for 3 days. Nothing was done to him except that he was given only pain tablets. Then he said;

Ngiyasola ukuthi mhlawumbe nginengculazi.
(I suspect that may be I have AIDS.)

I encouraged him to go for an AIDS test. He agreed to go to Bothas Hill Clinic on the following Monday to take a HIV/ AIDS test. Unfortunately he died on Sunday, 29 February 2005. He committed suicide. As discussed in chapter 2, young people with HIV may resort to end their lives; a phenomenon that anecdotal evidence at Intshanga make reference to. I attended the boy's funeral on the 6 March 2005. The speeches revealed the 'naked truth'. The boy who was speaking on behalf of friends told everyone that his friend (the deceased) and he were involved in drug abuse. He also confessed that they had lots of girlfriends and they practiced unsafe sex.

Phela thina besaziwa ukuthi siyizikhokho zalapha futhi bonke o-baby abethu.

(We are famous and heroes here and all the young girlfriends are ours.)

Confirming assertions made by literature discussed in chapter 2, a family member of the deceased told everyone that they knew that the boy had AIDS. He said it is still difficult for most people to accept and realize that AIDS is killing young people. He also said the family is relieved because they did not accuse neighbours of witch-craft. They knew that their son was suffering from AIDS and are not ashamed because AIDS is a killer disease. I spoke to the boy's mother after the funeral. She told me that a doctor at Edendale Hospital told her that his son has AIDS and that he must not be told. Expressed in isiZulu;

Udokotela wangibizela eceleni wangitshela ukuthi umfana wami unesifo sengculazi kodwa wathi mangingamtsheli yena ngoba uzogula kakhulu.

I found this strange because I think that the doctor should have given the patient counselling instead of revealing his status only to his mother. His mother and his

sisters said they are happy now that he is dead because he was very rude and violent when on drugs. They relayed this in isiZulu, saying they do not feel sorry for him and felt that he deserved what he got.

Asimzweli ubuhlungu ngoba ubethi uma esedakiwe asithuke, alwe nathi. Uyalunga ngoba sasimtshela ukuthi isalakutshelwa sibona ngomopho.

Indeed the life and experiences of teenagers lead them to do things that make their parents regret the day they were born (van Dyk, 2001). The study found that teenagers are suffering and their suffering causes more pain and suffering to their parents and such behaviour contribute to youth death incidents.

Commenting on the importance of a comprehensive caring approach towards teenagers, a caregiver at Intshanga hospice who is also a nun noted:

This community needs to be equipped with caring strategies that will make our future generation to have good morals. Some teenagers find themselves unable to cope with the extreme emotional upset. It is important for parents to love, care and support teenagers. In addition there may be a need to arrange further professional counselling to help them through the HIV and AIDS crisis. All efforts are necessary.

5.5. Some Coping Strategies

15 June 2005: Interview with a professional health practitioner, sister Nkosana, 43.

This is what this research participant said about her health service provider organization and their coping strategies. To appreciate the circumstances and the dynamics under which health providers have to operate I present the actual interview in detail. The experiences she shares involve caring for teenage patients as well.

We have a staff of 14 caregivers, 13 of which are females and 1 is a male. The females are dedicated to their caring job. Some of them work during the day and others work night shift. They take weekly turns. The caregiver's role is to wash/ bath patients, feed them, clean the wards, do the laundry and cook food for patients. Here also they take turns as to who is to be in the kitchen. I do not know their level of education but they are taught about home-based care here from time to time. The caregivers are all volunteers and we do not discriminate according to gender, age or religion. This is a Catholic Mission and though the caregivers are employed as volunteers but now they get R330 per month as a salary. The money came from the Durban Catholic Diocese. We admit all the AIDS patients who need help as long as the beds are available. Amongst these patients are distressed HIV positive teenage patients. Most of the patients are referred to us by the hospitals and clinics.

Samukela bonke abantu abagulayo asinandaba nokuthi ungakanani, ubulili buni, usukaphi. (We admit everybody who is ill irrespective of race, gender, age or the place where he/she comes from.) The accommodation in the hospice is free; there is no admission or boarding fee. The caregivers work 8 hours per day and they are always complaining and they are not satisfied with the condition under which they are working. We do not get any help from the government. We survive by donations from any good Samaritan. I do not have an accurate record about the statistics

because I only came here in March but I noticed that in May there has been an extremely high rate of teenage deaths. This is a concern for us. We have found of all the patients teenagers are the most affected emotionally.

The resources are scarce and we are working under such poor conditions. Having only one heater in a ten-bed ward is like nothing under the extremely cold winter of Intshanga. We have a female ward with ten beds with one heater and a male ward also with ten beds and one heater. We have one television set in the reception area.

Ngifisa sengathi angaba maningi ama-TV. Ukuze iziguli zizibukele- ke zikhohlwe yizihlungu. (I wish that we have some televisions in the wards for the patients to watch and ease their pain and stress). I have found that teenagers cope better with their health condition when there is some form of entertainment. We are always trying to cope under poor conditions. Many of our patients repent and turn to God.

Sister Nkosana's confirms what the female focus group pointed out as one strategy to prevent and/ or deal with HIV/AIDS, i.e. religion. Children have reported to find comfort and relieve in faith (Makiwane, 2001 and Denis & Makiwane, 2003). The authors discuss strategies that children orphaned by AIDS use to deal with their pain; including creating memory boxes.

Sister Nkosana also makes reference to the manner in which they deal with teenage patients, especially young male patients. She says the organisation is trying to encourage male caregivers to come on board as carers, as an attempt to reach out to young male patients, reported to have a tendency to alienate themselves. At this health site males are not involved in the caring of patients. The staff comprise of females with only one male. This is gender bias as the belief is that caring for the sick should be the main responsibility of women.

Some of the participants inferred that this belief extends over to the home where teenage girls are expected or forced to look after AIDS patients – leading to some either dropping out of school or being exposed to contracting HIV. As an attempt to deal with this suppression one learner referred to her need to find comfort in somebody who will console her. The learner found the 'needed comfort' in an older boyfriend. Older men are reported to have given HIV to young girls (UNAIDS, 2004).

Sister Nkosana is also responsible the rape crisis centre of the organisation. She says it brings a lot of stress to her having to run around the two centres though they are in the same vicinity and in turn compromise 'the care given to those that need it the most' – she was making reference to HIV positive teenage patients and their volatile emotive character.

15th June 2005: Interview with a home caregiver, Nomthandazo, 45

I have STD 10 and I was trained as a caregiver by the Red Cross Society in 1983. I also got training by this Roman Catholic Church in 1996. I also got training by St John's Ambulance in 2003. I have 5 children, 4 girls and 1 boy their ages are 27,23,21,18 and a 12 year old boy. I am a widower. My husband died in 1995. Since then I struggled by myself to make ends meet. My eldest daughter is now working and others are still at school. No one motivated me but it is because I have love and passion for the sick people. As I work with young HIV positive people I have come to understand their needs and the way they think. They have told me about the struggles they have at school due to their health condition.

Female are the most admitted in the hospice and also their death rate is higher than that of males I spend 8 hours a day and one week is day shift and the other is night shift. This is too much compared to the compensation we get at the end of the month. The time I spend is sufficient for me to socialize with my patients. Patients have good listening skills and they easily forgive and forget. We help patients by feeding and bathing those who cannot. We also comb their hair or cut them short and keep their beds clean. We also give patients medication at stipulated times and rub their bodies to soothe pain. Some times I feel tired because of working long hours and if the patient has diarrhoea but I still love my job. The families are good and encouraging us to continue doing our great job.

Nomthandazo quotes her patients' sociable nature as way to deal with their stressful situation. She finds that they have good listening skills and talk a lot. Given that most Intshanga HIV/AIDS patients are rejected by their families, partners and friends – they turn to those who care for them for solace and somehow replace them. In chapter 2 of this dissertation I refer to Bocknek, 1986 who discusses this phenomenon and points out that such rejection compromises young people's psychological needs.

Nomthandazo also said;

Young people are funny people. You cannot believe what they have told me, "That there are people who can heal AIDS by certain concoctions made from animal fat and some plants". How will this help them really?

Such misconceptions do not help the fight against HIV/AIDS. It is a fallacy that is destructive to both HIV positive and negative people. On the other hand one can understand where they come from as Nomthandazo asserts,

It is one way of dealing with the temporary pains they go through. It is a false hope.

It is sad that the false hope fuels myths held by young people and in turn do little to change behavioural patterns that are unacceptable.

15 June 2005: Interview with a female caregiver, Buhle (24 years)

I have my Matric and I also did care giving training with St John's Ambulance in 2003. I have two children aged 10 and 7. I still have my parents and they are both unemployed. I am no longer involved with the father of my children. I was still very young and confused when I got my children. I am now a born-again Christian and I do not have a boyfriend. The financial situation at home forced me to go out and search for a job. The females are more than males and more girls die than boys. No matter how little developed the love for my job and the sick patients. I spend about an hour with each patient per day and this time is sufficient for me to bond with them. I always wear gloves to protect myself. Caring for teenagers is not different from caring for older people as far as the physical aspects are concerned. It is emotional stuff that is a challenge for teenagers. The fact that they are young and HIV positive weighs heavy on them but is comforting to be associated with one HIV positive learner who talks to her peers about safe sex. She is at your school actually. She at times comes with me when I go visit home patients. She tells me she finds being involved with other HIV positive people reminds her that she is not alone in this kind of a health condition.

What I observe from the two caregivers and others is that the Intshanga Hospice does not discriminate according to age and marital status. Some of the caregivers are very young, but have chosen to work here so as to feed their children and families. This state of affairs is indicative of recurrent poverty that is rampant at Intshanga and that also affects teenage patients. Leclerc-Madlala (2005) in, "Women caregivers and leaders in the second phase of HIV/ AIDS" states that the HIV/AIDS pandemic has prompted women to seek ways in which

their particular talents, skills or situations could make a difference. This, I argue, is a form of dealing with an HIV/AIDS context as well as finding ways to cope with poverty within that context. The HIV teenage girl that accompanies Buhle in her home based care duties bears evidence to this fact – i.e. she helps out in caring for patients and subsequently gets to deal or live better with the fact that she herself is HIV positive.

20th June 2005: Interview with a female HIV/AIDS counsellor, Thandiwe, 30 years

The teenagers come to the clinic only when they are ill. They are not so keen to do an HIV test. They only come to the clinic when the disease has advanced in their bodies. Usually they deny their status even when the results have proved positive. The girls are the most who come to the clinic but they are not so open to talk about their private lives. It becomes difficult for me to get to the real problem because if I ask them serious issues they tend to become aggressive and burst into tears.

Amantombazane awafuni ngiwabuze ngempilo yasemakubo nangezothando uma begula, bavele babe nolaka badube bakhale. Kunzima –ke ukuthola umsuka wenkinga.

Once the HIV status is positive the clinic provides some pills and counselling from time to time. The Intshanga community believes in witchcraft and ancestral spirits, so they rely mainly on the medicines and herbs that are given by Sangomas or inyangas. The community of Intshanga is poor and most people do not afford but others are able to buy the traditional mixture called ubhejane from Mr Zeblon Gwala who sells at Pinetown near Mc Donalds. Their desperation makes teenagers to mix imbiza with bactrim and this [mixture] reacts adversely to many teenagers. The cause of many deaths is that they drink whatever they get hold of and some mixtures are so strong for their bodies and most of them do not get enough nutritious food.

Banele bazi nje ukuthi banegciwane, baphuze kwasani abalutholayo oluyizimbiza futhi baxube imbiza namaphilisi kanti lokhu kuyingozi ngoba kuba namandla kunemizimba yabo esuke ingenakho ukudla okunempilo."

People who are infected with HIV can feel healthy for a few years before they get sick with AIDS. Whether well or sick, the teenagers need love and support. Friends and family members sometimes worry that they might be infected when caring for a person with HIV. People must help those who are infected by showing love, respect and support. Families must know the facts about HIV / AIDS and talk openly about the disease. Parents must help teenagers to avoid stress by involving them in family discussions. The teenagers must be encouraged to take their medication timeously and to eat nutritious foods.

CHAPTER 6: Conclusions and Recommendations

6.1. Conclusions

This study highlights that HIV/AIDS has a major effect not only on the lives of the South African, KwaZulu-Natal rural HIV positive teenagers of Intshanga but also on other people that are part of their lives. It was then necessary to talk to such people, i.e. HIV negative teenagers, educators, parents, family members and care givers. The study found that teenagers are exposed to the virus or get HIV from a number of sources, i.e. exploratory sex, coerced sex with boys of their age group or older men, rape and alcohol/ drug abuse. The study and the findings demonstrate the value of canvassing the views of teenagers on issues which affect them in order to have an informed and better understanding of the reality teenagers face as they deal with the disease. Their understanding and perception of what is happening in their lives is however based on varied experiences. This study thus provides a platform for school teenagers to share their perceptions, experiences and recommendations on a range of HIV/AIDS related issues which directly affect them. As an educator I am convinced that my involvement in this study provided an opportunity to learn more about the lives of HIV positive learners and in turn contribute in strengthening the educator–learner relationship, although on a small scale. It is hoped that the relationship shall pave way towards finding solutions to some misunderstanding that prevailed between learners and educators.

I am confident that lessons learnt from the study will assist Intshanga schools in understanding and in turn attempt to respond to questions posed by Fiona Leach (2003). Reflecting on the possible role and contribution that education can play in the decline of HIV/AIDS, she asks;

- ***Have schools played a central part in helping to change sexual behaviour among adolescents?***
 - *The study found that a lot of effort needs to be placed on providing sex education in the classroom, form peer educators and support groups.*
 - *Despite the challenge of lack of resources at Intshanga schools, some efforts have been made on this aspect.*

- ***Does a change in sexual behaviour (fewer partners, abstinence, and use of condoms) include a change in the gendered nature of sexual relationships and in particular greater female control over when or how sex takes place?***
 - *It is still difficult for females to take control of their sexual lives. Patriarchy still puts females in a subordinate position and due to poverty and financial dependency females are suppressed even more.*
 - *Awareness programmes on human rights and information on organisations that fight for women's rights need to be collected, collated and distributed at Intshanga schools. It would be essential to teach boy learners about gender equity.*

Lorber (2003:101) a gender analyst submits that "most people voluntarily go along with their society's prescriptions for those of their gender status, because

norms and expectations get built into their sense of worth and identity, the way we think, the way we see and hear and speak, the way we feel...”

Concurring with Lobner (2003), Pattman and Chege (2003) say gender power relations are complex and we must be sensitive to the different ways in which people respond to them. Supported by statements made in the discussions of focus groups this study allowed me to reflect - that silence by most girls in class, and boys' domination can be seen as a form of collusion in the sense that it enables the boys to be dominant. It can also be seen as a strategy that girls adopt to protect themselves from potential abuse from boys, or even as a form of resistance against a male dominated classroom. The teenagers' responses indicated that the girls' reaction towards boys in the classroom gets reproduced outside the classroom. As Intshanga schools are infested with such patriarchal tendencies it is little wonder that HIV infection is a challenge.

On the other hand boys were found to display generally a different attitude. In accordance with van Rooyen and Ngwenya (1997) the study found that infected boys unlike girls, very often seem insensitive with a “devil-may-care” which at times sees them succumbing to alcohol and drugs in their effort of looking for comfort.

Some boy participants advised that parents should keep in mind that boys also have deep emotional experiences and therefore need as much care and guidance that is given to girls. According to Louw, et al. (2001) educators'

sensitive guidance to teenagers throughout life is of the utmost importance. Advancing the role of educators with teenagers, Packard and Race (2000) say educators should manage stressful situations and if a problem continues, seek support. Teachers, parents and health professionals have no choice about whether to give sex education or not. The study revealed that many young adults expressed resentment when they were not given a reasonable understanding or a basis on which to make decisions about their sexuality. Therefore teenagers need all the relevant information that will enable them to make sound decisions about their sexual values and interpersonal relationships.

The study was further an eye opener for me and validated my earlier observation in dealing with the youth. Whilst counselling young people on sex and sexuality matters I have found that ignorance and erroneous attitudes are underlying problematic factors. All *stakeholders* in teenagers' lives have to acknowledge that with lack of proper guidance and sex education the youth discover their sexuality through their peers, and are thus left to create, absorb and perpetuate the myths, misconceptions and incorrect attitudes. The fact that we are all responsible to provide for care and guidance to the youth cannot be overemphasized. Because of lack of knowledge and understanding, they find themselves in situations they had not expected nor intended to be in (Noller and Callan, 1991), and as a result have to cope with the consequences of irresponsible sex which has profound negative effects on their lives (Balfour et al, 2004). The yielded a fact that parents are still not equipped to provide the

necessary information, as many are not adequately informed, or are too embarrassed to discuss sexuality. It transpired that in many families, parent are incapable of discussing these subjects because they are frightened themselves or do not know how to express themselves.

The fact that formal sex education at Intshanga schools is not yet available is a negative contributor to the problem. This state of affairs is reported by Fiona Leach (2003) as recurrent in most South African schools. She says there is very little reference to HIV/AIDS in the formal curriculum. Schools have a tendency depend on invited guests, public campaigns and counselling from a few teachers to provide AIDS education to learners. Leach further points out that;

- Guidance and counselling are not yet part of the curriculum,
- HIV/AIDS is not seen as a major problem among learners,
- Schools are reluctant to teach sex education or HIV prevention in school in an open way,
- There is lack of appropriate training for teachers,
- There is reluctance to acknowledge girls' vulnerability to sexual coercion and violence (also highlighted by Tallis, 1998).

Besides the inevitable ideal role that educators and parents have to play in teaching the youth about sex, sexuality and gender equality; it is imperative for the adults as well as teenagers to change their attitudes and their behaviour. Backed by the findings of this study and recommendations made by its

participants, it is only in such a context that the struggle against HIV/AIDS shall be successful. Tallis, 1998 also argues that change of societal attitudes will come through a new education of boys and young men toward acceptance of their share of responsibility.

As rightly pointed out by Lee 2001 in other school contexts, there is a need at Intshanga for a preventive programme of sex education for adults and teenagers, with a clear, simple and frank explanation of biological facts and an opportunity for questions and discussion of attitudes.

The study revealed that HIV/AIDS is considered a shameful disease which most people do not want to accept or talk about. Intshanga proved to be a place which is still needs to be educated about HIV/AIDS issues and to eradicate myths and attitudes that people have.

There is an urgent need to address the needs of teenagers affected by HIV because when infected teenagers become vulnerable and are unable to speak for themselves, the struggle against HIV/AIDS gets weakened. It is under such unfavourable circumstances that it becomes easier for teenagers to make disastrous choices.

The Intshanga schools' study revealed the sad fact that stigma and discrimination contribute towards the spread of HIV/AIDS and continue to

discourage disclosure and acceptance. Some scholars have linked the effects of HIV and Aids stigma directly to the patriarchal system. According to Turshen (1991) the root of the stigma problem could partly be attributed to women's [and girls'] subordination and the limited opportunities African women [and girls] have to gain recognition and independence. In my opinion schools have a role to play in this situation; teachers need to work harder to help prepare all learners (especially girls) for a good grasp of human rights and their rights and thus reduce widespread female subordination. In turn, if girls are made aware about their rights, they might get more assertive and thereby limit their vulnerability to HIV infection.

A learner who is infected with HIV is no danger at school and teachers need to be educated to change their behaviour and mindset. Teachers should not punish the HIV infected teenagers for not learning well, but they must try to understand what may be stopping the child from learning and look for ways to help and give emotional support. What the HIV infected learner needs is care, love and support. Teenagers need to be encouraged to take good care of themselves and to manage stress. They must also be referred to counsellors or support groups where they will have a chance to talk about their HIV status and acquire techniques of dealing with pain.

The findings reveal how adults are capable of destroying teenagers' lives by calling them names. Language is a very powerful tool that is able to build or

destroy one's future. The society, parents, caregivers, teachers and learners must be mindful of the language they use, or put pressure on teenagers, and avoid derogatory names. Teenagers are so sensitive and they hurt easily. It is very important to take good care and be supportive to them always. Counselling and caring for teenagers lovingly, boosts their morale. The newspaper article in the Witness, 20 May 2005 talks about a St. Anne's Hospital nurse who is being investigated by both the hospital and the police after she allegedly beat and wrestled with an ill young woman. The young woman says "she violently stripped my drip." This incidence reveals the difficulties encountered by patients at hospitals. We believe that hospitals and hospices are places where we must get help but now nurses have lost patience and love due to an increase in sick people. Nurses only provide a drip and demand that the patient go home. To some patients it becomes very difficult because there is no one at home. There is a lot of abuse and violence in health care centre which makes teenagers hesitant to disclose their HIV status. The teenagers end up being stressed out and sick.

As a facilitator I have embarked on training teachers to be able to handle HIV positive learners, taking into cognizance the findings of the study. Intending to benefit my school in particular, I actively participate in government initiatives. The Government set up an Educator Assistance Programme (EAP) and the Prevention, Care, Treatment Access (PCTA) to help educators relieve stress and get medical help so that they remain effective in their teaching process. It is

trusted that information gained will assist educators in dealing with HIV positive school learners.

6.2. Some Specific Recommendations

The Government's efforts are not visible especially in rural areas since different departments operate on different levels about HIV and AIDS issues. There are programmes that are underway like Khomanani and Siyanqoba. There is a need for a study that will recognize Governments' efforts by incorporating what is being done in the Department of Health and the Social Welfare Department of Education, Department of Arts and Culture as well as the Department of Safety and Security. There is also a need for a study that will check the effectiveness of traditional medicines.

There are a number of workshops related to HIV/AIDS that the education departments runs. Having attended some of these programmes I have observed that there is a need for these programmes to be offered to the most affected schools, like those of the Intshanga area. The workshops are necessary to extract information from teenagers and form groups of teenage peer educators who could teach learners about the basic life skills and the basic prevention measures. I have had an opportunity to be involved in similar programmes and feel empowered to advance the fight against the AIDS scourge with the skills I have gained.

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08 April 2008

To whom it may concern

This letter serves as confirmation that Mrs. E.N. Luthuli conducted interviews with the counselor of Inchanga clinic and some of the HIV positive teenage patients.

The names of HIV positive teenage patients will be kept confidential. The information gathered will be used for her studies and it will not be used by or sold to the public.

It is important to keep HIV positive teenage patients' experiences confidential and be treated with respect

Counsellor 

FREDVILLE CLINIC

Letter of Permission to conduct Interview

Mrs. E.N. Luthuli has been granted permission to conduct interviews with HIV positive teenage learners whose names have been kept confidential.

She conducted interviews at the two high schools namely Siphesihle High School and Rietvallei High Schools starting from Grade 8 to Grade 12.

Research data collected will only be for academic purposes, not for public consumption.

Respect for learners and confidentiality will be her priority.

Principal: Siphesihle  YENI SMITH
:Rietvallei  MRS. LUTHULI M.B.

DEPT. OF EDUCATION
AMMARSDALE CIRCUIT
PHESIHLE H. SCHOOL
BOX 19250
INCHANGA
TEL : 7835348

Appendix 3: Interview Schedule

Teenagers¹

1. Briefly tell me about your family background. Do you have parents? Are they employed, if not how do they earn a living? Tell me about your siblings.
2. At what age did you start having sex? Was it your choice or was it coerced?
3. How and when did you discover you HIV status? Was it through voluntary testing?
4. Did you get pre-test and post-test counselling? Was it helpful?
5. What is the age difference between you and your partner? Are you still involved with the partner whom you suspect infected you?
6. Have you felt you have been isolated or discriminated against in the school, home or community?
7. What made you decide to come to the hospice?
8. Are you receiving ARV treatment?
9. Do you receive a social grant?
10. How do you feel about your situation?

Hospice Management and/ or Caregivers

1. How many caregivers do you have? Give a gender breakdown as well.
2. What is the job description of the caregivers?
3. What kind of training do your caregivers receive and why?
4. Are all your caregivers remunerated?
5. What are your funding sources?
6. What is your selection criteria for caregivers and why?
7. Take me through your normal day on the job identifying challenges and opportunities.
8. What is your motivation for doing this job?
9. What is the age and gender breakdown of your patients?
10. How is your relationship with teenage and younger patients? Comment on their attitude, behaviour and needs.
11. How is your relationship with the families of your patients and community at large?
12. Please let me into your coping strategies.

¹ This is a composite list of questions posed to various groups – not all the questions were posed to the same people.