

The impact of stigma and discrimination against people living with HIV and AIDS: An investigation into why family members attribute death to other diseases

by
Thomas Muladelo Mathavha

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Supervisor: Prof. JCD Augustyn

Faculty of Economic and Management Sciences
Africa Centre for HIV/AIDS Management

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Abstract

This research paper is based on the perception of people over the death by HIV and Aids. It looks at the impact of culture and beliefs on the management of HIV and Aids in the community and also in the country as whole.

This research aims to establish the root course of covering death of by HIV and Aids, often due to fear of discrimination and isolation. Communities need to be educated on discrimination and stigma that comes about with people living with HIV and Aids.

This study was conducted at Mvelaphanda Primary School children, in Tembisa, Ekurhuleni Metropolitan Municipality in Gauteng, South Africa. The main focus was on the death of parents of the learners at the school and ultimately learners themselves, who some of them where born with HIV epidemic. Some of the children became orphans of the disease.

The collection of data was in three fold: questionnaire, interview and observation and discussions. The information gathered was manipulated to bring about the expected results.

Analysis of the data indicated that where there is no behavioral and attitude change, there would be more death by the pandemic than ever before. It is the responsibility of everyone, be it heads of families, religious leaders, politicians, business people and teachers to fight against the spread of HIV and Aids pandemic.

This study has also discovered that medical report on the cause of death is concealed in order for policies to payout. This distortion of information does not help in the fight against the spread of HIV and Aids

All stakeholders should work together in the support of those will disclose their status without fear of rejection, isolation and discriminated against. Schools, churches and community gatherings should be better used as a plat-form for that. If such conditions are created the spread of the HIV will be reduced and the prevention strategy will succeed.

Opsomming

Die navorsing handel oor die persepsie van mense teenoor dood as gevolg van MIV/Vigs. Dit ondersoek die impak van kultuur en geloof op die bestuur van MIV/Vigs binne 'n gemeenskap in die besonder en binne die land in die algemeen.

Die doel van die navorsing was om die grondoorsaak waarom daar dikwels gediskrimineer word teenoor persone wat sterf weens MIV te identifiseer en om te bepaal waarom mense wat met MIV leef dikwels “uitgewerp” word uit die gemeenskap.

Die studie is gedoen by die Mvelaphanda Primêre Skool in Tembisa, in die Ekuhuleni Metropool van die Gauteng provinsie van Suid-Afrika. Die primêre fokus van die studie was op die invloed wat die dood as gevolg van Vigs op die kinders in die skool gehad het.

Data is ingesamel deur middel van vraelyste en onderhoude asook deur waarneming en besprekings.

Ontleding van die data het aangetoon dat indien daar nie positiewe gedragverandering plaasvind nie, daar meer sterftes as gevolg van Vigs verwag kan word.

Daar word aanbevelings gemaak oor hoe belangroepe kan meehelp om stigma en diskriminasie te verminder en sodoende kan meehelp om die verdere verspreiding van die pandemie te beperk

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Chapter 1. Introduction

HIV and Aids is a reality that cannot be avoided any longer. It affects all sectors of human life. HIV and Aids epidemic poses one of the greatest challenges to the existence of humanity globally. HIV and Aids has claimed more death than any war waged before. It has claimed life of most talented people, businessmen, politicians, scientists, and academics just to name the few. The most vulnerable are women aged between 15 and 24). Research has established that women tend to be more vulnerable than their male counterparts (Barnighausen et al, (2007). These young women get involved with men who are much older than them, who also have multiple girlfriends. This makes them vulnerable to HIV infection from tender ages. The most affected are the less educated and the poverty stricken community members. It is for this reason that this study will confine this project to the level of understanding of the research participants mostly youth from informal settlement of Winnie Mandela and Ivory Park.

1.1. Research Question

The impact of stigma and discrimination against people living with HIV and Aids: 'An investigation into why family members attribute the cause of death by Aids to other diseases '

1.2. Background about Problem

The researcher is a school principal of Mvelaphanda Primary School situated in Tembisa, the township ravaged by functional violence during the apartheid regime. It is situated in the Midrand, east of Johannesburg, the Golden City of South Africa. Most people migrated from all the provinces to settle near to the cities that form a Metropolitan City.

The school was established in 1969 and it caters for 800 learners who came from the poverty stricken informal settlement mentioned above. It has 25 staff members. Its sustenance and existence depend solely on the parents, mostly young people who were once learners at the school.

Some of these young parents are dropouts due to early teenage pregnancies, lack of finance to proceed with their studies. The fact that they become pregnant at early ages makes them vulnerable to STI and HIV infection.

As the statistics on the death by HIV and Aids related diseases rise, the school is gradually affected by this situation. To date as per school policy, family members have reported to the school about the death of learner's parents. Most of these deceased mothers were single mothers due to the fact that their children were born through rape by uncles, neighbours or migrant truck drivers. After the death of these young mothers, children who are some of them infected become orphans.

The school has a food gardening, which was established in order to provide these orphans with balanced diet. Community members and people living with HIV and

Aids, benefit out of this project. The project consists of PLHA (People living with HIV and Aids), learners, teachers and some community members. The problem is whether we will be able to sustain the project as the number of needy children rise.

1.3. Structure of the study

This chapter identifies the background of the research problem. It provides the objectives of the study and also gives an in-depth description of the cause of the problem identified. It addresses the assumptions to the problem such as moral decay stigmatization that goes with people who choose to disclose their HIV status without fear of discrimination and rejection. This chapter further outline the support required to deal with stigmatization and discrimination, and the support provided to the children affected by the scourge of Aids pandemic

Chapter 2 illustrates a review on the relevant literature on variables. It provides a review on the impact of HIV on the socio-economic life of the HIV infected person. It also provides a review on the statistic globally. It further describes the attitude of the community towards those infected by HI virus.

Chapter 3 describes the research method used in this study i.e. collection of data, procedures and techniques applied in trying to resolve the problem mention in

Chapter 1.

Chapter 4 deals with the interpretation and discussion of the analysed data. It also provides the expected results of the hypothesis.

Chapter 5 includes conclusion and also tables some recommendations to the problem.

1.4 Moral decay and HIV and Aids.

The UNAIDS Inter-Agency Task Team on education has alluded to the fact that education for prevention of HIV should begin at early ages of the children. Schools have a role to play in reducing risk and vulnerability associated with the epidemic (UNAIDS, 2003).

Children are exposed to sexual matters from early ages. They witness their parents engaging in sexual intercourse making love at their disposal. One typical example is by the time when people from a nearby informal settlement resided in a community hall because the municipality demolished their shacks. They stayed there for a year and within ten months a child was born right inside the hall. The child was named after the councilor because they regarded him as their stumbling block towards getting a proper place to stay. Children bring this ordeal to school where they direct their anger at other children and the teachers. Most of these children use abusive language. They also talk sexual matters with their schoolmates.

The place where they come from there are many cases of child rape, mostly by closest members of the families such as fathers, uncles family friends and neighbours. HIV infection is very much possible to children. Most of the children come from broken

families, where either father or mother alone raises them. These single parents leave children alone for weeks, while working as domestic workers in the city suburbs. Children become vulnerable to HIV and Aids infection and abuse. Children engage in sexual activities from their tender age. Studies has established that educated adolescents who attend school are less likely to have casual sexual partners and more likely use protection than peers with less schooling (UNAIDS, 2007).

1.5 Denial by community on Aids Deaths

The school is experiencing problem of intensifying the awareness of fight against HIV and Aids. Every week persons, mostly young women are buried. Some of these people are parents at the school. The problem is that even when family members are informed of the cause of death, which is likely to be Aids, they choose to inform people that the cause of death was 'witchcraft'. Children and other family members from a denial family tend to grow with the belief that there is no HIV and Aids, and they fear to be bewitched than being infected by the virus (UNAIDS (2003). This distortion of information does not help in the fight against HIV and Aids.

1.6 Care for orphans of HIV and Aids

Research has established that by 2004, it was estimated that there are 2,2 million orphaned children in the country this means that 13% of the children lost either a mother or a father, nearly half of all orphans were estimated to have lost parents to Aids related illnesses (UNAIDS, UNICEF, USAID, 2004)

The most hardly affected are children from impoverished households, whose social life is affected because of the loss of breadwinners and work adults. Sometimes these children fend for themselves or they are separated to stay with other relatives or carers (UNAIDS, 2003).

Children's well-being deteriorates long before their parents die. This is mainly because those working adults experience income and cash flows problem because they spend money on medicines and funerals. Most of the children drop out from better schools and some end up not going to school at all minimal resources are shared among more dependents and valuable assets are sold off UNAIDS,(2004).

Research has established that children are better off within their communities than in institutions. It is therefore imperative for caregivers to look at what is best for the children. Children fare better if they remain in familiar surroundings, in family units even if not with their biological families (UNAIDS, (2003).

It is there essential for early identification of vulnerable children so as to have proper planning such as kinship and community foster care, assistance with social grant applications, counseling and psycho-social support schools, government, corporate and private sector support should support initiative to address these problems.

The school has in conjunction with Gauteng department of education launched a campaign to help the children orphaned by HIV and Aids. At the moment the school has identified fifteen learners left alone fending for themselves due to death by HIV and Aids pandemic. The Department of social and welfare services through its

poverty alleviation program has a grant for such children. They receive R650 per child per month. With about more than 1000 sexually active adults infected daily, the number of Aids orphans will tremendously increase (Department of Health South Africa, 2007). Whether the state will sustain this grant, stands to be seen.

With the number of orphans and vulnerable children escalating, the community may not cope with such impact. It is estimated that 20 million orphan children will be found in the world, whether the country can cope with such a load stand to be seen.

The impact of orphans is very complex. Study has established that there is a correlation between numbers of orphans and an increase on the number of uneducated, poorly socialized, malnourished vulnerable young people have effect on the social stability. With the number of orphans and vulnerable children rising, families are pushed to the limit. Loosing parents to Aids makes children to be less educated and lead them to seek full-time jobs from early ages. Study has established that children as early as the ages between 5 and 14 are likely to less educated and work for more than 40 hours a week. Children orphaned by Aids are deprived stability of childhood, love and nurturing. Children become adults early (UNAIDS2003).

1.7 Establishment After-Care centre

After realizing the challenge faced with, Mvelaphanda Primary has in partnership with the Department of Social Development established an after care center. We all agree that the impact of orphans and vulnerable children require a multi-sectoral approach. Its objectives are as follows:

- To use an approach that is needs and rights based in addressing the needs of orphans
- To empower families and communities to cope with orphans and vulnerable children.
- To provide life skills to active members of the family.
- Provide emotional support and nutritious food
- To provide recreation and homework supervision.
- To increase access through improved referral system.
- To assist children to access statutory services such as social grants, school uniforms and bursaries.

The role of the social workers is to provide counseling to the children, caregivers and to provide advocacy campaign to the communities. The Department of Health and Social Development also provide emotional support and assist in referrals for those who need medical attention such as provision of Antiretroviral for the HIV infected.

The Department of Labour provides life skills such as training the active members of family. Training is provided in food gardening in order for them to plant vegetables in their back yard. They also provide training in income generating projects like sewing. Teachers at the school volunteer to in homework supervision since these children do not have adults to supervise them at home. They also help life skill training in

computer literacy and extra mural activities. The Department of Home Affairs provides identity documents to the orphans.

The sustainability of this project depends solely on the commitment of all stakeholders. The project requires a commitment from donors and sponsors in order to cope with the requirement financially. Good financial and property management is required for the sustainability of this project. Up to this far the project is however progressing well. The biggest challenge might be the rising number of orphans as this the trend globally.

1.8 Nutritional food programme

Poverty remains one the prospects of aggravating the speed under which people reach Full-blown Aids. HIV and Aids is not simply health issue but also of vital importance across a spectrum of issues including development, security, food production and life expectancy. The rapid spread of the epidemic in the sub saran countries, South Africa being one of them, is exacerbated by poverty (Clover J, 2003)

The food crisis now hitting the world is inextricably linked to the wide spread of HIV pandemic that has deepened crisis. Southern Africa is the hardest hit region globally. The region in the third world, meaning that is one of the poor of the poorest region in the world. Women are the one playing a meaningful role in agriculture. With 58% of those infected being women, food security at the household and community level is badly affected (Clover J, 2003). All efforts of food production are affected where the prevalence of HIV and Aids is high. Farming skills are being lost due to deaths by Aids. All development strategies fail, household livelihood, becomes disintegrated. Level of productivity drastically decline. The labour force decreases due to death by the pandemic. In countries such as South Africa extended family is drastically affected by loss of breadwinners.

The school has 400 learners on the programme. These are the children whose parents are unemployed and therefore could not afford pocket money or to prepare lunch boxes. Research has established that HIV and Aids and nutritional food cannot be isolated.

The school has a food garden where fresh vegetables are distributed to the needy children. The provision ARV'S cannot be successful unless poverty can be addressed first. Medicines cannot be taken on empty stomachs. Dr Manto Tshabalala-Msimang, South African Minister of Health alluded to the fact that food security is of vital importance (SOWETAN 22/01/2003).

1.9 Discrimination and Stigma

Stigma is described a way of “discrediting” and individual in the eyes of others. Those who are victims become ashamed. Stigmatization is a process under which someone is devaluated. HIV and Aids is associated with wrongdoing and therefore those who are infected are said to deserve what happened to them (UNAIDS, 2002). Discrimination is described as a violation of other people on the basis of belonging to particular group. e.g., discrimination based on ethnicity. Discrimination further violates other people human right to freedom of association and a sense of belonging.

Stigma and discrimination in HIV and Aids is associated with ‘wrongdoing’. Most often these wrongdoings is associated to sex or to illegal socially frowned upon activities such as injecting drug use. To men it is mostly associated with homosexuality, bisexual and presumed to have had sex with prostitutes.

Women who are positive are viewed as having been promiscuous or have been sex workers. Family and community members instill fear to those who may decide to come open on their status and put blame to those who might have been affected first.

HIV and Aids to Africa is viewed as the disease from ‘outsiders’ implying gays and homosexual in USA. In many countries of the world Aids is associated with sub-Saharan Africa where HIV prevalence is the highest.

Self-stigmatization, most people who are infected by the HI virus internalize the negative responses and reactions of others. Self-stigmatization leads to depression, withdrawal and feelings of worthlessness. They often blame themselves for their predicament. ‘It is silence, exclusion and isolation that limit our ability to provide the care and services needed by people living with HIV. It is silence, exclusion and isolation by our leaders that prevent people from developing and marketing effective HIV prevention efforts. When the virus infects partners, the blame is mostly apportioned to the women.

Discrimination is a violation of human rights. Discrimination like stigma causes people to be ashamed, conceal their status of epidemic, and cause them to withdraw from participating in social activities. Communities always blame those infected by HIV and Aids.

Mrs. Julia Mabaso, HIV and Aids activists, while addressing people on 01/12/2008, World Aids DAY at Tembisa Hospital, indicated that many people do not die of AIDS but killed by their friend and relatives. This is mainly because once someone is diagnosed HIV positive, people start associating him or her with bad behavior, which led him or her to HIV infection.

The school believes the war against HIV and Aids should be waged not only from within the school premises but to the families where children come from. Stigma and discrimination also undermine the human rights of individuals. Dr Peter Piot, Executive Directors at UNAIDS said, “we must use an Aids Lens to scrutinize the

realization of human rights and use these rights to increase the effectiveness of Aids responses”.

Stigma and discrimination are regarded as the barriers to preventing new infections. Stigma and discrimination instill fear to find out about their HIV status to their partners, family members, colleagues and friends.

This discourages people from practicing safe measures such as insisting on condom use during sex as that may imply that they are HIV-infected. Stigma and discrimination have become a social issue because many a time people living with HIV are socially excluded. In order to be accommodated, people display their ‘negative’ status by indulging in unprotected sex. Many people are afraid that once they behave differently, people will be suspicious of their HIV status. Fear for discrimination discourages people from seeking treatment for HIV. People are also deterred from using voluntary counseling and testing service in fear of discrimination.

Stigma and discrimination has an impact because it affects the capacity of societies to respond to the devastation caused constructively by the epidemic. People choose to be silent because of the fear to come open about their HIV status. In order to endeavor to address the existing widespread stigma and discrimination, the United Nations came up with the declaration on HIV and Aids.

1.10. United Nations Declaration on HIV and Aids:

‘Stigma, silence, discrimination and ideal, as well as lack of confidentiality, undermine prevention, care and treatment efforts and increase the impact of the epidemic on individuals, families, communities nations.’

By the year 2003, nations should ensure the development and the implementation of multi-sectoral national strategies and financing the plans for combating HIV and Aids that address the epidemic in forth-right terms, confront stigma, silence and denial; address gender and age-based dimensions of the epidemic and eliminate discrimination and marginalization.’

By the year 2003, nation should enact, strengthen or enforce, as appropriate, legislation, regulations and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV and Aids and members of vulnerable groups, in particular to ensure their access to, inter alia, education, inheritance, employment, healthcare social and health services, prevention, support and treatment, information and legal protection, while respecting their privacy and confidentiality; and develop strategies to combat stigma and social connection with the epidemic’ (UNAIDS 2003)

Stigma and discrimination make the prevention strategy so difficult in the sense that it encourages the spread of HIV pandemic to silent and underground. Peter Tiot sums it at the world conference in Durban on the 5th of September 2001 sums it as follows:

“HIV and Aids-related stigma comes from the powerful combination of shame and fear, shame because sex or drug injection that transmit HIV are surrounded by taboo and moral judgment, and fear because Aids is relatively new, and considered deadly. Responding to Aids with blame or abuse towards people living with Aids, simply forces the epidemic underground, creating the ideal conditions for HIV to spread. The only way of making progress against the epidemic is to replace shame with solidarity, and fear with hope.”(UNAIDS 2003:7)

This statement is very relevant in the fight against the spread of HIV pandemic. Without multi-sectoral approach to the fight against stigma and discrimination at all levels of life, communities are doomed to die in larger numbers than we are experiencing at the moment. We need to rally around those who are willing to come open about their HIV status. We must give hope to the people living with the virus. Encourage them to follow the doctor’s orders on the taking medicines (antiretroviral drugs. We must create a condition that is conducive for people to disclose their status without fear of being victimised.

Most of the people in Ivory Park and Tembisa choose seek health services from place such as Johannesburg and Pretoria where they are not known. One woman indicated that she is afraid to go the local clinic because she knew of the status of the other people who consulted at that clinic. So health workers disclose the status of their patients without the patient’s permission.

Those who consult at other places are those who can afford. The majority of the participants are poor hence they rather wait until their health deteriorates usually until when they are full blown aids, is then that they go the local health centre.

According to Merie van Oordt, a project manager at HIV and Aids initiative, “Only a few people come for testing because stigma is very high. Most people don’t know their status. They only come to the clinic when they are very sick”. Merie van Oordt further says, “when they finally come forward their CD4 count (which measures the strength of a person’s immune system) is very low. Their system is too weak for them to start ARV (antiretroviral) treatment. We have to treat the opportunistic infection first and can only start ARV later. But for many that’s too late”. (AllAfrica.com)

It a common practice that, they will be discriminated against and be rejected by the health workers. Many patients who qualify to be admitted at the hospitals are turned back to the care of their families. This research has established that patients receive harsh treatment from doctors and the nurses when they visit hospitals. One participant indicated the she was turned back by the nurses to the care of her family (UNAIDS, 2003).

Global survey conducted found that stigma and discrimination are rife in health care centers (UNAIDS, 2003). People suffer at the hands of health care workers. Lack of education around the virus transmission seems to be the contributory factor. Advocacy about the HIV and Aids should be conducted everywhere, in religious gatherings, schools funerals and in social gatherings.

Many people indicated that they face discrimination, commonly from within their families. People infected with HIV are regarded as immoral. They become isolated by the people, who should give them love, care and support. Survey has established that because of lack of knowledge about the disease, people living with HIV are seen as 'doomed' to die.

According to scholars, stigma is a result of factors such as ignorance, traditional beliefs, prejudice, absence of widespread treatment or a care, irresponsible of portrayal of the epidemic in the media, fears about death, and deep rooted taboos about sexuality, illness and drug use. All these can be defeated by proper legislation, education and support by teachers, leaders and family members.

To discriminate against people living with HIV or any speculation on people is a clear violation of human rights. The UN Commission on Human Rights clearly states that the term 'or other status' should be interpreted to cover health status in general and HIV and AIDS in particular.

Discrimination on the basis of HIV status actual or pressured is prohibited by the existing human rights standards 'In the case between Jacques Chart Hoffman vs. South African Airways, Justice Sandile Ngcobo stated at the end of proceedings, 'we must guard against allowing stereotyping and prejudice to creep in under the guise of commercial interests. The greater interests of society require the recognition of the inherent dignity of every human being and the elimination of all forms of discrimination our Constitution protects the weak, the marginalized, the socially outcast and the victims of the prejudice and stereotyping. It is only when groups are protected that we can be secured that our rights are protected. The court judgment was in favour of Hoffman.

1.11 Conclusion

It is therefore imperative for multiple interventions. Action should be taken both to prevent stigma and to challenge discrimination when it occurs. It is the duty of everyone, be it from political and social leaders to community members and celebrities, has a role to play in the fight against stigma and discrimination.

At least there is a sign of positive move towards the advocacy of human rights towards the stigma and discrimination of people living with HIV and Aids. Print and electronic media is playing a meaningful role in fight against stigma and discrimination. The social events such as Nelson Mandela 46664 Aids concert and a number music festival campaigning against stigma and discrimination leveled against people living with HIV and Aids.

People of high profile like Nelson Mandela, Mangosuthu Buthelezi, Bill Clinton and other political leaders are openly talking against the scourge HIV and Aids and against the stigma and discrimination against people infected and affected by the disease. That is a move in the positive direction.

Chapter 2 Literature Review

2. 1. Operational Definition of the Problem

The conceptual definitions below are meaning attached to the terms by the researcher for this study.

HIV refers to Human Immunodeficiency Virus. It is the virus that causes Aids. The virus is spread by contact with infected bodily fluids.

AIDS refers to Acquired Immune Deficiency Syndrome. The body loses its ability to fight infections. The virus called HIV weakens the immune system. It is diagnosed when a person infected with HIV becomes ill as results of infections.

STI: (Sexual Transmitted Infections). These infections passed from one person to another during sexual intercourse such as syphilis, gonorrhea and HIV.

2.1.1 What is HIV?

HIV refers to human immunodeficiency virus. A virus is a simple organism that requires living cell in which to multiply. The Latin word for virus is “poisonous fluid”, which is according to virologist. This virus only multiplies in the living human bodies. Through this “poison” the immune system of the body is destroyed. It weakens the immune system to be vulnerable to other opportunistic diseases such as TB, diarrhea, meningitis, pneumonia etc.

2. 1.2 How is HIV Transmitted?

HIV is commonly acquired through sexual contact i.e. through mucosal tissues of the genital tract. HIV can be transmitted through either heterosexual or homosexual contact. Using the same needle used by HIV infected person can also transmit it. Mothers can also transmit the virus during birth and through breast-feeding. There is no transmission through social contact.

HIV enters the body via CD4 receptor. HIV infects CD4 + T cells but it also infects other cells such as macrophages. It is generally accepted that a major role player in infection of CD4 + T cells is the dendrite cells. Continuation of stimulation of immune system, it eventually leads to immune exhaustion. The CD4 + T cells are quickly destroyed and cannot be replaced fast enough. The destructions of the immune response lead to opportunistic infections and ultimately death. The last stage is termed full blown aids or end-stage disease.

2. 1.3 Window Period

This is the period between initial infection with HIV and the production of antibodies. Usually it takes two weeks to 12 weeks

2. 1.4. Where does HIV come from?

In 1981 a new clinical syndrome was recorded in male homosexual in the USA and was termed acquired immunodeficiency syndrome (Aids). These patients suffered from a parasitic infection only found in server immune deficient people. The virus was isolated for the first at Pasteur institute in Paris in 1983 and was later called Human Immunodeficiency Virus. It is well known today that HIV was transmitted to human from Apes (non-human primates) through a zoonotic transmission. It should however be understood that non- human are not infected with HIV but SIV (Simian Immunodeficiency Virus). Phylogenetics analysis is regarded as to the key investigative tool the researcher has to apply in order to achieve “conclusive” results. Phylogenetics refers to the comparison of DNA sequences, or RNA in the case of HIV, among many different organisms. Phylogenetics analysis has established that HIV-1 and HIV-2 relate to different SIV’s and have different evolutionary origins. Research has established that hiv-2 has emerged from West Africa.

2. 1.5 The Symptoms and Diagnoses of HIV.

In 1986 the world Health organization (WHO) decided that there should be diagnostic HIV/AIDS record keeping. These should not however be judgmental but should be based on clinical diagnoses.

The symptoms and diagnoses are: Chronic Diarrhea for more than a month; Weight loss of 10% of body weight; Intermitted or constant fever for more than a year.

Minor signs are: Fever, Headache, Fatigue, Swollen Glands, Sore throat, Thrush, Generalized itchy skin rashes, night sweats.

Manifestation of acquired immunodeficiency opportunistic infections: Fungi, Bacteria parasites and viruses.

Unusual malignancies: Kaposi Sarcoma and certain types of lymphomas.

Autoimmune Disease: Occurrence of eczema skin rashes, arthritis, Kidney disease.

Constitutional symptom: Weigh loss, fever and diarrhea.

2. 1.6 Impact of HIV on Socio-Economic life of the infected persons.

Most of the infected people are breadwinners. They require support in order to endure the disease. Isolation and discrimination by employers, colleagues, family members and friends lead to a stressful condition, which ultimately develops into Aids, which is regarded as the end-stage. After being absent from work for more than required leave days, they are dismissed from work on incapacity leading them to cut expenditure in the house. Dependants like children drop out from better schools in order to live with pension their parents get. The future of the entire family is therefore affected.

Patients should however be motivated and supported throughout. HIV does not mean that you are on a death parole. HIV patients can be as productive as the negative infected people. It is informative patients to live a normal life: i.e. eating balance food, abstaining from alcohol, drugs, smoking and unprotected sex.

2. 1.7 Anti- Retroviral Therapy (Art)

Anti Retroviral Therapy refers to drugs used in the treatment of HIV (which belongs to the family of retroviruses)

2. 1.8 Different classes of drugs

Reverse transcriptase inhibitors: Two different kinds exist i.e. Nucleoside/nucleotide reverse transcriptase inhibitors (NRTI'S)

Different types of Art:

NRTI's: Zidovudine (AZT) stavudine.

d4T: Didanosine (ddI) Abcavir, Tenofovir

NRTI'S: Nevirapine and Efavirenz

Protease inhibitors (PI's): Indinavir, Nelfinavir, Ritonavir Saquinavir

Anti Retroviral drugs are more effective in combination than singularly. In MTCT a singular therapy is used to cut cost. Anti retroviral is more of prevention or therapeutic than cure. The highly active antiretroviral therapy (HAART) and usually effective if consisted of 2 NRTI's with PI or 2 NRTI's with NNRTI's. Zivodine and stavudine should never be used together. Clinical and laboratory criteria are used to decide on the starting time.

2.1.9 The Symptoms and diagnosis are:-

The Chronic Diarrhea for more than a month.

Weight loss of 10% of body weight.

Intermittent or constant fever for more than a year.

Minor signs are: fever, headache, fatigue, swollen glands, sore throat, thrush, generalized itchy skin, rashes, night sweats.

Manifestation of acquired immunodeficiency, opportunistic infections:

Fungi, bacteria, parasites and viruses.

Unusual malignancies: Kaposi sarcoma and certain types of lymphomas.

Autoimmune diseases:

Occurrence of eczema skin rashes, arthritis, kidney diseases.

Continual symptoms:

Weight loss, fever and diarrhea.

Universal precautionary measures by health workers and the community

Universal precautions include:

Careful handling and disposal of 'sharps' (items that could cause cuts or puncture wounds, including needles, hypodermic needles, scalpel and other blades, knives, infusion sets saws, broken glass and nails

Hand washing with soap before and after all procedures

Use protective barriers such as gloves and masks when in direct contact with blood and other fluids

Safe disposal of wastes contaminated with blood or body fluids
Disinfections of instruments and other contaminated equipments
Proper handling of bedding and clothing stained with blood, diarrhea or other body fluids

NB: Antiretroviral drugs can be prescribed within 72 hours of exposure potentially HIV infected blood or body fluids to prevent HIV sero-conversion. This is called 'post exposure prophylaxis HIV infection (HIV-PEP). It should be noted that HIV-PEP is not 100% safe, so one should always take prevention measures to avoid HIV transmission.

2.1.10 Factors that influence the spread of HIV and Aids

The spread of HIV and Aids may be influenced by many factors such as poverty, illiteracy, and social status of women in the society. There are however two significant factors that has been critical to the spread of the disease. These factors are a. Ignorance and denial, b. increase in mobility and industrialization.

2.1.10.1 Ignorance and denial

Many people, particularly in the third world, that is developing countries, there is a lot of misinformation about the nature of HIV and Aids and have little access to available preventative measures. Illiteracy and misinformation lead to people being misled in the causes

2.1.10.2 Increase of mobility and industrialization

A significant growth of international trade and travel play a significant role in spread of the disease. Had it not of transportation industry the spread would not be moving at a rate it is at the moment.

Increase in migration and in travelling industry; have made more people vulnerable to the HIV and Aids. The most affected is the transport industry where people move from one to the other mostly truck drivers. Industries such as mines, oilfields and roads and dams projects attract more young people from around informal settlement, who are mostly living in abject poverty. The majority of children in were born from people working the building industry in Olifantsfontein, Midrand (Gauteng Province) industrial area. Most of the young girls engaged in sex work industry, selling sex to the migrant labourers around such industries. (UNAIDS, 2000).

2.2 Review on the impact of Aids.

It is reported that more than 25 million men, women and children have died from AIDS. AIDS now kills more people worldwide than any other infectious diseases. It is further reported that more than 48 million people are living with HIV.

South African Department of Health estimated that 18.3% of adults (15-49) were living with HIV in 2006 (Department of Health South Africa, 2007). The provinces with highest number of infection are Kwazulu-Natal and Gauteng (55%) (Dorrington et al., 2006).

According to the global report South Africa has the fifth highest prevalence of HIV in the world. According to this report, 21, 5% of population of South Africa was estimated to be the highest infected by the pandemic. In 2003 it was estimated that the number of Aids related deaths in South Africa ranged anywhere between 270 000 and 520 000. South African data suggests that the epidemic might be stabilizing but there no clear evidence to relate major changes in HIV related behaviour. It is estimated that 5, 7 million was living with HIV in 2007. This leaves South Africa being regarded as having the most severe HIV epidemic in the world (Statistics South Africa, 2007)

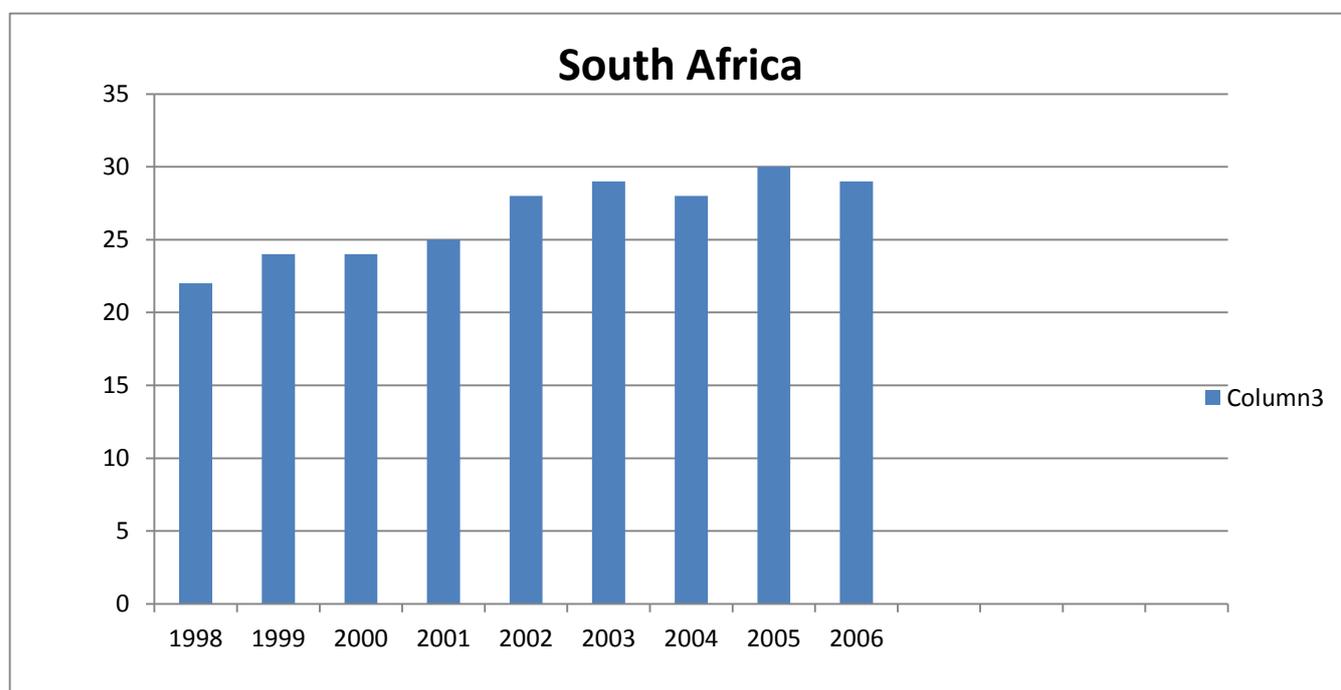


Figure 2.1 Median HIV prevalence among women (15-49 years) attending antenatal clinics in Consistent sites in South Africa, 1998-2006

Source: Various antenatal clinic surveys

The latest HIV data collection at antenatal clinics suggest that, HIV infection might be at level with its prevalence in pregnant women, i.e., 30% in 2005 and 29% in 2006 (Department of Health South Africa, 2007). It is also reported that there is a decline in

the percentage of young pregnant women (15-24). This also suggests the decline in the number of new infections

It is also imperative to note the prevalence of HIV prevalence in pregnant women per province. HIV prevalence among women is high in Kwazulu-Natal with (39%), the lowest being Northern Cape (15%), Western Cape (16%) and Limpopo (19%). The other five provinces (Eastern Cape, Free State, Gauteng, Mpumalanga and North West) have at least (25%)

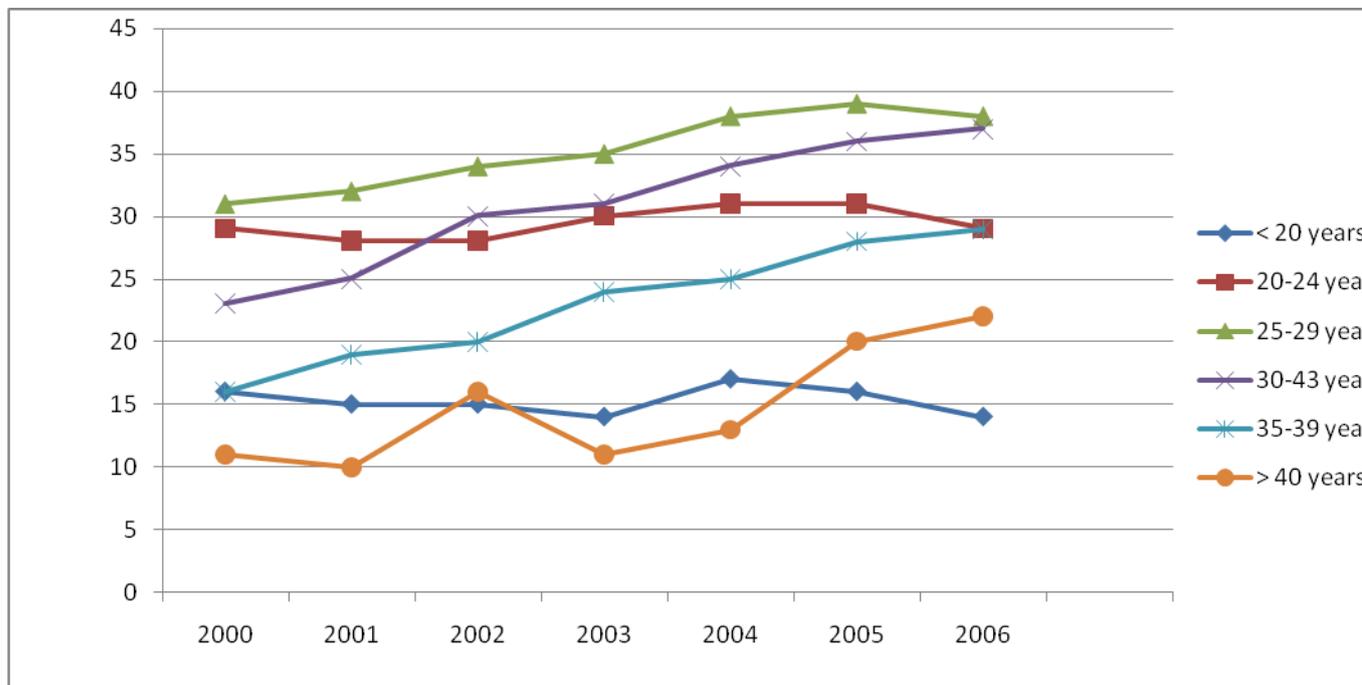


Figure 2.2 HIV prevalence by age group among antenatal clinic attendees in South Africa, 2000-2006

Source: Department of Health, South Africa, 2000-2006

Given the fact that this epidemic is still at early stages, the projected number of deaths is shocking. On the current trends, and in the absence of effective ARV programmes, it is estimated that two thirds of the 15 year- olds could be infected with HIV by the time they reach their 35th birthday (Barnighausen et al, 2007). Nearly all will die from Aids-related complication within the next decade. According to the report from Bangkok where world Aids Conference 2004 was held, about 700 000 infants worldwide are infected with HIV each year, either in the womb or through breast-feeding. Many of these pregnant women are from poor countries.

They do not know if they are infected with HIV and unwittingly transmit the virus to their newborn. (Sowetan, Tuesday 13, 2004). With the government of South Africa intending to de-administer and dump nevirapine without any alternative, there will be a disaster.

It is reported that young women in South Africa face greater risk of becoming infected than men. Indeed among 15-24 year olds women account 90% of New HIV infection (Rehle et al, 2007). HIV incidence among 20-29 year old women in 2005 was approximately 5,6% more than six times higher than for men of the same ages their (0,9%)(Rehle et al, 2007).

It is however reported high HIV incidence is being found also in men towards the upper end of this age group. The report indicated 8, 8% of men aged between 24-29 years had been infected in 2005(Barnighausen et al, 2007).

The total annual deaths from all causes have increased by eighty seven percent from (316 505 to 591 213) (Statistics South Africa, 2005 &2006) with at least forty percent of those deaths estimated to have been Aids related (Bradshaw et al, 2004, Medical Research Council 2005, Anderson and Philip, 2006).

The life expectancy is lower from birth to forty nine years to men and 52, 5 year for females I
0104n 2006 and have probably contribution to the decline from one, twenty five percent04 in 2001-2002 to slightly more than one percent in 2005-2006(Statistics South Africa, 2007).

2.3 South African HIV and Aids statistics

The following HIV and Aids statistics is extracted from Avert.org.com. The main objective is to have a review on the recent statistics of HIV and Aids in South Africa. This is also correlating with this research project that seeks to establish the reason why people attribute death by Aids to other diseases. This report will also be collaborating with other sources of similar approach.

According to the Avert. Org the statistics discussed here come from two prevalence studies that estimate how many people are living with living with HIV in South Africa, and two reports on Aids deaths. Viewed together these sources give an idea of the scale of South Africa's HIV epidemic.

The first section is based on the report of the Department of Health National HIV and Syphilis Sero-prevalence Survey in South Africa 2007, published in 2008. This annual study looks at data from antenatal clinics and uses it to estimate HIV prevalence amongst pregnant women.

The second section is based on the report of the South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey, 2008. In this survey, samples of people were chosen to represent the general population. Of those who were eligible, 64% agreed to give a blood sample to be anonymously tested for HIV. The report contains estimates of HIV prevalence in various groups of people, derived from this general population sample.

The third section looks at AIDS-related deaths using data from death certificates. Reports published by Statistics South Africa contain the raw data, while the article Identifying deaths from AIDS in South Africa analyses a large sample of death

certificates and attempts to estimate how many deaths caused by HIV have been misclassified.

2.4 The South African Department of Health Study, 2007

Based on its sample of 33,488 women attending 1,415 antenatal clinics across all nine provinces, the South African Department of Health Study estimates that 28% of pregnant women were living with HIV in 2007. The provinces that recorded the highest HIV rates were KwaZulu-Natal, Mpumalanga and Free State. The Northern Cape and Western Cape recorded the lowest prevalence.

Until 1998 South Africa had one of the fastest expanding epidemics in the world. The HIV prevalence situation now, appears to have stabilized, and may even be declining slightly, that's according to the recent estimates. Among teenage girls, the rate fell from 16.1% in 2004 to 12.9% in 2007, possibly indicating a drop in the rate of new infections. The health department believes this is due to a change in safer sexual practices among younger women. The inability to moderate cultural circumstances is believed to be a factor in the high and rising HIV prevalence among relatively older women.

Province	2001 prevalence %	2002 prevalence %	2003 prevalence %	2004 prevalence %	2005 prevalence %	2006 prevalence %	2007 prevalence %
KwaZulu-Natal	33.5	36.5	37.5	40.7	39.1	39.1	37.4
Mpumalanga	29.2	28.6	32.6	30.8	34.8	32.1	32.0
Free State	30.1	28.8	30.1	29.5	30.3	31.1	33.5
Gauteng	29.8	31.6	29.6	33.1	32.4	30.8	30.3
North West	25.2	26.2	29.9	26.7	31.8	29.0	29.0
Eastern Cape	21.7	23.6	27.1	28.0	29.5	28.6	26.0
Limpopo	14.5	15.6	17.5	19.3	21.5	20.6	18.5
Northern Cape	15.9	15.1	16.7	17.6	18.5	15.6	16.1
Western Cape	8.6	12.4	13.1	15.4	15.7	15.1	12.6
National	24.8	26.5	27.9	29.5	30.2	29.1	28.0

Figure 2.3 Estimated HIV prevalence among antenatal clinic attendees, by province

Age group	2001 prevalence %	2002 prevalence %	2003 prevalence %	2004 prevalence %	2005 prevalence %	2006 prevalence %	2007 prevalence %
<20	15.4	14.8	15.8	16.1	15.9	13.7	12.9
20-24	28.4	29.1	30.3	30.8	30.6	28.0	28.1
25-29	31.4	34.5	35.4	38.5	39.5	38.7	37.9
30-34	25.6	29.5	30.9	34.4	36.4	37.0	40.2
35-39	19.3	19.8	23.4	24.5	28.0	29.6	33.2
40+	9.8	17.2	15.8	17.5	19.8	21.3	21.5

Figure 2.4 Estimated HIV prevalence among antenatal clinic attendees, by age

2.5 The South African National HIV Survey, 2008

The National HIV Survey is a household survey. This involves sampling a proportional cross-section of society, including a large number of people from each geographical, racial and other social group. The researchers take great pains to try to make the sample as representative as possible, and the findings are later adjusted to correct for likely over- or under-representation of individual groups (according to census data). The surveys fieldworkers visited 15,000 households across South Africa, of which 13,440 (90%) took part in the survey. Of the 23,369 people within these households who were eligible to take part, 20,826 (89%) completed an interview and 15,851 (64%) agreed to take an HIV test.

Based on this survey, the researchers estimate that 10.9% of all South Africans over 2 years old were living with HIV in 2008. In 2002 and 2005, this figure was 11.4% and 10.8%, respectively, showing a degree of stabilisation. Among those between 15 and 49 years old, the estimated HIV prevalence was 16.9% in 2008. The survey found the prevalence among children aged 2-14 to be 2.5%, down significantly since 2002, when prevalence was 5.6%.

Age	2002	2005	2008
Children (2-14 years)	5.6	3.3	2.5
Youth (15-24 years)	9.3	10.3	8.7
Adults (25 and older)	15.5	15.6	16.8
15-49 year olds	15.6	16.92	16.9
Total (2 and older)	11.4	10.8	10.9

Figure 2.5: Estimated HIV prevalence (%) among South Africans aged 2 years and older, by age, 2002-2008

Age	Male prevalence %	Female prevalence %
2-14	3.0	2.0
15-19	2.5	6.7
20-24	5.1	21.1
25-29	15.7	32.7
30-34	25.8	29.1
35-39	18.5	24.8
40-44	19.2	16.3
45-49	6.4	14.1
50-54	10.4	10.2
55-59	6.2	7.7
60+	3.5	1.8
Total	7.9	13.6

Figure 2.6: Estimated HIV prevalence among South Africans, by age and sex, 2008

Among females, HIV prevalence is highest in those between 25 and 29 years old; among males, the peak is in the group aged 30-34 years.

Year of death	Age (years)					Total
	0-9	10-24	25-49	50+	Unspecified	
1997	35,441	22,639	92,829	160,076	5,574	316,559
1998	41,172	25,808	114,249	178,776	5,104	365,109
1999	41,835	27,690	129,916	178,892	2,704	381,037
2000	42,843	29,583	150,562	189,566	2,214	414,768
2001	44,902	31,452	173,226	202,009	1,920	453,509
2002	50,767	34,439	201,153	211,693	1,928	500,082
2003	56,708	37,499	229,418	227,778	2,796	554,199
2004	62,898	38,405	244,129	224,115	3,073	572,620
2005	67,715	38,389	250,897	233,101	3,235	593,337
2006	68,292	39,003	251,067	245,963	1,155	605,480
Increase 1997-2006	93%	72%	170%	54%	-79%	91%

Figure 2.7: Reported deaths from all causes, 1997 to 2006

The influence of population growth can be removed by looking at death rates per 100,000 people, which are provided by Statistics South Africa in another report called Adult mortality (age 15-64) based on death notification data in South Africa: 1997-2004.

These data show that between 1997 and 2004, the death rate among men aged 30-39 more than doubled, while that among women aged 25-34 more than quadrupled. The changes are even more pronounced when deaths from natural causes only are examined. Over the same period there was relatively little change in the death rates among people aged over 55 and those aged 15-20. In their report, Statistics South Africa calls such developments astounding, alarming and disturbing.

2.6.1 HIV and Aids Estimates in South Africa

Underestimation and overestimation of numbers confuse the whole system of reporting on the people living with the virus and those who died from Aids and Aids related illnesses. It is of no good for officials to report on the stability of the prevalence while people are infected every day.

In 2006, the HIV record shows the cause of death in only 14,783 cases. This record is on the national health study. The researchers from the Medical Research Council of South Africa (MRC) gave a different view, which according to them, the figure is a “massive underestimate”, because the majority of deaths due to HIV are misclassified. (www.avert.com)

This project has throughout shared sentiments that virus alone does not kill people whose deaths are caused by HIV, but HIV should be recorded as an underlying cause of death. “In other words, if someone contracts tuberculosis and dies from it is because HIV has weakened their immune system then HIV should be included among the underlying causes,” MRC researchers claim.

According to the MRC researchers doctors only record the immediate cause of death such as tuberculosis or respiratory infection. This could be primarily because the doctor does not know the deceased persons HIV status. In trying to appease both parties, they may seek to conceal HIV infection to protect relatives from stigmatisation or to avoid invalidating life insurance claims. As The Lancet notes, authorities are largely to blame:

“Social stigma associated with HIV/AIDS, tacitly perpetuated by the Governments reluctance to bring the crisis into the open and face it head on, prevents many from speaking out about the causes of illness and deaths of loved ones and leads doctors to record uncontroversial diagnoses on death certificates.... The South African Government needs to stop being defensive and show backbone and courage to acknowledge and seriously tackle the HIV/AIDS crisis of its people.” (www.avert.com)

The MRC team analysed a 12% sample of death certificate data from the year 2000-2001, and compared it to all the data from 1996. When they looked at deaths for which HIV was a reported cause, they discovered that rates (deaths per thousand) had increased according to a distinctive age-specific pattern. The greatest increases were

in the age groups 0-4 and 25-49 years, while death rates among teenagers and older people remained more or less unchanged.

They then estimated how much of the increases were likely to be caused by HIV, and concluded that: '61% of deaths related to HIV had been wrongly attributed to other causes in 2000-2001'. (Medical Research Council report: 2002)

Medical Research Council claim: 'in adults, tuberculosis accounted for 43% of misclassified deaths, and lower respiratory infections for another 32%. Among infants, most of the excess deaths had been misclassified as lower respiratory diseases or diarrhoeal diseases. According to the MRC results, HIV caused the deaths of 53,185 men aged 15-59 years, 59,445 women aged 15-59 years, and 40,727 children under 5 years old in the year 2000-2001'.

According to the researchers at Avert.com, the MRC estimates nearly similar to those made by a computer model of the Actuarial Society of South Africa, called ASSA2003. According to ASSA2003 calculations, HIV caused 108,170 deaths in 2000 and 147,525 deaths in 2001.

This project concurs with Statistics South Africa accepting MRC study and agreeing that its methods and conclusions are generally acceptable.

2.6.2 Recent HIV and Aids estimates

It is imperative to take note of the variation in estimates from different spheres of study: "The head of the MRC has stated that AIDS killed around 336,000 South Africans between mid-2005 and mid-2006".

"The ASSA2003 provincial model calculates that 345,640 people died because of AIDS in 2006 - comprising 47% of all deaths. Among adults aged 15-49 years, it estimates that 71% of all deaths were due to AIDS".

"UNAIDS/WHO estimate that AIDS claimed 350,000 lives in 2007 - nearly 1,000 every day". (www.Avert.com).

2.7 Comparing the prevalence studies

Comparing the two studies, National HIV Survey 2008 and Department of Health Study 2005 according to recent estimates makes it possible to get probable results

HIV prevalence according to the Department of Health Study 2005:

29.1-31.2% amongst antenatal clinic attendees (30.2% is the best estimate).

HIV prevalence according to the National HIV Survey 2008:

10.0-11.9% in the whole population (10.9% is the best estimate).

15.5-18.4% amongst all people aged 15-49 years old (16.9% is the best estimate).

2.8 National HIV and AIDS estimates

The following estimates are wakening up estimate and debatable issues in dealing with HIV and Aids prevalence. Though there are slightly similarities in their estimates, the fact remains the fraction implies that a large number of people are infected by the virus and ultimately died from Aids related illnesses.

‘Based on a wide range of data, including the household and antenatal studies, UNAIDS/WHO in July 2008 published an estimate of 18.1% prevalence in those aged 15-49 years old at the end of 2007. The UNAIDS/WHO high and low estimates are 15.4% and 20.9% respectively. According to their own estimate of total population (which is another contentious issue), this implies that around 5.7 million South Africans were living with HIV at the end of 2007, including 280,000 children under 15 years old.

The ASSA2003 model produces a similar estimate of 5.4 million people living with HIV in mid-2006, or around 11% of the total population. It predicts that the number will exceed 6 million by 2015, by which time around 5.4 million South Africans will have died of AIDS’. www.avert.com

2.9 Conclusion

We can try by all possible means to write about the stability of prevalence and the reduction in number of death case but fact remains the same people are dying in numbers. One death is death too many. It must ring in our minds that though women are the most infected than men, the disease affects all people from the population spectrum. Concealing numbers in prevalence and mortality rate is too risky to human population. The fact of the matter is adult, youths and children are dying in large numbers.

2.10 Attitude of the community towards stigmatization and discrimination

It was imperative for this research to look into the attitude of the community towards the stigmatization and discrimination for those infected and affected by the HIV disease. Negative attitude towards those infected does not help in the fight against the spread of HIV and Aids at all.

Different people define attitude differently. The Oxford Advanced learners’ Dictionary of current English (2005) defines attitude as ‘the way that you think and feel about something or somebody: the way that you behave towards somebody or something shows how you think or feel’ this definition focuses on how people feel and behave in a certain way displaying their belief and feelings.

Webster’s New Collegial Dictionary (1975) asserts the importance of belief and as an integral part of attitude. The definition defines the feeling of an individual that are stimulated by something which in turn determines the behaviour of an individual.

Oxford Primary Dictionary (2006) defines attitude as the way you think or feel about something and the way you behave.

Attitude can be both positive and negative. The Concise Oxford Dictionary (1976) defines positive as 'convinced, confident in opinion, constructive'. The Free Dictionary defines positive attitude as 'characterized by or displaying affirmation or acceptance or certainty etc a positive attitude'

The Collins Concise Dictionary and thesaurus (1992) gives a definition as well as an alternative of meaning in the thesaurus. The word positive is defined as 'certain, sure, definite, unquestionable, confident, not negative'.

The alternative meanings of positive are given as 'beneficial, effective, useful, practical, resourceful, progressive, productive, worthwhile, and constructive'. This study will follow the positive attitude approach that comes up with a constructive and effective way of dealing with stigmatization and discrimination in the progressive manner which will be beneficial to those living with virus.

These definitions show how positive attitude approach is required in the lives of all people not only the respondents or research participants but also everyone globally.

In order to prevent new infections to prevail we need to support those who are infected so that they don't go about infecting others in fear of being discriminated and isolated. If more people disclose their HIV status then fight against new infections will be actualised and be a success.

There are misconceptions about the transmission of the virus by sharing of food, cup, clothes, kissing and mosquito bite and as well as non-transmission through a single unprotected sexual encounter and sex with healthy-looking partner. These erroneous beliefs lead to people not only mocking those infected, but to fail to take necessary precautions to protect themselves, unwittingly contributing to the spread of the disease. (UNAIDS 2000: 10)

According to Merie van Oordt, a project manager of HIV and Aids initiative, South Africa faces a bleak future because of people who are in either ignorant or in denial. Van Oordt further says, "We still get people who don't know what HIV is and who believe it does not affect them. They are in denial and they don't want to know".

Chapter 3. Data Collection

It must be stated that using human as participants involves much more procedures than animals. In human, the researcher relies on the willingness and permission by the participant to participate in the project. The researcher should be sensitive and be in control all the time.

The researcher's confidence in the results can be enhanced when different methods of data collection yield the same results. Reliability of the study is also strengthened.

3.1. Research Participants

The research participants were selected by identifying learners without both parents. The second criteria were with learners staying with grandparents, this is precisely important because, the researcher needs to be sensitive all the time. Some of the children do not want it to be known that their parents have passed away. Some do not even know that they do not have parents. The third criterion was to get those staying with either mother or father (single parents). The fourth criterion was to interview all the children who are on the Food Nutrition Project of the school. Lastly, interview was conducted on some young parents, mostly those with children in grades 1 and 7 since most of them are still young mothers.

Parents and guardians were invited to the school. It was however difficult because parents mostly black parents do not co-operate when they are invited to schools. The letter was user friendly and the language used was persuasive to encourage them to come to the school.

The researcher used one to one interview with open questions. The aim is for the respondents to express themselves freely and open-up on their experience. Flick (1998:199) states, "In qualitative interviews, open-ended questions are asked which encourages the respondents to say more than less. Silverman (1993) differentiates between different types of interviews with different aims. He suggests that the survey interview used in small sample is investigated to find a description in survey format and where the researcher wants to participants not to be limited by item pre-designed in survey questionnaires.

An interview guide was used to direct my questions during the interview. Participants were given approximately 15 minutes. The interviews were held at the school. The participants were assured that the information collected will not be exposed and their identity will be protected and their rights will be respected. Appointments were made well in advance in order to avoid disappointments.

The data collected during interviews and observation was supplemented by data obtained from other sources related to the same problem. These sources were literature on the problem under investigation. Probing was used as a technique during interviews to make it more effective.

The other method used was a “covert” observation. Participants were not to be informed about being observed. The school was also organized HIV and Aids awareness day where all parents of learners and community members were invited.

3.2 Research Design.

The study is a qualitative survey, which was conducted over sometime. In order to collect data, the school organized HIV and Aids awareness campaign against the spread of HIV and Aids. Invited guests included medical doctors and tradition healers, PLWHA, social Workers, parents and members of the community.

3.3 Target Population

The largest groups are young parents and family members of children attending school at Mvelaphanda Primary School. Participants were selected from the learners orphaned by Aids related disease. It was also from the list of learners on the nutrition project. Data collected will help draw conclusions about the perception on the death by HIV and Aids by the communities. Because of fear of stigma and discrimination family members and the community attribute death by Aids to “witchcraft”. Most of these people still belong to the old school of thought that sex and sexual matters cannot be discussed with minors.

3.4. Sampling criteria

According to (Polit and Hungler, (1999), the researcher should be specific about the criteria to be applied in sampling of participants. In this study the selection was based on the parents of learners at Mvelaphanda Primary, Grade 7 learners and Learners who are on the Nutrition Programme of the school, mostly orphaned by Aids related diseases.

3.4.1 Sampling criteria for parents

The participant had to be a parent of the child at Mvelaphanda Primary School and was once a learner at the same school. The respondents were provided with a consent form, which also clarifies the intention for the research. Participants had to be willing to share his or her views with the researcher.

3.4.2 Sampling of Grade seven learners

The learners had to be a Grade seven learner at primary school. This is because Grade seven learners may be able to share their experiences at ease than learners in lower grade. Consent form was sent to parents and the school governing body to allow children to participate in the study. In acceptance they had to sign the consent forms.

3.4.3, Sampling of learners on School Nutrition Programme.

The participant had to be a learner at Mvelaphanda primary school and on school Nutrition Programme. The learner had to be willing to participate and to share their experiences. Permission was sort from the parents or guardians of the children. The School Governing Body had to grant permission for the interview to conduct on the

learners. Consent for the children to participate was first discussed with children themselves. In granting permission parents or guardians had to sign consent forms.

3.5 Data collection process

According to (Burns and Grove, 2001), data collection is a process of selecting and gathering data from the respondents.

3.5.1 Method applied in data collection

The researcher applied three methods of data collection, namely Questionnaire, observation and discussions in focus group. Data was collected from the parents and learners at Mvelaphanda Primary School in Tembisa, Gauteng Province.

3.5.1 Questionnaire

A questionnaire was drafted by the researcher with intention of gathering relevant information related to the problem being probed. According to (Leedy, 1993), questionnaire is used as a reliable and flexible tool that ensures objectivity. The method of data collection allows the respondent to answer questions without any prejudice. The questionnaire was sent to the parents together with the consent form and the letter detailing the purpose of the research. The respondents gave reliable and valid information for this study. Even though there was no hundred percent return of the questionnaire, it was easy to administer. Completed questionnaire were thoroughly analysed and grouped according to the responses.

3.5.2 Observation

The school organised an Aids Day event, whereby Aids activists, a medical doctor and traditional healers presented HIV and Aids issues. The researcher gathered information through observation of the proceedings at the event. Speaker after speaker alluded to stigma and discrimination against people living with HIV and Aids. The researcher further got in-depth information through interviewing some of the parents who attended that event. People who attended the event were encouraged to disclose their status without fear of discrimination or rejection.

3.5.3. Discussion with the focus group.

According to Johnson & Christensen, (2000), a focus group is described as a type of group interview in which the researcher leads a discussion with small groups of individuals to examine in detail how the group members think and feel about the research topic. Two focus groups were involved in group interview in which the researcher leads discussion with small groups of Grade seven learners and the earners on the Nutrition Programme of the school. Grade 7 learners were selected to investigate the level of education with regard to HIV and Aids. Learners on Nutrition programme were selected to investigate the situation at home because some of them come from child headed families and some are orphans themselves. The researcher wanted to investigate how they are coping under the circumstance. The learners were open to share their feeling and experience without any reservation.

3.5.4 Validity and reliability of the findings

According to (Gorg & Gall, 1989), validity refers to the extent that the study measures what it claims to measure. The researcher discovered that learners were more freely to talk than the parents interviewed. The reason for this might be because the researcher was a teacher at the same institution where research was conducted. Learners were sometimes hesitant when responding to the question posed within the focus group, while parents though reserved would share experience and answer questions accurately. The researcher was always in charge of the process and guarding participant not to lose focus. The internal validity was reliable it was conducted from within the school. The learners displayed knowledge of care and support for those living with HIV and Aids.

3.4 Factorial design in independent variables and dependent variables.

The expected results can be realized in factorial design. Factorial design refers to when two or more independent variables are simultaneously analysed to determine their independent and interactive effect on the dependant variable. In factorial design a researcher could test a number of hypotheses and this helps the researcher to maneuver on other hypothetical variables.

Chapter 4: Results

4.1 Introduction

The raw data collected during interview and observation was transcribed and the systematically coded. According to Straws and Corbin (Flick, 1998) coding means representing the operations by which data are broken down, conceptualized and put back together in a new ways. Open coding may be done in three ways: by analyzing the first interview and observation line-by-line or coding by sentence or paragraph. It means that one summarises and labels small sets of information in the study. Research methods belong to the interpretive paradigm. The assembling of all data materials is called axial coding in a ground theory methodology (Flick 1998). The presentation of data collected was done in tables and matrixes in order to display the data at glance.

4.2 Interpretations of Data

Most often researchers believe that once they have presented facts and figures they believe that they have accomplished all what needs to be done. Displaying of data is important but the interpretation of data gives essence of the research. Paul D Leedy and Jeanne Ellis Ormrod put it clear when they say “without the inquiring into the intrinsic meaning of the data, no resolution of the research problem or its sub-problem is possible (Leedy and Ormrod, 2005).

Interpretation makes the data speak for themselves. The researcher becomes the only the mouthpiece. (Leedy and Ormrod, 2005) further indicate that data collected may not conform to the researchers’ conviction or support the researcher’s preconceived opinion, but the researcher becomes the servant of the scientific method. The method looks at evidence squarely and without prejudice, it reports candidly and precisely what the impersonal data affirm.

When data is interpreted correctly then the researcher can be clearly defend his findings. Defend in this sense means “to justify one’s conclusions, to support one’s statement with the backing of the solid data that have been presented in the document.

4.2.1 Interpretation of the interview conducted on parents.

Question1. How old are you?

The researcher wanted to establish the age range of the respondents. Ninety percent interviewed were less than thirty years of age. Five percent were older than forty years. This research was based on parents of learners who are in Grade one and Grade seven

Question 2: Who is the breadwinner in your family?

This was meant to establish who the main source of support in the family is. Fifty percent were found to be still staying with their parents, so their parents supported these young parents. Thirty five percent were unmarried single parents but staying with their children in the informal settlement. Ten percent were unmarried single mothers staying with their grannies. Five percent were married staying with their husbands in Tembisa and also in informal settlement of Ivory Park, Winnie Mandela Park and Vusimuzi.

Question 3: What is the highest grade you passed?

This was mainly to establish the level of education of the respondent. Twenty percent of them passed grade twelve. Fifteen percent dropped-out in grade eleven when they got their children. Thirty five percent dropped-out in grade nine. Twenty five percent of the respondents are dropped-out in their first year at the secondary school. This is mainly because of the beginning of adolescent stage of these young parents. Five percent are dropped-out in Primary school due to poverty that struck the family. The researcher wanted to probe the level of education of the respondents because studies have established that those who are less education are likely to be infected by HIV and Aids.

Question 4: how old is your first-born child and how old were you when you got this child?

90% of the respondents got their first-born children when they were still teenagers. 10% got their children when they were older than 20 years old. All the respondents indicated that they were not ready to get children when they became pregnant. In simple terms they said that it was a mistake. This implies that they did not use protection when they engaged in sexual intercourse with their partners. That made them vulnerable for HIV infection and other STI (sexual transmitted infection) such as gonorrhoea and syphilis.

Question 5: What is HIV and Aids?

The respondents have a clear knowledge about the disease. This indicate that HIV and Aids education campaign was a success beside the ignorance of practicing safe sex strategy like the use of condoms during sex.

Question 6: How does HIV infect a person?

The respondents showed to have clear knowledge of how people get infected. They indicated that it through unprotected sex with the HIV infected person. They also know the other prevention strategy such as not using the same needles, razor blades, not sharing the same toothbrush and not in contact with blood without plastic gloves.

Question7: When last did you experience death in your family?

This was to establish whether the respondents experienced death in the families recently. Ninety five percent were reluctant to give respond to this question. Only a few were ready to indicate that they lost their siblings recently.

Talking about death among the Africans particularly in black Africans is very difficult.

Question 8: What was the cause of death?

The majority of the respondents were quick to say it was through natural death. Some indicated that they don't know, but it was said to pneumonia or TB or diabetic. Some alluded to witchcraft as the cause of death. It was established that the respondents would not share the cause of death of their family members freely and openly.

Question 9. How can we know whether we are infected with HIV or not?

It is only through taking voluntary testing that we can find out about our status; all the respondents gave that answer. The motive was to know if they know all about voluntary testing and counseling that is available in all public health institution free of charge.

Question 10. Do you of any family member who died of Aids? If yes how did you know it was Aids?

It was difficult to the respondents to come open on the cause of death of their family members. Only five respondents said yes and went further to say the doctor informed them some said they where told by the diseased before they died. As they were responding one respondent changed her face said 'no, no one died of Aids in our family'. The researcher could notice fear on the eyes of the respondents when this question was posed. This is precisely because of stigmatization around HIV and Aids pandemic.

Question 11. Personally would you encourage your family member to disclose their status?

Even though the majority said yes one could notice that they do not mean it.

Question12. What might be the reason why people don't want to disclose their HIV status?

The majority indicated that they fear that once they have disclosed they will not get the support they expect from their loved ones. They fear for isolation and rejection. Some went extend of saying their children will be discriminated by other children, teachers and the community at large.

4.3 Expected Results

The research deduced that there is fear among people to disclose their HIV status precisely because they are afraid of being discriminated against by relatives, family members and communities in their neighborhood. They also fear that their children might be discriminated by teachers and other children at school. It is out of this research that the researcher discovered that community member might forgive a criminal than a person died by Aids. They believe that people die as a result of bad behavior and any member attached to the person diseased of Aids will always be reminded of the “bad omen” that struck the family.

One other confusing but conflicting results is brought by the American descendents who refute the fact that HIV causes Aids. These decedents confuse more people by stating that HIV does not come through sex. They claim that the virus is harmless. They further mislead people by saying that people die by toxic antiviral drugs. Dr Heinz Ludwig Sanger, Emeritus Professor of Molecular Biology and Virology, Max-Planek-Institutes for Biochemistry, Munchen alluded to the point that the time has come to evaluate the HIV-AIDS hypothesis: IS HIV really the cause of AIDS? (www.virusmyths.org).

All these perception contribute more into people attributing death by Aids- related disease as caused by witchcraft, cancer, malaria, pneumonia or ulcer. The other confusing statement is the made by the Jacob Zuma, then deputy president of the ANC, who on his rape trial indicated that after having unprotected sex with HIV positive woman, he reduced the risk of infection by taking “shower”. This statement confuses our youths and the country as a whole more especially if it comes from a political figure of Zuma’s caliber.

4.4 Manipulation of independent variables to bring about expected results.

Research questions were biased in bringing up the expected results. Participants where channeled into producing the expected results. Such biases were not meant to change the attitude of the participants but make them to open up and be ready to share their experience. Out of this research, there is a great challenge for the researchers to explore the environment where people are encouraged to take voluntary testing to test their HIV status. The faster one tests the better one manages his or her life. There was a visit to the Hospice and hospitals organized in order for the researcher to have first hand information on HIV infected persons and the conditions they live in. A person living with HIV and Aids and prominent leaders within community addressed mass meetings on awareness campaign against HIV and Aids.

Chapter 5. Conclusion and Recommendations

5.1 Conclusions

The time has come that HIV and Aids should not be a traditional taboo. Referring to HIV and Aids as taboo, is suicidal to communities. Once it is treated as such communities will never experience any reduction on the number of new infections and therefore many people will die than ever before. While people think they are protecting their families of any embarrassment and stigma that HIV and Aids carries, their actions have impact on their children and other family members. Because these children might grow in fear of being bewitched, they will always be engulfed in the fact they will die just like their parents.

It is for this reason that those who credit Aids- related illness to bewitchment mostly traditional healers and prophets, be trained as counselors and be provided with information regarding HIV and Aids. Most black people consult traditional healers and prophets for any health problems they encounter in the family. Traditional healers and prophets may provide psychological support to children and families affected by the virus.

It is upon everybody to take the scourge of HIV and Aids seriously. The views of the American decedents should be discouraged in all possible terms. The people in power should not gamble with the lives of people. Decision on whether to administer anti-retroviral should be expedited. South African government should not just dump the use of the Nevirapine without any alternative. With about seven hundred thousand infants infected worldwide, the dumping of such drugs is suicidal and irresponsible. Hesitation to grant permission to other generic antiretroviral drugs is increasing for fatalities than when administered. There is a drug called Fuzeon, produced in India, which super powers like United States must approve. This three-in-one drug will be beneficial to the developing countries. The super powers and business personalities should heed the call by the statesman Nelson Mandela to fund the global fund to fight against the scourge of HIV and Aids pandemic.

If all the proposals mentioned above are to fall on death ears, schools like Mvelaphanda and education will collapse since all young people who give birth to children who will attend schools would have died and children will not reach the age of 3 years. Education as the mother of all professions, once it suffers, all the professions are affected.

The first former Democratic President of South Africa, Nelson Mandela said ‘it is war, time for arguments and debate is over but for action against Aids pandemic. Effective response to the Aids pandemics depends on the strong leadership’s help. Government from all over the world should support interventions that reduce the risk of infection among their citizens especially the poor. In a situation where people know that they will be supported, they are more likely to open up and work towards preventing new infections and provide care for those already infected’.

Countries should allow application of different strategies for implementation combination or multiple antiretroviral therapies can reduce development of HIV to Aids if applied to the maximum. South Africa though regarded, as a super power in Africa should adopt the strategy of countries such as Uganda, Kenya and Botswana where their Presidents are chairpersons HIV and Aids committees.

Reduction of Sexual consent of girls to sixteen in South Africa and fourteen in other countries such as Zimbabwe will not help in the fight against the epidemic but will spread it more than before. This is mainly because child molesters will now have sexual intercourse with minors without any fear of the law.

5.2 Recommendations

Stigmatization of HIV and Aids can be addressed through educational campaigns.

Most people rely on the services of traditional healers, and as such traditional healers and religious leaders such as prophets should play a role in management of HIV and Aids. HIV and Aids education should be provided to them.

Provision of shelter and food may not be sufficient enough if it is not accompanied by psychological support such as communication and tolerance.

Politicians should implement policies that are directed at sensitizing communities on the disclosure without fear of stigmatization and rejection.

It carries a more weight if the head of state is at the forefront of the sustainable programmes that deal with non-discrimination of people living with HIV and Aids. This creates a sustainable programme and strategy that prevent new HIV infection.

There must be a zero tolerance to rape and abuse of women and children. Creating the programmes that improves the socio-economic conditions of girls and young women.

There must be a prevention education program for girls and young women to foster risk-avoidance life skill. Those who takes care of the Aids patients for the love of it, mostly in the informal settlements and rural areas, do not only earn nothing for their services but risk “sliding deeper into poverty themselves because of the time they devote to this cause”.

It is within this background that the caregivers mostly grandparents be afforded the greater recognition for their extraordinary and selfless contribution to the battle against Aids pandemic.

There is an urgent need for social protection and interventions to support the most vulnerable communities and households affected by this epidemic.

5.3 Limitation of this study

The respondents in this study were mainly women, which make it difficult to give a conclusive report regarding the statistics of the people infected by the virus. For the fact that only women come forward through ante natal clinic, and their participation in

the support groups than their male counterpart, that does not qualify this project to have given a conclusive report. The questionnaire distributed were not all brought back with the children. According to Leedy & Ormrod, (2005), in the estimation of population mean, a larger sample size will give us a sample mean that is more closely approximate in population mean. This implies that the larger samples yield more accurate estimates of population parameters. If this study had covered more parents not only women as the case here, this study would have given a close estimates.

5.4 Areas for further investigation

This study has evoked some areas of concern that need to be investigated:

- Cultural beliefs versus the reality of HIV and Aids
- Leaders such as President Zuma should walk the talk: investigate the effectiveness of Moral Regeneration structure in the society.
- Guarantees of protection for those who disclose their HIV positive status coupled with the provision of antiretroviral before people's health deteriorates.
- The level of training of health workers like nurses and medical doctors on confidentiality and legal implication (HIV and Aids Policy and its application)

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Addenda

Addendum A- letter to the School Governing Body and the SMT

Enq: Thomas
Tel: 0823808683

5255 Birch Acress
17 Umgana Street
Kempton Park
1619
10 August 2009

To: Mvelaphanda Primary School

Attention: The School Governing Body
Cc: the School Management Team

RE: Permission to conduct a research at your school

I am Mathavha MT, Mphil (Masters Degree student: Management of HIV and Aids) at Stellenbosch University. I am engaged in a research entitled: Stigma and discrimination deter people living HIV from disclosing their HIV positive status: "An investigation into why family members attribute death by Aids to other diseases"

Learners at your school are selected as research participants. I therefore request for a permission to conduct a research at your school. I further promise that the information gathered during this research will remain anonymous and confidential. Children will be asked 10 questions related to this research.

Their participation relies on your permission and that of their parents or guardians and it is voluntary.

Your cooperation in this regard will be highly appreciated.

Yours faithfully

.....
Mathavha Thomas

Addendum B-Consent to participate in Research (Parents)

Researcher: Mathavha Muladelo Thomas

Cell number: 0823808683

E-mail Address: tmathavha@hotmail.com

The main objective of this research is to investigate why family members attribute the death by Aids to other diseases. The research is mainly focused on the parents of learners at Mvelaphanda Primary School.

Parents are requested to participate in a interview to share their HIV and Aids knowledge and their experience with the researcher. Please take note that the participants will remain anonymous and may not be used for any reason. Participation in this research is voluntary.

If you agree please sign the return slip and send it back to the researcher with your child

I.....being the parent/guardian of.....have read the consent request and understand that it is for the purpose of research. I therefore agree to participate in the in the interview.

Signature of the respondent..... Date.....

Signature of the Researcher..... Date.....

Addendum C-Consent to participate in Research

Researcher: Mathavha Muladelo Thomas

Cell number: 0823808683

E-mail Address: tmathavha@hotmail.com

The main objective of this research is to investigate why family members attribute the death by Aids to other diseases. The research is mainly focused on the learners at Mvelaphanda Primary School.

Children are requested to participate in a focus group to share their HIV and Aids knowledge and their experience with other learners. Please take note that the participants will remain anonymous and may not be used for any reason. Participation in this research is voluntary.

If you agree please sign the return slip and send it back to the researcher with your child

I.....being the parent/guardian of.....have read the consent request and understand that it is for the purpose of research. I therefore agree that my child participate in the focus group.

Signature of the parent..... Date.....

Signature of the Researcher..... Date.....

Addendum D- focus group discussion with Grade 7 learners

“Stigma and discrimination against people living with HIV and Aids deter people to disclose their HIV positive status”:

Guiding questions:

1. What is HIV?
2. What is Aids
3. How can one get HIV?
4. How can we prevent ourselves from getting HIV?
5. Can you tell by looking at a person that he or she is HIV positive?
6. How can one know whether he or she is HIV positive or not?
7. Can we get by touching or hugging someone with HIV?
8. Is a friend or a family member living with HIV and Aids a friend or Family member?
9. Aids kills, do you agree or not?
10. If the answer is yes. Do you know of someone who died of Aids?

Addendum E: Research questionnaire to the parents

The impact of stigma and discrimination against people living with HIV and Aids deter people to disclose their HIV positive status: “An investigation into why family members attribute death by Aids to other diseases”.

Questionnaire:

1. How old are you? -----
2. Tell me about your family background e.g. how many are you in your family, mother, father, siblings, your children:-----

4. Who is a breadwinner in your family? -----

What is the highest grade you passed? -----
6. How old is your first-born child and how old were you when you got this child?.....
Why did have a child at that age? -----
- Do know of the disease called HIV and Aids? -----
- Do you know how does one get infected with HIV? -----
10. When was the last time you experienced death in your family?-----

Do you know what the cause of death was? -----

How can we know whether we are infected with HIV or not? -----
- If you discover that you are indeed infected would you disclose you status to your family or to anyone you know? Explain the reason for that.-----

- Do you know of any family member who died of Aids? If yes how did you know about it? -----
- Personally would you encourage your family members to disclose their HIV status? -----
16. Why do think people don't want disclose the HIV status? -----
