

“THE SILENT SEPULCHRAL EFFECTS OF STIGMA”

*A study of the effects of HIV and AIDS-related stigma on the learners at
Ndweni Primary school and its surrounding community situated in the North
Durban area in KwaZulu-Natal.*

By

Kistamah Govender

A thesis submitted in partial fulfilment of the
requirements for the degree of

MASTER OF EDUCATION (Social Justice)

University of KwaZulu-Natal, Faculty of Education

2005

Supervisor: Dr T.M. Buthelezi

Declaration

I, KISTAMAH GOVENDER, the undersigned, declare that the contents of this thesis constitute my own original work which has not previously been presented to another institution, either in part or as a whole, for the purposes of obtaining a degree. Where use has been made of the work of others, this has been acknowledged and referenced.

SIGNATURE K. Govender DATE 2006-04-27

Acknowledgments

I am grateful as I conclude this project to many people:

First, thank you Ma and Dad for being my 'authentic' educators. A special thank you Mala for without you, this project would not have been possible.
Thank you Ndweni Community, YOU changed my life forever.

My husband and children: YOU were my "pillars of strength." My thanks support and love forever.

Dr T.M. Buthelezi: My most profound gratitude!

"Social Justice is a field necessary for the healing of the soul. Dr Buthelezi, you have that special healing touch!"

Last but not least, to you, Dr. E. Mgqwashu: For editing this thesis.

Table of Contents

Declaration.....	2
Acknowledgement	3
Monograph.....	4
Table of Contents.....	5
List of Figures.....	7
Acronyms.....	8
Key Concepts.....	10
Abstract.....	17
CHAPTER ONE	
1. Orientation.....	18
CHAPTER TWO	
2. Background and Statement of Problem.....	23
CHAPTER THREE	
3. Literature Review.....	38
3.1. The nature of HIV and AIDS-related stigma and its effect on learners and adults living with HIV and AIDS.	40
CHAPTER FOUR	
4. Theoretical Framework and Research Strategy	
4.1. SECTION A: Theoretical Framework	55
4.1.1. Oppression.....	56
4.1.2. Social Oppression.....	57
4.1.3. Labelling.....	61
4.1.4. Marginalization.....	62
4.1.5. Scapegoating.....	63
4.1.6. Fear.....	65
4.2. SECTION B: Research Strategy.....	66
4.2.1. The Qualitative Approach.....	67

CHAPTER FIVE

5. Findings and Analysis

5.1. SECTION A: Findings: ‘<i>The Silent Face of Stigma</i>’	
5.1.2. Isolation.....	79
5.1.3. Silence	97
5.1.4. Marginalization	101
5.1.5. Labelling.....	109
5.6. Scapegoating.....	112
5.2. SECTION B: Analysis: ‘<i>The Lethal Effects of Stigma</i>’	
5.2.1. The nature of stigma.....	122
5.2.2. Stigma and its effect on learners in Ndweni Primary School and the community	129

CHAPTER SIX

6. Recommendations and Conclusions	137
---	------------

References.....	144
------------------------	------------

Appendix

One Questions: PLWHA.....	159
Two Questions: Community Health Workers.....	163
Three Questions: Greenville Hospice/Clinic.....	166
Four Questions: Focus Group Sessions	168
Five Questions: Head of Department.....	170
Six Consent Form: Life Skills co-ordinators.....	171
Seven Consent Form: Principal	174
Eight Consent Form: Parent/Guardian/Foster Parent.....	176
Nine Consent Form: Key Informant	179
Ten Ethical Clearance.....	181

List of figures

Figure 1 A view of Ndweni	26
Figure 2 Interior of Ndweni Home	28
Figure 3 Picture of garden on vacant plots.	29
Figure 4 Garden: 'Labour of Love'	30
Figure 5 Washing area with children.....	31
Figure 6 Tuck-shop in Ndweni	32
Figure 7 Ndweni Primary School	35
Figure 8 Isolation of CLWHA.....	80
Figure 9 Isolation at home.	81
Figure 10 Isolation at school.....	83
Figure 11 CLWHA as depressed and suicidal.	84
Figure 12 Learners worry and stress.....	86
Figure 13 CLWHA plead for acceptance from oppressors.	87
Figure 14 Adults worry and stress.	88
Figure 15 Oppression causes powerlessness in PLWHA.	93
Figure 16 Learners assist in gardens after school	94
Figure 17 Perception that HIV or AIDS is class-related.	96
Figure 18 Adults advise silence to avoid stigma.....	98
Figure 19 Silent messages of fear.	104
Figure 20 Poverty affects caregivers.....	111
Figure 21 Scapegoating excludes caregivers.	113
Figure 22 Learners reveal violence and abuse.	117
Figure 23 Men advise caution during AIDS stage.....	119

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
AFSA	AIDS Foundation South Africa
ARV	Anti-rétroviral
AVERT Org.	Avert Organization (previously known as 'AIDS Education and Research Trust')
AUSAID	Australian Agency for International Development
CLWHA	Children living with HIV or AIDS
DoE	Department of Education
DoH	Department of Health
FARC	Revolutionary Armed Forces of Columbia
HDN	Health and Development Networks
HIV	Human Immunodeficiency Virus
HOD	Head of Department
HSRC	Human Sciences Research Council
INC	Incorporated
ICRW	International Centre for Research on Women
PLWHA	People living with HIV or AIDS
NPA	Natal Provincial Administration
MANET	Malawi Network of People Living with HIV or AIDS
SIDA	Swedish International Development Agency
UN	United Nations
UNAIDS	Joint United Nations Program on HIV and AIDS
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children's Fund
US	United States

VCT	Voluntary Counseling and Testing
WHA	World Health Assembly
WHO	World Health Organization
NRF	National Research Funding
TB	Tuberculosis

KEY CONCEPTS

PREVIEW

I define briefly the general characterizations of the fundamental concepts I employ later on during the more detailed analysis of the effects of HIV and AIDS-related stigma on learners and community members of Ndweni.

CULTURE OF SILENCE

Freire (1970:18) does not include a definition of the ‘culture of silence.’ Instead, he applies it functionally to mean that every person, however ignorant or submerged in the ‘culture of silence’, can look critically at his or her world through a process of dialogue with others, and can gradually come to perceive his or her personal and social reality, think about it, and take action with regard to it. In this study the ‘culture of silence’ refers to the silence that entombs the community of Ndweni.

DEHUMANISATION

According to Freire (1970:28), dehumanization is that which afflicts both people whose humanity has been stolen and those who have stolen it, thereby distorting the process of becoming more fully human. This study refers to the concept as explained by Freire.

DISCRIMINATION

According to the Joint United Nations Program on HIV and AIDS (UNAIDS 2001), discrimination is any measure entailing any arbitrary distinction among persons depending on their confirmed or suspected HIV sero-status state of health. According to the Department of Health (DoH 2001), discrimination occurs when someone is

unfairly treated because of colour, race, sex, religion or an illness. In this thesis, the DoH's definition will apply.

EDUCATION

Education is defined by the Merriam-Webster's electronic dictionary (cited in Wildeman 2001) as knowledge acquired by learning and instruction. Because the HI virus is spread mainly through sexual contact, HIV and AIDS education is presented in the context of sexuality education (discussed later under sexuality education). I have used the term education as education for prevention to mean the knowledge acquired in order to effectively prevent the spread of HIV and AIDS.

FEAR

The DoH (2001) in South Africa regards fear as an unpleasant emotional experience caused by an exposure to danger. Francis (2003) states that agents assume that people living with HIV or AIDS (PLWHA) deserve their predicament. These assumptions create overwhelming fears to be associated with HIV and AIDS. In this study the meaning of the DoH will apply.

HELPLESSNESS

Seligman (1992) asserts that helplessness occurs as a consequence of a cognitive breakdown between actions, outcomes and an inability to link actions to the consequences resulting in blaming others or external factors for their condition, situation and outcomes. In this study helplessness refers to the state where PLWHA cannot help themselves because of the helpless positions they find themselves in.

ISOLATION

The Oxford Thesaurus (2001) offers synonyms for isolation as loneliness, solitariness and segregation. In this thesis it is used to reflect the separation or the feelings

involved in being kept apart from others because of their association with HIV and AIDS.

LABELLING

The Oxford Thesaurus (2001) offers synonyms for labelling as branding or tagging. In this thesis it makes reference to the imagery, metaphors and euphemisms that agent groups tend to use on PLWHA.

LIFE SKILLS

WHO (1994) and UNICEF (2000) define, discuss and agree that the content of HIV and AIDS education should be knowledge, attitudes and skills. This thesis discusses life skills as knowledge about the transmission, protection, prevention, personal risk, care and support for infected people. This includes the human rights issues related to HIV and AIDS.

MARGINALISATION

Young (2000:41) explains marginalization as a process of expulsion of a whole category of people from useful participation in social life. In this thesis the same conceptual meaning will apply.

MYTH

The Oxford Thesaurus (2001) offers a synonym for a myth as a story or legend. In this thesis it is an idea that forms part of the beliefs of a group, but is not founded on fact.

OPPRESSION

Young (2000:40-41) gives both a traditional and structural definition of oppression. Traditionally it meant the exercise of tyranny by a ruling group, and structurally it designated the disadvantage and injustice some people suffer, not because a tyrannical

power coerces them, but because of the everyday practices of a well-intentioned liberal society.’ In this study the traditional definition of oppression will apply.

POVERTY

According to Knutsson (1997:18), there are many different types of poverties affecting the life of the poor and limiting their opportunities, and these are: the poverty of knowledge, health, power over one's life, social relationships and the poverty of deficient habitats and damaged environments. In this study poverty specifically refers to impoverished social groups who lack material well-being, experience social isolation, distress and are further disadvantaged by living in low-cost housing projects sponsored by donors (meaning international sponsors) and the government.

POWER AND POWERLESSNESS

Sennett and Cobb (1972) describe powerlessness as the lack of authority, status and power as possession of all of the above. The same conceptual explanation will apply in terms of both power and powerlessness.

PREJUDICE

Biernat and Dovidio (2000) define prejudice as attitudes which inform cognitive representations of other individuals or groups based on their social position. The DoH (2001) identifies prejudice as a preconceived opinion or idea belonging to someone else. In this thesis it is used to describe positive or negative preconceived ideas, feelings and attitudes about people based solely on their group membership in a society.

PRIVILEGE

A Merriam-Webster electronic dictionary (cited in Wildeman 2001) identifies privilege as advantages granted. The American Heritage Dictionary of the English Language (2000) defines privilege as a special advantage, immunity, permission, right

or benefit granted to or enjoyed by an individual, class or caste. This thesis looks at privilege as defined by the latter.

SCAPEGOATING

According to Namka (2003), this term originated with the ancient Hebrew tradition of placing the community's sins on the head of a goat and releasing it into the desert, thereby absolving the community of its sins. In this study, scapegoating refers to the process of blaming PLWHA for the ills of society.

SEXUALITY EDUCATION

The DoH (2001) defines Sexuality Education as education that involves sexuality as the total of a person's inherited characteristics, knowledge, attitudes, experience and behavior as they relate to being either a man or a woman. Sexuality education affects all areas of their lives, including their physical bodies, sexual intercourse, feelings and attitudes, beliefs and values, the way of walking, dressing, behaving and the decisions made, inherited characteristics, relationships between people, social and spiritual aspects that determine the sexuality that allows people to define themselves as men or women. Sexuality education in this thesis examines factors that influence and impact on sexual development, feelings, attitudes and practices. This thesis refers to sexuality education that offers people, both young and old, the knowledge of options available, the consequences of choosing any one of these options, a sense of self-esteem stemming from clarified values, and the skills needed to put chosen options into practice. Such education for prevention should make people aware of the myriad of social factors influencing their behaviours, attitudes and cultural taboos.

SEPULCHRE AND SEPULCHRAL

The Oxford Dictionary (2001) defines sepulchre as a grave, tomb or burial chamber and sepulchral as gloomy, sombre, melancholic, mournful and dismal. This thesis uses the same conceptual explanation as the Oxford Dictionary.

SOCIAL GROUP

Young (2000) defines a social group as a collective of persons differentiated from at least one other group by cultural forms, practices or way of life. In this thesis it refers to members of a particular group, either PLWA or oppressor groups who have a specific affinity with one another because of similar experiences and which prompt them to associate with one another more than those not identified with the group.

SOCIAL OPPRESSION

According to Hardiman and Jackson (1997), social oppression exists when the dominant group exploits subordinate groups. In this study it refers to the relationship that exists between the oppressed and the oppressor groups. This relationship keeps the system of domination and oppression alive in the society.

STEREOTYPES

Dovidio, Major and Crocker (2000) describe stereotypes as individuals with oversimplified cognitive conceptions or beliefs belonging to a particular social group. In this study stereotypes represent simplified beliefs about characteristics, attributes or behaviours of members of certain groups. They are generally negative and have little or no connection to actual behavior of individual members of the groups being stereotyped.

STIGMA

According to UNAIDS (2001), stigma is a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed by others as persons. The DoH (2001) provides a simplified definition of stigma as a mark of disgrace or discredit, loss of reputation or a false accusation. In this study both meanings of stigma apply.

VOICELESSNESS

The Oxford Dictionary (2001) defines voicelessness as incapacity to vocalize. In this study it refers to the defining experiences of PLWHA and their inability to make themselves heard or to control the discrimination that target them.

IDLISO

Dent and Nyembezi (2003) define *idliso* as poisoning. *Idliso* is an isiZulu term that refers to poisoning by ingestion, which presents with the signs and symptoms of a chest condition. The term may refer to both the disease and medicine. In this thesis it refers to poisoning as the cause of sickness.

INGCULAZI

Ingculazi is an isiZulu term meaning AIDS in this thesis.

INTELEZI

Dent and Nyembezi (2003) define *intelezi* as a protective charm. It refers to herbal medication taken from the aloe plant family and used for cleansing and healing. In this thesis, it has this conceptual meaning.

Abstract

“THE SILENT SEPULCHRAL EFFECTS OF STIGMA”

A study of the effects of HIV and AIDS-related stigma on the learners at Ndweni Primary School and its surrounding community situated in the North Durban area in KwaZulu-Natal

The effects of the Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV and AIDS)-related stigma in Ndweni preclude learning and the humane treatment of people living with HIV or AIDS (PLWHA). This is because stigma contributes to the isolation, marginalization and vulnerability, all of which do more harm than good to people infected and affected. Countering HIV and AIDS-related stigma implies addressing, among other things, the private contexts within which it occurs. While redress mechanisms may have effected systematic change, HIV prevention and AIDS-related education would interrupt the cycles of ignorance, prejudice, violence and sexism that exist at both school and community levels.

This study of the Ndweni Primary School and the surrounding community focuses on the HIV and AIDS-related stigma and its effect on learners. The findings reveal that HIV prevention and AIDS-related education is being marginalized by both educators at Ndweni Primary and members of the community. Although the learners gained some knowledge from occasional interaction with personnel from Ndweni Child Welfare, Ndweni Clinic, and volunteers, they retained most of their parents' views on HIV and AIDS. Within Ndweni Community, people do talk about the epidemic, but this is always in secret hushed tones and indirectly to PLWHA, waiting for them to 'break the silence' and disclose their status. The findings reveal, furthermore, the interconnectedness between poverty, prejudice and ignorance, violence and gender politics to the HIV and AIDS stigma.

I used social justice theories of oppression by Freire (1970), Hardiman and Jackson (1970) and others that focus directly on marginalization of PLWHA as well as of HIV and AIDS information. My recommendations include research into foster care birth documentation for placement of orphans within the education system and a merging of both educational and social institutions to keep a documented track of children who get lost once they transfer from schools or relocate to other areas. This thesis can be regarded as a step forward in the empowering process of creating knowledge and an understanding of HIV prevention and AIDS-related education at both the school and community levels, not only in Ndweni, but for all communities like Ndweni.

Chapter One

ORIENTATION

HIV and AIDS-related stigma has been recognized internationally as a problem. According to Singhal and Rogers (2003:243), no other epidemic has generated such a strong stigma across nations and cultures as has HIV and AIDS, with the possible ‘exception of leprosy in Biblical times.’ This has few hugely detrimental effects. Firstly, throughout the world, stigma related to HIV and AIDS remains a barrier to both learning and humane treatment of infected and affected individuals (Singhal and Rogers 2003). Secondly, this stigma contributes to the isolation of HIV and AIDS - affected and infected individuals and finally, this marginalization leads to further vulnerability to the HI virus (Jackson 2002). This is despite the availability of literature designed to educate the society on HIV and AIDS.

Although there is much literature on HIV and AIDS-related stigma and the discrimination experienced universally, inadequate information has been documented as to the exact extent of the effects of stigma experienced by affected and infected individuals in various areas in South Africa. The experiences of isolation, anger, ridicule, blame, punishment and categorization of PLWHA often occur in private settings that are not easily regulated by human rights legislations (France 2001). These include among other settings, families, friends, acquaintances and casual encounters. Within these contexts, victimization as a result of HIV infection is beyond control, with little or no encouragement for PLWHA to redress the situation. While redress mechanisms such as condom promotion, sexual behavioral change, prevention campaigns promoting abstinence and safer sexual practices may effect systematic

change, they do not help to change the beliefs and attitudes contributing to stigma as education would. One of the aims of education is to prevent and/or reduce the stigma that is associated with HIV and AIDS, not to respond to it after it has occurred. In areas where silence already surrounds HIV and AIDS issues, however, implementation of HIV and AIDS education programmes become a formidable challenge as stigma becomes a barrier to prevention (Singhal and Rogers 2003:243). Within the context of this study, Ndweni¹ represents one of such areas, and I explain in chapter 4 reasons for choosing this area. In this area the silence surrounding stigma interferes with the dissemination of accurate information about HIV transmission. This stigma consequently forms a barrier to the successful implementation of HIV and AIDS programmes in the community as well as in the school, thereby inhibiting effective testing, counseling, prevention, treatment and care. Two educators who form a Life Skills co-ordination committee in Ndweni Primary School, for instance, attended a workshop organized by the Department of Education (DoE) on HIV and AIDS in October 2002. These two educators disseminated a single basic awareness workshop for other staff members in the school. There seems to be no observable results, however, as a consequence of such dissemination, and instead, the silence seems to be even 'louder.'

Based on this, it is clear that knowledge about the subject of sexuality and HIV and AIDS is being marginalized in Ndweni Primary School particularly and Ndweni Community in general. The concept of marginalization has generally been used to refer to the exclusion of people from useful participation in social life and subjected to severe material and emotional deprivation (Young 2000). In this study, I am employing it to mean knowledge that has been conceptualized and arranged in eight learning areas by the DoE's policy. This policy includes the integration of HIV and

¹ A pseudonym was used for a township situated in North Durban in KwaZulu-Natal.

AIDS with Life Skills education and is organized under the Life Orientation learning area. This learning area also covers other subjects such as Guidance and Right Living. In Ndweni Primary School educators focus only on Right Living and Guidance issues during the Life Orientation periods and marginalize education about sexuality and HIV and AIDS. This is deprivation of crucial knowledge and it certainly affects learners of Ndweni Primary School negatively. Although at the school learners have received some information on HIV and AIDS from organizations such as Ndweni Child Welfare, Ndweni Clinic and talks by a volunteer from the community, the learners primary source of information about HIV and AIDS remain their parents with the view that this is a taboo subject and thus not to be discussed openly. The rights of these learners to access information and resources about HIV and AIDS have therefore been compromised and this affects not only the education of learners but also the implementation of prevention programmes in the school. All of this is a result of fear of the epidemic.

The fear of the epidemic results in the silence and secrecy surrounding HIV and AIDS. Learners' attitudes towards children living with HIV or AIDS (CLWHA) and PLWHA at Ndweni Primary School reflect their community's attitudes. In an attempt to contribute to the creation of an environment conducive to implementing HIV and AIDS prevention programmes in Ndweni Primary School and its surrounding community, this study focuses on the effects of HIV and AIDS-related stigma on learners and adults. It explores on the one hand, the exact nature and extent of the effects of the stigma and discrimination against learners at Ndweni Primary School and on the other hand, on its wider community. To achieve this, I have used participatory methodologies in assessing the effects of HIV and AIDS-related stigma on learners and adults. It is hoped that this study will encourage social change promoting openness and acceptance of both CLWHA and PLWHA. It should also foster successful implementation of HIV and AIDS education programmes, both in the

school and community by increasing access to HIV prevention and AIDS-related information. To realize the objectives of this study, the research questions are:

1. What is the nature of the stigma that exists in Ndweni community?
2. What is the nature of the stigma that exists at Ndweni Primary School?
3. What are the effects of the HIV and AIDS-related stigma on learners at Ndweni Primary School and its surrounding community?

This thesis is organized into seven chapters. Chapter 1 reveals stigma as a barrier to both learning and humane treatment of PLWHA in the community, contributing to their isolation, marginalization and further vulnerability to the HIV virus because it inhibits testing, prevention and care. At Ndweni Primary School, educator silence around the subject of HIV and AIDS interferes with the dissemination of accurate information to learners. This deprivation of such important knowledge affects learners negatively because their primary source of information remains their parents with their view of HIV and AIDS as a taboo subject, not to be discussed openly. In addition to these issues, this chapter provides a guide to the structural layout of the thesis.

Chapter 2 discusses the background to the thesis and I describe and analyze the problems existing in Ndweni Primary School and its surrounding community. This is done with the aid of photographs of the school and some of the areas in Ndweni community.

Chapter 3 provides a comprehensive review of the literature on the silent nature of HIV and AIDS-related stigma and its effect on the infected and affected individuals as documented in international and local literature.

This is followed by Chapter 4 with two sections. The first section discusses the theoretical framework that explores what Young (2000) describes as the different

faces of oppression. In this section I discuss specifically oppression, marginalization, labelling, dehumanization and powerlessness as conceptualized by the following scholars (Young 2000; Hardiman and Jackson 1997; UNICEF 2001; Freire 1970; ActionAid 2003). The discussion continues with the theory of scapegoating as formulated by Namka (2003) and Patterson (2002) and includes the theory of fear by Francis (2003). The second section discusses the research strategy used in conducting the present study.

Chapter 5 presents the findings in Section A and the analysis in Section B. Section A reveals the different themes that emerged from the data I collected. The emerging themes reveal the interconnectedness between the factors of poverty, prejudice and ignorance, violence and gender politics with HIV and AIDS-related stigma. Section B continues with an analysis of the nature of the stigma and its effect on both learners in Ndweni Primary School and its wider community. The analysis focuses on the interconnectedness between the social problems and HIV and AIDS-related stigma that emerged in Section A. This thesis reveals the adverse effect that stigma has on learners and the wider community.

The final chapter discusses the recommendations and conclusions I drew from my analysis of data collected. Here, my recommendations and conclusions indicate that although the effects of the stigma on the learners are negative, the implementation of proper formal education in the curriculum is the key to change.

Chapter Two

BACKGROUND AND STATEMENT OF PROBLEM

PREVIEW

In the previous chapter, I attempted to reveal the effect that marginalization of knowledge had on the learners at Ndweni Primary in particular and on Ndweni community in general. Fear of the epidemic emerges as the reason for the silence surrounding the subject of HIV and AIDS, both at school and community levels. The chapter concludes with an attempt to assess the nature of the effects of stigma and discrimination at both levels with the use of participatory methodologies, and the structural layout of the thesis. This chapter provides the background to the study. I first describe the problems, as they exist in Ndweni community. To highlight the situation, I present some of the photographs I took in some areas of Ndweni Community. Later on in this chapter, I analyse the problems existing specifically in Ndweni Community. Here, of particular interest were the problems associated with HIV and AIDS-related stigma. I further analyse their interconnectedness with poverty, prejudice and ignorance, violence and gender politics and the effects of this on vulnerable groups such as learners and members of Ndweni community.

BACKGROUND

As early as 1988, the World Health Assembly (WHA) recognised that the main barrier to effective prevention and care was the stigma and discrimination that targeted PLWHA (Mann 1995). Within the context of South Africa, researchers found that the discourse on HIV and AIDS continues to revolve around the hugely detrimental and

deadly trinity of stigma, fear and blame. They state that although there is a rapidly growing body of literature on stigma and its repercussions on PLWHA worldwide since the epidemic began, stigma remains amongst the most poorly understood concepts (Gilmore and Somerville 1994; Malcolm et al.1998; Mann 1987). The researchers assert that due to the poor understanding of HIV and AIDS-related stigma, inadequate information has been documented on the reality of the experiences that individuals and families in communities face where discrimination becomes intensely personal and takes many forms with poverty, culture, violence, gender, sexuality and class compounding the problem.

UNAIDS (2002) states that while people can live with AIDS for many years, they find it difficult to live with the repercussions of stigma that include social ostracism, rejection, shame and fear in their daily lives as a result of such variables. They found, furthermore, that reactions to the epidemic ranged from silence and denial to hostility and outright violence, thereby reducing the quality of life of PLWHAs as they marshal silence where ignorance and denial dominate and form a vicious circle by generating and reinforcing each other. The Trust, Avert. Org. (2001) found that stigma gained power through social ignorance, lack of understanding, misconceptions and superstitions that lead to the development of negative attitudes primarily out of fear of contagion and an intolerance of PLWHA. Furthermore, the negative attitudes blamed people rather than the disease itself and this facilitated the spread of the epidemic. The organisation found that stigma associated with HIV and AIDS perpetuated myths, prejudices, beliefs and fears about sexuality, disease and death triggered damaging attitudes in communities like Ndweni. AFSA (2005) reveals that community and households are most vulnerable to the impact of the HIV and AIDS epidemic because hundreds of people die daily. Furthermore, efforts to tide and control new infections in communities have had limited success. This occurs because behaviour and social change are long term processes and social factors such as poverty, illiteracy, gender inequalities, violence, stigma and discrimination, to

name a few, cannot be addressed in the short-term. Such social factors predispose people to high levels of infections. The Ndweni community is one such community context where these dynamics exist.

The community of Ndweni forms part of the North Durban region of KwaZulu Natal, a very poor community with many people living with either HIV or AIDS. In this community, stigma has its origins deep within the social structure of Ndweni and it interconnects with poverty, violence, gender, sexuality and class. PLWHA in Ndweni find it hard to live with social ostracism, rejection, shame and fear and choose to remain silent about their status even though it prevents them from accessing treatment, medication and care. During my research visits in Ndweni I managed to access its history.

The location came to being because of the Natal Provincial Administration (NPA)'s decision to alleviate the shortage of housing. In the process, the administration developed houses to accommodate 300 000 people with the help of donor-funded NGO and government-driven 'low-cost' housing projects. The project of its construction consisted of five phases with the sixth phase currently under construction. Thus far, 1 875 low-cost houses had been built and Figure 1 is a pictorial depiction of this township.



Figure 1: A view of Ndweni

These houses were for the lower-income groups who had to pay a deposit of R500. This amount presented an opportunity for all low-income persons from all race groups to get their own homes. Because of this leniency, Ndweni has approximately 98% Black and a 2% Indian population. For these residents of Ndweni, low-cost housing meant having homes built with AUSAID cost-effective earth-bricks that consisted of mud mixed with

an inexpensive bitumen-based stabilising agent² and sun drying into waterproof, durable and cheaper blocks (Bolton & Burroughs 2001). Earth for making these bricks came from nearby construction and excavation sites with assistance from residents from Ndweni community. Bolton and Burroughs (2001) however, found that despite these benefits, earth houses needed much maintenance or they eventually deteriorated and collapsed. They also found that to increase the strength and durability of these houses, some changes included using practices from conventional house building³. These changes needed to be minimal, nevertheless, to keep the cost of building and homes as low as possible for its people.

Like in all other townships that emerged because of low-cost housing projects, space exists as a problem in Ndweni community. Therefore, the houses are small and have only two rooms, and yet some accommodate approximately twelve to fifteen people. Figure 2 depicts the interior of one home in Ndweni.

² It is an emulsifier that is used to stabilise soils for makings blocks. However, it cannot be stored for longer than one month or be exposed to temperatures below freezing as it begins to separate and becomes unusable. This is used instead of cement to make blocks.

³ Method of building homes using blocks made from cement and covered by building regulations.

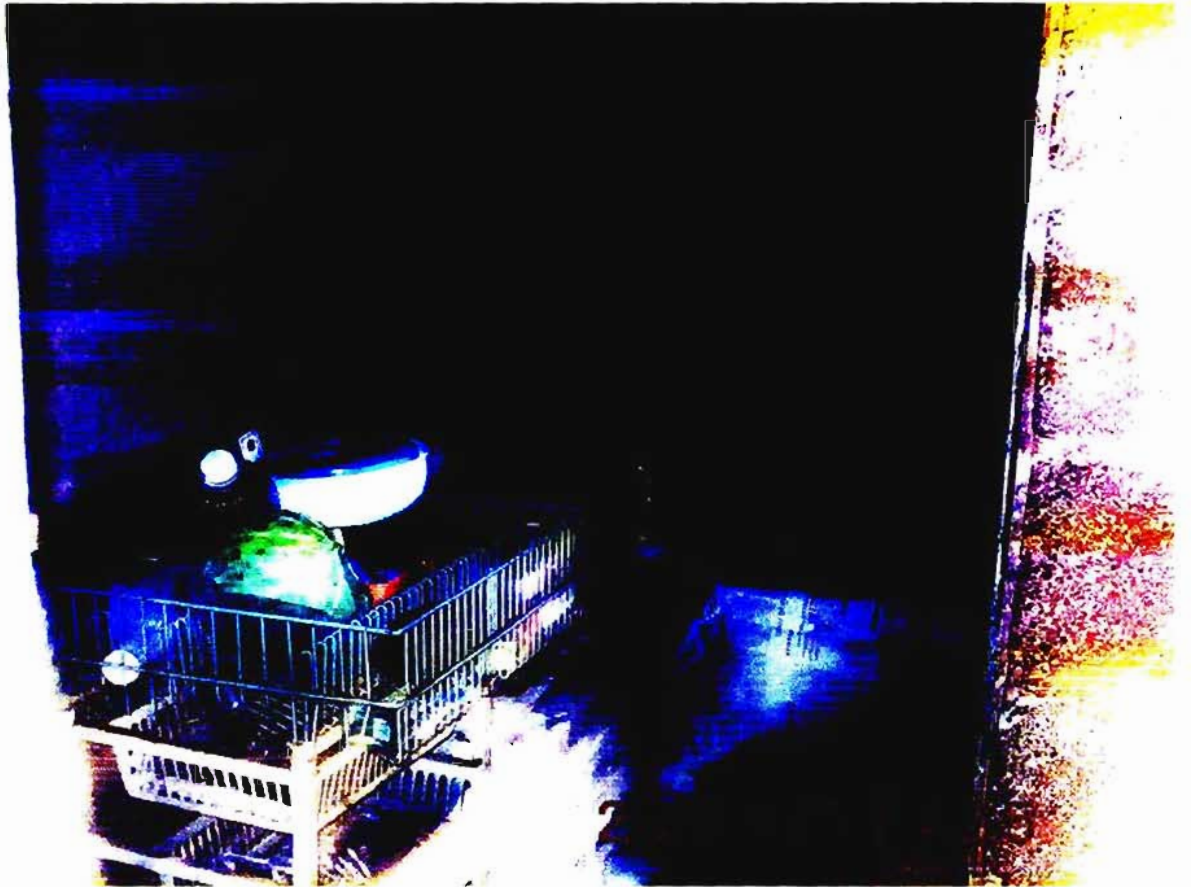


Figure 2: Interior of Ndweni home.

This high density in terms of houses on the one hand, and occupants on the other hand poses a health hazard should family members become infected with contagious diseases and limits the ability of family members to provide private treatment and care for family members who are ill. Ndweni residents and PLWHA, moreover, cannot afford adequate nutrition since they have little or no income and limited plot sizes. Many residents utilize neighbouring vacant plots to grow vegetables on. Figure 3 displays one of several gardens built on neighbouring vacant plots.



Figure 3: Picture of garden on vacant plots.

Income from such vacant sites provides food for the family as well as an additional income, but this ceases as soon as houses are constructed. Despite their problems with the epidemic, women in Ndweni utilise meagre available spaces in different ways, and one woman in particular used it to uplift her spirit. Figure 4 depicts a woman who used her limited space to create a flower and herb garden, which she refers to as her 'Labour of Love' primarily because of its potential to improve her life.



Figure 4: Garden: 'Labour of Love.'

Even though the NPA wanted to improve the lives of people in Ndweni by providing resources such as indoor electricity and water, many people could not afford to buy electricity cards for use. They continue to use candles for light and paraffin stoves for cooking. The 200 litres of free water per day they receive is also insufficient for both daily needs of families, ill members and vegetable gardens requiring the same water. As an alternative, many families use the free water supply from the tap that the NPA left unclosed as it was all that remained of the 'sugar cane fields',⁴ although it is very far

⁴ Ndweni was a sugar cane farm expropriated by the Natal Provincial Administration to Ndweni homes.

away from their homes. Young girls of Ndweni complete their house chores and either fetch pails of water or wash clothes at the distant and unsafe site, as Figure 5 shows.



Figure 5: Washing area with children.

Given the fact that what the NPA attempts to provide is not without its complications, people buy their basic necessities such as paraffin, candles and groceries from Ndweni's little tuck-shops that service different parts of the community. These tuck-shops themselves consist of available materials such as cardboard and timber. Figure 6 shows one little tuck-shop with its logo 'Poor Man Feel It.'⁵ Unlike the houses, the tuck-shops

⁵ Peter Tosh's song from the album *Mystic Man* (1987).

are unsteady because they are held together by boards, nails, tin roofs and any material that is available. These tuck-shops represent the poverty in Ndweni community.



Figure 6: Tuck-shop in Ndweni.

The health services, however minimal, provided for Ndweni indicates that government is aware of the HIV and AIDS situation in this community. Ndweni people seem to experience additional problems when attempting to use these services. They cannot access health services when required because Ndweni clinic is open on Mondays and Wednesdays only, and this clinic, furthermore, has insufficient medicinal supplies and medical personnel who refuse to conduct home visits. Voluntary counselling and testing (VCT) should have begun in June 2004, but to date the Department of Health has not

provided Ndweni clinic with personnel to conduct pre and post test counselling for PLWHA. Even though there are other possible centres around Ndweni where people can receive this help, PLWHA cannot afford to go for VCT to either Gandhi Hospital, which is 25 km, away in the north Durban area with a return trip that costs neither R20, nor McCord's Hospital with a return trip of R30. Likewise, PLWHA cannot afford to go to Ndweni Hospital for admission, medication or drugs for any illness or infections from AIDS because it is 10 km away and costs R10 per trip. People are unemployed and find it impossible to buy even a loaf of bread.

Across the road from Ndweni, community is the wealthy community of Greenville, which has a Hospice that offers support sessions for PLWHA from all surrounding communities. The sessions for Ndweni community are on Tuesdays from 10h00 to 12h00. These sessions include simple exercises, lunch, promotional packs of food items and motivational talks by visiting missionaries or HIV and AIDS counsellors and speakers. The Greenville Hospice advertises the service it provides for PLWHA in the form of newsletters, pamphlets and announcements via loudspeakers throughout the different communities regularly. Greenville Hospice also provides a mini-bus to pick up Ndweni PLWHA. Many PLWHA from Ndweni, however, tend to avoid using this service because the mini-bus has the Greenville Hospice logo and known for picking up only AIDS patients. Given the fact that many of them have not yet disclosed their status, it is rather difficult to use the shuttle.

Within Ndweni community itself, the most important resource is community health workers like Thuli Ganza known as 'MamaThuli' by most residents. She explained that most PLWHA do not visit her for help during the day, but seek her support services in the evenings or at night because friends, family and neighbours cannot see them. Although Ndweni Child Welfare has social workers, residents prefer to use their own community health workers like Thuli because they trust them. Thuli respects and

understands their need for silence because she is an affected parent who suffered discrimination from the very same community when she lost her daughter, two grandchildren and many relatives to AIDS. At that time, Thuli had never heard of HIV or AIDS, and neither had she understood how medical personnel could have treated both her and her daughter so badly. Thuli could not help her daughter because she had not known what to do. After her daughter's death, Thuli educated herself and is now a voluntary guest speaker who tells her story during support sessions. During my field visits, I attended most of the support sessions with Thuli at Greenville Hospice on Tuesdays.

Ndweni men, on the other hand, are either unemployed or migrant workers and most of them have an alcohol and drug problem, not to mention extra-marital affairs. This indicates that there are power imbalances that define gender relations and sexual interactions in Ndweni, and this imbalance of power increases the vulnerability of women to HIV and AIDS because it affects their use of available health services and treatment. Most of the women are young and tend to have partners who are seropositive, much older than they are and have many girlfriends. Many of the women are unemployed homemakers who grow vegetables to feed their families. They sell their extra vegetables, knitted garments and ornaments on the verges of roads. Some of the women foster orphans to collect grants because Ndweni has many orphans who have lost entire families to AIDS. Some of the other women work as house cleaners in wealthier surrounding communities such as Greenville.

In contrast to the impoverished community, Ndweni Primary School has modern facilities, more than adequate classrooms and educators, ground space for games, a tarred car park and well secured, as Figure 7 shows:



Figure 7: Ndweni Primary School

All the 35 permanent members of staff of Ndweni Primary School live in the surrounding wealthier north Durban areas such as Greenville and commute to Ndweni daily and their vehicles in the car park indicate clearly their class identities, which are different from the Ndweni homes. One temporary educator, who lived in Ndweni community, died of AIDS in June 2004. There is a language barrier between staff and pupils with the majority of the learners who speak, but cannot write in isiZulu but can write in English because they have educators who speak English with no knowledge of isiZulu. This intensifies problems of communication between learners and educators. The class differences intensifies the problem further because most staff members are

Indian compared to almost all learners who are Black and are not comfortable discussing personal issues with educators who are unable to understand their language. I spent much time conversing with educators, both male and female, cleaners, pupils and parents at Ndweni Primary School. During these conversations, personal details revealed existing stigma around HIV and AIDS in the school and community. In Ndweni Primary, educators do not implement the DoE's policy, which integrates HIV, and AIDS with Life Skills education organized under the Life Orientation learning area. At Ndweni Primary educators focus only on Right Living and Guidance issues and marginalize HIV and AIDS education. These results in knowledge about the subject of HIV and AIDS marginalized at Ndweni Primary School and of learners retaining the views of their parents and community members, all of which maintains the status quo regarding attitudes towards HIV and AIDS.

My research therefore focuses on the nature of the stigma that exists in both Ndweni Primary School and the community and determines the effects of HIV and AIDS-related stigma on learners at Ndweni Primary School and its wider community. It focuses on the recognition that if HIV and AIDS-related education is not implemented then the cycles of ignorance and prejudice, sexism and violence will continue unabated with dire consequences.

SUMMARY

In this chapter, I describe the general background of stigma associated with HIV and AIDS and provide an analysis of the problems existing in Ndweni. It was clear during the discussion that Ndweni is an impoverished community with many social problems that affect PLWHA, especially learners. This implies that social problems such as poverty, illiteracy, gender inequalities and violence interconnect with the epidemic and cannot be addressed within a short-term period. This is a challenge for S.A. because learners are the future and 'our only window of hope' as Thuli, the community health

worker calls them. My study will show that the solution could be that education is the key to change in terms of knowledge, attitudes and safer behaviour. In the next chapter, I will discuss international and local literature that focuses on the effects of HIV and AIDS-related stigma on learners and adults.

Chapter Three

LITERATURE REVIEW

PREVIEW

In the previous chapter, I discussed the background and analysed the statement of the problem existing in Ndweni Community. Simply put, Chapter 2 illustrated the fact that Ndweni was an impoverished community where stigma existed around HIV and AIDS in the school and in the community. This chapter discusses a comprehensive review of literature on the nature of HIV and AIDS-related stigma and explores its effects on children and adults living with HIV and AIDS.

INTRODUCTION

People who are living with HIV and AIDS are one of the most vulnerable groups in our society. Notwithstanding the availability of compelling medical evidence of the transmission of the virus, the prejudices and stereotypes against HIV positive people persist. In view of the prevailing prejudice against HIV positive people, any discrimination against them can, in my mind, be interpreted as a fresh instance of stigmatisation and I consider this an assault on their dignity. The impact of discrimination on HIV positive people is devastating. Justice Ngcobo (cited in Lodder 2004)

The HSRC (cited in Lodder 2004) estimates that there are approximately 5 million PLWHA in South Africa, and only half a million of them know their serostatus. South Africa has the fastest growing epidemic in the world, with approximately 1 700 new infections per day (Lodder 2004). For every ten persons affected, six are women and

many more may be unaware of their status (Ranchod 2005). At least one out of every nine PLWHA in South Africa has experienced some form of discrimination based on their HIV status, and have been subjected to stigmatisation, rejection and prejudice (Policy Project 2002). In terms of CLWHA, Ranchod (2005) states that official Government data indicates that children are not included in statistical information because there is no exact figure on the number of children who are HIV positive. He discusses a major recent and first comprehensive study by HSRC in 2004 that reveals 5.4% of children (under 14 years of age) between 250 000 to 300 000 are HIV positive. There is also very little concrete information that exists as to the exact nature and extent of stigma and discrimination that affects children and youth infected with, or affected by, HIV and AIDS in South Africa. To discuss the effect of HIV and AIDS stigma on children, Ranchod (2005:6) cites Gernolz who concluded her study for the Kaizer Foundation in 2003.

Children are the worst affected. They are affected by the epidemic in many ways- they are orphaned by it, they live with HIV and AIDS, they experience stigma and discrimination (whether or not they have HIV or AIDS), they live in households poorer than those that are not affected and are more vulnerable to abuse and exploitation. The epidemic is eroding many of the gains made for children in South Africa since 1994 and is undermining their rights to among other things, quality education, social security, nutrition and particularly health care.
Ranchod 2005:6

According to her, Asmal, the former Minister of Education of South Africa mentioned the failure of Life Skills and HIV and AIDS programmes in schools during his speech at the commemoration of World AIDS day 2002. He attributed this to the fact that learners left school and went into homes that were cold and unsupportive of the messages they received in school (Ministry of Education 2002). He acknowledged the interconnectedness between socio-economic contexts, high levels of poverty, sexual abuse, violence with HIV and AIDS, resulting in children experiencing stigma and

discrimination because they live in households where one or more members are ill. He insisted that Life Skills programmes needed to include values and context of the community within which the school operates and include participation of parents and the broader community to mitigate the effects of stigma on PLWHA.

The late Jonathan Mann (cited in Parker and Aggleton 2002) identified stigma in HIV and AIDS as an epidemic and its resultant discrimination as the most damaging in terms of social, cultural and political responses. Lodder (2004) stated that in South Africa, the unstable political conditions were responsible for the prevailing social, cultural and political climate that made disclosure difficult for the majority of PLWHA. He added that the questionable opinions of President Mbeki, who publicly denied that HIV causes AIDS and further contended that anti-retroviral drugs were toxic and dangerous merely added confusion and disbelief. Cornell and Heywood (cited in Lodder 2004) stated that Mbeki's view together with politics and violence strengthened denial and prejudices around HIV and AIDS, silencing most PLWHA in South Africa. The nature of HIV and AIDS-related stigma in South Africa is therefore a complex one that varies contextually. Individual contexts need to be looked at in relation to their own social issues such as poverty, resources, access to health, sexual culture and practices and others that affect the spread of the epidemic.

3.1. THE NATURE OF HIV AND AIDS-RELATED STIGMA AND ITS EFFECT ON LEARNERS AND ADULTS LIVING WITH HIV AND AIDS

The stigma related to HIV and AIDS is complex because it has far-reaching consequences, which trigger the best as well as the worst in people, their families and their communities. On the one hand, it triggers the best when individual groups get together to combat community denial and offer support and care to people living with HIV and AIDS and, on the other hand, brings out the worst when individuals are stigmatised and ostracised by their loved ones, their families and their communities. The

consequences of this state of affairs are far-reaching because the negative reactions come from people who should be supportive. Because of personal fears surrounding HIV and AIDS, individuals and societies stigmatize, halting progress in terms of treatment, prevention and care. The stigma, more importantly, hinders the development of an enabling environment, which promotes disclosure, and living openly with HIV and AIDS. Mandela summed this up effectively at Barcelona in 2002 when he said that PLWHA died from the effects of stigma rather than by the disease itself (Hodgson 2003). Govinden's (2003:259-285) poem below reveals the effect of HIV-related stigma and its resultant discrimination on PLWHA. This is the first verse of her poem.

Faces
Hollowed out by HIV and AIDS

Afraid and desolate

Lonely castaways
Spat upon and derided

Mirror

A poverty of dying

More stark
Than we can endure.

Govinden 2003:259-285

In many countries, there are well-documented cases of the stigmatization of PLWHA because of their HIV-status (UNAIDS 2001; UNAIDS 2002; Mill 2003; Green 1995). This stigmatization blinds some societies to the fact that people can live with HIV or AIDS for many years, even with a reduced quality of life (France 2001). Stigmatization, furthermore, tends to prevent people from testing, acknowledging and disclosing their HIV-status, suggesting safe sex and seeking treatment, care and support (Brown et al.

2002, UNAIDS 2002). According to UNAIDS (2002), this phenomenon harms PLWHA because they are already suffering in communities where ignorance and denial dominate and form a vicious circle that forces the epidemic underground, often with fatal outcomes.

Parker and Aggleton (2003) argue that for as long as countries struggle to respond to the epidemic of HIV and AIDS, the issue of stigma will remain poorly understood and continue to remain a major obstacle to effective prevention and care. Although many global organisations highlight consensus on the importance of addressing stigma and discrimination related to HIV and AIDS, Parker and Aggleton (2003) found that the focus has mostly been on prevention and information, and less on care and support for PLWHA who live with stigma on a daily basis. UNAIDS (2002) and the Policy Project (2002) identify research as urgently needed to deal effectively with stigma because it presents itself differently in different cultural contexts. Castells (1996; 1997; 1998) concur with this view by saying that global changes came with new forms of social exclusions that stigmatised the poor, homeless, landless and jobless. As a result, poverty increases vulnerability to HIV and AIDS, all of which exacerbates poverty (Parker, Easton and Klein 2000). AIDS deepens poverty by increasing inequalities at the level of the household and community. HIV and AIDS lead to financial, resource and income impoverishment. Households become poorer because of illness and death of members, and in many cases, income-earning adults are lost. Stigma causes PLWHA to avoid accessing resources that their communities offer in terms of support and treatment. The inter-relationship between poverty, low education and low social status increases dependency and vulnerability that increases risk behaviour, leading to more infections.

Gagnon and Simon's study (1973) reveals that stigma has been associated with sexually transmitted diseases, homosexuality, promiscuity, prostitution and sexual deviance. Stigma is therefore rooted in prejudices involving sexuality, disease and death and both

Plummer (1975) and Weeks (1981) concur. The Trust, Avert. Org. (2001) found that social ignorance, a lack of understanding, misconceptions and superstitions fuelled stigma and lead to negative attitudes because of a fear of contagion and intolerance of PLWHA. The organization found that such negative attitudes targeted people instead of the disease because the level of fear superseded the community's actual ignorance about HIV and AIDS and results in silence and secrecy around the epidemic. According to Singhal and Rogers (2003), the silence causes negative attitudes that prevent learning in institutions such as the school, family, health care religion and the community. A HIV-positive person in South Africa best describes this silence facing PLWHA:

Silence and shame
Prejudices and fear
It's all capsulated in a name
That is always so painful to hear.

It is challenging to understand
It continues to overwhelm
As we fail to comprehend

That it is no enigma
But simply something called stigma
That is enormously rife
In this process called life.

France 2001

The individual uses silence, shame, prejudice and fear to describe the stigma that overwhelms PLWHA. The words above explain reactions from individuals and communities that range from sympathy and caring to silence, denial, fear, anger and even violence. The words 'painful' and 'difficult' reveal how PLWHA feel about their experiences as a result of discrimination. PLWHA feel 'shame' because they are blamed and morally judged by oppressors who fear the HI virus as being lethal and deadly. Obieta (2004) regards shame, blame and silence as an old cocktail that reinforces stigma as a disease that is sometimes hard to name, even by PLWHA.

Throughout the world, HIV and AIDS-related stigma is enclosed by silence that shields the inhumane treatment of PLWHA (Singhal and Rogers 2003:45). Silence protects and nourishes discrimination against PLWHA mainly because these actions occur in private settings such as within families, among friends, acquaintances or in casual encounters. Anan in Avert. Org. (2003) compares the epidemic of HIV and AIDS with its stigma to a war and the silence protecting this stigma as a wall around it.

The first battle to be won in the war against AIDS is the battle to smash the wall of silence and stigma surrounding it.
Avert Org. 2003

The silence surrounding AIDS-related deaths in South Africa is evident in the usage of AIDS-related diseases such as TB and Pneumonia as codes for AIDS deaths. The aim of 'smashing the wall of silence' is therefore to expose matters of secrecy surrounding sex and break the control that oppressors have over PLWHA whose sexuality and sexual lives are marginalized simply because stigma is an emotional human reaction and silence affects all people through its secrecy. Research on secrecy in HIV and AIDS suggest that secrets and silences have become the norm in conflict ridden tense and fragile communities (Herdt 2003). Marcus (1999:10), in her research conducted in poor communities in and around Pietermaritzburg, found that AIDS is surrounded by secrecy and stigma because people do not refer to it by name, often talking about 'this thing' (intoyakhe) or as poisoning and bewitchment.

People do not speak openly about AIDS. They say that they have idliso (poisoning)
C2: Focus Group

The use of silence and coding indirectly labels PLWHA as well. The research conducted by UNICEF (2001) in Zambia describes metaphors and euphemisms for both the epidemic and PLWHA. In this research, the terms used associate PLWHA with socially

perceived immorality (meaning promiscuity) illness, death, denial and guilt. The Shona⁶ words describe PLWHA as 'zayero' (prostitutes), 'mombwe' (for men having sex with many women), 'mukondombero' (incurable disease) and 'kayaka' (the light shines through, meaning they cannot hide that they are sick). PLWHA are blamed and assumptions are made about their past sexual history with grandmothers as exceptions because they assist women in labour and 'deserve pity' if they become infected. They found that more subtle forms of stigma include strong resentment against the free medical scheme for local sex workers, making them feel 'special' when they were not. The research by UNICEF (2001) in India that PLWHA were labelled as 'galat kaam' (associated with immoral behaviour, extra-marital sexual relations, prostitution and deviance), 'khoon kharaab ho gaya' (those with dirty blood), 'lafdejaaj log' (those who have many affairs) and 'gand i naali ke keede' (worms from the gutter). They found the term 'AIDS' itself stigmatising because of the strong negative reactions it invoked.

According to Kegeles (1989), some communities placed emphasis on individualism and blame PLWHA for irresponsible behaviour. Eleanor Preston-Whyte (2003) feels that PLWHA become vulnerable when they encounter silent, secretive and subtle attitudes to sexuality within households and families. More importantly, she explains that these attitudes threaten the structure of social relations because the silence of tradition and culture divides the family by preventing the older generation from discussing sex with the younger generation. This division has a tragic impact on non-disclosure and social isolation in AIDS care, creating discriminatory actions such as gossiping and finger pointing at PLWHA. Posel (2003) explains that self-deception is a way of keeping secrets because many human beings could not face the truth. Secrecy in HIV and AIDS was therefore born out of a wish to avoid the negative, moral and social consequences of stigmatisation and discrimination. Reid and Walker (2003) found that in Africa,

⁶Shona is the main language of the research site.

although sex and secrecy linked with the AIDS epidemic, there was inadequate research by academics. The researchers assume that the power of the secret concealed the violence and abuse at home which was ironically supposed to be a place of safety. Secrecy therefore functions as a mechanism for maintaining unequal relations of power between spouses (Herdt 2003).

The HIV pandemic is highly gendered (Tallis 2000; Weiss and Whelan 2000). This occurs because infection rates differ between men and women as HIV transmission occurs through inequalities of gender power via the system of patriarchy. Aggleton and Warwick (1999) found that HIV and AIDS-related stigma and discrimination reinforced economic, educational, cultural and social disadvantages for women. Their studies conclude that men need to take responsibility for having multiple sexual partners and for placing their partners at risk to infection. In addition to this, their partners are faithful women who lead monogamous lives and are more likely to take the blame for the infection than their promiscuous partners are. Namka (2003) regards this perspective as scapegoating because oppressors move blame and responsibility away from themselves towards women because they need someone to vent anger on and blame. Sherr (1995) concurs because her research in Uganda revealed a 30-year old woman who told a counsellor:

I feel that even good people when they are being nice to me, all the time...underneath they silently look at me as a wrong-doer and blame me. That is how they see it and they are not able to accept me as anything else.

Sherr 1995

Interestingly, Bujra (2000) found a striking difference between what men said in private and what they said in public in her study in Africa. In private, both men and women confided that their greatest fear was of their most intimate partners. Men expected to be secure in their control over women and their sexuality and did not like the idea of a wife

taking control of her own protection, by refusing sex, demanding the use of a condom because only prostitutes used condoms. She explains the 'African perspective' where men regard themselves as the government in the home, leaders of the community and custodians of customs and traditions that enable them to rule their wives so that they did not stray. The men use scapegoating as a defence mechanism to shift all responsibility, blame and guilt away from themselves towards women who are already vulnerable, prejudiced and stereotyped as the carriers of the virus. Gupta (2000) feels that HIV positive women bear a double burden: they are infected and they are women. In view of this, they learn to cope with painful experiences of stigma and discrimination because of economic dependency and gender inequality. In many societies, women are socially ostracized, marginalized and even killed for exposing their status. To illustrate the experience of women in South Africa, the brutal murder of Gugu Dlamini by her own community members for disclosing her HIV status can be used (Singhal and Rogers 2003:96). South African gay white judge Edwin Cameron disclosed his status after the murder of Gugu Dlamini, although diagnosed HIV-positive in the mid-1980 (Singhal and Rogers 2003:96).

The harm done physically to PLWHA has been documented in the United States of America and in developing countries as well (North and Rothenberg 1993; Rothenberg and Paskey 1995; Sowell 1999; Ziegler 2000; Ogunyombo 1999). In the United States, infected individuals were highly stigmatized, making it very difficult or virtually impossible to communicate with them about the subject of HIV and AIDS or education for prevention programmes (Singhal and Rogers 2003:53). Because of stigmatization in small towns and other United States cities, thousands of stigmatized gay men migrated to San Francisco, which became the first metropolitan centre for the AIDS epidemic. In India, HIV positive people were punished via lynching for behaving immorally (Singhal and Rogers 2003:45). Stigma in Indian hospitals included large HIV+ signs on hospital beds, medical charts written in red ink and ward

renamed as AIDS wards (Singhal and Rogers 2003:244). In 1996, in Tennessee a strong degree of local stigma kept the epidemic in low profile, with the result that little was done to control its spread. In Columbia, the revolutionary guerrilla group, FARC, forced all adults who lived in FARC-controlled territory to undergo HIV tests and those found positive were evicted (Singhal and Rogers 2003:246)). In Brazil, people with AIDS chose not to register themselves for free anti-retroviral drugs or carry bags with AIDS medication out of fear of being stigmatized (Singhal and Rogers 2003:246).

The study by UNAIDS, HDN and SIDA (2001) on stigma in Africa concluded that alongside women, children were cited as being particularly vulnerable in schools where they were teased, bullied, threatened and isolated. In Botswana, only children who could prove an HIV-negative status got into day care centres. In Tanzania, HIV-positive children could go to schools only if they wore a distinguishing mark⁷. Singhal and Rogers' (2003) study found stigmatising attitudes in education and schools that prevented learning. In South Africa, HIV-positive Nkosi Johnson was refused admission at a predominantly white school in Johannesburg on the basis of his infecting other children (Singhal and Rogers 2003:81). His adoptive parent, activist Gail Johnson ensued in a high profile court battle, which led to his acceptance at the very same New-Park Primary and most importantly to a government policy forbidding schools to discriminate against HIV-positive children. In a similar incident in Indiana, Ryan White, a 13 year old was prevented from attending his junior high school by local authorities because he had contacted AIDS through blood transfusions. His family lived with stigma and hostility for several months before they moved away (Singhal and Rogers 2003:88). Shiela Cortopassi de Oliveira was a 4-year-old child from Brazil who could not attend school in Sao Paulo in 1991 because she was an HIV-positive orphan

⁷ They wore either a red ribbon or a red star on their uniforms.

(Singhal and Rogers 2003:273). A wealthy couple adopted her after the death of her mother and tried to enrol her in the Colegio San Luis, an elite Jesuit school in Sao Paulo where she was not accepted. Her parents sued the school in a widely publicized lawsuit and won.

Schools are supposed to be vital in reducing HIV transmission because as public institutions, they offer an important opportunity for interventions that can create respect for fellow human beings, reduce power imbalances between male and female, and foster gender identities that did not allow for domination and subordination. Schools are supposed to produce, refine, teach measure and examine knowledge while offering a suitable environment for AIDS prevention campaigns. Life Skills programmes targeting young people in and out of school represent one of the identified key strategies of the South African government's National AIDS programme since 1995. The original HIV and AIDS interventions were premised on the beliefs that teaching children knowledge about HIV transmission and the consequences of infection would be sufficient to curb behaviours that transmit HIV (Casey and Thorn 1999). This did not prove to be true because educators realised that while students must have a strong foundation of knowledge, attitude and skills was also necessary.

In South Africa, Life Skills training did not begin for educators until 1997, and the learning area of Life Orientation that included Life Skills and HIV and AIDS was not introduced until 2000. As discussed earlier, the Ministry of Education (2002) found that Life Skills, HIV, and AIDS education did not succeed because minimal research evaluated the impact of Life Skills and HIV and AIDS education on behaviours that caused the epidemic to spread. Furthermore, teacher training began only three years prior to implementation of the new curriculum, not allowing teachers sufficient time to appreciate the Life Skills curriculum or the philosophies that accompanied them. When

teachers finally received some training on student-centred lessons, it was not effectively implemented (James 2002).

Kelly (2000) found that the Department of Education had under-estimated the central role educators needed to play in promoting effective life skills and reproductive health programmes in schools in their training programme. She found that this heavy dependence on teachers could currently be the weakest aspect of well-conceived programmes and their failure to take adequate account of the situation prevailing on the ground in terms of:

- Inadequacy of teacher knowledge and confidence;
- Teacher embarrassment in treating sexuality issues with the young and with those of the opposite sex;
- Teacher concern about lack of preparation to teach psycho-social life-skills and HIV and AIDS prevention, arising from awareness that they or members of their families are HIV-infected;
- The reluctance of teachers to teach something which is so painfully close to home;
- Teacher feelings that this part of the curriculum is not critically important and their anxiety in dealing with sexuality and sexual behaviour and;
- Teacher fears of breaking traditional taboos and offend parents.

ActionAid (2003) revealed teacher attitudes in terms of knowledge and information about HIV and AIDS. They found that 45% of Kenyan teachers did not have enough knowledge to discuss HIV and AIDS as compared to 20% of Indian teachers. The majority of teachers in both countries reported never having been on a training course on HIV and AIDS. In India, 70% was compared to 54% of teachers in Kenya. In

personal interviews conducted with teachers, ActionAid also found that cultural barriers included both the 'paradox of safe sex' and gender specific issues where teachers did not feel confident teaching students of the opposite sex. They also found that 24% of Kenyan students stated that teachers did not set good role models when it came to sexual behaviour compared to 12% of students in India.

This brings us to a question asked repeatedly by Khoza in commentary on the colloquium on gender held by the University of KwaZulu Natal:

However, how do young people develop their sexual personalities safely and with joy and pleasure in a society, whose educators and parents are they so confused about gender roles, sexuality, HIV, and AIDS? Burns 2002:6

This overwhelming confusion seems to be responsible for the fear leading to stigma both in the school and in the community. Kirumura (cited in Burns 2002) suggests in the same article that HIV and AIDS among youth needed to be looked at in terms of gender roles, sexual maturation and experimentation, peer pressure and the mixed messages youth receive from their society. The study of two township schools in Durban found that although the students had reasonably good knowledge on HIV and AIDS, their knowledge differed in terms of their social location and gendered experiences (Morrell et al. 2001). These gendered differences affected the way in which boys and girls learn about life skills and HIV and AIDS. James (2002), in her research on NGOs working with HIV and AIDS interventions, found that relationships characterised by gender inequality between students and their educators promoted sexual interaction instead of encouraging safe and healthy sexual behaviour. Jewkes (2000) suggests Stepping Stones as a participatory intervention programme for learners in South Africa because it incorporated life skills and gender roles to empower participants and increase control over their sexual and emotional relationships by challenging gender norms. Welbourn (2002) found that this type of intervention could not take place in all schools due to its

openness and confrontation of cultural and gender issues. Leclerc-Madlala's study (2001) in a township in Durban reveals that culture exacerbates silence in HIV and AIDS. Zulu cultural values operating within and between families did not allow boys and girls to ask probing questions about the death of their parents or elders who die of AIDS (Denis 2003). The climate of *ukuhlonipha*⁸ explains the Sinomlando Project as an initiative of the former University of Natal⁹ to facilitate an inter-generational dialogue around family accounts that deal with untimely illness, death and stigma and discrimination.

Asmal (cited in Marcus 1999) states that children become orphans, in need of care and support, and have to face death and dying at an early age. Marcus (1999:9-19) states that there is general awareness of HIV and AIDS as a growing cause of death in communities, reflecting the advance of the AIDS pandemic.

People used to die from stab wounds and accidents, but now it is these diseases that are causing death. These diseases are new and were not there before...cancer, TB and this new disease, which people do not talk about openly.

M2: Focus group

Her study identifies youth and young adults as particularly affected by AIDS.

We feel bad because the youth are dying. It is everywhere. The other day I went to S... and I heard that so many people have died of the disease. I was shocked because these children are so young and the people would say 'cant they die from something else?' The sad thing is that these people leave children behind and as you know, children are bearing children at a very young age. I wish to know what will happen to these orphaned children when their grannies die?

C2: Focus group

⁸ isiZulu customary respect for and avoidance of elders.

⁹ On the first of January 2004, the University of Natal merged with the University of Durban-Westville to form a new University of KwaZulu-Natal.

AFSA (2005) found that the hardship for the infected and their families begin long before they die. This stems from the stigma related to suspected infection, fear and despair following diagnosis, loss of income and support when a breadwinner or caregiver becomes ill, diversion of household resources to provide care, terrible burden on family members, particularly on children caring for terminally ill parents, and the trauma of bereavement and orphan-hood. The statistics compiled by the Durban Child Welfare society in KwaZulu Natal show a 300% increase in the number of orphan cases they received between 2001 and 2002 (Children First 2002). In South Africa, almost 20 % of infected adults and relatives of orphans are reluctant to take them because of social issues and stigma attached to HIV and AIDS.

I conclude this review with AFSA (2005) who assert that for many years, the burden of care and support has fallen heavily on the shoulders of impoverished communities, where sick family members return when they can no longer work or care for themselves. Community-based care has proved to be the best option since it would be impossible to care properly for hundreds of thousands of people dying from AIDS in public hospitals. However, it is dangerous to assume that communities have limitless resilience and capacity to care for dying people and provide for those they leave behind. There is therefore an acute need for social protection and intervention to support the most vulnerable communities and households affected by this epidemic.

SUMMARY

In this chapter, I have discussed comprehensive literature on HIV-related stigma found in both schools and communities worldwide. This chapter made it clear that despite the availability of literature designed to educate societies, PLWHA, more especially children are the ones most affected by the epidemic. It seems obvious, as the literature demonstrates that the negative effects of stigma lead to the barrier of both learning and humane treatment of infected and affected individuals. Perhaps, as Parker and Aggleton

(2003) argue in this chapter, the way forward could be to focus more on care and support of PLWHA who live with either HIV or AIDS on a daily basis and less on prevention. In the following chapter, I will discuss the theories of oppression that focus on silence and stigma and the research strategy used in the accumulation of data in this study.

Chapter Four

THEORETICAL FRAMEWORK AND RESEARCH STRATEGY

PREVIEW

The previous chapter presented the body of literature about the nature of HIV and AIDS-related stigma and its effects on children and adults living with either HIV or AIDS. Several researchers and scholars seem to agree on reasons for the negative effects of stigmatization that goes with being HIV positive, and insist that unless the government, NGO's, community leaders and groups come up with strategies to combat the stigma, more pre-mature deaths are still to be expected. While Parker and Aggleton (2003) argue that for as long as countries struggled to respond to the epidemic of HIV and AIDS, the issue of stigma will remain poorly understood and remain a major obstacle to prevention and care, Govinden (2003:259-285) insists that the effects of HIV-related stigma and its resultant discrimination is 'more stark than we can endure' on PLWHA. These are but few examples presented in chapter 3.

This chapter presents the theoretical framework and research strategies that were useful for the collection of data in this study. Section A presents the theoretical framework that informs the study and it includes the theories of social oppression, labelling, discrimination, marginalization, scapegoating and fear. The theories discussed in this chapter focus on silence and stigma that, according to the findings in this study, negatively affect on both the oppressor and the oppressed. Section B concentrates on the research strategies used in conducting the present study of stigma in Ndweni

community. This section presents, furthermore, the rationale for the selection of the topic, the research site, the qualitative approach itself, the design instrument, the gathering, verification and analysis of data. The concluding remarks of the chapter tackles issues surrounding research ethics as these pertain to this study.

4.1. SECTION A: Theoretical Framework

4.1.1. OPPRESSION

Within every society, rich or poor, those who are oppressed are most
vulnerable to HIV and AIDS. UNAIDS 2002

HIV and AIDS-related stigma has had a catastrophic effect on South African communities because of their vulnerability to the epidemic, which is due to, among other things, the high unemployment rate levels that create circumstances for adverse poverty (Ranchod 2005). There have been attempts to theorise the stigma within the framework of oppression, which, traditionally meant the exercise of tyranny by a ruling group (Young 2000; Hardiman and Jackson 1997; Tatum 2000). According to them, over time, the concept of oppression has changed to include the disadvantages and injustices suffered by some people because of the everyday practices of a well-intentioned, yet supposedly liberal society. This redefinition fits accurately to the circumstances of PLWHA in communities disadvantaged by both stigma and the epidemic. In such communities, the injustices inflicted by institutions of health care, religion, education and the workplace on PLWHA supersede well-intentioned policies and legislations of the South African government, and this has adverse effects on those infected and affected. Goldenberg (1978:23) describes the effects of oppression over the oppressed in the following way:

Oppression is above anything else, a condition of being, a particular stance one is forced to assume with respect to oneself, the world and the exigencies of change. This is the pattern of hopelessness and helplessness in which one sees one as static, limited and expendable. The end product is an individual who is alienated or isolated from the society of which he nominally remains a member. Goldenberg 1978:23

Freire (1970:40) regards oppression as any state or situation where an individual or group exploits another, by making decisions for the other, prescribing the other's consciousness and perception, and hindering the pursuit of self-affirmation as a responsible person. He asserts that this situation constituted violence beneath the facade of false generosity because it interfered with the human being's vocation to become more fully human. The silence surrounding stigma and discrimination towards PLWHA in communities provides a shield for this type of violence.

4.1.2. SOCIAL OPPRESSION

Social oppression, according to Hardiman and Jackson (1997:14) occurs when the dominant or agent group, knowingly or unconsciously, exploits the target or subordinate group. Tatum (2000:9) insists that it is the dominant group that sets the parameters within which the subordinate or target group operates. We may therefore conclude that social oppression involves an asymmetrical relationship between the dominant and the subordinate groups, and that this relationship keeps oppression alive. In HIV and AIDS discourse, the target group includes PLWHA and the dominant groups include those individuals who are HIV-negative or are unaware of their HIV status.

Freire (1970:20:44) in his theory of humanization in his book, *The Pedagogy of the Oppressed*, correctly points out that social oppression occurs when oppressors themselves are dehumanised for engaging in the action of stealing the humanity of others. According to him, the oppressors' dehumanization comes about because of the act of oppression while the existential reality of oppression and the internalization of the

image of the oppressor dehumanize the oppressed. Freire states further that those who oppress others dehumanize themselves and engender the process that blinds them from seeing how their dominating and manipulative behaviour is self-destructive, all of which results in horizontal violence that occurs when the oppressors attack their family or community members. Within the context of HIV and AIDS-related stigma, this occurred when PLWHA are abandoned and orphaned CLWHA thrown out of educational institutions and communities by 'oppressors.' This type of violence prevented CLWHA such as Nkosi Johnson, for instance, from enrolling at a predominantly white school in the elegant Johannesburg suburb of Melville and Ryan White from attending his junior high school (Singal and Rogers: 2003:81).

Freire's theory (1970:46) further emphasises that the oppressors who oppress and exploit by virtue of their power cannot find within this power the strength to liberate, either the oppressed or themselves. He states that only the power that springs from the weakness of the oppressed will be sufficiently strong enough to free both the oppressor and the oppressed and restore humanity. This theory will apply to both Nkosi Johnson and Ryan Whyte, mentioned in the paragraph above but discussed on page 49 of the literature chapter. Nkosi's adoptive mother found the strength within herself to overpower her oppressor and enrol Nkosi at the very same institution. In contrast, the oppressor's greater power drove Ryan Whyte's family away because they could no longer live with the stigmatization and hostility.

One other insightful argument by Freire (1970:20-44) is that oppressors do not recognize themselves as oppressors and the oppressed do not consider themselves to be oppressed. The reason for this, Freire insists, is that both do not recognise or acknowledge the process of dehumanisation or oppression. He notes that oppression moves from generation to generation as new generations become its heirs and are shaped within its climate. He states that agents have the power to define their own

reality and see themselves as normal, whereas targets see themselves as deviant, abnormal, substandard and defective because of being labelled in such a way. Within the context of this study, target groups namely PLWHA, see their suffering in a completely negative light: as inevitable, they have sinned, and they pose a threat to their community. Patterson (2002) explains scapegoating as used by dominant groups to punish PLWHA. The dominant groups convince themselves that they are merely following the norms and values of their society. As a result, Patterson found that dominant groups or oppressors saw themselves as occupying moral high ground with their own perfection enhanced by the so-called blemishes observed in the stigmatised individual or group. Namka (2002) added that the existence of such categories of outsiders was useful because it boosted the image of the majority and enabled the hysterical hounding of minorities to appear virtuous. This process, she found, was highly contagious and very difficult for individual members of a community to resist. She insists that everyone participates in the exclusion game, even the affected and infected in order to divert attention because of fear. It is therefore the fear of stigma that kills and not the disease itself.

Both in general terms and in the instance of HIV and AIDS, the oppressed groups are usually poor people, women, child labourers, street children and those at risk for prostitution, and therefore most vulnerable to the epidemic (Fumento 1990). He added that these groups, individuals, and communities, constitute the bottom rung of the socio-economic ladder, and had the least power and the most limited access to information and the fewest resources with which to fight the raging HIV and AIDS epidemic. These underprivileged groups and individuals of society have poor nutritional status, little access to health care, and are least able to afford medical services. Melkote et al. (Cited in Singhal and Rogers 2003:44) identify developing countries like Africa as most vulnerable to the epidemic. The relative poverty, malnutrition, unemployment, illiteracy and inadequate health care, rural-urban migration, income and gender inequality in such

countries exposes PLWHA to the suffering and injustices imposed by the societies. Stigma becomes a powerful tool or weapon of social control for agent groups because it allows them to place blame on PLWHA and thus absolve themselves from their responsibility to care for the infected and affected individuals.

Marilyn Frye (cited in Young 2000:36) defines oppression as an 'enclosing structure of forces and barriers which tend to immobilize and reduce a group or category of people.' The barriers of oppression she refers to may be the unconscious assumptions and actions of oppressors on oppressed groups until the social identities of the oppressed are gradually suppressed and eventually obliterated. She found that the oppression lead to stigma of both the disease and of groups affected or infected by the virus. Because oppression is a sensitive subject, it becomes taboo and shrouded in silence. UNAIDS, HDN and SIDA (2001) found that this silence becomes as dangerous as the epidemic of stigma itself due to the impact it has had on education at all institutional levels in the community (religion, health care, family, workplace, education and media.). Piot (cited in Aggleton 2000) calls it the powerful combination of shame and fear; shame because sex is a taboo and immoral concept, and fear because AIDS is relatively new and deadly. He says that responding to AIDS by blaming PLWHA forces the epidemic underground, creating the ideal conditions for HIV to spread. Piot also considers intolerance a mobile force that attaches new fears to old forms and hard to overcome with rational argument.

According to Hardiman and Jackson (1997:2), it is the one up group (agents) who have this power to define, name reality and determine what is normal, real or correct. They found that because this group was the norm for humanity, it assigns roles that reflect the latter is devalued status while reserving the most highly valued roles for themselves. Subordinates are supposed to be innately incapable of performing the preferred roles. They found that this incapacity occurs to the extent that those in the target group

internalise the images that the dominant group reflects back to them and may even have trouble in believing in their own ability. UNICEF (2001) and Aggleton (2000) concur and add further that this is typical of how people living with HIV and AIDS as the agents from useful social and economic participation and are expelled a social group inevitably subjected to material deprivation

Francis (2003) states that PLWHA (targets) who accept the negative views and treatment of themselves internalise the oppression. This refers to the feelings of shame, self-blame and guilt that PLWHA experience when they internalise the negative responses and reactions from agent groups. Francis argues further that by internalising the agent group's ideology, PLWHA collude with oppression by thinking, feeling and acting in ways that the agent group expects. He found it interesting to note that even when a subordinate demonstrates positive qualities believed to be more characteristic of dominants, the individual is an anomaly.

4.1.3. LABELLING

Through the labelling of PLWHA, the agent groups establish and maintain their dominance and power. In the literature review chapter, this became clearly visible when UNICEF (2001) found that powerful imagery, metaphors and euphemisms were terms that applied both to the epidemic and to PLWHA. These terms or labels associated PLWHA with socially perceived immorality, illness, death, denial, innocence and guilt. They noted further that PLWHA were labelled because of their past sexual history and excluded from the society of which they are members. This exclusion is a consequence of stigmatization: prejudice and discrimination against the targeted groups because of the interaction with pre-existing stigma and discrimination associated with sexuality, gender, poverty and fears about contagion, death and disease. Hardiman and Jackson (1997:8) assert that the root of oppression is illegitimate privilege claimed by agents by virtue of their social group membership.

4.1.4. MARGINALIZATION

The concept of marginalization as, explained by Young (2000:41), is one of the most dangerous forms of oppression. She describes it as a process of excluding a whole category of people from useful participation in social life and subjecting them to severe material and emotional deprivation. As discussed earlier by UNICEF (2001), in some African communities, PLWHA receive patronizing, punitive, demeaning and arbitrary treatment because they have become 'dependent' on society due to their HIV and AIDS status. Dependency in a liberal society certainly does not warrant a suspension to basic rights of privacy, respect and individual choice. Although dependency produces conditions of injustice, it does not necessarily need to be oppressive. All societies have some people who are dependent on others, at least at some point in their lives. The emotionally needy persons may be children, sick persons, women recovering from childbirth and old people who have become frail or depressed, for instance, have a moral right to depend on others for subsistence and support. It is concerning to realise that PLWHA dependence seems to be warranting some form of oppression in our societies.

According to UNICEF (2001), the concept of marginalization stresses that even if one has shelter and food, one can still be oppressed. Although many PLWHA have sufficient means to live, they remain oppressed in their marginal status. Most of society's recognized activities take place within contexts of organized social co-operation that target and marginalize PLWHA. According to Young (2000), the targeted minorities are marginalized in terms of cultural and institutional recognition and interaction. She found that poverty and low socio-economic status creates classism, powerlessness and decreases the voice of the poor. We can conclude that people who live in low-cost housing become vulnerable because of poverty, oppression and stigma. Young (2000) found that both dominant (oppressors) and target groups (oppressed) existed within low-income groups and stigmatised each other.

Finally, marginalization as oppression occurs within the education sector. The manifestation of this begins in our classrooms when educators marginalize information about the epidemic because they feel uncomfortable discussing sexuality, HIV, and AIDS with their younger learners and avoid the responsibility of teaching sexuality education to the younger generation, while parents on the other hand are uncomfortable talking about sex to their children.

According to Boler et al., (2003) the sensitivities that surround sex and the HI virus occurs because teachers marginalise HIV and AIDS by discussing the body without direct reference to sexual relationships. They found that in some cases, sex is discussed within 'acceptable' boundaries of abstinence. In addition, discussions of HIV without direct reference to sex or advocating abstinence without mentioning safe sex merely succeeds in bonding notions of HIV to immorality and leads to a 'them and not us' attitude. They also found that it fails to help the many young people who are sexually active, making it less likely that they will seek advice or personalise their risk of becoming HIV positive. Their research revealed that silences in communication over the issue of condoms or messages other than abstinence arose out of a paradox of safe sex. This paradox occurs between the societal assumption that young people do not, and will not, have pre-marital sex, and the necessary assumption that young people do have pre-marital sex, hence the need to discuss preventive measures such as condoms.

4.1.5. SCAPEGOATING

The theory of scapegoating originated from the ancient Hebrew tradition where the Rabbi, on the Day of Atonement, would confess the sins of the community over the head of a goat and release it into the desert to carry the sins away (Namka 2002). The Scapegoat Society defines scapegoating as a hostile social-psychological discrediting routine by which people move blame and responsibility away from themselves and

towards a target person or group (Namka 2002). It is a practice by which angry, hostile accusations are projected at target groups. With the HIV and AIDS epidemic, the powerful agent groups use the target group as a scapegoat in order to avoid examining their own actions.

Scapegoating becomes an exercise used to socially exclude and marginalize PLWHA. According to Gupta (2000), women become ostracised instead of men who have multiple sex partners and spread the virus, and in the process, become the scapegoat for the men who marginalize them so that they can enjoy their own power. Patterson (2000) observes that stigma may also be interpreted as punishment effected on a particular individual or group as retribution for violating community norms. Namka (2000) found that PLWHA become responsible for real or imagined problems affecting the community, with the powerful groups deciding to cleanse their community by excluding and isolating these individuals because they present a threat to the survival of the whole community. Accordingly, exclusion, victimisation and scapegoating follow and these are further justified by the belief that PLWHA are different because they carry a death sentence.

Patterson (2000) states that the media uses scapegoating to save it from having to investigate the true origins and nature of problems experienced by society. It is common to find the media blaming impoverished communities for the rapid infection increase instead of acknowledging the interconnectedness between socio- economic factors and HIV and AIDS. Similarly, politicians use PLWHA to cover up their failure in establishing a just, equitable and peaceful society, and this shows that it is easier to blame PLWHA for social ills.

4.1.6. FEAR

The agent group has a tendency to stereotype all PLWHA as sinners, immoral beings and sexually promiscuous deserving of their predicament (Francis 2003). Francis sees labelling and stereotyping as having a potential to cause PLWHA to feel devalued and ashamed while the agent group is elevated to a position of superiority and normalcy. He feels that these assumptions create overwhelming fears for both PLWHA and community members, and it starts at the individual level, but soon penetrates all other levels of society. In the context of HIV and AIDS, he found that fear is so great that it exceeds even the physical infection of the HI virus itself and is embedded in the association of myths and beliefs of sex, disease and death. All of this, he found, renders PLWHA nervous and afraid, causing them not to disclose their status and reveal their vulnerability. He confirmed the fact that because HIV was sexually transmitted, it confirms the fear that sex is dangerous and that PLWHA carry a death sentence.

Oppression drives different kinds of fears that actually silence people and perpetuates fears in both the oppressed and the oppressor. According to UNAIDS, HDN and SIDA (2001), the silence becomes a 'conspiracy of silence,' because it leads to the fear mentioned, missed opportunities and barriers to access prevention, treatment and care. PLWHA are afraid to disclose their status, even if it becomes detrimental to their own health. Their research included oppression by health care workers who instilled fear into PLWHA. They found that health care workers who were supposed to be role models, both at work and in the communities: feared being infected at their workplace; feared dealing with their patients' emotional reactions; feared their own vulnerability and death because it was inevitable. The researchers found that the fear made the health care workers judgemental and resentful of the overemphasis placed on confidentiality almost to the point of 'secrecy for PLWHA. The oppressors feared the unknown and ostracised PLWHA to keep the virus away from them while PLWHA became depressed over their circumstances in life.

4.2. SECTION B: Research Strategy

In order to investigate the effects of HIV and AIDS-related stigma on learners at Ndweni Primary School and its surrounding community, qualitative methods of research were used. Data collection occurred over a period of eleven months in the impoverished community of Ndweni. With interviews, I drew on the lived experiences of PLWHA. I also drew on the readings of Van Manen (1997) who describes how our socio-cultural and historical traditions gave meaning to our lived experiences.

The focus of the study drew from my involvement as a student in Social Justice HIV and AIDS and Sexuality module in 2002. My interest in stigma deepened when I met and heard the extremely personal experiences of the panel of members either affected or infected by the HI virus. I needed to see for myself how individual communities experienced stigma, and accordingly read a body of available literature on the subject of stigma. During this process, I found myself agreeing with Piot (2001) that stigma and its resultant discrimination formed part of an unfinished agenda that needed to be addressed when tackling the HIV and AIDS epidemic.

Due to this personal interest in HIV and AIDS stigma, I attended the AIDS Indaba in 2003 after it appeared in the South African newspaper, *The Sunday Times*. The experiences of people who spoke during this information-gathering session encouraged and motivated me to pursue this area of research. I met Thuli Ganza, one of the key speakers at the AIDS Indaba when she took the vacant seat beside me. We talked and I learned of the HIV and AIDS situation existing in Ndweni community, especially in terms of HIV-related stigma. She invited me to Ndweni community and volunteered to assist me to get into the community for research purposes. She was an affected parent and wanted to discuss her personal story. As our relationship matured, she introduced me to most of the people in Ndweni Community. Here I was afforded the time, patience

and respect because of the trust PLWHA had in Thuli. Her commitment to her community made her well-liked voluntary peer educator and community worker.

Children and adults alike know her as 'MamaThuli' and although she is available during the day, the people of Ndweni seek her assistance mainly in the evenings and at night because they do not want to be seen, as one of my respondents explained. Thuli assists PLWHA by taking them to selected hospitals where they can get their CD4 count that would make them eligible for the HIV state grant. She also takes them to the Ndweni Child Welfare Agency to receive food vouchers, to visit the Ndweni Hospice for support sessions and she counsels them in her own home. It is common to find her walking through the streets of Ndweni trying to assist and educate more people about HIV and AIDS. The vegetables from her garden have fed many families Ndweni.

During the eleven months I spent in Ndweni both weekdays and on the weekends, I was welcomed in many homes. Although I was the outsider, I did not feel like one because I had gained the trust from most members of the community. On many Sunday mornings, I visited when the men were at their homes and observed them with their families. At Ndweni Primary, the learners grew accustomed to seeing me at the school.

4.3 THE QUALITATIVE APPROACH

As mentioned in the previous section, this study was conducted through a qualitative paradigm of research. Three distinguishing features of qualitative studies used were:

The researcher shared in the understandings and perceptions of others and explored how people structured and gave meaning to their daily lives

Berg 2001:7

People were deliberate and creative in their actions and they acted intentionally and made meanings in and through their activities.

Their situations were fluid and could be changed rather than fixed and static- events and behaviours evolved over time and were richly affected by context. Cohen and Manion 2001:22

McMillan and Wergin (2000:8) assert that literature review in qualitative studies serves as foundation for the conceptual framework because it integrates with methodology, analysis and findings as well. Babbie and Mouton (2001) state that qualitative researchers have a view those social scientists cannot understand human behaviour without firstly understanding the framework from within which the subjects interpret their thoughts, feelings and actions. This study attempts to focus on studying human action from the insider's perspective rather than from an outsider perspective and this approach was necessary as it helped to unravel the complexities and diversity of the lives of the respondents by describing the silence about HIV issues that surrounded the learners, educators and members of the community. This approach also revealed the experiences of the persons affected and infected by HIV from their own diverse subjective perspectives. Babbie and Mouton (2001:275) confirmed further that the use of multiple methods in collecting data raised the researcher above personal biases.

In order to gather relevant data, I selected semi-structured and focus group interviews within the qualitative paradigm to get this insider perspective. Cohen and Manion (2001:272) claim that Tuckman described the interview as one of the best tools that allows the researchers to access what is in the participant's mind. Morgan (cited in Babbie and Mouton 2001:292), furthermore observes that the advantage of focus group interviews lay in the ability to observe a large amount of interaction within a shorter duration of time. The focus group sessions provided this study with direct evidence about similarities and differences in the participants' opinions and experiences.

Although qualitative research allowed for a number of data-gathering methods, I tailored my techniques to my specific research questions and my particular site of research. To achieve this, I used open-ended questions to get information in a friendly and relaxed environment for both semi-structured interviews and focus group interviews. I collected four sets of data, both from Ndweni Primary School and Ndweni Community. Sources of data included the following:

- learner drawings with text,
- written explanations of learner drawings,
- transcripts of interviews from two Life Skills co-ordinators, two community health care workers, two HIV positive persons, and finally,
- field notes from my journal of conversations with members of Ndweni community that included personnel from Greenville Hospice and Ndweni Clinic, educators, caretakers and parents from Ndweni Primary School.

At the beginning of my research, Thuli introduced me to Dr Dube, the Principal who agreed to let me conduct my research at his school. He signed the original consent form and introduced me to his Deputy Principal. The Deputy Principal introduced me to both Life-Skills educators who became my key informants. Although both educators were of different gender, they were both Indians. Both co-ordinators agreed to assist me and signed the consent forms. Both the Principal and Deputy Principal explained that there could be no choice in the selection of educators as interviewees because only two staff members had attended the HIV and AIDS meeting held by the Department. The Principal explained the problem he experienced because none of his staff had wanted to attend any meetings on the subject. He had introduced the rotation roster to ensure that all educators had turns attending meetings.

After this introductory and administrative protocol, I spent eleven months on the premises and became quite familiar with all other staff members. Ndweni Primary School had 36 staff members, 7 were Black and 29 were Indian. The pupil enrolment was 762, of which 758 were Black and 4 were Indian learners. All staff members, excluding one, lived in the surrounding wealthy north Durban areas and commuted to Ndweni daily. Although the majority of the learners spoke isiZulu, they wrote in English because their educators had no knowledge of isiZulu.

Although the staff members had a good relationship, a distinct division existed between Black and Indian educators with regard to divulging information on the subject of HIV and AIDS. On the one hand, while the Indian educators offered information freely, the Black educators on the other hand insisted that they had no information on the premise that HIV and AIDS was a taboo subject and not discussed openly by staff or learners at school. All contributions from members of staff, together with conversations with learners who did not form part of my focus group discussions, caretakers and Governing Body parents formed part of my journal as additional information from Ndweni Primary School. For additional information from the community, I noted my conversations with members of Ndweni community and personnel at Greenville Hospice, Ndweni Clinic, other than those that formed key personnel. Thuli introduced me to everyone I met in Ndweni Community.

In terms of the selection of learners for my focus group at Ndweni Primary School, the HOD and I agreed to select fourteen learners randomly from two grade six class registers. I selected grade six because they had been the only grade in the intermediate phase that had completed HIV and AIDS during their Life Orientation periods for a single term in 2003. This area was covered only because the school had received activity books from the DoE.

The initial focus group session was a disaster because the HOD had been absent and learners became aware that I would not be able to recognize the selected 14 learners. When I called out the 14 names, 35 learners emerged and insisted that they were selected and neither their class teachers nor I could deter them. During what should have been my first focus group session, the learners refused to be quiet or let me talk. They continued talking loudly in the vernacular and soon the noise reverberated throughout the school. The Principal and another HOD heard the noise, noticed my predicament and asked all 35 learners to return to their classes. They refused to listen and insisted that their rights were violated. The Principal then assisted me to select 14 participants from the 35 learners, again using the random register selection method.

The Principal assisted me further by sending two staff members with me to get consent forms signed by parents, legal guardians and foster parents. This task proved to be difficult because the addresses of the homes in Ndweni did not follow the usual numerical system and educators were unfamiliar with the area themselves. The educators admitted knowledge of just the main tarred road into and out of Ndweni community. None of the staff had visited any of Ndweni homes. It took almost three weeks and innumerable home visits to collect all signed forms.

It was only during focus group session two that I realised a language barrier existed because very few of the students could speak some English and I could not speak isiZulu. To break the ice I decided to play isiZulu music. Learners responded with a smile and a nod. I then gave them sweets, as this was relevant to their age. Based on recommendations by Thuli, for session three I prepared for the session with a translator. This session, however, was unsuccessful because as soon as the translator and I explained the reason for our presence, our area of focus and our initial purpose for conducting an open discussion with them, a few of the learners began questioning the translator in the vernacular, a few became silent and unresponsive and yet others

requested to use the toilet urgently. I learnt that whenever learners did not want to respond, they used the toilet as an excuse to leave the room. This revealed that the learners selected for the focus group interviews were not intimidated, by either the research environment, the researcher or the translator because they had a voice in terms of what they wanted to say or do.

During the same session, a few of the remaining learners tried to respond to the translator's questions but were silenced by others with a few words in isiZulu that immediately halted all participation. The translator questioned them in isiZulu and the learners expressed fear that open discussion might expose family members, friends and loved ones who were either affected or infected by the epidemic. Learners explained their parent's requests for silence due to discrimination family members and loved ones would experience. The translator and I decided to change our strategy and use drawings to illustrate the data instead.

During focus group interview four, learners agreed to draw and give written text to illustrate data. I had typed the question in both English and isiZulu and it was:

Draw your own personal experiences with HIV and AIDS
Dweba ngokwani kwakho malunga ngngculaza?

After the stationery was distributed and the translator explained the necessary guidelines, the learners began to draw. While they were still drawing, the siren went and it was time for the learners to leave. They requested to complete the drawings at home and I agreed. I collected most of the pictures the following day and the drawings had all the details that learners did not want to divulge during the group session. When we tried to follow up on the drawings by encouraging discussion on the drawings during the following session, the learners refused and after a discussion with the translator, they

agreed to the suggestion of written textual explanations of their drawings. When time was insufficient during the session, they requested to complete the responses at home. My questions for their textual responses were:

Tell me about your drawings. Ngitshele ngomdwebo wakho.

Tell me what you thought about as you drew your picture. Ngitshele ngako konke okade ukucabanga ngenkathi volweba isithombe?

Does the picture talk about your experiences? Ingaba isithombe sakho sichaza ngqo ngolwazi lwakho.

Of the fourteen learners, only one learner refused to explain her drawing, even in a textual form. During my discussion with her teacher after school, I learnt that she had lost both her parents to AIDS and that she and her siblings were awaiting placement into foster homes. The other textual responses yielded so much experience, knowledge and silence that I wondered about the source of this information. At the next focus group session, the translator asked learners about the source of the data they presented in their written texts. Learners' reminded us that they had initially only agreed to give their data in text to maintain anonymity within group sessions. They further requested that we read the data privately and avoid disclosing their responses to their friends. After another lengthy discussion with the translator, learners agreed to reveal the source of their data in written text and on tape individually, privately and in their own vernacular. My final questions were:

There is so much evidence from your drawings and your written answers about your personal experiences with people living with AIDS. How do you actually know that these people are infected? How do children know their status if they have not been tested?

I arranged with the HOD to tape individual responses in her private office. During the next focus group session, I collected only eight anonymously written responses. I questioned the grade six educators generally about the language barrier and they explained that learners did not encourage discussion on sensitive issues and since educators themselves did not speak or understand the vernacular; they respected the learners' silence and had instead focussed on those learners who could speak English and chose to respond. One of the two grade six educators explained that most of her colleagues experience this particular problem and responded in a similar way. The DoE has selected Ndweni Primary School to be their workplace. Although they had requested transfers out because of the language barrier, the DoE refused to transfer them unless they made their own internal and personal arrangements.

In this school, all Indian educators speak English and have no knowledge of isiZulu. The problem of written and oral communication existed between Black learners and Indian educators. The language barrier created a problem because learners were uncomfortable discussing personal issues with educators who could not speak or understand their language, let alone understand their needs. Although the HOD assisted me tremendously, she refused to discuss the subject of HIV and AIDS although she lost her colleague to AIDS in June 2004. The Indian educators revealed the cause of the educator's death as AIDS, subsequently denied by African educators. The HOD explained that at Ndweni Primary, nobody discussed HIV or AIDS and that Black culture did not allow for any open discussion on the subject. I found that Indian educators were prepared to discuss the subject of HIV and AIDS with the researcher and not with their own staff members or learners.

The interviews with both Life Skills co-ordinators answered many questions and filled in many gaps about the situation in Ndweni Primary School. The co-ordinators volunteered much information about the HIV and AIDS situation in terms of curriculum

and implementation. These co-ordinators openly admitted their own and their colleagues reservations about teaching sexuality in the classroom. The reservations included being uncomfortable on any discussion relating to sexuality or to HIV and AIDS and of having insufficient knowledge, confidence and vocabulary, experiencing embarrassment due to a conservative upbringing and finally they believed that parents would disapprove of the dissemination of information on sexuality to their children. Several educators mentioned the incident in 2003 with a grade six parent who complained to the Principal that that his child was too young to learn about sexuality education because it would incite the learner into the sexual act long before he was ready.

At the community level, a comparative study included personal semi-structured interviews with both a male and a female person infected with the HI virus and two voluntary health care workers who were peer-educators. One was Thuli¹⁰ and the other Prudence¹¹, both of whom were volunteer community workers as well as parents affected by the epidemic. Thuli assisted me by organizing all interviews with PLWHA and with Prudence. Prudence could not accompany us for the interviews because she had to care for her two little foster children.

Thuli had gained their trust and permission from all interviewees. She was also present during all interviews, assisted with translations, and reassured her friends. Beauty, the translator accompanied us for all interviews. We visited the Greenville Hospice on several Tuesdays from 10h00 to 12h00 because Thuli gave reassuring talks to PLWHA about her own personal experiences with the epidemic and conducted little exercises with them. Key informants signed all consent forms and all conversations were taped. During the eleven months, I spent in Ndweni, Thuli, Beauty and I visited other families

¹⁰ A pseudonym was used.

¹¹ A pseudonym was used.

that were not interview participants and spent much time together collecting and distributing many items of clothing and food to the people of Ndweni.

The members of the Faculty of Education in the University of KwaZulu had originally developed the research instrument for a similar type of study currently taking place in the Richmond area. The study focused on HIV as a barrier to learning and funded by the National Research Fund (NRF) organization. However, I piloted the instrument with learners from Ndweni Primary and adults from Ndweni community who were not participants. Many alterations and adaptations had to be made before implementation.

During my interview sessions with key informants, I drew information from my respondents with open-ended questions that focused on engaging them in dialogue about their experiences within their own environmental context of HIV and AIDS. I noticed that all interviews with the women in particular, could only be conducted in the absence of male partners and within their own home environments. The women feared their partners' reactions to disclosure of any information. I interviewed Busile at Thuli's house because he lived with her until she could find accommodation for him.

As explained before, I collected four sets of data from both Ndweni Primary School and Ndweni community. All semi-structured interviews at school and community took between 45 to 60 minutes each and were tape-recorded. Informal conversations and data accumulated over the period of eleven months. All semi-structured interviews were recorded in isiZulu on tape, transcribed firstly into written isiZulu, and then into English. Each of the three sets of questions for students in the focus group responses were written in both isiZulu and English and all responses were taped and verified by my supervisor, Dr Buthelezi. She verified both original isiZulu and English translations of tapes and written responses. This was extremely time-consuming, but my supervisor persevered to the very end. She gave me hours of undivided attention, supervision and

unlimited guidance. She also verified extensive field notes, journal entries and documented reflections. Dr Buthelezi verified that digital photographs taken of pupil's drawings protected participant identities. My research project was ethically cleared with an approval number from the University Research Faculty¹² (see final appendix) I also gained valuable information on computer competency. Because my research was carried out in real world circumstances and involved personal communication with the persons mentioned above, I adhered strictly to all ethical aspects concerning confidentiality.

4.4 SUMMARY

The discussion on theoretical framework and methods of research and experiences presented in this chapter reveals that research on HIV and AIDS stigma requires urgent intervention. This became evident when some of the learners I interviewed showed silent, unresponsive behaviour patterns, especially when they did not want to answer particular questions or disclose identities of friends and families. These attitudes are understandable when one considers the fact that some of them are personally affected by the epidemic. It has to be noted, as the chapter indicates, that research around HIV and AIDS has to consider the fact that society has a responsibility to care for those emotionally needy persons who need subsistence and support. The comments by teachers at Ndweni Primary, for instance, show that they experience similar problems as learners. The next chapter attempts analyse data gathered through focus groups and interviews.

¹² Ethical clearance approval number: HSS/06087A .

Chapter Five

FINDINGS AND ANALYSIS

PREVIEW

Chapter 4 was an attempt to offer the research theoretical underpinnings relevant to the subject of this thesis. I argued, for instance, that the relevance of qualitative methods of research relates to the fact that human action be studied from the insider's perspective rather than from the outsider's perspective. As I indicated, several researchers such as Cohen and Manion (1997) and Morgan (cited in Babbie and Mouton 2001), to name a few, used qualitative methods in their studies and discovered that the interview was one of the best tools for the researcher to access what was in the participant's mind as well as to observe a large amount of interaction on a topic within a shorter duration. The chapter also looked at the theoretical framework for the study and described several concepts relevant to this study.

This chapter draws from the understanding of these concepts as it offers the analysis of data collected through focus group sessions and interviews. This chapter is divided into two sections. Section A presents the findings, which follow the theoretical framework that informs as, presented in chapter 4. Data captured and analysed revealed oppression as a central theme discussed within theories of oppression as existing in Ndweni. These theories include isolation, silence, marginalization, labelling and scapegoating with the theory of fear incorporated into all theories. There were significant theoretical overlaps from learner and adult responses that illustrated the nature of HIV and AIDS-related stigma and its effects on learners and community members. Ten learners submitted one drawing each and four learners submitted two drawings each. These learners will be referred to as participants (E.g. P5 for one drawing and P7ii for two drawings).

Section B of this chapter analyses these findings and reveals interconnections between social issues such as poverty, prejudice and ignorance, gender politics and violence with HIV and AIDS-related stigma existing in Ndweni community.

5.1. SECTION A: Findings: 'The Silent Face of Stigma'

As chapter 4 indicated, oppression emerged as a central theme in Ndweni community due to the existence of what Young (2000) calls the exercise of tyranny by a powerful group who found themselves becoming dehumanized because they stole the humanity of the oppressed. Freire (1970) states that those who oppress do not actually see how their dominating and manipulative behaviour becomes destructive and violent to both themselves and PLWHA. In Ndweni, horizontal violence occurs when oppressors attack their own families and community members and causes negative effects such as isolation, silence, marginalization, labelling and scapegoating, concepts discussed as theories of oppression. The following sub-sections offer a detailed discussion on each theme.

5.1.1. ISOLATION

Isolation is defined in this study as a separation and of being kept apart from other people. This is a deliberate discriminatory action that causes persons who are excluded to feel lonely and segregated. In Ndweni, oppressors are either uninfected and of unknown status, oppress PLWHA because they are ignorant and lack accurate information about the subject of HIV and AIDS. Consequentially, PLWHA are deliberately isolated on a daily basis, causing them much worry, stress and sorrow. There is considerable evidence from learners' drawings, their written texts and adult interviews that oppressors refuse to identify or associate with PLWHA to avoid becoming infected. Responses from both learners and adults illustrate this view: Participant responses are used as evidence without additions or corrections.

My friends don't want to play with me or even to share with me because they says I'M HIV positive. What I'M gonna do (sic). P9

Mandla is lonely now becous other children don't want to play with him, they thought he got HIV too becous he father and mother die of HIV. He is sad and he is poor and stay in the house where they find the big snake that eat people. P3ji

I am alone, nobody help me. I didn't have no money or support. In my home, they don't like me and say get out. I don't know what to do. Busile (HIV+)



Figure 8: Isolation of CLWHA. (P1)

The responses above indicate that learners and adults who are known to be infected with HIV, or perceived to be living with AIDS, are stigmatized quite often. Almost all drawings show learners at play together and isolating only CLWHA. This isolation makes CLWHA feel as if they had done something wrong, a phenomenon that takes place both at home and at school. The drawings and text from learners disclosed that adults participate in the discrimination process, some quite consciously and deliberately. Figure 9 below, for instance, reveals parents witnessing their children discriminate CLWHA during play.



Figure 9: Isolation at home. (P2)

According to the learner who drew the picture, both parents did not intervene or stop the discrimination in process. The text of the learner who drew the picture reveals that:

The man who is washing the car is looking how they play and don't play with Bongiwe. He says good don't play with her. The man is the father of the girl with the rope. The boy who is her brother say chase her away. The girls mother in the house is sad. Her family don't know she got hiv because she didn't tell them. She know they will chase her when they know it (sic). P2

Learners use 'the other' to reveal the effects of isolation on CLWHA. Several learners drew 'the other' as being isolated but never themselves. This reveals that learners feared disclosure because of stigmatizing and discriminatory attitudes. In Figure 10, P3 in her first drawing (P3i) drew 'the other' as a learner wearing the uniform of Ndweni Primary and her text revealed 'the other' as an orphan in foster care. This links to the information from the class teacher that P3 herself and her siblings are orphans placed in foster-care. P3 also submitted the drawing in Figure 11 as her second drawing. In this drawing, she draws a male as 'the other' wearing the uniform of Ndweni Primary. This male is also an orphan who lives with his aunt and is isolated by friends and family due to association with the epidemic.

The findings reveal, among other things, that PLWHA are disadvantaged by both the epidemic and stigma. The effects of both on PLWHA make them to see themselves as static, limited and expendable because of alienation from their own society, friends and relatives. Several learners feel depressed and suicidal because their parents are either ill or have died from AIDS. Participant 3 in her second textual response describes Mandla's state of mind. Both her drawings and text reveal loneliness and solitariness as CLWHA experience it.

Mandla, he say he wanted to die. This picture remind me of lonely he going to school alone without any frinds and look like a madness person (sic). P3ii



ABOUT HIV + AIDS

NDWENI 
PRIMARY - SCHOOL
* Excellent *

My friend
dont want
to play
with me
or even
to share
with me
because they
say I'm HIV
positive what
IN GODS do



I'm HIV POSI-
tive I need
love, care and
help
I also need
Support from
MY FAMILY

Now she want to be
my friend because I
have HIV POSITIVE I
can make them Sick
if I will be friend with
THEM !!!

This poster is about HIV + AIDS



Figure 10: Isolation at school. (1'3)

Hiv Aids

The boy who lived in our area was very sad because he was an orphan. He was crying because his parents died of HIV and AIDS. They did not love him anymore. His friends and neighbors were taking him just like a dog. They don't allow them to play with him because they will get AIDS from him. The life is so sad. Thabiso says kill himself. He is crying all the time thinking about his parents.

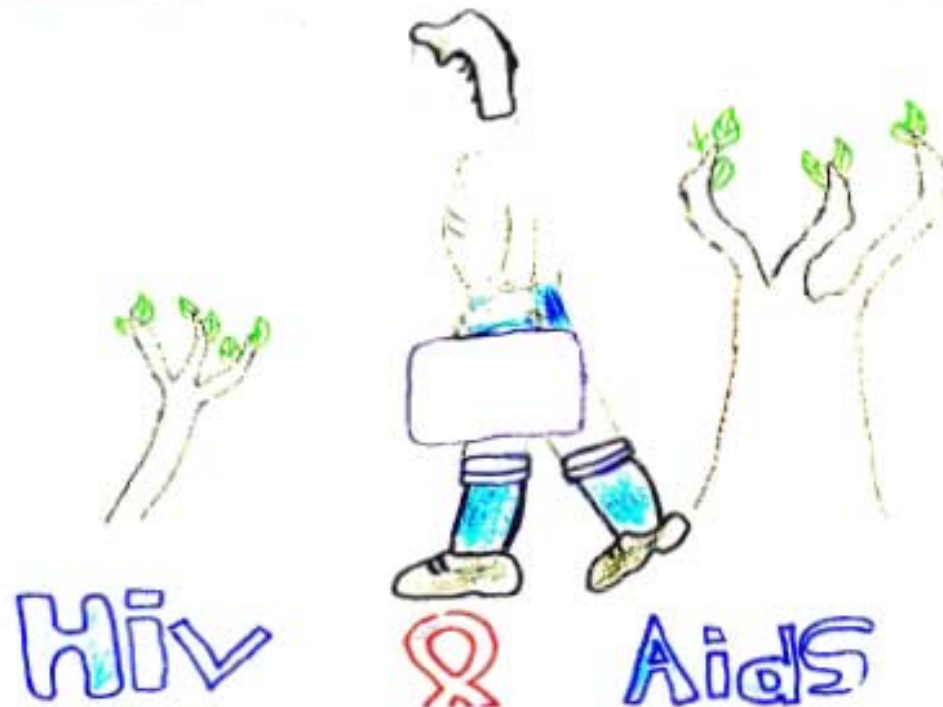


Figure 11: CJ.WHA as depressed and suicidal. (P36)

I drew a boy that is an orphan. He was crying because his parents die of HIV and he staying with her uncle. His friends and neighbors taking him just like a dog. They parents don't allow them to play him becos they will getting aids from him. The life is so sad Thabiso say kill himself. He is crying all the time he thinking (sic). P10

Adult PLWHA also expressed a depressive and suicidal state of mind. Their interviews reveal both physical and emotional stigma they experience from oppressors who are often their own family members, friends or relatives. Adults such as Busile and Maggie explain their own depressive and suicidal experiences.

The time I found out, I wish to die, to take my life with my hand because then I didn't have any friend left. Even my girlfriend she left me and then I got sick. When I got sick they didn't help me. They ignore me and swear me bad words. They hit me and throw stones on my house (sic). Busile (HIV+)

I suffer so much. I like to die. Last week I try to kill myself. I die but who look after my babies (sic). Maggie (HIV+)

The findings revealed that affected learners lost their emotional, financial and physical support systems when their parents died of AIDS. Several community members revealed that young parents die in large numbers and that their children are placed in foster-care, orphanages or adoptive families and grow up with little or no attention. Sometimes learners like P4 in Figure 12 have to look after parents who are ill for long periods, often until the death of the parent and learners are then placed into foster or adoptive care. In situations where learners have lost parents and have ill siblings they carry the responsibilities as head of the family for long periods of time until they are placed into foster or adoptive care. Thuli confirms this view:

I try to do whatever I can do with food from my garden to help the children who have to look after their brothers and sisters when their mother and father die. I speak to the families and see if they can take the children into their homes and then I tell the Ndweni Child Welfare about it. It is easy if the families they agree otherwise it take a long time to get homes for them and I don't see them when they go far away (sic). Thuli

Narratives from several learners revealed the extent to which poverty interconnected with the epidemic and affected their education when some educational institutions discriminated against CLWHA. Sipho's narrative reveals this:

I am Sipho and I am 18 years old. All the other schools didn't want to take me because my mother she was HIV sick and my father was died of HIV. I look after my mother by myself because nobody help me and I have no money (sic). P11i

Figures 12 to 14 reveal the worry that assails adults and learners during what should have been the process of illness, grief and bereavement. The rejection of isolation instead adds to the loneliness and sorrow CLWHA and PLWHA experience with the loss of family relationships and more especially friendships.

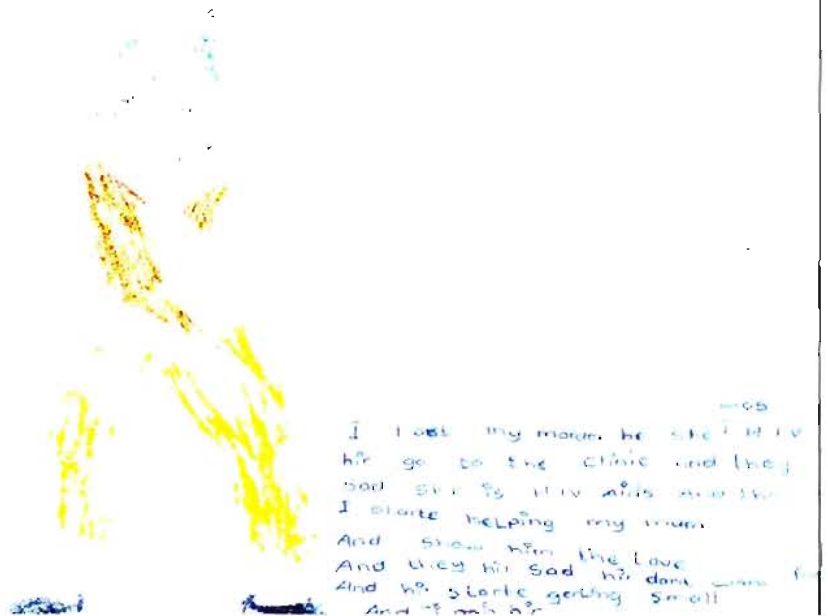


Figure 12: Learners worry and stress. (P4)



Figure 13: CLWHA plead for acceptance from oppressors.(P5)

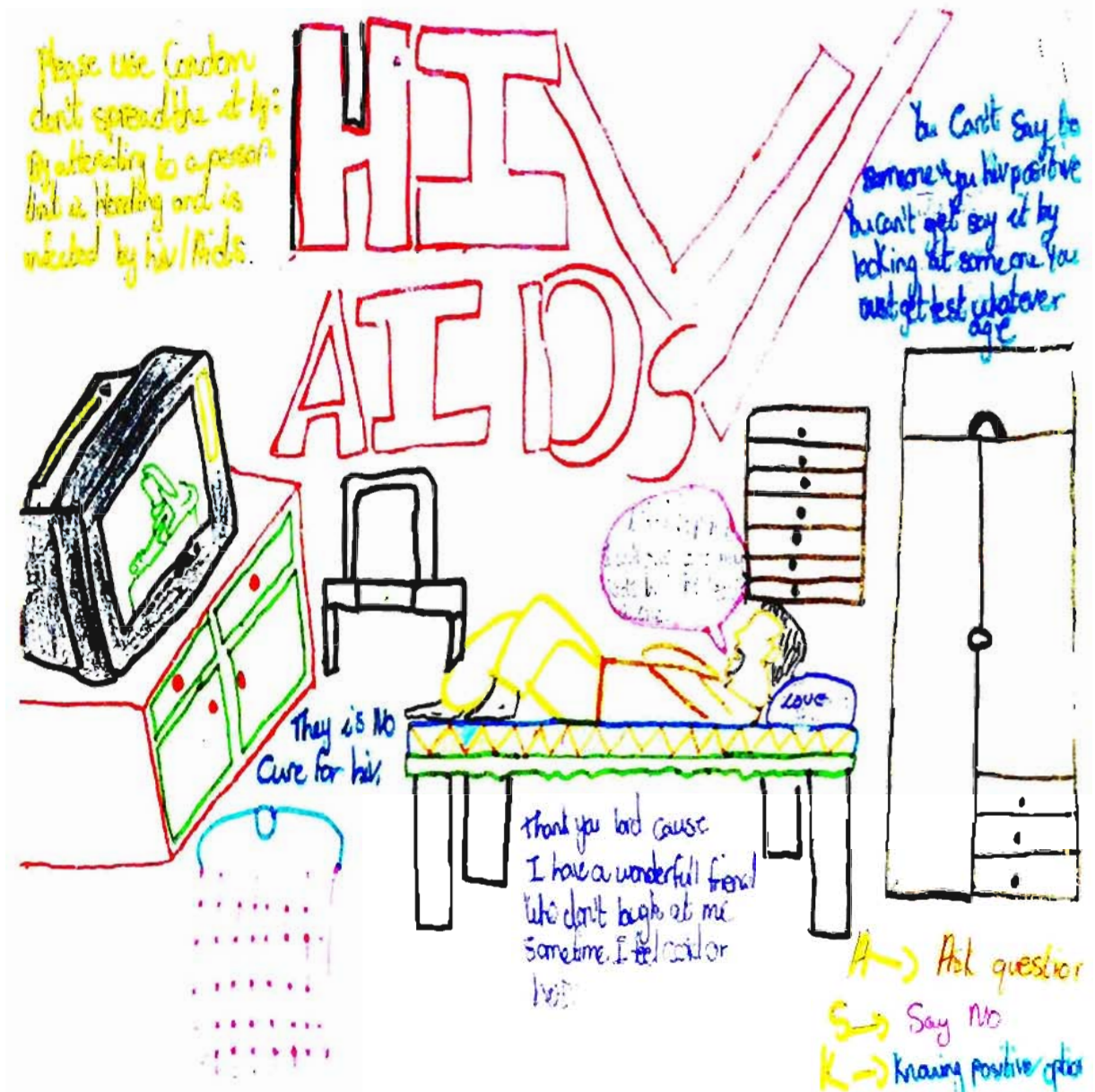


Figure 14: Adult worry and stress. (P6i)

Such emotions are presented by learners through speech bubbles to describe their experiences as subtle, but causing much pain and stress. Several illustrations revealed

CLWHA pleading openly during play for acceptance, sympathy and love but receiving rejection instead. P5 who drew Figure 13 represents what all the other drawings say about the attitudes of oppressors who isolate CLWHA due to their association with the epidemic.

If you like you can hug me.

If I hug you I am gowing to have HIV.

Don't hug him. She has AIDS (sic). P5

Learners are aware that oppressors isolate them because of the loss of their parents to HIV and they are now perceived to be infected themselves. P5 in Figure 13 reveals this within a thought bubble directed with arrows to the mind instead of to the mouth.

People don't like me because I'm HIV (sic). P5

Learners revealed knowledge of sexual abuse of several children in foster-care. Learners' text reveal much intimate detail of such abuse and their narratives expose foster-parents as being aware of the abuse and blaming the abused learners for encouraging foster family relatives and friends who abuse them. Several learners reveal foster-parents who traumatise them further with incorrect information on the mortality rate of persons living with AIDS. P3's response reveals the abusive attitude of her foster-parent who is also her aunt.

My aunty, she say 'nobody gonna help you. You gonna die. My friend he tole me you ask and force him to have sex with you (sic). P3i

Learners need the foster-care system to offer them the support, love and care they went there to receive. Parents are aware, firstly, of the discrimination that AIDS orphans

endure from foster- families and, secondly, that most families prefer to foster orphans who are not infected to collect foster-care grants. This causes seropositive parents much worry and stress about the discrimination their children would experience after their demise. Maggie's words confirm her relief that her children are not infected.

Now I die with this sickness, my biggest worry is my children and food and school fees. I am happy my two children are neat (meaning HIV negative). If they were not neat, then no foster family they want look after them when I die (sic). ..Maggie (HIV+)

After the death of their parents, AIDS orphans face a more serious problem when they need to transfer to new schools and foster families. Learners found that if they could not produce birth documents they could not register at any educational institution. The situation is even worse for orphans of refugee parent status who cannot obtain registration documents.

If they have their birth documents, they are quickly placed into foster care and then back into the education system. Those that have no official birth documentation cannot be get foster-care placement, foster-care grant, official acknowledgement of their name, nationality, protection of their rights and have no home or money. When their parents die, these children become lost and not even our social work departments can trace them (sic). Health Official: Ndweni Child Welfare

Ndweni Primary School policy does not allow orphans or learners in foster-care to register without their birth documentation. I found that the children of refugee parents were not registered because they have no documentation. I noted further that learners from families 'perceived' normal were registered even though birth documents were pending. Many of these documents were not submitted, even after such learners left for secondary schooling. This is stigma directed at AIDS orphans and foster-care learners. One of the Life Skills co-ordinators mentioned that educators do not know when their

own learners become orphans or placed into foster-care. This occurs because of a lack of communication between the Social Work Department and the Department of Education. Educators are aware of learner's long period of absence from school and of transfers out of school. The co-ordinator informed me that:

Approximately fifteen to twenty children leave at the end of each term never to return and their forms for transfers include unknown forwarding address (sic).

Life Skills co-ordinator

When asked about this matter, the school had no idea because the forms returned with no forwarding addresses. The school did not contact the Social Work Department or the Education Department to resolve the situation and these learners remain forgotten.

Grandparents of AIDS orphans in Ndweni are vulnerable because they have to care for their grandchildren when their children die from AIDS-related infections. They care for them in their old age and feel vulnerable. Although grandparents who care for their orphaned grandchildren are eligible for the collection of grants, many of them do not have the correct documentation, sometimes for their grandchildren or themselves. One of the grandmothers mentioned that:

I am looking after two of my grand-children for about 8 years and I do not get a foster care grant because my grandchildren's papers are not right they say. Thuli

The problems experienced by PLWHA of Ndweni interconnect with their poverty. Poverty extracts and reduces their power, self-esteem and confidence as survivors. Learner and adult narratives reveal the extent to which poverty, due to unemployment, affects their lives. Several texts revealed poverty so severe that some of the Ndweni children remain permanently hungry, go to bed hungry, having drunk water to fill up their stomachs and wake up hungry. A few of the narratives point out that:

My mother she cry to and we got no food most time and we drink water and sleep. We poor and my mother she wash clothes for rich people house who pay her small money (sic). P6ii

My mother she help everybody hiv sick, she work in the garden she grow vegetables cos we have no food otherwise. Daddy he work here and there whenever he get job. He sad when he hav no work and no money. Me maam she say bring school fees and we got no money and she say we poor and see the principal. Lot peoples in my school they say cant pay fees cos they got no money. They poor too (sic). P10

The community health worker, Thuli discusses the interconnectedness between the realities of poverty with the epidemic in Ndweni.

To be poor means to live from day to day, you have no money and power, no food and no hope and if you have HIV too, then you are seen as dead already (sic). Thuli

This instils powerlessness that renders adult PLWHA vulnerable and helpless, and learners witnessing their parents' powerlessness and helplessness, become more depressed. The feeling emerges in words such as 'What I'm gonna do?' Figure 15 illustrated such helplessness combined with powerlessness.

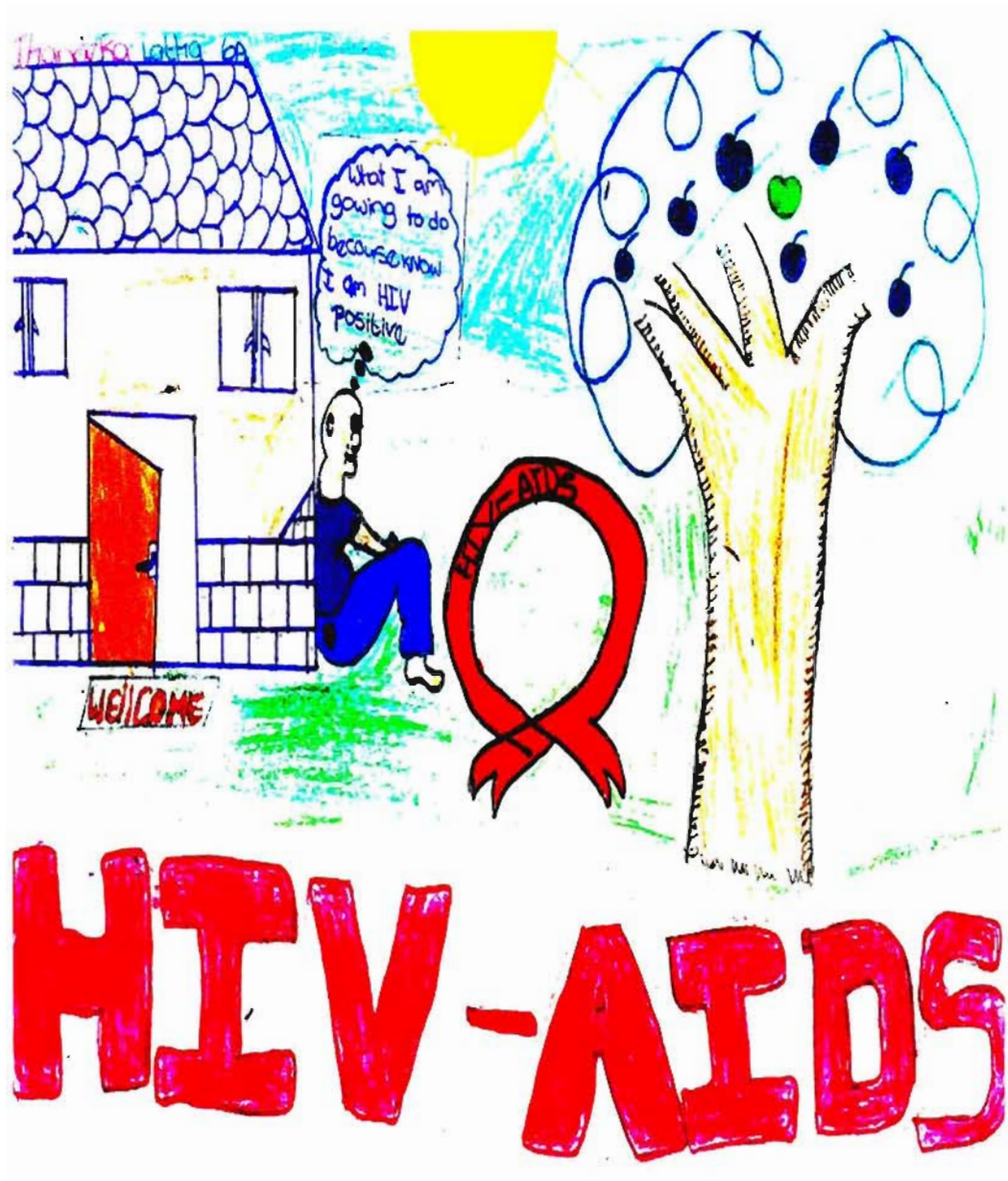


Figure 15: HIV and poverty make PLWHA feel powerless. (P7)

Powerlessness stems from poverty resulting from unemployment, again interconnecting with HIV and AIDS and adding to the burden of both adults and children. As discussed

in the background chapter, most of the men in Ndweni are either unemployed or migrant workers with alcohol or drug problems. Some of them have extra-marital affairs and infect their partners. P7 in Figure 15 above reveals a male who feels powerless because he is unemployed and seropositive. Similarly, some women feel powerless because they are unemployed homemakers who grow vegetables to feed their families. Some of the women sell their extra vegetable, knitted garments and offer childcare facilities to earn money for food. In addition to the extra workload, they become unwell because their partners have infected them. Learners assist their parents in the garden after school, as Figure 16 reveals.



Figure 16: Learners assist in gardens after school.

Several respondents, one of which was participant 4, reveal the effects of the interconnectedness between poverty and unemployment with the epidemic on learners and their families.

My father he was working when he get sick he don't work ther was no money for food. My mother he don't work and his neighbors give hem food. She grow potatoes for the seeds his neighbors give her. And my mother she die now and I got no food most days. I miss her (sic). P4

With powerlessness as a defining feature, in communities like Ndweni the perception is that white people are rich and blamed for the lack of medication and subsequent deaths. The learners have very little contact with the 'rich people' and quote their parents to illustrate this view.

Baba say everyday what we gonna do because only poor people lik us get HIV. Only the rich people can buy medicine and get nice doctors make them better and they don't die like the poor people who die with no medicin (sic). P9

HIV is the diseas that get you rich or poor. And it can get you Whether you black or whit and wantever colour (sic). P6ii

All the rich peoples everywhere look down on poor people, and is very bad if you got the virus too (sic). Busile (HIV+)

Only rich people they get medicine and the poor people they die cos they got no rich doctors medicin. I don't like white peoples. they take everything that's wy we got no food or medicin (sic). .P6ii

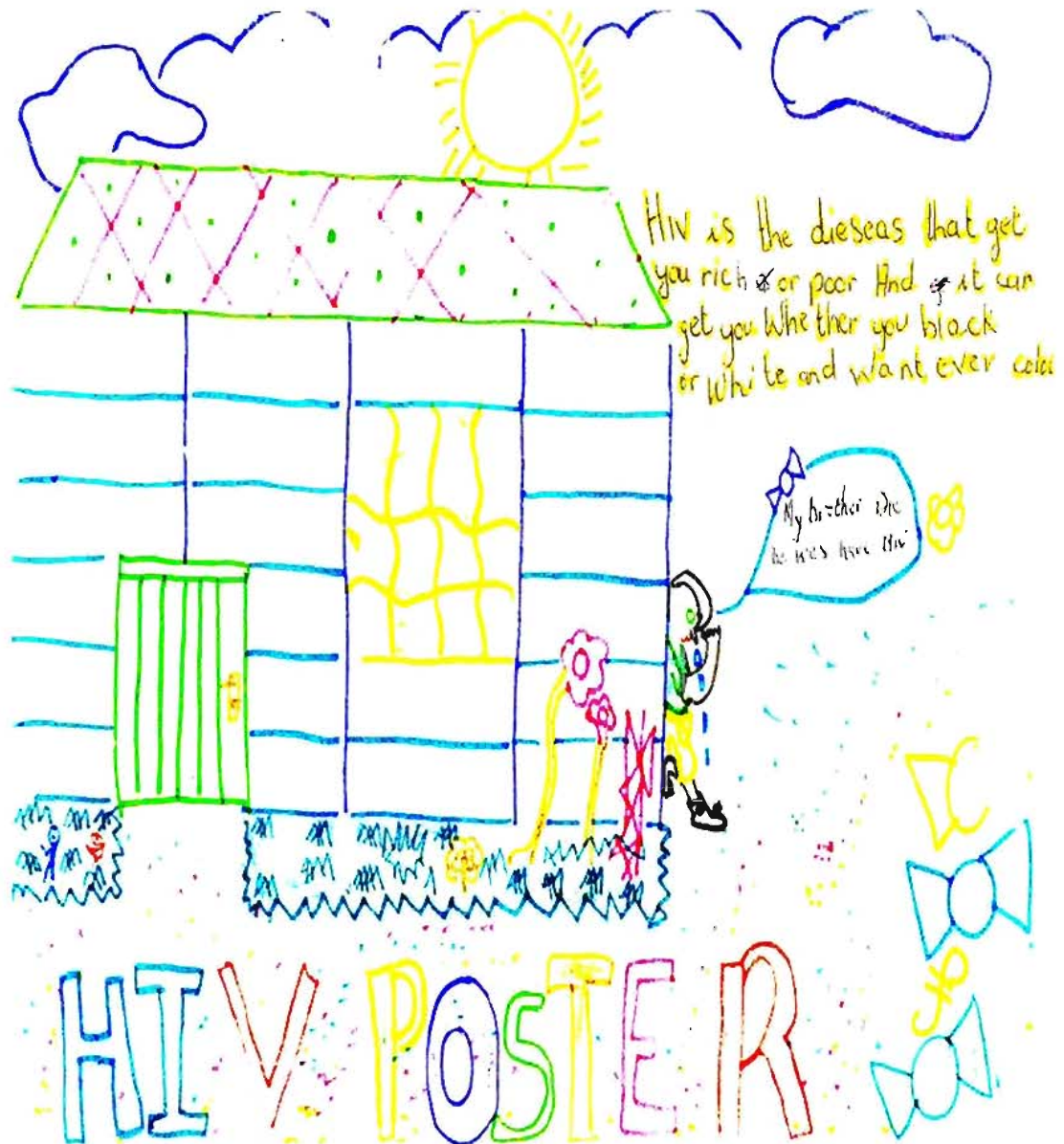


Figure 17: Perception that HIV or AIDS is class-related.
(P6ii)

Adults' reveal interconnectedness between the epidemic, poverty and classism. Their traumatic experiences make them believe that poverty and HIV affect impoverished

communities because PLWHA are already dead if they are poor with an HIV infection. Maggie's words below confirm this view.

Poor people with HIV is sad cos poor make more sick people. Poor and HIV sick is already dead because nobody cares about me or my family (sic).
Maggie (HIV+)

5.1.2. SILENCE

Ndweni community residents chose to adopt the culture of silence as their personal and social reality. PLWHA chose silence to escape stigmatization from oppressors by colluding with oppression and not disclosing any association with the epidemic. This culture of silence passed onto their children, sometimes consciously. Several texts from learners confirm that they got their information from their community members, namely their parents, grandparents, sangomas, traditional healers and friends and associates. Parents regard the subject of HIV and AIDS as 'taboo' and all information and messages, however incorrect or selective learners received at home circulates amongst friends and learners at school. Learners adopt their parents' silence and this was evident when learners drew and quoted adults who advised them to be silent and not to disclose their status to avoid discrimination. Learners learnt that HIV carried a death sentence because there was no cure or medication with the exception of the sangoma's medicine. This represents inaccurate information and parental beliefs in their own culture.

Do not talk to anyone about it because nobody can help because everybody with HIV they die. No medicine makes anyone better. Only the sangoma do intelezi (witch-doctor's medicine) make sick people better (sic). P4

If you have HIV you must keep quiet. If you keep quiet then nobody would pick on you but if you told anybody then nobody would love you (sic). P9



Figure 18: Adults advise silence to avoid stigma. (P9)

This indicated that PLWHA preferred to live with HIV but not with stigma. In Ndweni, the subject of HIV and AIDS is so sensitive that the silence adopted by the oppressed

has become as dangerous as the epidemic itself. Adult interviews revealed the fear they lived with on a daily basis that caused them to maintain their culture of silence.

My husband he say if I tell anybody I sick he hit me and kill me. Maggie (HIV+)

The stigma and its resultant negative discriminatory attitudes extend to family members and friends as well, deliberately isolating them from social involvement. During focus group sessions, learners did not want to reveal information because they wanted to protect their own identities as well as those of their families and friends. As discussed in the research strategy section, learners requested not to participate in discussions for fear of disclosure of the status of their loved ones. Learners agreed to participate if they could remain anonymous. One learner withdrew after submitting her drawing. She refused to participate in further focus group discussions. This reveals clearly that learners wanted to avoid exposing personal links to the epidemic while using 'the other' to expose stigmatizing attitudes and behaviour they either witnessed or experienced in their community.

In the picture the boy is for everybody with HIV who is treated not good by their friends and famlys. We should not do this but people are bad people. Friends are bad. They lagh at us and make us sad. Look in the picture...see how the other girl is pointing finger at him crying (sic). P2

PLWHA revealed the effects of stigma that left no area of their lives untouched or invulnerable to discrimination, and that their experiences continued because they did not report discrimination. Prudence's response clarifies this:

Is hard to get someone who has got the HIV to tell you unless he trust you but they feel hard to tell because they think you is going to spread it all over and the friends and familys and relatives start to hate him, that is why most of the HIV peoples they didn't want to tell anyone that they are sick. They don't tell the social workers too. They keep it quiet (sic). Prudence

Although PLWHA are silent, they are aware of being treated differently and isolated from other human beings. PLWHA are also aware that this treatment emanates from the perception that AIDS is a dirty sexually transmitted sickness attached to irresponsible, promiscuous behaviour with deviant sexual practices. At Ndweni Primary School, learner responses indicate that they are aware of AIDS treated differently from other diseases and that PLWHA are marginalized because of their association with the epidemic. The words of P14 below reveal this view.

Everybody think that everybody with HIV is dirty people. So why don't everybody see flu or tb as dirty only hiv. I want to teach people not to say bad things about sick people. They are sick and still so frighten of what other peoples say and do that they are frighten to tell other people that they have HIV (sic). P14i

The most effective impact of the silence on learners emerged when eight learners chose to send in their written replies without including their names. All eight textual responses revealed extensive knowledge of physical symptoms of AIDS. Text one below will represent what all eight responses reveal.

You can see a person with HIV because everytime she is sick. She is coughing one way, non stop. She is getting thin without using slimming things. The stomach runs and she always scratch the body. She is get big on the face. This person is loosing power (meaning strength) and the skin looks dry and with black sores. She always feel tired and crying for nothing (sic). anonymous

A second text discusses the symptoms that adults in the community experience.

The old ones their bodies stays tired, didn't like food, always sitting in the sun. You can see her when she is coughing and the lungs smells and getting small and the face skin getting sores, pimples with smelling things inside. Even if it is hot she is always cold and coughing. She always think about the deads. She always thinks to change the place, to go and stay far (sic). anonymous

The silence that exists in Ndweni is therefore not a quiet silence. There is tremendous pretence of false caring for sick family members, friends and relatives. This means that although oppressors are aware of the status of the ill persons, they pretend ignorance and are silently waiting for PLWHA to break the silence. This silence hurts those PLWHA who are already suffering because it entombs them with the fear of discrimination that disclosure would bring. The title of this thesis is significant because it relates to the silence existing in Ndweni.

5.1.3. MARGINALIZATION

The theory of marginalization emerged from the fear of disclosure and discrimination discussed. Young (2000) considers marginalization to be one of the most dangerous forms of oppression because it excludes categories of people from useful participation in social life, subjecting them to severe material and emotional deprivation. Communities such as Ndweni are marginalized because they are low-cost housing projects. This means that donors who assist NGOs and the South African government to provide houses for the lower-income groups fund their houses. Adults revealed strong views on this particular issue:

Because we are a low-cost housing we become a vulnerable and get a stigma because of the poverty and now the HIV (sic). Thuli

Thuli's comment above indicates that even with minimal food and shelter, oppression takes place. Within this low cost-housing community of Ndweni, people were made to feel powerless and voiceless by oppressors who systemically disadvantage and marginalize PLWHA, thereby depriving them of prevention, treatment and care. This occurs because PLWHA cannot access the resources provided by the NPA without disclosing their status and being subjected to discrimination and violence.

The quality of treatment PLWHA receive from personnel in the health sector adds to the powerlessness experienced by PLWHA in Ndweni.. The personnel at Ndweni Hospital are often exclusionary, rude and uncaring. Both volunteer community health-care workers describe the reactions of the professional staff at Ndweni hospital as:

Uncaring and inhumane. Many people preferred to die at home than go to the Ndweni Hospital (sic). Prudence

One of the participants' anonymous responses confirmed this by revealing the treatment her mother received at the hospital.

My mother she don't like to go to Ndweni Hospital because the nurses and doctors are horrible, cruel and nasty to her. They say she gonna die with the sick and her heart pain with what the nurses they tell her (sic). anonymous

PLWHA who did get taxi fares to go to Ndweni Hospital complained of intense discrimination by medical personnel. The findings chapter revealed nursing personnel who advocated for death and not life. Patients disclosed that as HIV patients, they did not receive treatment because medical personnel knew they were going to die. The discriminatory attitude had been observed and reported at a support session at Greenville Hospice by a visiting missionary and his wife. They witnessed an HIV positive female patient vomit on the floor and then fall over from her bed onto the floor. The missionary and his wife had watched the nursing personnel step over the patient and go about their duties. The missionary and his wife helped the patient back into bed and then questioned the nurse. Her response had been:

She is HIV positive and she will die anyway. We have really sick patients to attend to (sic). Nurse from Ndweni Hospital

PLWHA need to depend on their own informal network of kin and friends they trust for survival and solace.

I can only trust Gongiwe who is my friend. She know I am hiv sick but she wont tell no one. She give me money to care for her baby when she go work. She help me. She know my husband he giv me this sickness (sic). Maggie

Marginalization at Ndweni Primary School occurred because the curriculum that had been conceptualized according to learner age to minimize the effects of the epidemic on learners was not implemented. The curriculum had been designed by the DoE with the intention of taking learners through each phase of the epidemic according to their own age and environmental contexts. This would have ensured that learners developed a proper understanding of HIV and AIDS and accepted it as another communicable disease. Learners feared the HI virus because they did not understand it. This lack of understanding arose from the lack of accurate information on HIV prevention and AIDS-related education both at school and in the community. This fear became the nightmares where learners unconsciously personified the virus into enormous proportions. The nightmares centered on huge pythons with voracious appetites found in Ndweni community. The silence and lack of communication adopted by both parents and educators increased the effect on learners, as Figure 19 and the written texts below illustrate:

One day somebody told me about the big python that ate that construction man who was cutting the grass. They said he was hungry and ate him. When they found him and saw the lump in his stomach because he ate that man. The snake people took the python in one big cage. But I was frighten lot and dream of the snake with the man inside him (sic). P8

The fear that learners had of the virus personifies itself in the mind of the learner as the snake that would eventually destroy all PLWHA in Ndweni. This image is

significant because learners blame the epidemic for the escalating deaths in Ndweni Community. The illustration below represents what most of the other drawings say about their fear of the virus.



Figure 19: Silent messages of fear. (P8)

HIV will kill all in Ndweni like this snake. He is big, big, big and his mouth is so big and his teeth and eyes are so big, yellow and black. This big python has a rattle on his tail that ring like an ice-cream bell ting..ling.. ling and tell all the HIV sick people, I'm coming to catch you, eat you. I was so frightened when I was dreaming. I made pee in my bed one night when the snake was chasing me (sic). P8

At Ndweni Primary School, information about the subject of HIV and AIDS itself was marginalized. The research strategy section explains the large class sizes and the language barrier (none of the Indian teachers spoke isiZulu) that existed at the school. Educators marginalize the subject of HIV and AIDS by concentrating on Right Living and Guidance issues during the Life-Orientation periods. The management at this school aids in this marginalization because their priority was to ensure that all classes of approximately fifty-five to seventy-two learners have educators on a daily basis.

Furthermore, because HIV and AIDS is a sensitive subject, teachers marginalise the discussion of sexuality and the epidemic by discussing the body without directly referring to sexual relationships. In other cases, sex was discussed, but only within the boundaries of abstinence. This was done only for one term during 2003 and because the school received Activity Books for the intermediate phase from the DoE. The school's two Life Skills co-ordinators revealed that they had attended one workshop on HIV and AIDS in the latter part of 2003 and had held an awareness workshop immediately thereafter to disseminate this information. Before or after the year 2003, educators had not taught the subject of HIV and AIDS. Several educators expressed similar reasons for avoiding the subject. The words of one educator represent all others.

I feel uncomfortable discussing sexuality and HIV and AIDS and I know that my friends feel the same way (sic). educator

Some of the educators mentioned that they lacked sufficient knowledge, confidence and vocabulary while others were embarrassed to talk about sexuality issues, let alone attend meetings where such topics were discussed. Furthermore, most of the educators believed that parents would not approve if they disseminated sexual information to the learners because both Indian and African culture did not allow for open discussion on both sexuality and HIV and AIDS.

Educators, on the one hand, did not discuss the epidemic openly, not even when they lost a colleague to AIDS in June 2004 while learners, on the other hand, revealed the educator's cause of death using the incorrect information she had disclosed to them.

My teacher die from AIDS not so long now this year. She stays near my house. Our neighbours she told us how my teacher she die. She told us if we get HIV no-one will make us better and we die (sic). P14i

My teacher she died in June this year. In my school nobody talk about HIV. The teachers they don't teach us about it. They say it is a virus just like the flu and TB. They don't teach us about sex. But we know about it because many boys and girls have sex in my school. We give them the condoms the social worker she gave us (sic). P11ii

Several learners discussed the social worker who spoke to them about abstinence and condom usage and later died of AIDS herself. Learners questioned the validity of the education they received from her.

The social worker came to Ndweni Primary School and spoke to them about abstinence and condom usage (sic). Female Life Skills co-ordinator

Learner data produced much evidence that silence and secrecy surrounded the subject of HIV, AIDS, affected learners, and adults at home and at school. Several learners discussed parents and educators who avoided the subject of HIV and AIDS.

Everybody keep it quiet like it is a big secret. even the teachers don't teach us about It and sex. But I know many boys and girls have sex in my school. We give them all the condoms the social worker give us (sic). P4

Some educators and parents do not disseminate information on HIV and AIDS to the learners because they are confused about who should actually discuss what content. The educators, on the one hand, discuss HIV without directly referring to sex, abstinence or safer sex because they feel that it the duty of parents while some parents; on the other hand, feel it is the duty of the educators to teach their children about sexuality and HIV and AIDS. This confusion only succeeds in sending a message to the learners that HIV is transmitted during sex and linked to immoral behaviour. It fails to help the many young people who are sexually active, making it less likely that they will seek advice and instead take the risk of becoming HIV positive. This emerges in learners adopting a moral view that 'they and not us' attitude that points fingers at 'others' as indulging in immoral behaviour. The rights of these learners to information about HIV and AIDS have become marginalized at school. P3 and P12 explain the view of educators and parents.

My sir he only teach us about the virus HIV last year (2003), he teach us sex parts in the body. He say nobody say he must do sex in the class work. He say mummy and daddy must do the sex part with us (sic). P3i

Mummy shes a help-nurse at Ndweni hospital and she teached me all about HIV and sick and death. She telled me that boys and man make Aids. She teached me about sex and age for sex over 21. My teacher, he teached me about girls and boys they boddy parts only last year. The boys and girls they was laghing when teacher he was teaching us. After the lesson, the guyz they draw our girls boddy parts down there on pieces of paper and sen it round and round the class and lagh at us (sic). P12

Due to this marginalization at school, learners have mixed messages with regard to knowledge about the epidemic including that of the AIDS Ribbon, as learners' interviews reveal:

It is red in colour so it says 'danger'. You wear this ribbon to say 'don't touch me.' Anyone who sees this ribbon will know that hiv is dangerous (sic). P10 & P12

It is a good luck symbol (sic). P11ii & P7

It must be worn because the sangoma or the traditional healers gave it to their family members for protection (sic). P11ii

It is a bad luck symbol (sic). P7

Wear it to chase away the HIV disease (sic). P9

Figure 25: Wear it to stop the spread of AIDS (sic). P5

Wear it to show everybody that you are HIV positive (sic). P1ii

Wear it to show caring and sharing of giving love (sic). P2

The male Life Skills co-ordinator himself was unaware of the significance of the AIDS Ribbon. His view was that:

The Aids Ribbon was just to remind us of Aids. male Life Skills co-ordinator

This indicates that educators marginalize information because they lack accurate information on the AIDS Ribbon and HIV and AIDS themselves. The learners' knowledge represents the limited views of their community. This lack of information causes confusion and denial in learners about AIDS-related deaths such as tuberculosis,

headaches and opportunistic infections. One educator confirms what several educators mentioned about the large number of children that reside with grandparents and foster-parents because they have lost their parents to AIDS.

Many classes have about half of their children living with grand parents, relatives and foster parents due to loss of their parents from tuberculosis, headaches and diarrhoea (sic).
educator

The effects of marginalization on learners who lost their loved ones caused them to either deny or confuse the cause of their deaths. P14 and P11 give evidence of denial.

My father he die of the running stamack but he don't die of HIV. I saw him look sad everyday at my mother until he die (sic).
P14i

But daddy didn't die of HIV, he died of headaches and mummy died of T.B. She was so scared to go to hospital. She was so sick and I miss her so much (sic).
P11ii

Implementation of the curriculum would have eliminated such confusion, denial and labelling that accompanies marginalization.

5.1.5. LABELLING

UNICEF (2001) found that people infected with the HI virus were labelled because they were associated with immoral behaviour, extra-marital sexual relations, prostitution and deviance. UNICEF found the term 'AIDS' itself stigmatising because of the strong negative reactions it invoked in the context. HIV and AIDS is one of the many diseases that has no cure but has care, treatment and prevention. Oppressors label PLWHA to establish and maintain power through powerful imagery, metaphors and euphemisms associating them with immorality, illness and death. Community health-workers explain how stigma and labelling prevents PLWHA from seeking assistance during the early

stages of the epidemic. They seek assistance during the final stages under cover of darkness for fear of being seen, labelled and stigmatized. Thuli describes labelling in Ndweni.

What I can say there is a bad label on people with HIV and AIDS. That is why they don't come out to the open to disclose to everybody that is why they come late in evenings to our homes and that is why sometimes, theyre getting more sick. Because if a person, its easier to talk about 'that im positive', I don't think we're gonna have so many deaths, its because of the labels and the stigma that is causing so much harm because we can help the person when this thing is still HIV, not to come to a part when a person is having AIDS, because it is not so easy to help that person when they have full blown AIDS (sic). Thuli

PLWHA are blamed because assumptions are made about their past sexual history. These assumptions and labels make PLWHA to feel fear and shame and they internalise blame for becoming infected. Maggie, an HIV positive individual person notes that:

The other people they say laugh and fight and say only fast dirty people get HIV and AIDS. I frighten for them all because I feel shame and I know they laugh at me (sic). Maggie (HIV+)

Several learners confirm similar acts of stigmatization with written texts. One learner stated:

I drew this picture because I can see so many familys are affected with this diseas. We must take care of those who are AIDS but our peoples they no do that. They lagh and teas everybody with aids. They call them sidosos. Thes very bad name for hivsick peoples (sic). P10

Learners blame poverty for caregiver infection because they cannot afford basic items like gloves whilst caring for PLWHA. One learner blames his grandmother for infecting his family members in Figure 20 below.



Figure 20. Poverty infects caregivers. (P10)

Stigma and labelling threatens public health and human rights of all individuals because HIV has been associated with images of sexual deviancy and social transgression. The

stigma of HIV is such that very few people, especially if they have lost family members to AIDS, will choose to test to know their status because of stigmatization and discrimination. The fears of discrimination prevent disclosure to partners or family members and deprivation of prevention, treatment and care. The silence protects them as a shield from oppression.

5.1.6. SCAPEGOATING

According to Namka (2000), the Scapegoat Society defines scapegoating as a hostile social-psychological discrediting routine by which people move blame and responsibility away from themselves and towards a target person or group. The technique of scapegoating blames impoverished low-cost communities like Ndweni and PLWHA for the rapid increase in infection instead of acknowledging that the interconnectedness between social problems and the epidemic are responsible. It is easier to blame the vulnerable PLWHA than to face the responsibility of caring for them.

In Ndweni, scapegoating emerged because oppressors, those persons who are HIV negative or unaware of their sero-status, punish PLWHA for violating community norms, one that includes the belief that PLWHA threaten the survival of the entire community because they carry a death sentence. Learners provided much evidence of the effects of stigma on both CLWHA and adults throughout all themes as witnesses of oppression by oppressors who use strategies of silence, secrecy and denial. This became clear when learners described the resultant discrimination as often subtle but with painful effects. Although several respondents drew similar experiences of exclusion, the drawing by P11 in Figure 21 of Thabiso's tears of loneliness and sorrow showing his grief will represent learner experiences with exclusion. Thabiso's words reveal the lack of accurate information that learners have.



The boy who is Thomas, sitting alone on a dark corner. He has no Mother and father two of them passed away last year. How he miss them he loved them and they loved him. There of them was a happy family while here Mother and father pass away because of HIV/AIDS - he ~~stay with~~ ^{live} uncle at home. And the children don't want to play with him. So he is being condemned.



Figure 21: Scapegoating excludes CLW/IA. (P11)

Furthermore, in Ndweni women are ostracised instead of men who have multiple sex partners and spread the virus. Here, men used the scapegoating technique to shift responsibility, blame and guilt away from themselves towards the women who are already vulnerable, prejudiced and stereotyped as the carriers of the virus. Gupta (2000) states that gender vulnerability and inequality lay at the root of painful experiences in coping with the stigma and discrimination associated with HIV infection. Gupta feels that HIV positive women bear a double burden: they are infected and they are women. Her statements describe the situation at Ndweni because several women speak of similar experiences. Maggie's words will represent what all the women feel:

But I know he got other girlfriends and he give me this disease. He say he don't sleep with anyone else but I don't believe him. How I get this disease then? (sic) Maggie (HIV+)

According to Tallis; Weiss & Whelan (2000) the ways in which HIV is transmitted involves inequalities of gender power, namely: through patriarchal power. In Ndweni, women feel burdened by the unequal balance of power between men and women. This patriarchy system allow men greater power because they are expected to be more knowledgeable and experienced about sex, to have a variety of sexual partners, and to be sexually dominant in relationships to prove their masculinity. Thuli, the community health worker describes the situation in Ndweni.

What I can also say, our husbands and all the males here, they are dominating. Their culure also is I think the men they got the old things in their heads that a woman is a woman and they must listen to a man. That's why also because we cant tell your husband why you don't try and behave yourself like this way, you cant tell a man. Also there is a lot of abuse on a male domination in this society. Because sometimes at home, you feel like running away from home because of the power over us as women (sic). Thuli

This power imbalance increases both men's and women's vulnerability to the HIV infection. This causes men to be at risk to HIV and AIDS and furthermore to place their entire society in a similar position. Men use denial to cover their promiscuity. Maggie points out that:

My husband he give me sick and he got girlfriends, no job and money. I learn here everybody blame a good wife who get HIV from her husban. He say nobody here got HIV sick (sic).
Maggie (HIV+)

The culture of silence hides the effects of traditional norms that insist on 'good' women being ignorant about sex, passive in sexual relationships and unmarried girls remain virgins. These norms make women in Ndweni vulnerable by preventing them from negotiating safer sex practices and increases young girl's risk of infection because it restricts the ability to ask for information about sex out of fear of being thought to be sexually active. Female learners reveal how their female friends feel oppressed because they cannot negotiate condom usage during sex for fear of violence and retribution from their partners. P14 confirms this view.

But some of my girlfriends say her boyfriends don't like to use it when they do sex. The girls are frighten to force their boyfriends so they do sex with no condoms (sic).
P14i

Young women and several female partners and wives explained that their men were very conscious that their ego and masculinity was at stake if they accepted their partners' requests for safer sex. Thuli calls it the 'power of the ego' that says quite clearly:

If I can put the blame on you, I don't have to recognize and take responsibility for the negative qualities in myself. What I can't stand about myself, I really hate in you and have to attack you for it in order to deny that I have the same quality (sic).
Thuli.

The social worker from Ndweni Child Welfare who gave talks at Ndweni Primary and a sister from Ndweni Clinic explained that women and children experience exclusion and ostracism from their community.

Men say whether sex takes place and if a condom is used. Men have two or more consecutive partners, contract the virus and pass it on to their wives and partners. It is the women of Ndweni who are vulnerable to HIV but men who are at risk (sic).
(Sister: Ndweni Clinic)

The women in Ndweni have to prove their worth by being passive, quiet and subordinate to their men. HIV positive Maggie is expected to care for her unemployed, unfaithful and physically abusive husband, even though she provides for herself and her children with no assistance from him. My visits on Sunday mornings revealed how relaxed the men of Ndweni really are. They relax with their friends, drink beer and smoke dagga outside their homes, while their women labour inside. Women are especially vulnerable to HIV because they are most vulnerable and least empowered. While females in Ndweni are blamed for the spread of HIV, men determine whether sexual intercourse takes place and condoms are used. Through fear, women continue to engage in unprotected sex, even if she knows her partner is unfaithful. Women in Ndweni internalise this blame and accept the shame by colluding with their own oppression. Women blame their fate for making them scapegoats of men. HIV positive Maggie and some of the women, for instance, stated that they had to take care of everything and still get beaten up every night when their husbands return home drunk. The experiences of both PLWHA and women in Ndweni reveal their inability to make them heard or to influence and control what happens to them. Powerlessness results from multiple, interlinking disadvantages which, when combined, make it difficult for women to escape their poverty.

As mentioned earlier, because HIV and AIDS is labelled as dirty and immoral, it is linked to violence and abuse. The background chapter revealed most Ndweni men as possessing dominant and violent characteristics. Although women and children are affected by the consequences of HIV and AIDS, the sexual, drug-taking and alcoholic behaviour of the men increases the spread of the virus. In figure 15, learners reveal that violence occurs at the physical, emotional, verbal and gender-based level in Ndweni.



Figure 22: Learners reveal violence and abuse. (P12)

Learner perception is that males are the perpetrators of violence and abuse. Several drawings and text from both male and female learners confirm that men place women at

risk because they believe that sex with a virgin cleanses all infection. Learner text reveals that:

The tears are for those who cry when they are rapped and abused. The tears are for those who die and have died from HIV. I pray everyday for the guyz to learn that HIV wont be cured if you have sex with a small babby or a virgin. I think about the husbands they drink drink drink and fight and give blue eyes to their children and wives (sic). P12

We have the elder person who can rape the smaller kid because he think sex with the kid can cure him of HIV (sic). Thuli.

Several learners drew seropositive men encouraging faithfulness to partners, as they lie thin and emaciated in their beds. The tears in Figure 23 reveals that men want to make amends for their infidelity and offer advice to both men and women about faithfulness and safe sex.



Figure 23: Men advise caution during final stages of AIDS (P13)

The HIV epidemic is caused by men. Men should not be allowed in Heaven (sic).
A woman in Ndweni

Women are ostracized because they fear the responses of their own families, friends and relatives if they disclose their status. Some of them are dependent on the financial support they receive from family members and disclosure meant starvation, as one respondent reveals:

I don't tell my mother or brother my problems and they don't know im sick. Also, they won't come see me or bring food my children. Only when I get the govement grant then I tell them I sick (sic). Maggile (HIV+)

Furthermore, in patriarchal communities, restrictions with regard to gender roles cause some women to become financially dependent on their partners and subjected to violence from their male counterparts. Poverty supersedes fear and contagion of the virus and young girls exchange sex for gifts and basic living necessities. One learner discusses his experience.

Nandi shares her perfume spray and gel that her boyfriend Innocent buys with me. My grandmother say Nandi must leave Innocent because he is bad but Nandi dont listen because she want Innocent's gifts (sic). P8

5.2. SECTION B: Analysis: 'The Lethal Effects of Stigma'

Section A revealed a nature of stigma that silently oppressed all PLWHA even if they were affected by AIDS and not infected with HIV. This occurred because oppressors feared contagion and the 'death sentence' due to a lack of accurate information of HIV and AIDS. This fear forces adult PLWHA to remain silent by not reporting discriminatory acts which are witnessed and internalized by their children. This internalized fear later emerges as nightmares for learners because they had not received accurate information on HIV and AIDS from Ndweni Primary themselves.

In addition to this, social factors such as poverty, violence, gender politics and class interconnect with the epidemic, thereby increasing the negative effects on PLWHA and more especially on learners who revealed the stigma present in Ndweni. This section hopes to bring awareness to the fact that learners seem to have lost faith in the systems provided to alleviate the intense pain and sorrow that months or years of stress, suffering and depression learners experience before their loved ones eventually die. This can be done if all Social Work Departments and Education Departments merge.

Section B continues with an analysis of the nature of the stigma and its effect on both learners in Ndweni Primary School and its wider community. This analysis focuses on the interconnectedness between factors such as poverty, prejudice and ignorance, fear resulting in violence and gender politics with HIV and AIDS-related stigma in Ndweni community.

5.2.1. THE NATURE OF STIGMA IN NDWENI

In Ndweni, discrimination occurs because oppressors act on their feelings of prejudice and discredit PLWHA because oppressors perceive them to be different. The feelings of prejudice emerge from an unwillingness to accept PLWHA because they are different from themselves. The findings revealed the negative effects of stigma that left no part of the lives of PLWHA untouched or invulnerable to discrimination.

These negative effects occur at the individual, community and societal levels. While the negative effects cause undue anxiety, stress and depression at the level of the individual, it creates feelings of shame on behalf of those who conceal links with the epidemic. They withdraw from positive social responses, and at the societal level, the stigma and discrimination reinforce mistaken beliefs that such action is acceptable, implying that PLWHA should be ostracized.

The title of this thesis, 'The sepulchral effects of stigma.' is significant because it relates to the silence existing in Ndweni that is different from the silence of quietude. The word sepulchre reflects a tomb, grave or burial chamber but sepulchral describes the situation in Ndweni as gloomy, sombre and carrying the connotations of death and of deathly silence. In Ndweni, individuals do not say what they really feel because it associates with death and the graveyard. This silence is a result of fear that transmits negative messages to the community members who avoid the subject of HIV and AIDS with PLWHA.

Within the Ndweni community, it seems as if PLWHA blame the negative reactions on stigma rather than to the intolerance of the oppressors. This is important because the reaction from oppressors have affected negatively on PLWHA by decreasing their belief in their own ability and motivation to stand up for themselves. In other words, PLWHA

have entombed themselves within their own silence. Friends and family members, on the one hand, know and appear to be silently waiting for PLWHA to reveal their status and break the silence, while PLWHA, on the other hand are terrified because the silence seems to threaten and declare them different by segregation and victimization. PLWHA are also aware that their community members know their status, but would not talk to them directly because they carry a death sentence. Knowing this and terrified, they remain alone trapped within their own silent worlds, with their children as silent observers.

Given the endless number of deaths, especially of young parents to AIDS-related illnesses, the reaction it evokes in Ndweni ranges from caring to silence, denial, fear, and anger to violence. The reactions cause PLWHA to deny their own risk of HIV, their right to insist on condom usage, their right to care treatment and prevention and finally, their right to disclose their HIV status for fear of negative reactions of family, friends and community. The silence became evident when a social worker and an educator, with all the knowledge of transmission and advice on how to live positively, died themselves of AIDS without colleagues, family and friends knowing. The learners questioned the validity of the information given by both these personnel who did not follow their own advice. This incident represents circumstances that fuel fear that accompanies the spread of AIDS. If people who should know about it also die, what about those who don't know anything? Other factors relate to death because of their deeply ingrained moral and cultural beliefs about sex, sexual behaviour and the shame it brings to the family and community.

In Ndweni, PLWHA regard non-disclosure as a survival strategy to avoid ostracism and stigmatization. On the basis of this, adult PLWHA do not consciously internalise their oppression or realise how their silence fuels stigma and affect their children. In the minds of their children, this silence assumes enormous proportions and personifies

itself to represent their unspoken fear of death, especially since they are aware that there is no cure for HIV.

The findings revealed that although the formal curriculum designed for implementation by the DoE includes sexuality, HIV prevention and AIDS-related education is not being implemented during the Life Orientation period at Ndweni Primary School. Educators teach issues relating only to Right Living and Guidance, deliberately marginalising firstly, information on sexuality and HIV and AIDS information and secondly, the learners' right to this information. The research findings also revealed that the DoE-designed curriculum could not change negative attitudes and prejudices surrounding the epidemic alone at Ndweni Primary School. As the research indicates, if HIV prevention and AIDS-related education had been implemented, learners would understand that it is possible to live a healthy and positive life with AIDS.

In Ndweni, the silence takes the form of marginalization, fuelling myths and stereotypes and creates a non-supportive environment for CLWHA. At the school level, knowledge and the subject of HIV and AIDS is marginalized. The methodology chapter explains the problems of silence I encountered with learners during focus group sessions. These problems reveal the effects of stigma on the learners. The initial focus group sessions revealed learners who were curious about the project but reluctant to disclose any personal information, while the following sessions revealed learners who did not want to reveal the identities of affected close family members and friends. Learners agreed to submit drawings and written responses to reveal information they could not discuss in the presence of their friends. This suggests that learners wanted to expose the stigma prevailing in Ndweni, yet simultaneously maintain anonymity.

Learner responses reveal how silence links with personal emotional experiences. This applies to the unspoken but visible silence that caused one learner to submit her drawing

and thereafter withdraw from written or verbal explanations. This learner stated that her drawing would reveal visual evidence she chose not to reveal in writing. Her withdrawal revealed the existence of the invisible silence more than her reluctant participation would have. The learner's silence linked her fear of AIDS-related stigma to her recent loss of both her parents to AIDS and her subsequent placement in foster-care placement. The learner represents all children in Ndweni conditioned not to reveal their inner emotions, but accept silence to avoid stigma and discrimination. Learners inherited their information, beliefs, expectations of life from those closest to them, namely their parents who endured the effects of oppression when they were children.

The findings chapter revealed Ndweni as an impoverished low-cost housing community with the words 'low-cost' itself labelling its residents. Ndweni adults and learners revealed that they struggled for survival on a daily basis because of poverty. Although Ndweni was an impoverished community, its resources could not be accessed because of stigma. Some of these included the Ndweni clinic that offers services for two days of the week due to insufficient medication and staff. This means that PLWHA have to either go to Ndweni Hospital or buy their medication, neither of which PLWHA could afford due to unemployment. Stigma prevents PLWHA from accessing support and transport service from Greenville Hospice because it meant disclosure of their status to their partners, family and friends. PLWHA were afraid of visiting Thuli during the day for fear of identification. Lack of money for bus fares prevents PLWHA from accessing medical care at Ndweni Hospital and VCT at either Gandhi or McCords hospitals that have long waiting lists. PLWHA receive assistance from community health workers who face the risk of stigma themselves. PLWHA therefore equate poverty with no power or money for food or medication and, interconnectedness with the epidemic. The learners' data clearly reveal their own stress and worry because they witness their parents' struggle to survive each day. Education at home therefore played a minor role

in families where parents had to make a choice between feeding their children and sending them to school.

Poverty makes PLWHA powerless and voiceless because it interconnects with the epidemic. The powerlessness of Ndweni's PLWHA is evident in the quality of the treatment they receive from personnel in health sector who are often exclusionary, rude and uncaring. The findings chapter revealed nursing personnel who advocated for death instead of life. Medical personnel did not treat PLWHA because they were going to die. Both volunteer community health-care workers and PLWHA who managed to get taxi fares to the hospital described the reactions of the professional staff at Ndweni hospital as discriminatory and so inhumane that many residents preferred to die at home rather than go to the hospital. PLWHA had to depend on their own informal network of kin and friends they trust for survival and solace.

In Ndweni, family and friends seem to think that a critical part of living with AIDS is the fact that AIDS is a terminal illness with no cure and those infected will have to face death. Caring for PLWHA and the burial with its religious rituals that follow is an expensive business and poverty does not allow for the ever-increasing number of loved ones to rest in peace. PLWHA, especially surviving children who care for ill parents do not have the support of family members. What they have instead is the stigma, discrimination and the exorbitant burial costs due to the community treating HIV and AIDS differently from other diseases. They regard it as dirty and shameful because of its relationship to sex, promiscuity, death and remains hidden for much of the time. This attitude stigmatizes and compromises the care of those PLWHA who lie ill in cramped spaces with limited access to medication, lights and water. When families exhaust available treatment options and its own meagre resources, care and treatment are likely to be reduced. The people of Ndweni equate poverty to pain, disease and death because it attacks them both financially and morally. Poverty links the high rate of abuse and

unemployment in Ndweni. Most of the men are unemployed migrant workers who drink alcohol, smoke dagga and are abusive at home. For most families the primary concern is providing food for their children and this, most women do with produce from their gardens, child-care facilities and fostering of children. Their poverty renders them vulnerable, but affectedness by HIV and AIDS renders them even more helpless and powerless. All data sets reveal an unequal balance of power in Ndweni community where abuse and violence abounds.

Gender inequality links with violence in Ndweni and the findings reveal that men use violence to devalue females. The violence ensures the spread of the HI virus because of sexual abuse that includes the rape of the younger generation by men who may be infected. These youngsters grow up with the virus, infect their partners and the cycle continues with social problems interconnecting with the epidemic. Unfaithful husbands infect many women like Maggie. The husbands expect sex without condoms and react violently if their partners refuse or object. Women who disclose their HIV positive status are exposed to violence in intimate relationships. Data reveals that most men in Ndweni are HIV positive but refuse to test or acknowledge their status. Many of them believe that they are better off not knowing. They become very ill and then find that it is too late to come to terms with HIV or receive treatment and care which could have delayed disease progression. Evidence of this was the seropositive male in Figure 23 who offered advice about the wisdom in being faithful to partners and using condoms in sexual relationships. The younger male generation witness and emulate the behaviour and attitudes adopted by the older generation.

Men use the power of scapegoating to claim power within their families. They transfer feelings of guilt, aggression and blame and suffering away from themselves onto their wives, girlfriends and children. They demand their rights as husbands and fathers, but not the responsibilities that go with them. Women and children experience exclusion

and ostracism from their community. The women of Ndweni call it the 'power of the male ego' that creates dominance in men and the need to make women subservient. Women are especially vulnerable because HIV affects them as individuals, mothers and caregivers in their socially defined roles. The women in Ndweni reveal that as subordinates, they are expected to be passive. HIV positive Maggie is expected to care for her unemployed, unfaithful and physically abusive husband, even though she provides for herself and her children with no assistance from him. My visits on Sunday mornings reveal how relaxed the men of Ndweni are with their friends, drinking beer and smoking dagga outside their homes while their women labour inside.

While females in Ndweni are blamed for the spread of HIV, men determine whether sexual intercourse takes place and condoms are used. A fear of violence makes women continue to engage in unprotected sex, even if they know that their partners are unfaithful. Women in Ndweni internalise this blame and accept the shame by colluding with their own oppression. Women blame their fate for making them scapegoats of men. HIV positive Maggie and some of the women, for instance, stated that they had to take care of everything and are still physically abused every night when their husbands return home drunk. The experiences of both PLWHA and women in Ndweni reveal their inability to make themselves heard or to control what happens to them. Powerlessness results from multiple, interlinking disadvantages which, when combined, make it difficult for women to escape their poverty. Thuli and Prudence are both community workers and women of Ndweni. They explain that their social context is responsible for the powerlessness they feel when their partners fail to take preventive measures. Men in Ndweni do not seem to perceive the risk to be more significant than their other social problems. They talk of HIV and AIDS as one disaster among many for them.

The findings revealed that male learners knowingly take risks because they envision no improvement, hope or escape from their circumstances. They state clearly that they are

resigned to living with poverty, violence and death and are not afraid to die of AIDS-related infections.

Although Ndweni is a poor community, there are different levels of power that creates a difference of class between oppressors and PLWHA. The oppressors feel powerful and superior and cause PLWHA to feel devalued, ashamed and powerless. Agent groups keep the cycle of stigma alive through the process of discrimination. These attitudes extend to families of PLWHA and caregivers as well. PLWHA, their family members and caregivers are trapped within this vicious cycle of class, stigma and discrimination. In addition, at Ndweni Primary School, the majority of the educators belong to a different class from their learners because they reside out of the community in which they work. This emerged from their cars and homes in the surrounding wealthy areas such as Greenville. Furthermore, the educators who assisted me to sign consent forms, admitted that they had not conducted any home visits and had no idea of the conditions in which their learners lived because they lived out of the area and used only one road to get into and out of school. The findings revealed further how the language barrier created a wall of silence between educators and learners where both experienced communication problems and learners were uncomfortable to share problems or experiences. Furthermore, educators reported being uncomfortable with the subject, the subject, language, pupils and parents. Parents also experienced such communication problems, but many admitted being more afraid of attending meetings because they had not paid the children's school fees.

5.2.2. STIGMA AND ITS EFFECT ON LEARNERS IN NDWENI

PRIMARY SCHOOL AND THE COMMUNITY

The literature review revealed the highest rate of infection in the twelve to twenty five year age group. This made school learners at school particularly vulnerable as they explore their own sexuality and dabble in risky behaviours because they believe they are

not at risk. They need to know the risks involved in unsafe sex and drug use before they are old enough to find out for themselves.

However, in Ndweni Primary School, learners did not learn that their sex drive is the most basic human need, capable of being controlled and enjoyed, instead of proving to be the main channel for exacerbating the spread of the epidemic. Education for prevention does not occur at this school and therefore the present young generation continue to take the risks and make the mistakes of past generations. The findings reveal, furthermore, a fear of sexuality education that denies pupils the right to behaviour change in terms of sexual feelings, attitudes and practices. In the community, adults felt that sexuality education encouraged very young children to experiment with sex before they could understand and corrupt their children's minds by lowering the moral tone of the community. The male HIV co-ordinator expressed similar views from the parents of his own class children.

The effect of HIV and AIDS-related stigma on education in Ndweni Primary School has resulted in a silence which interferes with the dissemination of accurate information about HIV transmission, prevention and AIDS-related education. Data from learners and interviews with educators reveal misinformation, incorrect perceptions and mixed messages. Educators themselves confirm their own discomfort and reluctance in conducting intervention programmes. Both HIV co-ordinators confirmed that educators mentioned discomfort teaching sexuality, HIV prevention and AIDS-related education with teenagers, and the management staff mentioned that all educators were reluctant to attend meetings of such nature. To address this, the Principal explained the rotation system he adopted to ensure attendance of staff members at the meeting on the subject of HIV and AIDS. Both co-ordinators attended the single meeting during 2003 and conducted one dissemination workshop. The grade six pupils received material of HIV and AIDS from the DoE for the next term during 2003. Educators admitted to

selectively teaching the topic, clearly bypassing important skills to encourage behaviour change. The senior HOD admitted awareness of the situation, but excused her teachers based on their stress with discipline problems due to large class sizes, extensive working hours and the language barrier. Silence around sexuality, HIV, and AIDS deprived children of vital education and has a lethal effect on their education, and ultimately, their lives.

Children are portraying educationally incorrect messages in terms of their images of HIV infected persons. Their drawings reveal HIV positive individuals as thin, emaciated, bed-ridden and ill. The drawings also reflect isolated individuals hiding away in dark corners and behind houses, always sad, crying and obviously missing parents, siblings and friends. Learners seem to have no knowledge of being healthy and living positively with HIV. Learner data reveals, furthermore, mixed messages with respect to the AIDS ribbon and knowledge and beliefs of HIV and AIDS. The origin of these messages seems to emerge from their observation of parent behaviour. These are the messages that learners take forward and circulate within the school environment. The messages affect the silence already existing at school and become an unchallenged culture of silence both at home and at the school level. This serves to exacerbate the AIDS epidemic and increase confusion, denial and stigmatisation. Learners do not know that there is a clear distinction between HIV and AIDS refer to it as being HIV sick throughout all of their drawings and text. Their drawings reveal denial and isolation from social life and their responses include substitution of 'other children' to distance themselves from saying that 'I am part of the stigmatising group' or that 'I am HIV positive.'

In Ndweni, data reveals the effects of a sexual culture that included a high degree of sexual activity in pre-marital and extramarital relationships within both the younger and older generations. Much evidence emerged from learner data that proved that men and

boys disregarded safer-sex measures and were violent in their relationships. The women and young girls could not insist on condom usage because they feared violent retributions from their partners or boyfriends. In Ndweni, women such as Maggie and friends of learners were beaten for suggesting condom usage and refusing sex. Young girls, on the other hand, accept 'gifts for sex from boys and men, knowing that the males have unprotected sex with other partners. Selling sex for money is symbolic of the poverty in Ndweni and the patriarchy system makes Ndweni people believe that there is a need for males to have regular sex and with more than one partner. Young girls and boys believe that sex is an expression of love in a 'normal' relationship. Females seem to compromise in terms of condom usage because they fear losing steady relationships and threats of violence from their partners. Females have insufficient information about HIV transmission and believe that if HIV- positive, one cannot have a marriage or life with a partner because HIV has no vaccine or cure and carries a death sentence.

The learners' data revealed that the silence their parents, their teachers and their community maintain around the epidemic is responsible for the stigma that prevents disclosure to loved ones who cannot access care and treatment from available resources in Ndweni and Greenville communities. Also evident is the emotional impact of stigma and discrimination on children. This increases their vulnerability and most significantly, learners experience a violation of their rights when they are stigmatized. Instead, discrimination replaces dignity and results in isolating the child and his family. Learners do not talk to each other, their guardians or caregivers about their treatment. They learn to cope with their own grief, their fear for their ill parents and their fear for the future. These emotions reduce the learner's ability to engage positively with adults and other children in the community. AIDS orphans in Ndweni often endure a double loss. They lose their parents and their secure parent-headed households. The qualities of their lives

deteriorate because some of them have no birth documentation and therefore no homes as revealed in the findings chapter. They remain marginalised throughout their lives.

The experiences of AIDS orphans in Ndweni reveal their vulnerability and those live in foster homes do not experience the nurturing they need. Parents like Maggie live below the breadline and cannot give their children the nurturing they need because they have to support their children without the help of husbands. The parents worry and stress about their children after their deaths. Discussion with community members revealed that young parents die in large numbers and their children placed in foster care, orphanages or adoptive families and grow up with less or no adult attention. In some situations where the parents die and there are no remaining family members, children 'head their households' for long periods of time until they are placed into foster or adoptive care.

CLWHA are therefore, even more vulnerable than adult PLWHA as they face the stigma relating to their own status as well as stigma emanating from their parent or caregiver's status. This stigma continues after the death of their caregiver because orphans who have been taken in by relatives or neighbours are used as domestic servants, sexually and physically abused and denied health care. This forms part of the denial of the epidemic because CLWHA are a constant reminder of the death of a parent or sibling, something that our community does not want to face or confront.

Learners and adult PLWHA reveal much evidence of the psychological effects on learners who witness their parents, friends, relatives and close associates dying of AIDS. Children are exposed to months or years of stress, suffering and depression before their parent or loved ones eventually die. The death of their parents and adult relatives rob children, parents and partners of their loved ones and breadwinners. Information from interviews and focus group sessions revealed that the bereavement process for most survivors become complicated by a code of silence. This silent mourning prevents

family and friends from openly acknowledging the true circumstances of death and the special nature of the relationships they shared with the deceased. It also leaves survivors feeling more alone and bereft, leading to depression and feelings of anger.

Stigma prevents those who survive from freely mourning their loved ones. Ndweni Community has no facilities for the psychological and clinical counselling required for children to come to terms with the death of their loved ones. Multiple loss has become commonplace in Ndweni and has made the task of surviving overwhelming for those remaining behind. It becomes an overwhelming experience to be mourning a recent loss, to be remembering several past losses, and to anticipate further losses yet to come simultaneously. As a possible way out of these painful emotions, some psychologists prescribe hypnotic sessions to relive the trauma of the incident in order to exorcise the suppressed rage and fear within the victim.

The code of silence prevents these children from talking about their experiences to their friends, their loved ones and associates and prevents the healing process. Family members cannot assist them because they themselves are bound by a similar code of silence and hurt. Because of this, healing process does not take place as the stigma prevents programmes for prevention and intervention. As children lose their friends, their forums for talking and open discussion remain sealed and inaccessible, and this leads to the situation where the healing processes remains forever denied to them. This kind of suppression as revealed earlier is oppression and has fatal consequences because it leads to death and the grave, hence the choice of my title, 'The silent sepulchral effects of stigma'.

The women of Ndweni are also at the receiving end of discrimination, exploitation and abuse. Their traditional customs bind them with its culture of silence. Many women, although infected by their husbands, are forced into caring for their unfaithful infected

husbands who return home to reclaim loyalty and care because their traditional marriage vows included the words, 'in sickness and in health and till death do us part.' Inadequate power and education allows the women of Ndweni to accept the traditional patriarchy system without question. The system promotes monogamy for the wife and polygamy for the husbands whose unhealthy sexual behaviour proves to exacerbate the spread of the epidemic.

All sets of data, both formally and informally collected reveal the intensely painful experiences of PLWHA in Ndweni community. These experiences include painful humiliations and shame, which overwhelm them into surviving daily with both physical and emotional pain. To suppress the memory of pain and their shame, they exist in their own private worlds and accept the stigma as something they deserved. The feelings may constitute inner rage and anger which could later become a messenger from their inner world to ours, especially if the aims of education are not achieved. This eruption could have severe consequences although it would have been only a cry for help.

The effects of stigma on learners due to the education they have received or not received will also have very severe consequences for them because of the traumas they have experienced within their homes. Because of their experiences, their future means working to generate income to support and care for younger sibling and family members who may be sick. For many children, the heart and hope seems to have gone out of them and they see little value in education and lose interest in getting a formal school education.

The findings of this research coincides with, and on the whole, does deviate from, previous research done in South Africa on the HIV-related stigma as it personally affects learners in Ndweni Primary School and its community members. The analysis based on the above findings reveals that in spite of all the knowledge, literature and

intervention programmes conducted at Ndweni Primary School by others, there have been no apparent changes in the quality of teaching by educators and learning by learners. The Department of Education failed in its desired impact of including HIV prevention and AIDS-related education into the content of the curriculum to bring about behaviour change. Urgent interventions are required for education to become a social service with the potential to stem the advance of the epidemic and assist in providing coping skills to its casualties.

SUMMARY

In this chapter, I analysed the data that revealed considerable stigma as the reason for the people of Ndweni adopting a code of silence around HIV and AIDS. This chapter revealed silence that entombed PLWHA because of its connectedness to fear, disease and death. It revealed the situation in Ndweni to be gloomy and sombre where individuals do not say what they really feel because of this fear, transmitting negative messages to their children that educators add to by marginalizing accurate information on HIV and AIDS. The key to break this code of silence follows in the next chapter that includes recommendations and conclusions.

Chapter Six

RECOMMENDATIONS AND CONCLUSION

PREVIEW

The focus of the previous chapter was essentially to reveal and discuss the findings based on the research questions used as instruments for data collection. The discussion revealed, among other things, the extent to which societal attitudes contribute to the exaggeration of HIV and AIDS-related stigma. While young girls and older women experience stigma in two ways: they are infected and they are women, men seem to be in denial and tend to use patriarchy to gain power over them. In this chapter, recommendations will be made based on the findings obtained from the study and the conclusion will follow.

6. Recommendations and Conclusions

The findings of this study have revealed that young people in the developing world are most vulnerable to HIV and AIDS and, because of this, present the opportunity to halt the epidemic with targeted prevention strategies. Learners are the relatively accessible and are more likely to adopt sexual behaviours that prevent HIV and AIDS since their sexual habits are not as firmly established as those of adults. Therefore, by offering new and viable patterns of behaviour for the next generation, young people offer hope for the future.

Culture, tradition and beliefs around sex and sexuality are invisible, unmanageable and difficult concepts to get control over, but sensitivity is needed when addressing the issue because it is culture that gives the society of Ndweni direction and meaning.

Culture as a social phenomenon, however, is dynamic and alters from one generation to the next as new possibilities and dimensions are learned. Beliefs, norms and values that have been learned can be unlearned and eventually replaced as learning takes place. As cultures change, groups and individuals within them can change, and this can be done through the teaching of Life Skills in the Life Orientation period. Research into content of curriculum for implementation from the Department of Education should operate within a gender context. Gender politics in terms of gender roles and inequalities should be included as content to be examined and tested. Appropriate and effective intervention programmes can alter sexual behaviours, and this can have a positive impact on attitudes towards females. Issues such as rape, unwanted teenage pregnancies and sexual infections need to be examined within the course of school-based interventions in order to change attitudes and sexual behaviour.

Additional research, furthermore, needs to go into documents tracking orphans that go into foster care, while schools and welfare organizations need to be able to track the movement of children changing foster homes and entering into new families. Professional assistance is required for foster children from the Social Work Departments and this has to be accompanied by psychological assistance from the State Departments needs to reach children who are forced to make so many adjustments when moving to new environments, making new friends and undergoing new and additional traumas. These departments need to have structures in place to assist such children.

To fight HIV and AIDS effectively educators need to fight stigma and discrimination and to achieve this, it is necessary to start by examining personal attitudes. This is because the subject of HIV and AIDS is sensitive and educators need to be specifically trained and supported by suitably qualified personnel responsible for Life Skills and HIV and AIDS education in the school and province. At schools, education needs to

stress sexual health and relationships messages that are anti-HIV and not anti-sex and to achieve this, it is important to work with young people on the pleasurable aspects of sexual relationships as special and important. Everyone has a right to enjoy relationships and to refuse unwanted sex and emotional pressures. This is going to assist in affirming positive discourse and links love with self-esteem and awareness of one's own needs. All of this requires concerted efforts to educate parents and children vulnerable to the infection.

Education is necessary for vulnerable, infected parents because they need to be aware of the danger they pose in making young children vulnerable. This means that parents that are infected need additional support to be able to provide the care their children need for healthy growth and development. Most parents infect their children vertically and feel tremendous guilt and often need emotional support. They need support groups that address the guilt, stigma, shame, social isolation and discrimination associated with HIV, as well as the planning of a child's future if parents die. This means most of these parents have a double burden of providing for their children and planning their future while they are alive. This planning includes providing them with Education.

The role of the Education Department will be to intervene and check that policy is implemented and lessons are taught with sensitivity for educators who are conservative and have been oppressed themselves. There is an urgent need, therefore, to integrate the health, education and social work departments. This will lead to a positive discourse on HIV and AIDS and in the process, demonstrate hope and support to prevent infection in order for learners to live productive and fulfilling lives. A positive discourse needs to stress the benefits of knowing one's status in order to access care and support and delay disease progression in the body. Promoting hope and acceptance is a key response to stigma at all levels of society, with accountability based on transparency in education being a key component in improving the HIV and

AIDS education received at schools. All of this has potential to remove stigma as barrier in order to reduce its effects on learners.

PLWHA are invaluable resources in terms of planning research, teacher training, material design and implementation. They provide a perspective that can enrich the content and encourage involvement and collaboration. The active involvement of PLWHA is central in the fight against HIV and AIDS-related stigma. Community health workers in all impoverished communities, on the other hand, need to have support structures. All individuals and all sectors of society need to accept the moral obligation to fight the stigma and to promote openness, acceptance and solidarity.

Social workers and teachers who employ double standards need to lead by example and serve as role models for children who emulate them. Stigma within the family or directed toward an affected family is the subtlest and most debilitating form of stigma and also the hardest to address. This is why research on disclosure and stigma needs to promote an openness and acceptance in the family setting. First and foremost, promoting life skills in sexuality education and counselling is needed to help HIV-infected and affected children cope with stigma at Ndweni and the Clinic needs to offer services such as VCT and follow-up care to enable individuals to learn their sero-status and provide support for disclosure to family members. To support all of these initiatives, the Government, NGO's, and others need to extend information and education on care for PLWHA, children affected by HIV and AIDS and their families to teachers, community care groups and churches so that they become knowledgeable and better positioned to provide necessary support.

The use of formal standards alone cannot change negative attitudes and prejudices surrounding HIV and AIDS and public education should be designed to reduce stigma by creating a supportive environment which is more tolerant and understanding. Here,

the aim needs to challenge ignorant beliefs, prejudices and punitive attitudes by appealing to human compassion and identification with visible individuals. The main attitude to this would come from media.

Psychological structures need to be in place for children who lose their parents. This process needs to look at the psychological healing process from the child's perspective. The foster parent needs to be aware of how to assist in the emotional healing of the child, and this process is important because children that bottle up violent emotions can become violent adults. The repercussions can be drastic if these procedures are not in place. Teachers should be taught skills to recognize such children and offer assistance through referrals should the need arise.

A special policy statement needs to be made as part of a code of best practices nationwide to guide and encourage medical personnel to recognize the need to provide proper treatment to PLWHA. It should be made an offence for medical personnel, for instance, to deliberately deny proper treatment and care for PLWHA if they are proved to have done so beyond reasonable doubt.

The mindsets of educators need to be changed as well. Because of the crucial nature of their profession and the fact that they spend 80 % of the time with the learners, these professionals need to understand poor people's realities. They must be willing to listen and understand poor people's knowledge, priorities, and actions and then to respond to their concerns, some with learners happenings. They also need to keep inquiring about learners' home circumstances. There should be structures for investing in poor people's assets, which they need to reduce their vulnerability within their context of the poor. These include the body that is more often than not, their only asset, their organizational ability because they will be able to get their voices heard and their interests represented. Strong networks extending beyond the family and immediate

community are essential to gain access to other assets and resources, information, education and entrepreneurship. Poor people need protection so that they too can be the beneficiaries of their ideas and practices, and to achieve this, their property rights need to be registered.

Grandparents need to be given consideration because AIDS orphans are often cared for by grandparents who are too old to care for young children adequately due to financial constraints. Grandparents' household resources are usually minimal and they may be sick or lack financial means to support a new family of young children. There is therefore an urgent need to make HIV grants accessible even to grandparents and not see caring for their grandchildren as their responsibility.

SUMMARY

Stigma needs to be thoroughly understood before it can be dealt with constructively. As the study shows, there are no simple answers or easy solutions on how to deal with the challenges of HIV and AIDS-related stigma in Ndweni Community. The research conducted in Ndweni Community proves that education is the key to change in knowledge, attitudes and behaviours. Education about HIV and AIDS must be improved in order to reduce gaps between policies and grassroots implementation and ensure adoption of effective prevention strategies. This thesis can be regarded as a step forward in the empowering process of PLWHA through the provision of knowledge and awareness it provides. It is hoped that raising awareness and an understanding of how important a role education plays at the school level will contribute to a more educated and tolerant society.

More importantly, not sustaining a cultural sensitivity stance in Ndweni can become seriously complicated, especially when confronting cultural practices that facilitate HIV and AIDS-related stigma and increase the spread of HIV and AIDS. Culture can

become an obstacle, as beliefs and traditions that are harmful, or in opposition to human rights, need to be challenged. Cultural aspects can be dealt with through sensitive promotion of education. The alleviation and prevention of HIV and AIDS-related stigma requires open dialogue on sexual issues to break existing cultural taboos in Ndweni. What needs to be acknowledged is that personal vulnerability to HIV and AIDS infection stems significantly from societal vulnerability.

If we can have effective education systems, there is a chance that today's uninfected children will grow up into uninfected adults. World Bank 2002

REFERENCES

ActionAid 2003, *Global Education Review*. London, ActionAid.

<http://niace.org.uk/information/PDFS/RAprilMay03pdf>

Site visited on 2004/07/22

AFSA 2005, HIV and AIDS in South Africa.

<http://www.aids.foundation.sa>. Site visited on 2005-07-22.

Aggleton, P. and Warwick, I. 1999, *Household and Community Responses to HIV and AIDS in Developing Countries: Findings from Multi-site Studies*: Geneva: UNAIDS.

Aggleton, P. 2000, *Comparative analysis: Research studies from India and Uganda: HIV and AIDS-related discrimination, stigmatization and denial*. Geneva: UNAIDS.

AVERT. Org. 1998-2002, The history of AIDS.

<http://www.avert.org/his98-99htm>. Site visited on 2004-05-04.

AVERT. Org. 2003, HIV and AIDS Stigma and Discrimination: Attitudes towards HIV and AIDS. <http://www.avert.org/aidsstigma.htm> Site visited on 2004-06-07

Barnett, T. and Whiteside, A. 2002, *AIDS in the Twenty-First Century. Disease and Globalization*. Hampshire, New York: Palgrave Macmillan

Babbie, E. and Mouton, J. 2001, *The practice of social research*. New York: Oxford University Press.

Berg, B. 2001, *Qualitative Research Methods for the Social Sciences*. Allyn and Bacon: Boston.

Biernat and Dovidio 2000, Chapter 4: *Schema Theories*. The Nature of Schema.
<http://www.ruf.rice.edu/sch/stereotype%20book/chapter%204%20-%20schemas.pdf>.
Site visited on 2004-05-02.

Boler, T., Adoss, R., Ibrahim, A. and Shaw, M. 2003, *The Sound of Silence: Difficulties in communicating on HIV/AIDS in schools*. London, ActionAid.
<http://www.actionaid.org>. Site visited on 2004-06-07.

Bolton, M. and Burroughs, S. 2001, *Building Houses with Earth Blocks*. A guide for upgrading traditional building methods using handmade earth blocks.
<http://www.agrement.co.za/PDFS/introdandpart1.pdf>.
Site visited on 200/04/26.

Burns, C. 2002, 'A commentary on the colloquium Instituting Gender Equality in Schools: Working in an HIV/AIDS Environment.' In *Agenda* 53: 6-10.

Brown, T., Franklin, B., MacNeil, J. and Mills, S. 2002, *Effective Strategies in low prevalence settings*. Family Health International.

Bujra, J. 2000, 'Targeting men for a change: AIDS discourse and activism in Africa!' In *Agenda* 44: 6-20.

Campbell, C. 2003, '*Letting them die.*' *Why HIV/AIDS Intervention Programmes Fail*. Cape Town: Double Storey (a) Juta Company.

Casey, N. and Thorn, A. 1999, *Lessons for Life. HIV/AIDS and Life skills education in schools*. United Kingdom: European Commission.

Castells, M. 1996, *The Network Society*. Oxford: Blackwell Publishers, Inc.

Castells, M. 1997, *The Power of Identity*. Oxford: Blackwell Publishers, Inc.

Castells, M. 1998, *End of Millenium*. Oxford: Blackwell Publishers, Inc.

Cohen, L. and Manion, L. (4th edition) 2001, *Research Methods in Education*. London: Routledge.

Daniel, H. and Parker, R. 1993, *Sexuality, Politics and AIDS in Brazil*. London: Farmer Press.

Denis, P. 2003, *Are Zulu Children Allowed to Ask Questions? Silence, Death and Memory in the Time of AIDS*. University of Natal.

Dent and Nyembezi (11th Edition) 2003, *Scholars' Zulu Dictionary: English-Zulu/ Zulu-English*. New York: Hippocrene Books.

Department of Education 2002, *Revised National Curriculum Statement for Grades R-9 Life Orientation*. Department of Education: Pretoria.

<http://education.pwv.gov.za> Site visited on 2005/06/23.

Department of Health 2001, *HIV/AIDS: Care of Support of Affected and Infected learners. A Guide for Educators*. Department of Health: South Africa.

De Rosa, C. and Marks, G. 1998, 'Preventive counseling of HIV positive men and self-disclosure of serostatus to sex partners; new opportunities for prevention,' *Health Psychology* 17(3): 224-231.

Dovidio, J.K., Major, B., and Crocker, J. 2000, Stigma: Introduction and Overview. In Heatherton, T.F.; Kleck, R.E.; Hebl, M.L. and Hull, J.G. (Eds.). *The social psychology of stigma*. New York: The Guilford Press.

France, N. 2001, *Stigma and HIV/AIDS in Africa*. Review of issues and responses based on literature review, focus group discussions and Stigma-AIDS email discussion forum: South Africa: Health and Development Networks (HDN).
<http://www.hdnet.org/Stigma/Background> Site visited on 2004-05-03

Francis, D. 2003, Conversations around Amagama Amathathu (people living with HIV/AIDS). In *Perspectives in Education*. Volume 21(3): 121-126.

Freire, P. 1970 *Pedagogy of the Oppressed*. New York: Seabury Press

Fumento, M. 1990, *The myth of heterosexual Aids*. New York: Basic Books.

Gagnon, J.H. and Simon. 1973, *Sexual Conduct*. Chicago: Aldine.

Gilmore, N. and Somerville, M. 1994, 'Stigmatization, Scapegoating and Discrimination in Sexually Transmitted Diseases: Overcoming Them and Us.' In *Social Science and Medicine* 39(9): 1339-1358.

Goldenberg, I. 1978, *Oppression and Social Interventions: Essays on the Human Condition and the problems of change*. Chicago: Nelson Hall.

Govinden, D. B. 2003, 'This is my Body Broken for You.' Liturgical resources for Dealing with HIV/AIDS. In Phiri, I.A., Haddad, B. and Masenya, M. *African Women, HIV/AIDS and Faith Communities* (259-290). Pietermaritzburg: Cluster Publications.

Grant, K.B., Fine, D., Heywood, M. and Strode, A. (Eds) 2003, *HIV/AIDS and The Law*. A resource manual. The AIDS Law Project and the AIDS Legal Network. Third Edition. South Africa.

Green, .1995, The participation of African traditional healers in AIDS/STD prevention programmes. *AIDSLINE*, 36: 14-15.

Gupta, G.R. 2000, 'Gender, Sexuality, and HIV/AIDS: The What, the Why, and the How?' ICRW. Washington. <http://www.icrw.org> Site visited on 2004-07-06.

Hardiman, R. and Jackson, B.W. 1997, Conceptual Foundations for Social Justice courses. In Adams. M.; Bell and Griffin, P. (Eds). *Teaching for diversity and social justice: A source book*. New York. Routledge.

Herdt, G. 2003, *Sexuality and Secrecy*. Plenary address at the Sex and Secrecy Conference, 4th International IASSCS Conference, University of the Witwatersrand, Johannesburg, South Africa, 22-25 June 2003.

Hodgson, I. 2003, Self-stigma and HIV/AIDS.
<http://www.archives.healthdev.net/stigma-aids/msg00047.html>.
Site visited on 2004/07/05.

HRSA 2003, Gendering AIDS: women, men, empowerment, mobilization.
http://www.vso.org.uk/umages/gendering_aids_tcm8-809.pdf. Print site visited on
2004-060-07.

Jackson, H. 2002, *AIDS Africa. Continent in crisis*. Harare: SAFAIDS.

James, D. 2002, 'To take the information down to the people: life skills and HIV/AIDS peer educators in the Durban area.' In *African Studies*, 6:1.

Jewkes, R. 2000 'Stepping Stones: Feedback from the Field.'
<http://www.talcuk.org.org/stratshope/ssjewkes.html> Site visited on 2004-005-04.

Joint United Nations 1999, *Stigma and Discrimination: Definitions and Concepts*.
<http://www.aidslaw.ca> Site visited on 2004-07-05.

Karim, A.Q. 2001, 'Barriers to preventing Human Immunodeficiency Virus in women: experiences from Kwa-Zulu Natal,' South Africa. In *Journal of American Medical Women's Association*, 56.

Kegeles, S.M. 1989, 'Perceptions of AIDS, the continuing saga of AIDS-related stigma,' *AIDS 3 Supplement 1*: 253-S258.

Knutsson, K.E. 1997, *Children: Noble Causes or Worthy Citizens?* England:
Arena, UNICEF

Kelly, M.J. 2000, *The Encounter Between HIV/AIDS and Education*. University of
Zambia. Lusaka.

Leclerc-Madlala, S. 1997, 'Infect one, infect all: Zulu Youth response to the AIDS Epidemic in South Africa.' In: *Medical Anthropology*, 17.

Leclerc-Madlala, S. 2001, Silence, AIDS and Sexual culture in Africa.
<http://articles.findarticles.com/p/articles/mi m 2872/is 1 27/ai 71563341/>
Print site visited on 2004-06-05.

Lodder, M. 2004, HIV/AIDS Related stigma and the persuasion of at-risk individuals to go for voluntary counseling, testing, and referral.
<http://www.epidasa.org/documents/scriptie-michel-lodder.PDF/>. Print site visited on 2005-07-17.

Malcolm, A., Aggleton, P., Bronfman, M., Galvao, J., Mane, P. and Verall, J. 1998, 'HIV and AIDS-related stigmatization and discrimination: Its form and contexts.' In *Critical Public Health* 8(4): 347-370.

Mann, J. 1987, Statement at an informal briefing on AIDS to the 42nd Session of the United Nations General Assembly, 20 October, New York.

Mann, J.M. 1995, 'AIDS, health and human rights: the future of the pandemic.' *Royal Society of Arts Journal*, 40-48.

MANET 2003, Voices for Equality and Dignity. Qualitative Research on Stigma and Discrimination Issues as they affect PLWHA in Malawi. Lilongwe: Malawi.

Marcus, T. 1999, *Wo Zaphela Izingane. It is destroying the Children. Living and Dying with AIDS*. Pietermaritzburg: CINDI.

McIntyre, K. 2001, *Transitions to Adulthood in the Context of AIDS in South Africa: Report of Wave One.*

<http://www.unesco.org/education/educprog/AIDSGB/AIDSGBtx/CadImp>

Site visited on 2004/05/2.

McMillan, J.H. and F. Wergin 2000, (2nd edition). *Understanding and Evaluating Educational Research.* New Jersey: Merrill Prentice Hall.

Melkote, Srinivas R., Sundeep, R., Muppidi and Goswami, D. 2000, 'Social and economic factors in an integrated behavioral and societal approach to communications in HIV/AIDS.' In *Journal of Health Communication*, 5: 17-28.

Mill. 2003, The Enigma of HIV/AIDS-related Stigma. A theoretical exploration of HIV/AIDS-related stigma in Sub-Saharan Africa.

<http://www.ub.uib.no/elpub/2003/h/320001/hovedoppgave.pdf>.

Site visited on 2004/08/12.

Ministry of Education 2002, Address by the Minister of Education, Professor Kader Asmal, MP, at the Commemoration of World AIDS Day 2002.

<http://www.info.gov.za/speeches/2002/02120615461001.htm>. Site visited on 2005/0/21.

Morgan, D.L. 1997, *Focus Groups on Qualitative Research.* SAGE Publications: London.

Morrell, R. 1998, 'Gender and education in South African Schools.' In *South African Journal of Education*, 18:4.

Morrell, R., Unterhalter, E., Moletsane, L. and Epstein, D. 2001, 'What kind of future can we make: Education, Youth and HIV/AIDS.' In *Agenda* 53:3-5.

Morrell, R., Unterhalter, E., Moletsane, L. and Epstein, D. 2001, 'HIV/AIDS Policies, Schools, and Gender Identities.' In *Indicator SA*, 18, 2, 51-57.

Mouton, J. 2003, *How to succeed in your Masters and Doctoral Studies. A South African Guide and Resource*. Pretoria: Van Schaik Publishers.

Namka, L. 2003, Scapegoating - An Insidious Family Pattern of Blame and Shame on One Family Member.

<http://www.byregion.net/articles-healers/Scapegoating.html/>

Site visited on 2004-07-28

Ngcobo, C. 2002, 'The Department of Education Life Skills, Sexuality and HIV/AIDS Programme.' In *Agenda* 53: 96-98.

North, R.L. and Rothenberg, K.H. 1993, 'Partner notification and the threat of domestic violence against women with HIV infection.' In *New England Journal of Medicine*, 329(16): 1194-6.

Obieta, E. 2004, Stigma, HIV/AIDS and Disclosure. STIGMA-AIDS eForum: stigma-aids@forums.healthdev.org. Site visited on 2004-06-06

Ogunyombo, D. 1999, 'Living with AIDS-an unforgivable crime?' *Growing Up* 7(3): 8.

Oxford Dictionary 2001, A Survey of Modern English. Routledge: Taylor and Francis Group.

Oxford Thesaurus 2001, Great Britain. Oxford University Press.

Parker, R.D., Easton, D. and Klein, C. 2000, 'Structural Barriers and facilitators in HIV prevention: a review of international research,' In *AIDS* 14 Supplement 1: 22-32.

Parker, R., and Aggleton, P. 2002, *HIV and AIDS-related Stigma, Discrimination and Denial: Conceptual Framework and Practical Dilemmas*: Horizons Program. The Population Council Inc.

<http://www.popcouncil.org/pdfs/horizons/sdcncptlfrmwrk.pdf>

Site visited on 2004-05-6.

Patterson, G. 2002, *Church, Aids and Stigma*. A Discussion Paper.

<http://chwww.e-alliance.chEcumenicalAdvocacy-Alliance/>

Site visited on 2004-07-10

Patton, C. 1990, *Inventing AIDS*. Routledge. New York.

Piot, P. 2000, Report by the Executive Director. Programme Co-ordinating Board.

Joint United Nations Programme on AIDS, Rio de Janeiro. 14-15 December.

Piot, P. 2001, 'The fight against HIV/AIDS: The UN at work.' In *Choices*, 10(4): 23.

Posel, D. 2003, Getting the Nation Talking about Sex: Reflections on the Politics of Sexuality and 'Nation-building' in Post-Apartheid South Africa.

<http://wiserweb.wits.ac.za/PD29/PD%20files/wiserbriefjune2003.pdf>. Site visited on 2004/07/25

Plummer, K. 1975, *Sexual Stigma: An Interactionist Approach*: London: Routledge and Kegan Paul.

Policy Project, South Africa 2002, Siyamkela. Measuring HIV/AIDS-related Stigma. <http://www.policyproject.com> Site visited on 2004-06-12.

Population Council 2002, *Challenging HIV-related Stigma and Discrimination: A Conceptual Framework and an Agenda for Action*. New York: Horizons Program.

Preston-Whyte, E. 2003, 'Contexts of Vulnerability: Sex, secrecy and HIV/AIDS.' In *African Journal of AIDS Research* 2(2): 89-94.

Ranchod, B. 2005, *HIV/AIDS and its impact on children in South Africa*. 4th World Congress on Family Law and Children's Rights. Cape Town International Convention Centre 20-23 March 2005.

Reid, G. and Walker, L. 2003a, 'Coming out of the closet: Sex in Africa.' *Mail and Guardian*: Johannesburg: December 19.

Reid, G. and Walker, L. 2003b, 'Secrecy, stigma and HIV/AIDS: An introduction. In *African Journal of AIDS Research*', 2(2): 85-88. South Africa.

Rothenberg, K.H. and Paskey, S.J. 1995, 'The risk of domestic violence and women with HIV infection: Implications for partner notification, public policy, and the law.' In *American Journal of Public Health*, 85(11): 1569-1576.

Schaeffer, S. 1994, Section for Preventive Education. A review of literature and experience. Paris. UNESCO: Stockholm

<http://www.unescobkk.org/ips/resources/aids/hiv-aids> Site visited on 2004-07-03.

Seligman, E.P. 1992, Personal Power. Curing helplessness and learning optimism.

<http://www.buildfreedom.com/tl/wual.shtml> Site visited on 2004-07-30.

Sennet, R. and Cobb, J. 1972, *The Hidden Injuries of Class*. New York: Vintage.

Sigxashe et al. 2001, 'Attitudes to disclosure of HIV status to sexual partners'. In *South African Medical Journal*, 91:11-13.

Sherr, L. (Ed.) 1995, *Grief and AIDS*. Chichester: John Wiley and Sons.

Singhal, A. and Rogers, E.M. 2003, *Combating AIDS. Communication Strategies in Action*. London, Delhi, California: Sage Publications.

Sowell, R. 1999, 'Experiences of violence in HIV-positive women in the South-Eastern United States of America,' In *Journal of Advanced Nursing* 30(3): 606-615.

Stein, M. 1998, 'Sexual Ethics: Disclosure of HIV positive status partners.' In *International Medicine* 158(3):253-257.

Tallis, V. 2000, 'Gendering the response to HIV/AIDS: Challenging gender inequality.' In *Agenda* 44: 58-66.

Tatum, B.D. 2000, The Complexity of Identity: 'Who Am I?' In Adams, M, et al. *Readings for Diversity and Social Justice*. (174-191). New York and London: Routledge.

The American Heritage Dictionary of the English Language 2000, Fourth Edition. Boston: Houghton Mifflin.

Townsend, L. and Dawes, D. 2002, Willingness to care for children orphaned by HIV/AIDS: a study of foster and adoptive parents. *Children First*.

<http://www.hsrc.ac.za/research/output/willingnesstocareforchnorpbbyHIVpdf>.

Site visited on 2004/07/02.

UNAIDS 2001, Regional Consultation Report. Stigma and HIV/AIDS in Africa: Setting the operational Agenda.

<http://www.aids.org> Site visited on 2004-06-10.

UNAIDS 2002, A conceptual framework and basis for action: HIV/AIDS stigma and discrimination. Geneva. http://www.dec.org/pdf_docs/PNACP852.pdf.

Site visited on 2004-06-05.

UNAIDS, HDN and SIDA 2001, Stigma and HIV/AIDS in Africa: Setting the Operational Research Agenda. Dar-es-Salaam. Tanzania.

<http://www.unaids.org> site visited on 2004-05-04.

UNICEF 2000, The State of the World's Children. New York. UNICEF.

<http://www.unicef.org/programme/hiv/focus/edu/life.html> Site visited on 2004-05-7.

UNICEF 2001, Stigma, HIV/AIDS and prevention of mother-to-child transmission: A pilot study in Zambia, India, Ukraine and Burkina Faso. London: UNICEF.

<http://www.unicef.org/htm> Site visited on 2004-06-07.

Van Manen, M. 1997, Second Edition with new expanded preface. *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*: London, Althouse Press.

Viola, W. 1960, *Child Art*. University of London Press Linked.

Weeks, J. 1981, *Sex, Politics and Society: The Regulation of Sexuality since 1800*. New York: Longman.

Weiss, E. and Whelan, D. 2000, 'Gender, sexuality and HIV: making a difference in the lives of young women in developing countries.' *Sexual Relationship Therapy*, 15.

Welbourn, A. 2002, 'Stepping Stones: shifting gender inequities to combat HIV.' In *Agenda* 53: 54-60.

WHO 1994, School Health Education to Prevent AIDS and STI: A resource package for curriculum planners, Geneva.

Wildeman, R. 2001, Funding the Fight Against HIV/AIDS: Funding the Like Skills and HIV/AIDS Programme. Idasa: Cape Town.

<http://www.school.za/report/education-final.doc>. Site visited on 2004-06-09.

World Bank 2002, *Education and HIV/AIDS, A Window of Hope*. Washington, DC: The World Bank.

Young, I. 2000, *Five faces of oppression*. Princeton University Press.

Ziegler, S. 2000, 'Violence' victimization after HIV infection in a US probability sample of adult patients in primary care,' *American Journal of Public Health* 90(2): 208-215.

APPENDIX ONE

QUESTIONS: PLWHA

NAME:

1. SOCIO-ECONOMIC BACKGROUND

Tell me about yourself and your family Ngitshele ngawe kanye nomndeni wakho?

Where do you live? Uhlala kephi?

With whom do you live? Uhlala nabani?

How many dependents that you have? Bangaki abantu abanganphantsi kwakho/
obanakekele?

Are these dependents attending school? Bonke labo obanakekele bayafunda?

What about you, what level of education do you have? Wena wenzani, uphume kabani
esikoleni?

Did you find out about your HIV status during or after you finished school? Uthoile
ukufunda ngengculaza esikoleni noma emuva kokuba ufundile

Are you attending any courses on HIV and AIDS at the moment? Kukho izifundo
ozenzayo manje?

If yes, does being HIV positive affect your learning in any way? Uma unazo, kukho
yini esithintana nengculaza?

Do you have children? Unazo izingane?

What about your children are they affected? Zinjani zona izingane zakho nazo zinomthelela?

How do you earn your living? Uphila ndlelani/ hloboluphi

Do you earn less than R500 or more than R500: R1000: R2000 or more? uholo imali engabhansi kuka R500, noma ngaphezu kaR500; R1000; R2000 noma ngaphezulu?

In what area of your life do you spend most of your money? Yiyiphi indawo epilweni yakho osebenzisa imali enkulu/eninzi?

2. KNOWLEDGE ABOUT HIV and AIDS (transmission, prevention, treatment and support in your community) Ulwazi ngengculaza(indlela ethelelana ngayo, indlela ongayivikela ngayo, indlela ongayigoma ngayo nesizwe)

Before testing. Ngaphambi kokuba uhlolwe

After testing. Emveni koba usuhloliwe

Present Nje ngamanje

Are there any differences in your knowledge and your life from before to present?

Kukhona umahluko wolwazi empilweni yako ngaphambili noma manje?

Considering the knowledge you have about living positively with AIDS, has it been easy for you to implement these techniques? (eg. using condoms to prevent re-infection, eating fresh food, disclosing your status to get support, avoiding alcohol and

cigarettes etc.) Ngokubangela ngolwozi lwakho ukuthi uphila nengculaza kungalula yini ukuhamba uzendlala ukuba usunayo, nezinto ozinvekela ngazo Ezinje ngokusebenzisa amajazi ukuvikela uqhubeko ukudla okusekusha, ungaphuzi izidako mizwa kanye nogwayi nokunye.

What has made it easier/ harder? Yini eyenza kube lula nobanzima?

Who helps and supports you when you are sick or experience other problems? Uma ugula noma unenkinga wubani okusizayo?

Have you disclosed your status to anyone? Why? Ukhona yini umuntu oke waxoxa naye ngasese malunga nalesisifo?

How does your community view PLWHA? Abantu bendawo babahlalisa kanjani nabantu abanengculaza

Have you ever lost someone to AIDS or other disease? How did this affect you? Uke washonelwa/waswelekelwa womunye ununtu ngenxa yengculaza noma hesinye isifo?

3. EXPERIENCES WITH AIDS ULWAZI NGENCULAZA

How would you describe your life with AIDS? Uma uchaza ngemphilo yakho umna unengculaza, ungayichaza kanjani into enjalo.

What are the some of the challenges you have experienced living with AIDS and how have you dealt with them? Yiziphi izichwetso ozifundile ekubeni uphila nengculaza ulwa njani Nazo.

How is your family dealing with the fact that you are HIV positive? Umndeni wakho uzama njani malunga nengculaza ekuphetheyo?

4. LIVING POSITIVELY WITH AIDS (UKUHLALA UZAZI UKUTHI UNENGCULAZA).

What are some of the lessons you have learnt through living with AIDS that you can share with us? Zeziphi izifundo ozifundile ekubeni uphila nengculaza zeziphi ongazixoxa nathi?

APPENDIX TWO

QUESTIONS: HEALTH-CARE WORKER

1. SOCIO-ECONOMIC BACKGROUND

Tell me about yourself and your family.

Where do you live?

How many dependents do you have?

Are these dependents at school?

What level of education do you have?

Are you a registered nurse/health-worker/volunteer/community health worker?

What qualification/training do you have?

When did you enter this type of work?

What made you choose this career/community-work?

How does this work impact on you and your family life?

2. EXPERIENCES IN DEALING WITH THE EPIDEMIC

What exactly does your work involve?

To what extent does poverty affect the epidemic in this area?

To what extent does the community utilize your services? Why?

How much experience do you have in dealing with the epidemic and persons affected?

How do you identify people who need help because they are sick but won't ask for it?

What do you do to assist or educate/advise them?

Do you think the epidemic has increased/decreased in this area? Why?

What about counseling programmes? What does this clinic have in place for HIV positive/negative persons? Does the clinic offer pre/post test counseling sessions?

Do you offer after-hours care/treatment/counseling for persons affected or infected?

3. PERSONAL EXPERIENCES WITH AIDS

What have you learnt about HIV and AIDS?

This profession/work is extremely demanding? How do you cope?

How does your work affect your family life positively?

How does your work affect your family life negatively?

How does working with PLWHA affect your view of life?

How does your community view people living with AIDS?

What kind of treatment is offered by the community for those who are afraid of disclosing their status?

How do you cope with loss of friends and loved ones?

What makes you continue helping people?

How much does your help affect the lives of PLWHA/CLWHA?

What are your plans/hopes for the future?

4. HIV PREVENTION AND AIDS-RELATED INFORMATION

What type of education would you offer for your clients? How do you think it would be useful to PLWHA/CLWHA?

What information about sexuality education would you recommend for all children who are our future generation? How do you think this would be useful?

Has your organization been to schools and offered HIV and AIDS programmes/educational talks? How do the schools respond?

What kind of future do you see for PLWHA/CLWHA?

What kind of future do you see for PLWHA with/without government support structures?

In your experience, do you see education affecting the sexual behaviour of both males and females? Do you think education is the key to prevention? Why?

APPENDIX THREE

QUESTIONS: NDWENI CLINIC/ HOSPITAL/ GREENVILLE HOSPICE

- A.1. Does the epidemic affect people in Ndweni district?
2. What are the factors that continue to promote the spread of AIDS in your community?
3. What measures are you taking to prevent HIV and AIDS from spreading?
4. What advice/measures are you offering for persons to live positively with AIDS?

B.1. What type of care, treatment and support services do you think PLWHA need in your community?

2. What other support services exist in your community for the chronically ill who have developed full-blown AIDS?
3. What is the level of knowledge about Anti Retroviral drugs for PLWHA?
4. What suggestions would you make to increase knowledge about ARVs among PLWHA?

VCT AND DISCLOSURE QUESTIONS

1. What are your views about VCT services in Ndweni district?
2. What are the shortfalls in VCT services?

3. What needs to be done to improve VCT services in the area to reduce cases of stigma and discrimination amongst PLWHA, if any exist?
4. What are the advantages of people knowing that they are HIV positive or negative?
5. What are the disadvantages of people knowing that they are HIV positive or negative?
6. If you made the decision to have an HIV test, where would you feel more comfortable to access such a test?
7. How easy would it be for a person diagnosed HIV+ to disclose his/her status?
8. What has been the reaction of Ndweni Community to people known to have AIDS?
9. What mechanisms should be put in place to promote disclosure of sero-status amongst PLWHA?
10. What are the advantages/disadvantages of disclosure of one's sero status?

(Thuli and Prudence are voluntary community health workers who speak and understand the English Language very well. Prudence answered her questions in Zulu on tape that was later translated into English.)

APPENDIX FOUR

QUESTIONS: FOCUS GROUP SESSIONS

FOCUS GROUP: SESSION ONE

Draw your experiences with HIV and AIDS. Dweba ngokwani kwakho malunga ngngculaza?

FOCUS GROUP: SESSION TWO

WRITE DOWN YOUR ANSWERS.

1. Tell me about your drawings. Ngitshele ngomdwebo wakho.
 2. Tell me what you thought about as you drew your picture! Ngitshele ngako konke okade ukucabanga ngenkathi volweba isithombe?
 3. Does your picture talk about your experiences? Ingaba isithombe sakho sichaza ngqo ngolwazi lwakho. Uma kungenjalo yini ubuyicabanga ngaleyo nkathi volweba?
-

FOCUS GROUP: SESSION THREE

There is so much of evidence from your drawings and your written answers about your personal experiences with people living with AIDS. How do you know that they are infected? How do children know they are HIV positive if they are not tested?

Zoininzi izinto okhulume ngazo kwimpendulo yezithombe zakho ngokwazi kwakho ngabantu abaphila nengculaza. Wazi kanjani ukuthi lababaqntu sebenengulaza? Izingani zizazi kanjani ukuthi zinengculaza zibe zingahlolwanga igazi?

APPENDIX FIVE

QUESTIONS: HEAD OF DEPARTMENT

1. Name of school.
2. Name of HIV and AIDS co-ordinators
3. Is there an HIV and AIDS policy at school?
4. Are there programmes organized for children/staff/parents?
5. Are the Principal/staff/SGB/parents supportive of HIV and AIDS programmes?
6. Do you encounter any barriers in conducting programmes effectively?
7. Do you think HIV and AIDS is a major problem in Ndweni school/community?
8. Do you think stigma/discrimination exists against pupils/cleaners/staff/parents?
Why/How?
9. Does Ndweni Primary offer any assistance/support programmes?
10. What assistance do you receive in terms of funding HIV and AIDS projects?
11. What precautions are taken when attending to ill pupils?
12. VCT Testing. How does you/staff/Principal feel about it?
13. How do poverty/ socio-economic conditions in Ndweni Community contribute to HIV and AIDS situation?

APPENDIX SIX

QUESTIONS: LIFE SKILLS CO-ORDINATORS: NDWENI PRIMARY SCHOOL

A.GENERAL

1. What is the general situation of HIV and AIDS in Ndweni Primary School?
2. What are the factors that promote the spread of AIDS in Ndweni Primary?
3. What measures of prevention have been encouraged or adopted?
4. What measures are you aware of that PLWHA have adopted to living positively with AIDS?

B.LIFE-SKILLS PROGRAMMES AT SCHOOL

1. As an educator/ Life Skills co-ordinator, one attending departmental workshops, have you implemented programmes/dissemination information worksops at school?
2. Has the subject of HIV/AIDS been included in the Life Orientation periods at Ndweni Primary School?
3. What is your opinion of the content of the curriculum for your grade and age?
4. What are your/general staff views on HIV and AIDS stigma/disclosure?
5. What is the rate of absenteeism amongst educators and pupils?

C.QUESTIONS: CARE & SUPPORT

1. What type of care, treatment and support services do you think CLWHA/PLWHA need in Ndweni Primary School, if any?

2. What support services exists at Ndweni Primary for pupils/educators/cleaners etc who may be HIV positive?
3. What is the level of knowledge about ARVs at school amongst staff/pupils?
4. What suggestions would you make to increase knowledge about ARVs?

D. VCT AND DISCLOSURE QUESTIONS

1. What are your views about VCT?
2. What is the level of knowledge about VCT at school amongst staff/pupils?
3. What are the advantages/disadvantages of people knowing and disclosing their positive status?
4. If you made the decision to have an HIV test, where would you feel more comfortable to access such a test and why?
5. How easy would it be for a person diagnosed HIV positive to disclose his/her status at this school?
6. What has been the reaction of Ndweni Primary School to people known to have AIDS?
7. What mechanisms should be put in place to promote disclosure of sero status amongst PLWHA?

EDUCATION FOR PREVENTION

1. What type of education would you recommend for HIV positive/negative pupils/educators? How do you think this would be beneficial?
2. As an HIV and AIDS co-ordinator do you think education is the key to sexual behaviour change?
3. Do you think education is linked to prevention? Why?
4. What kind of future do you see for our children with/without government support structures?
5. Do you think educators play a vital role in education for prevention?

APPENDIX SEVEN

CONSENT FORM: PRINCIPAL

School Address

Date

The School Principal and the Chairperson of the School Governing Body

Ndweni Primary School

Ndweni

Dear Dr Dlala

REQUEST: PERMISSION TO CONDUCT A STUDY AT NDWENI PRIMARY SCHOOL.

I am writing to request for permission to conduct a study in Ndweni Primary School. I am pursuing a Masters in Education degree at the University of KwaZulu-Natal this year 2004. I am presently working on a dissertation on HIV and AIDS-related stigma in partial fulfillment of the requirements for the completion of my studies.

The full title of my proposed study is “The silent sepulchral effects of stigma”: a study of the nature of HIV and AIDS-related stigma in a primary school and its surrounding impoverished community situated in the Durban area in KwaZulu-Natal.

The study is focused on early teens (12-14 year olds). Learners from this age group will be drawn from grades 6. I have chosen the school for convenience in collecting data. I anticipate the following participants to form a sample for this study; key

informants in the school (principal, HIV and AIDS coordinators, chairperson of the SGB and 14 learners) and in the community key informants from the clinic, council, hospice and community members (PLWHA). Permission from parents of all learners that will participate in the study will be sought.

I will ensure minimal use of school time in collecting data from selected sample and no disruption of classes will occur. The study will not harm the image of the school, as the name of the school will not be linked to any of the data collected. For the purpose of analysis, the discussion and interviews will be tape-recorded. Some pictures will be taken but at all times the identity of participants will be protected.

The study has many possibilities and may benefit the school in a number of ways:

The school will have an opportunity to discuss the nature of the stigma and its impact on education.

Findings will be disseminated to the school.

It is envisaged that the study will result in articles and forums whereby the issue of stigma will be addressed.

If you have any queries about this study, you can contact my supervisor at the University of KwaZulu- Natal, Durban School of education, Dr T.M Buthelezi. Her contact details are: Tel: 031 – 260 3471; Fax 031- 260 3423; e-mail: Buthelezit10@ukzn.ac.za.

Thank you for considering my request. Letters to request participants' consent to get involved in the study are prepared and will be forwarded after your response. I would like to answer any questions, which you may like me to clarify.

Yours Sincerely

K. GOVENDER (Student no 202520219)

APPENDIX EIGHT

CONSENT FORM: PARENT/GUARDIAN/FOSTER PARENT

School Address

Date

The Parent

.....
.....
.....

Dear Parent/Guardian/Foster-Parent

REQUEST FOR PERMISSION TO ALLOW YOUR CHILD TO PARTICIPATE IN
THE FOCUS GROUP DISCUSSIONS

I am pursuing a Masters in Education degree at the University of KwaZulu-Natal this year 2004. I am presently working on a dissertation on gender equality in partial fulfillment of the requirements for completion of my studies.

I need some learners to participate in the study. I have identified your child as one of the potential contributors. I am writing to request your permission and consent to involve your child/ward in my research.

The full title of my proposed study is “The silent sepulchral effects of stigma”: a study of the nature of HIV and AIDS-related stigma in a primary school and its surrounding impoverished community situated in the Durban area in KwaZulu-Natal.

The study is focused on early teens (12-14 year olds). Learners from this age group will be drawn from grade 6. I have chosen the school for convenience in collecting

data. I anticipate the following number of participants to form a sample for this study: chairperson of the board, principal, two educators and fourteen learners.

I will ensure minimal use of school time in collecting data from selected sample and no disruption of classes will occur. The study will not harm the image of the school, as the name of the school will not be linked to any of the data collected. For the purpose of analysis, the discussion and interviews will be tape- recorded. Some pictures will be taken but at all times the identity of participants will be protected.

The study has many possibilities and may benefit the school in a number of ways:

The school will have an opportunity to discuss the nature of the stigma and its impact on education.

Findings will be disseminated to the school.

It is envisaged that the study will result in articles and forums whereby the issue of stigma will be addressed.

If you have any queries about this study, you can contact my supervisor at the University of KwaZulu- Natal, Durban School of education, Dr T.M Buthelezi. Her contact details are: Tel: 031 – 260 3471; Fax 031- 260 3423; e-mail: Buthelezit10@ukzn.ac.za . Thank you for considering my request. I would like to answer any questions, which you may like me to clarify.

Yours Sincerely

K. GOVENDER (Student no 202520219)

Please fill in the form below and indicate by ticking where appropriate:

Consent given	Yes	No
Name of person giving consent		
Relationship to the child	Parent / guardian	
Signature		
Date		

[

 ■

 3

 ;

 (

)

)

 ;

 -

 (

)

APPENDIX NINE

CONSENT FORM: KEY INFORMANT

School Address

Date

The Key Informant

.....
.....
.....

Dear Key Informant

REQUEST FOR YOUR PARTICIPATION IN AN INTERVIEW

I am pursuing a Masters in Education degree at the University of KwaZulu-Natal this year 2004. I am presently working on a dissertation on gender equality in partial fulfillment of the requirements for completion of my studies.

I will be conducting interviews from key informants and you have been identified as one of them based on the role you play in the school/community. I would like to request you to participate in an interview.

The full title of my proposed study is “The silent sepulchral effects of stigma”: a study of the nature of HIV/AIDS-related stigma in a primary school and its surrounding impoverished community situated in the Durban area in KwaZulu-Natal.

Your name will not be linked to any of the data collected. For the purpose of analysis, the interview will be tape-recorded. The interview will take 45 minutes and notes will be taken during the interview.

The study has many possibilities and may benefit the school in a number of ways:
The school will have an opportunity to discuss the nature of the stigma and its impact on education.

Findings will be disseminated to the school.

It is envisaged that the study will result in articles and forums whereby the issue of stigma will be addressed.

If you have any queries about this study, you can contact my supervisor at the University of KwaZulu- Natal, Durban School of education, Dr T.M Buthelezi. Her contact details are: Tel: 031 – 260 3471; Fax 031- 260 3423; e-mail: Buthelezit10@ukzn.ac.za.

Thank you for considering my request. I would like to answer any questions, which you may like me to clarify.

Yours Sincerely

K. GOVENDER (Student no 202520219)

Please fill in the form below and indicate by ticking where appropriate

Consent given	Yes	No
Name of person giving consent		
Signature		
Date		



RESEARCH OFFICE (GOVAN MBEKI CENTRE)
WESTVILLE CAMPUS
TELEPHONE NO.: 031 – 2603587
EMAIL: ximbap@ukzn.ac.za

10 APRIL 2006

MRS. K GOVENDER (202520219)
EDUCATION

Dear Mr. Govender

ETHICAL CLEARANCE: "THE SILENT SEPULCHRAL EFFECTS OF STIGMA: A STUDY OF THE EFFECTS OF HIV AND AIDS-RELATED STIGMA ON THE LEARNERS AT NDWENI PRIMARY SCHOOL AND ITS SURROUNDING COMMUNITY SITUATED IN THE NORTH DURBAN AREA IN KWAZULU-NATAL"

I wish to confirm that ethical clearance has been granted for the above project, but the Committee noted that voluntary nature of the participation should have been indicated on the informed consent document:

APPROVAL NUMBER: HSS/06087A

Yours faithfully


.....
MS. PHUMELELE XIMBA
RESEARCH OFFICE

PS: The following general condition is applicable to all projects that have been granted ethical clearance:

THE RELEVANT AUTHORITIES SHOULD BE CONTACTED IN ORDER TO OBTAIN THE NECESSARY APPROVAL SHOULD THE RESEARCH INVOLVE UTILIZATION OF SPACE AND/OR FACILITIES AT OTHER INSTITUTIONS/ORGANISATIONS. WHERE QUESTIONNAIRES ARE USED IN THE PROJECT, THE RESEARCHER SHOULD ENSURE THAT THE QUESTIONNAIRE INCLUDES A SECTION AT THE END WHICH SHOULD BE COMPLETED BY THE PARTICIPANT (PRIOR TO THE COMPLETION OF THE QUESTIONNAIRE) INDICATING THAT HE/SHE WAS INFORMED OF THE NATURE AND PURPOSE OF THE PROJECT AND THAT THE INFORMATION GIVEN WILL BE KEPT CONFIDENTIAL.

cc. Derek Buchler
→ cc. Supervisor (Dr. T Buthelezi)